



Dimensions of Sadness—expanding awareness of community nurses' practice in palliative care

Ysanne B. Chapman

RN, Dip. Nse. Ed., Grad. Dip. Ext., B. Ed. (Nsg), M.Sc. (Hons) (Social Ecology)

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in praise of conversation

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Abstract

There is a paucity of literature concerning community nurses' perceptions of their work. They go quietly about their business, out of the spotlight of healthcare institutions, much of their daily work is and remains invisible to other nurses and to the wider society. Nurses who practice palliative care in a community setting are even more marginalised. Their work, surrounded by taboo subjects such as death, cancer and intractable pain, to name but few, is either talked about by others in hushed tones, or not discussed at all. The loneliness of their circumstances is made even more apparent by a scarcity of support services for staff who may be struggling to come to terms with a client's death or relatives grief. Nurses who work with dying patients suggest that an ambience of sadness pervades their experiences. It is through a conduit of sadness that this study illuminates the work of sixteen community nurses who are predominantly engaged in palliative care.

Events of sadness from their daily routine are described by the sixteen participants and retold as stories. Inspired by philosophical and methodological ideology situated firmly within the interpretive paradigm, an analysis of these stories is undertaken using an interpretive, hermeneutical lens. The sadness experiences and sadness responses are woven throughout the two interlacing themes entitled, temporal rhythms of sadness and kinship sadness. The sub-themes within each main theme move the reader from traditional, accepted views of sadness towards different insights and possible new meanings of sadness for these sixteen nurses. Using a musical metaphor and occasional poetics, sadness as embodied by these sixteen participants is exposed, recreated and understood as complex, paradoxical and multidimensional holographs. These holographs in turn reflect a creative yet compassionate energy; an energy that is informed by and also informs the wise practice of these women.

Foreword

An Invitation

A new day beckons with senses freshened,
an expectation to witness explicitly
her skin colour change; his tearful eye;
her anxious expression; his flinch of pain.
A hunger for preciseness, heeding
his breath expire; her sobbing grief;
his strained lament; her muted prayers.

Governed by trust and honesty,
friendships ebb and flow as the tide
of life retreats, revealing another dying, another death.
A knowing hand offered in peace,
to connect, to calm, to stroke
another's body, or bruised soul.
Hands that somehow reach beyond the boundaries into a space of comforted hopeless.

Who are they these sentient beings?
who take tea with Jack or Jane:
pouring stories of love now lost,
stirring a cup of sweetness since dispersed,
swallowing tales of lives shared,
washing up possibilities for a future,
putting the crockery of shattered dreams
in a safe place, perhaps to return tomorrow, maybe next week.

Welcome to their day—their everyday.
Each day they face little dyings,
little deaths moving closer
towards their own last hurrah. Although together they
journey towards the abyss,
chances are, or is it luck?
those in their care will know death before them.

Tarry with me,
travel, not as bystander or interloper,
rather, co-exist and connect
with the harmony and dissonance
which makes their practice meaningful.
Plunge with me into the chasm,
allowing relationships to find our passage, to be our guide.

We shall story several characters,
play in a conversational soup,
give voice to different melodies.
Perhaps we shall hear unique music,
perchance a striking composition,
possibly a different stillness,
within this symphony of sadness.



Chapter One

Introduction

*Sitting here alone, in peace
With my private sadness
Bared of the acquirements
Of the mind's eye
Vision reversed, upended,
Seeing only the holdings
Inside the walls of me,
Feeling the roots that bind me,
To this mere human tree ...*

(Bob Kaufman)

Introduction

Palliative care, death and dying and nursing within the community setting have been significant markers in my nursing career over the past thirty years. Having been a community nurse practitioner in an isolated setting, sometimes engaging in palliative care on a daily basis, I came to appreciate the vicissitude and complexity of feelings and emotional responses I had to my work. More recently as an academic, teaching, researching and writing in these areas (palliative care, death and dying, community nursing) it became obvious to me that nurses are at the cutting edge of caring for and coping with situations where people are at their most vulnerable. No other health profession is asked to coalesce a unique combination of physical care, intellectual competence and emotional coping with sometimes unrelenting succession of all forms of human suffering as does nursing. Yet, many of those experiences are marginalised from the public perception of what 'is' nursing, sometimes greeted with expressions of amazement and wonder, or perhaps concealing fears of the unfamiliar or the unthinkable.

A call to the question

In spite of these societal anxieties, grief and bereavement issues are integral to the work of community nurses yet, little has been written in the professional or public literature about the variety of emotions associated with the personal involvement of community nurses' work. Nevertheless, several recent researchers have attempted to capture a diversity of emotional responses that have been observed and experienced by nurses while caring for dying people and their families (see Chapman 1994; Vohland 1994; Meyrick 1997;

Chapman 1998 & Loftus 1998 for example). In doing so these studies create spaces in which nurses can give voice to emotional expressions: expressions that are often concealed or held as secret as they go about their business of nursing. Grieving and the open expression of emotion is often expected or encouraged in the dying person, their family and friends and yet it is not often fully expected or encouraged to be expressed by nurses themselves.

In a previous study (Chapman 1994) with registered nurses working in the acute care hospital environment, I noted that many emotions arose from and permeated the experiences of these nurses as they engaged in the care of the dying. The emotion most often expressed in this initial study was that of sadness. Participants in the study often spoke about sadness in their recollections of their experiences with end of life care. While the study pointed to sadness as a frequent expression of nurses' work with the dying, it was not however, part of the study's design to develop the notion of sadness. Rather, questions such as, what is the nature and extent of the relationship between sadness and loss or, is sadness necessarily a negative event in nursing work, emerged as potential issues for another study. Subsequently, in the aftermath of my Master's research more questions began to etch my being and I started to contemplate how sadness might be significant in the meaning making for community nurses caring for patients who require palliative care.

My Master's research also highlights that caring for those who are dying involves much more than the performance of procedures. The care required includes ongoing interaction and connections with the dying person and their loved ones. I came to realise that such facets of caring depend upon and interface with those personal qualities the nurse possesses as an individual. Consequently, after completing my Master's research I began to question the nature of the relationship between the nurse-patient-family, wondering how it might develop if it is constantly embroiled in an ambience of sadness. Also, I was seeking some understanding of the character of any inner dissonance for nurses as they continually encounter multiple death events, juxtaposed with caring for other patients in the community. Reisetter and Thomas (1986, p. 39) expand on the personal conflict that may exist as the professional tendency towards cure is confronted both with the reality of impending death and the personal death anxieties of the nurse. Taking a phenomenological viewpoint I would argue that it is impossible to separate the personal from the professional and this melding of the two is of particular importance and interest in the provision of end of life care. As nurses themselves, Styles and Moccia (1993, p. 307) share the view that nurses '... see life at its most intimate, most exposed, most vulnerable, and most heroic' and through exposure to human pathos can construct magnificent stories reflecting the powerful lessons learned from these experiences.

According to Chinn (1994), research into experience, with particular reference to women's experience is important. She professes:

... women's experiences are worthy of study, that women's perspectives on their own health and well-being are valuable, and that women's knowledge of their own health experiences reflect important insights that need to be integrated into health care practices (Chinn 1994, p. iv).

Thus a passionate inquiry and exploration of emotional repercussions such as sadness is appropriate and needed to inform the profession.

Investigation into the lived experience of other emotional states has been the subject of several phenomenological research studies, not only in the discipline of nursing but also in psychology. Heuristic phenomenological methods appear to be particularly popular, with the researcher's experience being the initial impetus for the invitation of others to join a research project as participants or co-researchers (Blau 1980; MacIntyre 1982; McNally 1982; Thompson, Waldo et al. 1994; Parse 1997). Many of the studies cited utilise artistic compositions such as music, art, poetry and drama to accentuate the portrayal of individual experiences of the phenomenon in question. Thematic interpretation forms the framework of presenting the analysis in the research projects mentioned.

This study seeks to add to this small collection of experiential inquiries by examining the meaning of sadness for community nurses engaged in palliative care. In doing so a group of sixteen nurses working in the community and assigned to palliative care, either as a specialist or generalist nurse, were asked to assist me with this exploration. This exploration is aesthetic rather than measurable in nature and so sits appropriately within the interpretive, as opposed to an empirical/analytical research framework. Chinn (1985 cited in Taylor 1993, p. 173) notes that:

Qualitative methods allow exploration of human by humans in ways which acknowledge the value of all evidence, the inevitability and worth of subjectivity, the value of a holistic view, the integration of all patterns of knowing into the whole knowing.

To suggest that phenomena can be objectively measured is to almost nullify the context (experience) within which those phenomena are brought forth. A fuller understanding of such phenomena can be brought about by retaining the exploration within the experience in which it is lived. In so doing, '... the intersubjective, subjective and objective components interplay, so the meanings and understandings developed are approximate' rather than cemented in an absolute truth (Geanellos 1997, p. 15). Using the philosophical stances of hermeneutic phenomenology, constructivism and cognitivism as beacons to illuminate my quest, provides experiential insights into how these sixteen

participants create meaning from their experiences. By asking these participants to describe their sadness while engaged in palliative care, I not only seek understanding to the question but also gain some profound awareness into the ontological basis of what it might mean to be a community nurse practising palliative home-based care. Sadness therefore becomes a conduit from which insight into the life-world of palliative care nursing can be realised.

Polkinghorne (1988, p. 130), in his portrayal of temporality within phenomenology, agrees with Heidegger's perception that understanding experience is analogous to a symphony. In his elaboration of Heidegger's ideas he further suggests that this symphony is composed of different melodies, each playing simultaneously. Impressed by this notion I have decided to utilise, to some extent, a musical metaphor within the writing of this thesis, as it appears to me to be in 'natural' harmony with what emerges from the data. In this thesis, the different melodies brought forth cover a multiplicity of experiences of the sixteen participants. In turn, and musing with the musical metaphor, these stories resonate with myself as a nurse and researcher, who also has some background understanding of palliative care nursing.

In addition, Miller Mair (1989, p. 254) claims '... we are woven together by metaphor' and that our realities, like shifting sands, are in constant movement. In conversation, metaphors may clarify, enhance or illuminate meaning for both the speaker and the listener, sometimes seeking in vain, the notion of total commensurability of understanding human experience. Nevertheless, in the search for such understanding parts of our human experience are highlighted, narrated and prioritised through deeply personal metaphors that conjure up the meaning of being and sanction us to construct our own sense of phenomena in the world (Lakoff & Johnson 1980, p. 34).

Background to the study

The changeable nature of causes of death, with an emphasis on chronicity, has resulted in nurses becoming increasingly involved with those experiencing protracted dying and death at home. Ten years ago Davis and George (1988, p. 310) heralded a change in the primary killers of Australian society. '[It is] ... the degenerative diseases of ageing, such as heart and circulatory diseases and cancers' that are primarily causing death. The demand for palliative care is expected to increase as the number and proportion of cancer deaths have been increasing since the 1940s (Australian Institute of Health and Welfare 1992, in Calder 1998, p. 64). Field and James (1993, p. 7) determine that changes in

health care delivery have shifted the focus of nursing the dying person from the acute care sector to the community¹. In 1988, one state in Australia recorded that only forty eight per cent of deaths occurred in public hospitals (Sherson 1998, p. 141). Patients requiring long-term care have become the typical client of the generalist community nurse, rather than the exception.

Contemporary community generalist nurses² have a significantly increased proportion of chronically ill patients to care for than say fifteen years ago (in the late 1970s to the early 1980s). This movement of the chronically ill from the acute care sector to the home means also that families too have become important members of the caring team. Remaining at home is becoming a preferred option for many terminally ill people although ultimately some patients may choose to die elsewhere (Field and James 1993, p. 8). The question of where to die is influenced by a complex relationship of personal choice vis-a-vis family preferences, the availability of resources (family, friends, professionals) balanced with the severity of the illness or condition, and individual perceptions of symptom control and pain management.

Historically, the place of dying moved from in the home to in the hospital or institution. Currently however, we are witnessing the dawn of a reversal of this trend, and the preferred choice of where people die is moving slowly away from hospital and community institutions back into the home. Where death takes place has followed a pattern closely paralleling broader social values. Changes to family structures, geographical mobility and better standards of health care have influenced the care of the terminally or chronically ill. With the rise of life expectancy and a decline in infant mortality rates in the post industrialisation era, the pattern of dying has changed. Blauner (1966 cited in Field and James 1993, p. 7) suggests that:

... death ... becomes increasingly a phenomenon of the old, who are usually retired from work and finished with their parental responsibilities, mortality in modern society rarely interrupts the business of life.

It could be argued therefore that the 'glamour' attached to working with dying patients is diminishing. Palliative care is no longer the exclusive domain of people with cancer. The somewhat idyllic notion of palliative care being the sole benefactor where death takes the young, the innocent 'victims' of terminal disease has given way to a less romantic, more

¹ Community includes residential care settings such as private hospices, hostels and nursing homes, as well as private homes.

² In some areas of Australia, community generalist nurses are known also as home nurses or district nurses.

mundane, yet pragmatic realisation that palliative care is appropriate for those people suffering from chronic diseases where death is their only release. Carey and Sorensen (1997) allude to these changes and infer that Aries (1978) contention that Western society in the twentieth century is in 'death denial' might well be overturning as we approach the forthcoming millennium. If health care continues to move outwards from institutions to community, as is the present pattern, death as a commonplace occurrence within the home could well become as culturally acceptable as death in an institution. As a consequence, our Western society may witness a return of death from the confines of its present mystical, sometimes invisible position removed from everyday life, to an understanding of it as the more ordinary experience that it is, could or should be.

Collectively, dying and death have been a source of fascination for several artists, many writers and philosophers as well as contemporary researchers. Bearing witness to the science and art of dying however, has largely remained the prerogative of the health professions (Wilkes 1998). Within these professions it is the nurse who journeys closest with the dying patient and his/her family. Nurses learn quickly that not all death is humane (Sherson 1998, p. 139). Death can be traumatic and robust, noisy and peaceful, distressing and docile. No matter how death is encountered, in a palliative care environment within the home, it is nurses who often metaphorically 'walk with' dying patients as they confront possible major changes with their remaining life. As a shadow to their patient on a sometimes difficult journey towards death, the nurse enters into a connected relationship (Chapman 1998). It is within this special relationship that sadness may emanate, exist and end.

Gow (1982, p. 1) contends that most nurses '... are willing to share and risk themselves in meaningful relationships' with those in their care. It is this bringing of self to the nurse-patient relationship that makes a difference in the outcome for the patient. Both Gow (1982) and I (Chapman 1998) question the use of detachment as a protective measure for the nurse. Gow (1982, p. 1) argues that nurses, in their quest to be on a par with other health professionals, have adopted Talcot Parsons' (1951, cited in Gow 1982) notion of professional detachment. This theory however, is largely based on the premise that helpful relationships are more likely to develop with patients when the health professional does not embrace the notion of a connected relationship.

The dichotomy between detachment and involvement in nurse-patient relationships, continues to be debated and critiqued (Stein-Parbury 1993) without significant resolution. This unresolved conflict is ongoing with some nursing theorists continuously demanding that nurses show empathy, place themselves in the shoes of the other and understand the emotions and the plight of their patients (Gow 1982, p. 2). As the nursing literature

suggests there are several points of view about the nurse-patient relationship and a similar plethora of ideas about the development of that relationship. In spite of these theories however, there is no definitive or clear way forward that informs nurses or the nursing profession about how their relationships with others may advance.

Peplau's (Brophy, Carey et al. 1994, p. 327) principles of human relations suggests that nurses who attempt to understand their own feelings and behaviour are better placed to interpret similar difficulties in others. Human-to-human relationships and the therapeutic use of self are central to the design of Travelbee's 'Interpersonal Aspects of Nursing' theory (Hobble, Lansinger et al. 1994, p. 356). Yet, becoming close to patients is a contentious issue with a long history. Goffman (1957, cited in Gow 1982, p. 5) indicates that some nurses have been socialised into believing that encroaching on a patient's privacy, or becoming involved with their feelings is tantamount to '... a breach of professional etiquette'. Thus, knowledge from eminent nursing theorists has been at best questioned and at worst unheeded, as their ideas appear to place these nurses in a double bind.

This conundrum is recapitulated by Barnsteiner and Donovan (1990), Trygstad (1986) and Rawnsley (1990) who acknowledge the risks and struggles, happiness and joy that nurses often encounter when giving skilled comfort, in the form of both spoken and wordless moments, to patients in crisis situations. 'What is spoken is never, and in no language, what is said' (Heidegger 1975, p. 11). Yet in responding to the needs of these special people within the community it is recognised that nurses are likewise part of that same community. Some consideration therefore is warranted towards the non-fiscal cost of caring worn by community health nurses as they engage in palliative nursing care. Additionally, legitimate acknowledgment of nurses' invalidated grief is appropriate since their rights to grieve are at best challenged and at worst socially denied.

Disenfranchised grief

The concept of disenfranchised grief concedes that societies have accepted codes, rules and norms that identify the who, when, where, how and how long of a grieving event. By making such distinctions society concedes there are those whose grief cannot be publicly acknowledged or socially sanctioned (Doka 1989, p. 4). Perhaps the relationship is not endorsed, or the loss not recognised as being significant, or the status of griever is not approved for that person. All three may be possible grounds for nurses to be distinguished as disenfranchised grievers.

In their work with dying patients palliative care nurses, like relatives, could be construed as survivors. Although they experience varying senses of loss, they are not usually the people who receive support. Unlike relatives however, these nurses are the support givers, as their work incorporates bereavement counselling. Kalish (1985, cited in Lev 1989, p. 288) further claims that it is nurses readiness to constantly render care-oriented behaviours in spite of the consequence that fuels the experiences of disenfranchised grief. This ongoingness of palliative care nurses' caring and resultant grieving may be likened to a merry-go-round, difficult to stop or disembark from. Indeed, Vachon (1978 cited in Lev 1989, p. 291) in suggesting there are many reasons why nurses choose to work with dying patients claims nurses set themselves up for grief:

... resolving past losses, relieving one's own feelings of guilt, perceiving oneself to have a special calling, proving that one can care for the dying better than others, may have cared for their own dying loved ones, having a hidden agenda, wanting to make this one's entire life, and having unrealistic expectations of the tasks required by the role.

Taking a more negative stance, Vachon's reasons may be seen to contribute to nurses vulnerability. Yet these reasons do not feature in my conversations with the sixteen community nurses. In contrast to Vachon's views, I gain the impression from the participants in this study that their main reason for working with dying people is that they derive satisfaction from the work.

Perhaps the most significant aspect of disenfranchised grief when relating it to community nurses' experiences is the question of relationship. Doka's (1989) opinion of a non-endorsed relationship is problematic for nurses. As argued previously, nurses' involvement with patients as people is regarded as central to the nurse-patient interaction. Relationships do form, albeit some are more friendly than others. Nurse-patient friendships argues Hunt (1991) can work towards a sense of partnership in which each person can freely articulate their hopes and fears. In doing so the more traditional barriers such as distancing of the nurse or taking an authoritarian stance are potentially removed. However, in our day-to-day existence friendships are usually voluntarily chosen for reasons other than usefulness: and in the process of palliative care nursing much can be shared between nurse and patient that surpasses even the best of friendships. By viewing nurses involvement with dying people as a '... natural expression of the healthy human heart' (Larson 1992, p. 857) a more positive sentiment (vis-a-vis Vachon's ideas) presents itself. Rawnsley (1990, p. 237) attests that:

[T]he concept of caregiver as survivor rests on the premise that an interpersonal connection developing between one who is struggling with a life-occluding illness and a professional who is willing to risk examining the lived experience of that struggle, transcends traditional parameters of a more protected professional stance.

The significance of the study

On the whole community nurses work in professional isolation. Their work may involve moving between persons in their care without an opportunity to discuss or debrief tragic or traumatic situations as they arise in practice. Community nurses engaged constantly and consistently in the delivery of end of life care are supportive, not only of the patient but of their immediate family or circle of friends associated with the dying person. Involvement with each family may vary from an empathetic presencing to becoming a part of the patient's extended family. Like nursing work in general, much end of life care may be deemed invisible. The recurrence of sadness for the caregiver, in this instance the community nurse, may pass unnoticed or unacknowledged. Unacknowledged not only by nurses themselves, but also by those in the business of overseeing or coordinating this care.

I can identify with the 'aloneness' of working in the field because I too practiced as a community nurse in an isolated community. This perceived isolation was compounded by other factors including; large case loads, with patients living sometimes up to fifty kilometres apart, constraints of time and poor accessibility to patients' homes more often than not as a result of inclement weather. These influencing factors were part of the turmoil of being a community nurse in a small, but fragmented community. Delivery of palliative care was only one part of my daily services to this community and with no other nursing personnel working in close proximity much of the sadness I experienced became cumulative, unnoticed and at times, unresolved. To exacerbate matters, when meetings permitted some sort of relationship with other health professionals, priority was given to discussing and planning the health care of the consumers of community care and hardly ever the well-being of the delivers of that care.

Regretfully, there has been little change in the daily experiences of rural-based community nurses work. Sally, one of the participants in the study who works from a rural based practice describes her typical day. The following diary, compiled by Sally at my request, encompasses her activities within a linear time setting, as well as comments about the activities and the people she meets. Sally's comments, like our conversations, are intermittently flavoured with humour.

A TYPICAL MONDAY IN RURAL COMMUNITY HEALTH

- up at 6:30 a.m. after self bargaining for extra 10 mins in bed.
- shower, breakfast, 25 kms drive to health centre to pick up 4-wheel drive Government vehicle; check for messages on answering machine; collect patient files and dressing stocks required for the day; quick “hello” with cleaner who starts in the health centre at 7:00 a.m. and who always looks as though she’s done a day’s work when I see her at about 7:45 a.m.
- check car’s 2-way radio and off to first patient 25 kms from health centre.
- arrive shortly after 8:00 a.m. in small township. 82 year old Mrs. B. lives alone. Had CVA Sept ‘97 and has Insulin Dependent Diabetes Mellitus (IDDM) and chronic rheumatoid arthritis. I am always pleased to see plume of smoke from chimney—means patient is up and I don’t have to bang on the door or get help from the neighbour to let myself in to find her in a ‘hypo’.
- Mrs. B’s greeting is always the same, “You must have got up early Sister?” My reply varies little “Oh yes, before daybreak. Frost/foggy/sunny/wet morning” (or whatever the weather is). Mrs B. rarely opens the curtains until after breakfast. Thereafter she can report on every car, pedestrian, human, furred or feathered beast which passes her home.
- check her blood sugar level (BSL): administer her insulin: restock her medication box while she prepares her breakfast: stoke up the fire: check she’s got food for lunch: write up notes and after saying “see you tomorrow” set off to the next patient.
- back track a few kilometres to Mrs G. 78 year old with IDDM. Lives with 81 year old spouse. Patient monitors own BSL and administers insulin prior to visit. Check BSL reading; take blood pressure (BP) and report to GP if elevated and/or patient symptomatic: restock medication box. Update on recent specialist visit. Arrange community transport for next appointment. Accept spouse’s offer of a bunch of silver beet “if you pick it yourself Sister”.
- Mrs A. lives close by. Visit to check small venous ulcer to malleolus. Mrs A. attends to dressing alternate days between my weekly visits. A few weeks ago when ulcer had deteriorated she admitted to having used an ointment known to rural folks as ‘Man and Beast’ - claiming that it ‘had worked wonders on the cow’s teats when they were cracked”. And yes it was the same tin of ointment she’d last used on the cows before she ceased having a dairy six years ago. Agreed to give the moist healing and bandaging method another go.
- Mr and Mrs T. are neighbours of Mrs A. Mr T. has cancer of the lung (diagnosed six months ago). He is losing weight rapidly and Mrs T. is concerned about his ability to tolerate nourishing foods and fluids. Talk to them both about cancer and its usual progression. Arrange for palliative care specialist nurse to visit with me tomorrow morning. Suggest to Mr and Mrs T. that they make a list of questions to ask the palliative care specialist nurse. Make a note in diary to telephone community palliative care nurse prior to next visit.

- Mr and Mrs J. both 90+ live in small township in own home with daily support of bachelor son who lives nearby. Mrs. J. has renal artery stenosis and hypertension. Mr J. has right sided paralysis from CVA³. Blood pressure checks for both and urinalysis for Mrs J. as she suffers from recurrent infections. Support son when present. Discussion re. vicar's sermon on previous day or on decreasing number of worshippers. Occasionally a tip for a "sure winner in the next horse race" from Mr J.—to date none of his well intentioned tips have been 'painful'!
- Mrs S. 62 years old lives in the same township. Requires assistance with hygiene—has COAD⁴ and a history of depression. COAD is long standing and much of her care is palliative in nature.
- Mr A. lives in same street and is visited weekly to check blood pressure and encourage exercise and socialisation at Day Centre. Cut toe nails 6 weekly.
- 'Bob' is almost 80 years old and has lived in township all his life. Known to community for miles around. Lives with his sister who has also cared for both parents and invalid sister before their deaths, in addition to rearing her own four children and helping in family bakery business which until about six years ago baked daily. Bob, in addition to having Paget's disease⁵ and end stage COAD is also mute. For several years he has been confined to a wheelchair. Visited daily (except weekends) for general nursing care (his sister and a brother assist at weekends). In addition to attending to Bob's care and supporting his family there is always an exchange of family life gossip, the sewing machine to re-thread or assistance with form filling.
- still in the township...
- Mrs C. 87 years old lives alone in childhood home and past memories. Visited weekly to wash her hair before attending to the care of external graft site on scalp following malignant tumour—recurrent graft breakdown taking weeks to heal. Designed headware which protects scalp—looks good, feels comfortable and which patient likes to wear. Chat about garden, family, weather—all over canary's persistent whistling.
- drive 25 kms to central highlands farming township.
- call by health centre for any referrals, messages and arrange time to liaise with GP.

³ CVA: Cerebrovascular accident is an abnormal condition of the blood vessels of the brain characterized by occlusion by an embolus, thrombus, or cerebrovascular haemorrhage, resulting in ischemia of the brain tissues normally perfused by the damaged vessels (Anderson, Anderson & Gfanze 1994, p. 297).

⁴ Chronic Obstructive Airways Disease: characterised by disturbances with breathing, sometime barrel chestedness and/or pursed-lip breathing. Clinical signs are seen in cases of emphysema and chronic bronchitis (Anderson et al. 1994, p. 331).

⁵ Paget's disease: a common, nonmetabolic disease of bone of unknown cause, usually affecting middle-aged and elderly people, characterized by excessive bone destruction and unorganised bone repair.

- Monday morning ‘tea at Pop G’s’ has been a tradition for years. It started while caring for his wife whom I nursed for several years with assistance from their two daughters. She died from cancer five years ago. On Mondays both daughters spend the day with their 87 year old father (as they did for years before their mother’s death) to do the housework, have lunch and once a month “say the Rosary together”. After Mrs G’s death the morning teas continued even though until recently Mr G. did not require nursing services. Earlier this year he developed NIDDM⁶—now well controlled and last month [he] had an excision [of a] facial skin cancer which has required dressings. Morning tea follows official business and is always scones straight from the oven with homemade jam which I provide. Often joined by an adult or child. Lively discussion, usually initiated by Mr G. on one or all of three forbidden subjects for nurses to discuss with patients—sex, politics or religion. I’m always given several scones to take with me “in case you get hungry Sister.” Also tradition is the Monday closest to Christmas I have lunch with them and provide the plum pudding.
- Mrs Z 90+ years old has possible cancer of the pancreas. Only diagnosed recently. Appears to have good pain control at this stage. Lives in the same township in a tiny brick cottage with a tiny wood stove on which she cooks all her meals and boils water in two big black kettles. Check Red Cross alarm system. She is visited twice a week to assist with bathing. Hot water is heated in an electric copper at the end of the bath and using a dipper she fills her bath. Medications are checked and stocks ordered and collected from GP. On Mondays after bathing I serve up her lunch which she has prepared.
- Mrs P 81 years old with THR, has an abdominal herniation following wound breakdown (hysterectomy) and recently suffered a fractured neck of femur to which she had a pin fixation. She requires assistance with her hygiene and wound care. Ongoing support and counselling patient as she has poor family relationships. Check environmental risks factors—rugs, electrical cords.
- drive back to health centre to discuss any referrals and/or ongoing care for patients with the GP.
- liaise with personal carers and home helps employed by the agency.
- make telephone calls to other disciplines/district manager/hospitals etc
- arrange health promotion/staff development
- return to ‘base’ health centre for meetings
- respond to messages left at centre
- complete workload statistics and other documentation.
- liaise with child health personnel/social worker/mental health personnel and colleagues regarding the patients.
- leave for home 4:30-5:15 p.m.
- average kms travelled per day 150.
- phone calls to own home after hours are usually only from patients who are terminally ill and their families.

Table 1: Diary of a typical working day submitted by Participant ‘Sally’.

From my engagement with the participants in the study it became obvious that the nagging almost subliminal questions that arose for me in my own nursing practice are still current today. Ongoing questions such as, should I become involved or should I remain detached

⁶ Non Insulin Dependent Diabetis Mellitis.

from these people who welcome me into their home each day? How can I manage expanding case loads and where and how can I seek better peer support? There are no easy answers to these questions and raising them might well effect more questions than answers. The questions I raise are but a sample. I submit that for some community nurses many of their questions hover below the surface of their daily practice, are devoid of professional critique and subsequently remain unresolved.

If nurses continually overlook or neglect their own emotionality, the impact of the accumulation of seemingly negative processes within themselves (such as the accumulation of grief, sadness, anger) may lead to a severely compromised ability of nurses to respond (response-ability) within this vital nurse-patient relationship. Knowledge pertaining to the consequences of feelings of grief when caring for the dying person has been debated within the health care milieu and is well documented by authors such as Kübler-Ross (1969; 1974), Kastenbaum (1988), Raphael (1984) and Quint Benoliel (1988).

In my Master's study (Chapman 1994) the taken-for-granted, cumulative sadness expressed by the participants is indicative of the manner that some nurses almost 'dismiss' the emotional wrenching they might experience in their practice. While ever these powerful emotions remain unrecognised within this specific nursing context, the consequential way of being-in-the-world of community palliative care is not heard, and so in Heideggerian terms, is forgotten. But is it forgotten? By ignoring, displacing and minimising these powerful emotions community palliative care nurses do not allow themselves to take responsibility (response-ability) for their own emotions. Subsequently, they may place themselves in a jeopardised position within the palliative care team whose principle drive is to support patients and their families. Aranda (1998, p. 27) argues that the notion of a team approach to palliative care can be deceptive. She claims that often, as patients become moribund, they may reject other health care team members and favour an increasing presence of the attending nurse, as it is the nurse who appears best placed to nurture this responsive relationship with the dying person and their family.

Not so well documented within the literature is the integration of sadness to nurses' experiences in their practice. Sadness within the health care literature features rarely and when presented is couched in terms of sorrow or chronic sorrow. There is some dissension about the value of literature reviews in interpretive research with their inclusion in research reports at times adjudged controversial (Grubb 1995). Nevertheless, in this study an examination of the material referring to sadness as an emotion and feeling is pertinent. Sorrow and chronic sorrow as expressed and given shape and form by society

is presented in an attempt to provide some background understandings to the 'what' of sadness.

A brief consideration of the literature about sadness

The participants in this study were asked to describe their sadness as they engaged in palliative care work in a community setting. While a definition of sadness was neither presented nor postulated, it would have been naive, indeed philosophically antithetical for me to assume that these participants entered this study, or any conversation about sadness with a *tabula rasa*. Thus, this section of the chapter considers sadness from three differing, yet connected perspectives; the structure of sadness, sadness as a perceived attribute of being human and sadness as an experiential category (Varela, Thompson et al. 1992, p. 157).

The context-stripping of concepts, intrinsic in the positivist approach to research has been criticised by some researchers using a new paradigm perspective (Reason & Rowan 1981), with recent authors agreeing that the use of literature reviews to contextually ground research within the interpretive paradigm is useful (Hickey 1997; Robinson & McKenna 1998). Mishler (1979, p. 2) contests that context has been viewed previously as antagonistic to understanding rather than acknowledgment of context as integral to how we know. Moreover, recognition of context bound knowledge as central to the interpretive approach is encompassed by Geertz in his reference to 'thick descriptions' (Mishler 1979, p. 11). These thick descriptions encompass the multiplicity of background meanings of a phenomenon (in this case, sadness) assigned to each participants' experiences.

Feeling sad is a common response to many life events, even a propensity for some people as their life perspective. This predilection towards a certain manner of being-in-the-world is interpreted by Heidegger (1962, p. 134) as 'mood' and is discussed within the following chapter. Moods however, differ from emotions. Emotions come and go and being emotional is a process (Crawford & Kippax 1992, p. 15).

The question of whether emotions are synonymous feelings has been addressed by Bedford (1962 cited by Crawford and Kippax 1992, p. 28). Using a social constructionist view he distinguishes between 'being' angry and 'feeling' angry. Bedford concludes that '[T]he feeling associated with the emotion is not to be equated with the emotion. Emotion is more than this, although it may include the feeling.' Similarly, Averill (1994, p. 379) suggests the two terms (emotion and feeling) are often used interchangeably. Consequently, judgements have been made that feelings are essential

features of emotions. However, he further argues that to suggest emotions involve feelings is not particularly informative and cites the following examples:

First, “feeling” is one of the vaguest terms in the English language. I can feel the prick of a pin, the touch of velvet, the cold of a winter day, and the pounding of my heart after climbing six flights of stairs. Sometimes, I feel ill or nauseous. At other times I feel confused and disoriented. Once in a great while, I even feel knowledgeable or enlightened. Now and then, I also feel like going to a movie. And all too often, I feel like doing nothing (Averill 1994, p. 379).

Given that the notion of feeling is indeterminate and that feelings are neither obligatory nor adequate contingencies for emotional states, it is nevertheless true that subjective experience is among the more archetypical features of emotion. Averill (1994, p. 380) concedes that the idea of ‘emotional feelings’ forms the substantive framework for the analysis of emotion.

The ‘emotion syndrome’ (Averill cited in Crawford and Kippax 1992, p. 110) consists of five points, namely:

1. emotions involve affect or feelings, often equated with certain physiological events;
2. emotions also involve cognition, however fleeting, in the form of remembering or appraising;
3. emotions are expressions of inner feeling;
4. emotions communicate our feelings to others;
5. emotions overcome us.

These five elements recognise the interplay of subjective and objective views of the same phenomenon. This subjective/objective dichotomy regarding feelings is lively debated by Averill (1994) and Charles Birch (1995). Many of the ideas postulated by these authors are mirrored in Heidegger (1962) and Gadamer’s (1975) philosophies (discussed in a later chapter). Briefly though, Birch (1995, p. 13) and Averill (1994) profess that feelings are both subjective and objective and cannot be separated from the person.

Indeed, Birch appears to side step the issue, pronouncing that subjectivity and objectivity are ‘... the two sides of the one phenomenon’ (Birch 1995, p. 14). Birch gives numerous examples to explain these ideas. One such example, which is perhaps appropriate for this study, is the experience of pain. Couched in simplicity, this exemplar does not acknowledge the complexity of the pain response. However, it recognises that ‘feeling’ pain (and by implication, emotions) is relational and dependent upon an individual’s past, present and future experience. Birch (1995, p. 14) submits that the subjective aspect of feeling pain is the person’s experience of ‘unpleasant sensations’. Whereas the objective side is the network of ‘... physical and chemical links from pain receptors ... through pathways of the nervous system to your brain’. Birch maintains that descriptions of the

objective aspects provide little information to an observer about the subjective experience, the 'feeling of' pain. Objective description alone is by no means incorrect, but it is incomplete, unbalanced. Both subjective and objective descriptions arise from our past, present and future experiences. Our five senses mediate in and influence our descriptions of feelings. Birch's (1995, p. 35) refreshingly different conclusions about feelings provides some clues as to how different dimensions of sadness might emerge in this study:

... we can say that all experiencing is 'feeling of feeling'. Memory is feeling of past feelings. Anticipation is feelings of feelings not yet concretely real in our experience.

Moving back to the early literature specifically targeting the structure of sadness, the two leading authors who emanate as key informants are the psychologists Freud (1957) and Bowlby (1980), both of whom link sadness with loss. In Freud's opus *Mourning and Melancholia* (1957, p. 245) melancholy⁷ is claimed to be a response to both a conscious or an unconscious loss. The former, although recognised by Freud as significantly painful, is not pathological; whereas experiencing the latter, he believes the person constructs a portrait of self as worthless and '... incapable of any achievement and morally despicable' (Freud 1957, p. 246). I am not suggesting that the participants' sadness solely dwells in the unconscious, as they were conscious, willing, fluent and articulate when sharing their experiences with me even though some of those experiences may have been marginalised. For the most part, the participants' sadness experiences, closely linked to relationships, were more in keeping with Bowlby's extension of Freud's work. Much of Bowlby's research centres around the notions of sadness juxtaposed with attachment (1980, p. 245). Furthermore, Bowlby (1980, p. 250) seeks to question the extent to which depressive disorders are related to loss. Bowlby's research and other studies (see Eakes 1993; Hainsworth 1994 & Teel 1991 for example) document an understanding that persistent sadness is a precursor to chronic clinical depression.

Correspondingly, it is well known that stressors from life events appear to contribute to the development of diseases in some people. In these situations, one major stressful event, or a series of stressors may overwhelm the person's coping abilities and render them vulnerable. Likewise, nurses engaged in palliative care nursing consistently place themselves in positions of ostensible disadvantage by their daily engagement with patients who are themselves entangled within the syndrome of chronic sorrow (Lindgren, Burke et al. 1992; Saunders & Valente 1994; Parse 1997).

⁷ According to the Macquarie Dictionary (1992, p. 1108) melancholy is synonymous with sadness.

Sharing the sorrow of the family in the delivery of end of life care to the patient is not generally given credence by nurses themselves or their colleagues. In my previous study (Chapman 1994) the readiness of some of the participants to hide from sadness under the guise of maintaining 'professionalism' was clearly visible in their responses. This comportment also had a bearing on the individual's willingness and fervour to enter into a connected relationship with the dying person and their family. On the other hand, some nurses interviewed in this previous study experienced a sudden outpouring of emotion following the trigger of a sad situation. Wolff (1994) describes such a situation in his study, when one nurse, overcome with sadness at the sudden death of a particular patient, cried for the loss of all previous patients whom he had nursed to their death.

The experience of sorrow or sadness following relocation is the focus of a recent phenomenological nursing inquiry (Thompson, Waldo et al. 1994). Using heuristic phenomenology based on the ideas of Moustakas (1990 in Thompson, Waldo et al. 1994, p. 122) a group of three co-researchers used a combination of in-depth personal narratives, reflection, through sharing, and explication of common meanings and creative synthesis revealing unfolding themes. The implication for nurses resulting from this particular study is the need for nurses to consider a number of issues when trying to assess the impact of relocation on the individual. Thompson et al. (1994, p. 131) identify deliberation on past history, affective coping mechanisms, individual characteristics and traits, together with an appreciation of a person's social network as the complex interrelationship needing to be unpacked to understand sadness in this context.

The difficulties analogous to researching sadness as lived by nurses is bounded in part by the discourse on emotional labour (Phillips 1996). James (1992, p. 489) contends that:

emotional labour is hard work and can be sorrowful and difficult.
It demands that the labourer gives personal attention ... not just a
formulaic response ...

Interestingly, James further claims that nurses with skill in emotional labour command a lower status than nurses who are not directly involved with people requiring care involving passionate and turbulent feelings. However, James (1992, p. 500) does admit that '[E]motional labour is about action and reaction, doing and being, and can be demanding and skilled work.' James places most emotional labour in the framework of common sense and likens it to physical labour suggesting that the consequence of such work is dependent upon '... how skilfully each situation is managed' (James 1992, p. 500). Anthony (1977, cited in James 1992, p. 501) contends that emotional expression is acceptable within the domestic domain but it is not considered affable within the workplace. Nurses work in home-based care do so in the environment of the patient's

own home. Thus they are at a possible disadvantage in making the distinction between what is domestic and what is workplace emotion. This inability to segregate and subsequent lack of legitimisation for emotions, could potentially exacerbate further conflict and confusion within the nurse.

Hochschild's analysis (1983), in considering the work of air stewards, views emotional labour as the antithesis of rational labour. Just as women are frequently judged as emotional, men in apposition are surmised as rational. This world view pervades many aspects of life as well as nursing and not surprisingly nurses, whose practice is deemed to be grounded on the rational biomedical, task oriented foundation are conceivably more 'prestigious and real' than those embroiled in emotional labour (Phillips 1996, p. 142).

Fagin and Diers (1983, p. 116) articulate that:

Nursing is a metaphor for intimacy. Nurses are involved in the most private aspects of people's lives, and they cannot hide behind technology or a veil of omniscience as other practitioners or technicians in hospitals may do. Nurses do for others publicly what healthy persons do for themselves behind closed doors. Nurses, as trusted peers, are there to hear secrets, especially the ones born of vulnerability.

Subsequently, much of nursing work remains invisible to others, even to closely associated health care team members. It is highly likely that powerful non-affirming feelings associated with private interactions between nurses and their patients may not be shared for fear of revealing these entrusted secrets (Aranda & Kelso 1997). Yet it is also within these close relationships that professional rewards are reaped. Benner and Wrubel (1989) contend that there is a relationship between emotions and meanings which allow nurses to attune intuitively to whole situations. Nevertheless, I would argue that in doing so nurses, especially those working in palliative care, may often precariously balance their own feelings on the edge of a situation, fearing that if they become involved they may get hurt yet, also knowing that if they do not engage, they risk not making a difference in the person's life. Aranda's current research into the nature and expression of professional friendships confirms that most palliative care nurses are prepared to take that risk (Aranda 1997).

Appreciation of the work of home-based palliative care nurses rests predominantly with those who have experienced it and their loved ones. Much of these commendations therefore are either buried with the dead people or subsumed within the grief of their families. There is little public appraisal of this work and even much less compassion for the intricacies of emotions related to the involvement these nurses have with the dying person and their family or friends. This study thus, through a conduit of sadness,

examines the often convoluted individual experiences of these sixteen participants, to edify and make accessible an understanding of nurses own emotional dilemmas in the impassioned and important branch of nursing, palliative care.

Palliative care—a brief history

The nature of palliative care as a distinctive specialty has been acknowledged by society and is reflected in the provision of care both within institutions and the community (Field and James 1993). Nevertheless, palliative care as a specialty is a relatively new phenomenon given that death and dying have always been bed partners of nursing. Dame Cicely Saunders is usually credited with the development of the modern hospice and palliative care movement with the opening of St. Christopher's hospice in Sydenham, London although history suggests also that St Luke's hospital began research in pain control in 1948. In Australia, O'Connor (1995, p. 195) proposes that hospice care '... had its beginnings towards the end of the 19th century, being mainly work of catholic religious orders providing inpatient care.'

Prior to the twentieth century 'hospice' was seen to be a sanctuary for the chronically ill and disabled, where people taking religious orders assumed care and control. Yet the word 'hospice', with its root in the Latin *hospes* originally meant 'guest'. Cicero (106-43 BC) talks of *hospes* as a host who welcomes the unexpected guest. Gradually the term hospice became associated with the place of rest for pilgrims and travellers—primarily for the weary to partake of nourishment and sleep. Gradually, and in response to the injured in the Holy Wars, hospices were seen as 'way-stations' where the wounded could be treated and the dying crusaders finally rest.

As medicine's empiricism advanced the objectification of disease, the contagious and infirm patients were segregated from the travellers. Hence, the caring functions of these hospices were overtaken by a curing focus and the concept of the modern day hospital was born. The biomedical model of cure took centre stage and death was relegated almost to a position of invisibility. In the post-war years (World War II) there was a perceived laxity in adequate and responsive health care for the dying (Ashby 1998, p. 47). Indeed, throughout the mid-twentieth century medicine and technology's symbiotic movements nurtured the discovery of therapeutic alternatives that evaded death. Subsequently, health care personnel soon adopted the premise that death equated with failure and dying patients were seemingly banished into isolation, either physically or cognitively and sometimes both.

The partitioning of palliation as a specialty in both medicine and nursing gave credence, value and worth to health care personnel's involvements with the dying patient. Mainstreaming of palliative care advanced largely by developments within medical specialists groups such as oncologists and government funding was diverted to establish multidisciplinary palliative services to support those specialists. Funding appeared to be forthcoming for those people suffering from cancer. However, people dying from chronic illnesses were largely ignored by the growing specialist groups and remain as a reminder of the sad legacy that nurses now have to traverse to gain recognition for their work in this area within the community. Most community generalist nurses had a previous commitment to palliative care principles for chronically ill patients long before the medical specialty came into vogue.

The development of palliative services differed within each state of Australia. However, the risks of medicalisation of dying became a reality with some palliative care teams being managed by medical practitioners with little or no insight into the complexities of care (Kearney 1992, cited in Rumbold 1998, p. 10). Finlay and Jones (1995, cited in Ashby 1998, p. 51) describe three separate yet complementary guises of palliative care:

... the *palliative approach*, which should be a core skill-base of all clinicians; *palliative interventions*, which are often carried out by other medical or allied health specialists (eg. radiotherapy, surgery and physiotherapy); and *specialist palliative care*, which is delivered by specialist clinicians in the context of a dedicated multidisciplinary team.

Such segmentation acknowledges on the one hand that specialised care is warranted for dying people, but also asserts and authorises interventions from general practitioners. In this study, three participants (Pauline, Sally, Yvonne) advise that the knowledge base of many rural general practitioners regarding the principles of palliative care can be severely inadequate. The present fashionable movement within health care, heralding a future direction towards home-based care, places pressure upon medical personnel to advance their scholarship in palliative care. Indeed, the medical academy has already contrived the space for the development of educational programs to assist general practitioners with the appointment of six medical academics, for the palliative specialty, at professorial level. Regrettably, the number of rural based medical practitioners responding to educational opportunities in order to expand their palliative care knowledge appears sluggish (Ashby 1998, p. 50).

In direct contrast however, is the high proportion of curiosity and interest in specialised palliative nursing courses at both the undergraduate and post graduate level. Within Australian Universities post graduate nursing courses, palliative care is either offered as a

discreet unit or subsumed within an oncology program. In addition, the need for palliative care input into acute care areas as cardiac intensive care is increasing (Robertson-Malt 1996). As in-patients of hospitals in the last decade of the twentieth century appear to be chronic sufferers of illness and the nursing care required is intensive (at a palliative level) in nature, the requirement that all nurses have extensive skills in palliation is ostensibly important. Nevertheless, this demand could be judged as problematic. Many 'specialists' could argue that all 'generalists' should have a working knowledge of their particular area. However, it could be argued that in doing so it could be likened to spreading the jam too thinly over the bread. Ultimately, it would be the patient who would suffer as maintaining high standards of care could become an issue. Advanced nursing practice appears in part to address these anomalies (Castledine 1994). However, it remains to be seen whether or not nursing successfully embraces the increasing demand for palliative services in the generalist arena without compromising its professional values.

White (1998b) attests that it is important to set up palliative care nurse consultants positions within the acute hospital setting. White (1998b, pp. 219-223) declares that a palliative nurse clinical consultant could provide a consultancy service to all health care workers; serve as an education resource for staff, patients and families; act as a counsellor; assist the discharge planner and become pivotal in research enterprises surrounding palliative care. However, in acknowledging that as a resource person the consultant will be invaluable, one specialist cannot be expected to be the 'grass roots' player in each situation. Role expansion and role extension could be developed at a team level. Using the central tenet of palliative care, namely a multidisciplinary approach, each member of the team could accomplish and fulfil these demanding and time consuming role functions appropriately.

Currently, the palliative nursing care debate surrounds the questions of whether or not palliative nursing is a specialised practice or, if the principles of palliative nursing are the precepts of all holistic nursing care. Lee (1998, p. 209) contests the latter is an unrealistic expectation on two counts:

First, this suggestion assumes that prior to the introduction of palliative care organisations, the problems regarding care, as experienced by people who were dying, were due primarily to a lack of education about holistic care. ... Second, it ignores the complexity of the problems that people and their families face at the end of life.

Similarly, Aranda (1998, p. 24) explores some of the contemporary tensions between the generalist/specialists models of palliative care in an already expansive health care system. She warns that with declining funding and increasing patient through-put, the risk of a

creeping mediocrity infiltrating an already overburdened acute care workforce is eminently possible and highly probable. There are no easy propositions to overcome this developing tension. Certainly there is some expectation that all nurses will know how to care for dying patients but that prospect negates the special needs of some dying patients and favours a generic approach to dying. Aranda (1998, p. 24) considers there will always be a need for a specialist focus in palliative nursing care so as to encourage research and the development of new knowledges for complex and difficult situations.

Aranda (1998, p. 30) further suggests that the future of palliative nursing as a specialty may be precarious, even dubious, especially if practitioners do not continuously contest its ideological and philosophical bases. Notwithstanding that the early hospice enthusiasts created the space in which care of the dying could be celebrated, the visions they effected have to be constantly reassessed against contemporary and ever changing demands. Leaders and clinicians within palliative nursing circles have to learn to juggle many balls simultaneously. Politically, in responding to increasing demands for funding research and health care services, and seeking and maintaining nursing input into policy making. Clinically, in continually advancing therapies, and sustaining a central role for nursing within the multidisciplinary team. Professionally, by ensuring that as advocates for patients they are appropriately placed in decision making within the palliative care milieu and that nurses continue to energetically probe conventional and unconventional understanding(s) of their practice.

Palliative nursing in the community setting

Home-based care has become increasingly significant regarding the amount of time terminally ill patients spend at home in their final year of life. Neale (1993, p. 61) claims that in Britain, patients requiring palliative care spend 90% of their last year at home being cared for by family, supported by members of a community health team. In Australia, the growth of palliative care services is seen as a hallmark of the 1980s. In the early part of that decade palliative care was confined to a few hospice programs in major cities, mainly organised through religious affiliated health care institutions (Ashby 1998, p. 48). However, during the mid and late 1980s, considerable interest, sparked in part by community demands and shrinking health care funds, led to the establishment of outreach community hospice programs and the founding of community palliative care services as we know them today. Presently, there exists an open system of care whereby patients can access hospital, home and hospice care according to their needs (Maddocks 1990). However, this system is made possible only when and where the triangulation of services is available, most often limited to within major metropolitan or urban areas. There is still a paucity of extended services in rural and remote areas, with some patients

having to travel enormous distances to achieve comparable assistance (FitzGerald 1995a; Sharp, Nay et al. 1996).

Within the community setting in Australia, it is argued that palliative nursing parallels the generalist/specialist debate and follows two distinct models of provision (Lee 1998, p. 209). Palliative care nursing can be provided by those nurses who work only with palliative care patients or, by generalist community nurses who work with several patients, a few of whom require palliative nursing care (for example Sally's daily routine as previously explicated by her diary entry). While both models are indispensable within the current community based health care system, the level of palliative nursing expertise within the generalist group tends to fluctuate widely. Consequently, the friction between those who uphold one model contra to the other is discernible (Lee 1998, p. 210) and is evidenced by one participant in this study (Erica). The consultative capacity of the specialist group is balanced by the twenty-four hour service offered by generalist nurses. The former being an invaluable resource for the latter in many circumstances of compromised care. There could be an inference of ownership issues within this rivalry which is exacerbated or appeased according to the nature of the relationship between the two groups, or individuals within those groups. Rather than entering into this debate, which serves only to alienate and divide members of each group and in light of the previous discussion which seeks to ascribe a hierarchy of worth to each group, I have chosen to uphold my appreciation of the worth of both models as they currently stand. The participants in this study emanate from both groups. Having developed a high regard for the roles they individually and collectively play in the care of patients, I would suggest that rather than entering into a seemingly unresolvable debate in this thesis, there should be some acknowledgment and recognition of future potential for both groups to work together in suiting the needs of the patient.

Palliative care requires flexibility on the practitioner's behalf and a shift from the cure aspects of medically dominated health care to the multidisciplinary aspect of care. The role of community nurses in delivering palliative care is central to this collegial focus of care which encompasses the patient, their family and their friends. Samarel (1989, p. 314) notes that 'as the possibility of cure diminishes, the less aggressive caring aspect of attention assumes a greater importance.' Explicitly the emphasis in palliative care and the hospice movement has always been to treat the family as the unit of care (Neale 1993, p. 59). In rural and remote areas however, the family inevitably assume the role of caregivers and so become primary to the success of community palliative care. Twigg (1989) alludes to the ambiguity of the status of family as informal carers as they often move in, out and between the position of being a client or patient in their own right. Many community nurses view 'family as carers' as co-workers and an inestimable resource in

the provision of some aspects of personal care. However, these conflicting notions can be problematic for the carer if the community nurse does not have the skills to distinguish the immediate needs of the carer. Moreover as co-workers, family members can at worst be susceptible to exploitation and marginalisation (Neale 1993, p. 65). Relationship ethics described by Astrom, Jansson, Norberg and Hallberg (1993) dictate that nurses are well placed to act morally and supportively to confront and prevent such abuses occurring.

As health professionals who work alone, community nurses have always cared for the terminally ill. The current trend appears to be that hospice philosophy is increasingly shaping their perceptions of their work with the dying (Harris & Finlay-Jones 1987, p. 82). It is escalatingly difficult however, to fulfil these principles working in isolation, professionally unsupported and financially disadvantaged. In a number of Australian states trained volunteers have been used to supplement and extend palliative care services where funding has become scarce. Maddocks (1990, p. 537) claims that some volunteers provide services such as listening, friendship, comfort and time better than many professionals. While these qualities might propose partially what a nurse might bring to the palliative care situation, they by no means paint the whole picture. Palliative care nurses' work is confrontational and calming, calling for highly developed skills in pharmacological and symptomatic interventions, as well as counselling and comfort performance. Notwithstanding that there is a role for volunteers in an already stretched health care system, I contest that consumers of palliative care are worthy of skilled and professional health care given by well educated, highly competent registered nursing staff capable of entering into an authentic therapeutic relationship.

There is no doubt that trained volunteers do have a place within the provision of palliative care however, sometimes good listening needs to be undertaken by professionals who can also interpret the patient's needs and simultaneously deliver the high level skills required. I contend that the use of volunteers as 'first line' personnel is tantamount to false economy on a number of levels. The costs associated with persistent procrastination are not necessarily manifested in fiscal terms. Patients and their families nevertheless, may suffer needlessly and substantive care may be unnecessarily detained because educated personnel were unable to be present through lack of appropriate funding. Additionally, recruitment and training of volunteers can be expensive, especially if the volunteer coordinator is a salaried worker (Mount 1992, p. 61). There is lack of evidence however, in terms of efficiency, that volunteers are less cost effective and I would herald the need for further research into the financial benefits or disadvantages of using volunteers in the community palliative care setting.

Until changes in the valuing, credibility and worth of palliative care are reflected in the funding arrangements, palliative care will continue to be devalued and its status truncated. Financing community health programs, of which community nursing and community palliative care are integral remains convoluted and sometimes enigmatic. The demands for community based services (across all health care areas) is approximately eighty percent of the total health care demands (Calder 1998). The remaining twenty percent demand is concentrated within the institutions (hospitals etc). However, the funding allocated to these two areas is inversely proportional, with eighty percent of the health dollar directed to institutions and twenty percent to community. In spite of the moves to take health care out of institutions, community care continues to remain the poor relation.

There is inequity in the financial arrangements of health care at both the macro and micro levels. Cost sharing arrangements between the Commonwealth and individual state bodies have set an agenda to redress the imbalance between institutional and community care (Calder 1998, p. 58). However, funding for palliative care appears to be caught within a web of intrigue and complex arrangements which do little to reverse this perceived discrepancy (Calder 1998, p. 64). While ever the delivery of palliative care continues to commit to tripartite arrangements (home, hospice and hospital) the institutions (hospice and hospital) will drain a high proportion of those allocated funds. Yet it is this very notion of coordinated care that makes the present arrangements of palliative care so attractive to health care planners. The conception of services from hospital, hospice and home working together to procure advances in access, fairness and options in cost effectiveness and cost benefit has been identified as crucial to the delivery of viable services in isolated community and rural settings (Calder 1998, p. 66).

This coordinated care concept has been examined with a view of developing a national palliative care casemix classification (Smith 1995) and (Calder 1998). Both authors agree that Maddocks' (1990) request for equality of care between the three areas where palliative care is practiced viz. home, hospice and hospital, should be mirrored in the funding arrangements and casemix appears initially to be a transient answer. Given that in 1997, federal funding for palliative care at all levels decreased significantly with the termination of funds via the Commonwealth Palliative Care Program (CPCP), the Medicare Incentive Package (MIP) was to assume total financial responsibility (Calder 1998, p. 62). Clearly with requests for palliative care services increasing, MIP alone with recurrent funds of less than \$40 million nationally, will not meet these demands (Calder 1998). Palliative Care Casemix Classification (PCCC) was trialed in Victoria, New South Wales and Western Australia and revisions made resulted in a further study to be conducted in five states from 1996 which ultimately influenced the future budget allocation nationally (Smith 1995, p. 6). This model and the results of the study are

lauded as the blueprint for funding of other, similar areas of health care that simulate cognate circumstances to palliative care (Smith 1995).

In the particular area of the Australian state where this study, the subject of this thesis, was conducted, the MIP and CPCP funding in 1989 enabled increases in the palliative care services to accommodate twenty four consultative services to clients and health professionals in the community. It also provided for the equivalent of three nights per week nursing for dying people who wished to remain at home and required comprehensive nursing care (night sits). Palliative care services were also mandated to integrate and in 1992 a project officer was employed to explore the possibilities of this union occurring. However, during the following twelve months it became clear that there were some structural and organisational difficulties that precluded integration and so negotiations were temporarily truncated. In 1995, in response to escalating inquiries, expanding referrals and increasing demand on palliative care resources, integration was again muted for discussion towards reaching a workable resolution. Today, several matters remain pending on the negotiating table. I contend that while these issues stagnate developments at one level, community palliative care clients continue to crave care. Thus it is with on-going promises of reductions in funding, uneasy alliances and capricious futures that the participants in this study passage their way through their daily practices of palliative care.

The future of palliative care and questions surrounding funding, interrelationships and grief are realised contributors to the experience of sadness in this context. This study therefore seeks to explore dimensions of sadness as experienced by these sixteen community nurses.

A summary of the thesis

This thesis records brief moments in the lives of the sixteen participants as they recall their experiences of being sad while engaged in the delivery of palliative care nursing in their respective community settings. It is also a sojourn for you and I as we contemplate their stories, retelling them within ourselves to make meaning of the various experiences. Short-lived as it may be, this research signals a different way of thinking about nurses' sadness as they become involved with patients when they are both at their most vulnerable.

Foreword

van Manen (1990, p. 130) claims that 'phenomenological research is a poetizing [sic] activity'. Linking together, in a primal sense, language and world, poetry transforms everyday living into poetic thought, bringing intensity to the most ordinary of human experiences. It is within this vein that, in the prelude, I stage symbolic episodes, as poetry, from my own practice as a community nurse engaged in palliative care. In each stanza I provide the reader with a glimpse of the shared world of the participants and myself. Finally, I issue an invitation to readers of this thesis, to join with me and enter the lived world of the participants in this study. The poem ends with a promise of the possibility that this study will re-vision and re-search dimensions of sadness for the community palliative care nurses involved in this study. By understanding these dimensions of sadness we, the readers of this thesis, will also be privileged in gaining further insight into their day-to-day relationships with dying people.

Chapter One: Introduction

This introductory chapter paints, with broad brush strokes, a background for the study. The story of how the research question was formulated and my role in its configuration has been delineated. As embodied human beings the participants and I continuously self interpret as we join in a dialogue about their experiences of sadness while engaged in palliative care in a community setting. By recognising the primacy of intuition and experience, these interpretations of human experience, defined by their self-understandings, opens a plethora of possibilities of meaning for the phenomenon in question (Dreyfus 1994).

Included in this chapter is a brief but focused exposé of some of the literature about sadness. Its relationship to nursing as played out in the nursing literature is also unmasked and presented. Incorporation of such a commentary is partially to put the study into context and also to highlight the paucity of literature discussing sadness as an experiential category. A short history of palliative care as a medical and nursing specialty is explored and the unpredictable development of palliative nursing is brought forth for further questioning and debate. Further, roles and functions of community nurses and specialist community palliative nurses, together with the vagaries of funding mechanisms, are realised as pertinent sources of sadness for participants in this study. Side by side in this discussion a possible future for palliative care services within the community is pondered. Finally in this chapter, brief synopses of subsequent chapters within this thesis are collated to provide a summary of the work as a whole.

Chapter Two: Reflections on the pathways of thinking, a choice of methodology

Consideration of my journey through the philosophical, methodological underpinnings of this research is traced in Chapter Two. The researcher's research journey is as important as the research journey itself and this chapter moves the reader through the various methodological magnets that attract and capture my thinking as I make my meaningful pilgrimage through the process. At the forefront of my methodological choices is my own bias for the centrality of experience in this research, combined with an understanding that multiple realities and possibilities will most likely be the thesis outcome. I clarify the reasons why I am drawn towards weaving congruent understandings that emerge from similar philosophical bases. Methodologies that '... resonate with the interpretivists' emphasis on the world of experience as it is lived' (Schwandt 1994, p. 125) coin the research framework from which flows the resultant methods and study design. In addition, I discuss why I choose to colour the research lens by the writings of contemporary scholars who, like myself, do not cement their thinking in a singular schema.

Once I have articulated the reasons behind my choice of philosophical premise I launch into an in-depth discussion of the life and writings of various philosophers chosen to guide this research. Following this thorough coverage I present a synopsis of established nursing research that has used similar philosophical formulae.

Chapter Three: Study Design and Methods

The substantive content of this chapter is a detailed explication of how I have mapped the research process. Using seven stages through the research cycle I enumerate my actions within each stage. The participants are introduced in this chapter and the reader is able to locate them in their various worlds of community nursing practice. The ethical and moral issues surrounding this research are of great importance to me and the consequences of researching with people who may be vulnerable are deliberated. I have dedicated this thesis 'in praise of conversation'. While developing how I engaged with the participants this section of the chapter will illustrate how the flow of conversation between the participants and myself allowed us to probe deeper into their meanings of sadness. The use of a computer assisted tool may seem at first to be antithetical to this research. However, with the large amounts of data it was necessary to employ such a tool as a means to effectively manage the data, as is evidenced in this particular section of the chapter. The final stage of the method, engaging with the text, is related back to the paradigmatic stance debated in Chapter Two. I bring this chapter to an end with a non-

conclusive discussion about rigour in research and its applicability to interpretive research projects.

Chapter Four: “Old Dogs and Tough Old Tarts”

In this chapter I take great pleasure in introducing six of the sixteen participants to the reader. I spend most of the chapter interpreting and retelling their stories of sadness and to lend authenticity to the process, punctuate my interpretations with text from the particular participant’s transcript. On completion of each story I provide a boxed entry that signals the nodes used in the NUD•IST program. Following each boxed entry I have written a personal poetics of each participant’s experience. As well as showing my aesthetic thinking within this research these poems are public marks of tribute to the six participants who shared some of their most tragic life-tales. This chapter is indeed the first stage of analysis and at the end of this chapter the reader will be led towards the following chapters, the two substantive chapters of analysis.

Chapter Five: Temporal Rhythms of Sadness and Chapter Six: Kinship Sadness

The decision to place one chapter before another was very difficult as for me the temporal rhythms of sadness and kinship sadness are in a circular relationship. Nevertheless, for convenience of reading and for articulating the differences between the two ideas I have made two distinct chapters of analysis. The concepts and issues brought forth in both chapters however, are constantly braided with the lived experience of these sixteen participants and their interconnectedness is a powerful and important message to convey here in this introductory chapter. The reader is moved through each of the analysis chapters in a manner that is unique to each chapter. At the end of chapter six the circularity of the two chapters is emphasised and the reader is invited to move towards some understanding of what it might mean for these sixteen participants to be sad.

Chapter Seven: Complexity, paradox and Multidimensionality: an interlacing trinity towards understanding

This final chapter of the thesis does indeed present the thesis of the work. Through a recognition of complexity, paradox and multidimensionality portrayed by a textual holographic model the reader is again brought back to the substantive practice of these sixteen community health nurses through the conduit of sadness. By understanding their sadness the reader can also gain insight into their practice and vice versa. The thesis

concludes as it began with a poetical appreciation of the work of community nurses who are engaged in palliative nursing care. This set of stanzas however, dramatise the work of these community nurses from the data collected and interpreted in this research. As well as providing the reader with a condensed narrative of the study it is another personal response of gratitude to the sixteen nurses who helped me with this research. Like most of my work in life, this research comes from my heart and my poetry a mirror of my soul. I trust this thesis will be read with sensitivity, awakening acclamation and celebration for the work of community nurses everywhere.

Styles used in this thesis

Conversation is the main word used in this thesis to signify how the participants and I related and exchanged information. At times however, I refer to our time together as an interview, as in my explanation of the research to each participant I informed them that I would gather information from them at interview. Thus the two words are used interchangeably.

Words written in the font *italic Times* are transcribed verbatim of the taped data from the participants.

The referencing style follows the Author-Date system and is guided by the rules set down in the Australian Government Publishing Service Guide [AGPS] (1994, pp. 148-169).

Single inverted commas have been used for short quotations or emphasis. Double inverted commas have been used for direct speech from participants except when their words are within a block, indented quotation.

Footnotes has been used extensively to define medical and nursing terminology and to explain further certain words or phrases used in this thesis.

Surnames preceded by particles, such as van Manen, follow the form of lower case initial letter for the particle rather than using an anglicised form of capitalising the initial letter (AGPS 1994, pp. 47-48).

Chapter Two

Reflections on the pathways of thinking: a choice of methodology

*Do not give me a guru
To sit at the feet of.
Do not provide me with a prophet
To follow into the wilderness.
Do not send me a seer with secrets
To guide me to life everlasting.
I am not looking any more
For someone to tell me the way.
I have found, in my life, many answers,
None of which turned out to be The Answer.
I have chosen various messiahs to follow in my time,
But each of them turned out to be false.
Now I know that I must follow my own heart
Along my own path.
Now I know that there are no answers
But only questions,
And the whole joy and anguish of living.*

(Anne Spencer Parry and Marjorie Pizer)

Introduction

In the previous chapter I presented the questions central to this research. These questions emerged, not as a result of the inquiry acting upon me but rather they stem from me: rising from the person that I am, through my own lenses of gender, social class, race, ethnicity and language. My observations of the research are situated within myself, the observer and researcher. My experience of the research 'taints' what I see and what I perceive to be of importance to interpret. Thus, at best I can hope to furnish only a partial exegesis of the picture I have of the study, together with its possible consequence. Similarly, the participants in this study cannot re-present their exact experiences of sadness; '... all they can offer are accounts, or stories, about what they did and why' (Denzin & Lincoln 1994, p. 12). By seeking to understand another's world of experience, I have chosen a design of interconnected 'ways of knowing' that relates directly to the philosophical traditions in which this study is situated. These traditions or prejudices⁸ (as Gadamer 1975 would favour) herald the ontological and epistemological

⁸ A central tenet of Gadamer's philosophy which is discussed in detail later in this chapter (see p. 58).

foundations of this methodology which in turn guides the research design including methods of data collection and interpretation (the latter to be addressed in the following chapter).

Simply defined, methodology is the study of method. In some contemporary research manuscripts the section devoted to methodology typically contains discussions and critiques of the ways and means by which these methods are attained. What I propose to submit in this chapter is an arrangement of ideas, *informed* in part by the philosophical traditions that have been interpreted by myself and are re-presented here. The chapter refers to the writings of Heidegger and Gadamer, whose phenomenological and hermeneutical works traditionally 'fit' within the interpretive paradigm. In addition, I have found that the contemporary writings of Birch, Maturana, Varela and Capra resonate with my opinions about knowledge and knowledge construction. Thus this chapter weaves together ideas from phenomenology, hermeneutics, constructivism and cognitive science, and, like the words of Parry and Pizer (1982) in the opening poem of this chapter, I assent to their acclamation of the self creating direction towards understanding.

In pulling together all these conceptions and laying down a pathway of thinking I am inviting the arbiters of this research to determine its integrity, its trustworthiness as well as judging its usefulness for informing the discipline of nursing (Guba & Lincoln 1989). By initiating a 'decision trail' (Koch 1994) underlying assumptions about my interpretations about coming to knowledge are unveiled for scrutiny and assessment. The resultant methods and design choices (enunciated fully in the following chapter) can be evaluated for their suitability, congruity and applicability, a process of 'merit' that Sandelowski and Darbyshire allude to in their conversation with Emden (1997, p. 138).

Issues about methodology underpin the organisation of any scientific inquiry. According to van Manen (1990) a methodology, its underlying philosophy and resultant methods, must show congruence within any research initiative. Ideally these three orientations (methodology, philosophy and method) need to be congruent with the world views of the researcher and the applicability to the question(s) posed. Stanley and Wise (1993, p. 150), among others, indicate that the researcher's presence in any research activity cannot be discounted or ignored. They profess that rather than continuing a pretence that researchers and research are not inextricably linked, that methodologies be utilised which recognise and make use of the strengths of the personal as experienced. It is with these notions, together with the overwhelming desire to be considered a seeker of understanding rather than a repository of 'facts', that I use this chapter to unfold my pathways of thinking, and at the same time verify the use of 'interpretation' as the paradigmatic preference for this research.

Choosing a paradigm

This inquiry, concerned with the meaning of experience, sits appropriately within the interpretive paradigm. Additionally, the context of the research is firmly set in nursing and describes issues that are of significance to the practice of nursing. While contemporary nursing research avails itself of all research paradigms I concur with Taylor (1994a, p. 50) in her appreciation of the parallels between nursing and the interpretive paradigm, more especially the pursuits within phenomenology. However, Allen, Benner and Diekelmann (1986, p. 37) argue for pluralism when it comes to choosing a methodological model for nursing research, claiming that decisions about appropriate approaches should be context driven, rather than outcome bound. Cody (1996) further argues that nursing researchers should strive to describe the phenomenon in question from a nursing perspective rather than 'drowning' in the glut of viewpoints that are strafing nursing from other disciplines. Both Cody (1996) and Allen et al.(1986) invoke nursing researchers to continually and critically appraise philosophic foundations for their relevancy to nursing science.

In leaning towards an interpretive stance rather than a critical-social or empirical-analytical position I am making certain suppositions about knowledge, reality, experience and truth. Using these criteria, culminating in a brief sketch of the central tenet(s) of each model, Table 2.1 articulates the main differences between these divergent paradigms.

The health professions have traditionally been metaphorically 'wedded' to the empirical-analytical paradigm, using 'scientific methods' for the conduct of research. It is only of late that some social science researchers and an increasing number of nursing researchers have become interested in pursuing inquiries that sanction the use of methodologies within the interpretive or critical frameworks. It is perhaps nursing's greatest challenge as health care researchers, to work alongside other professionals who view research processes other than solely within the scientific methodology as irrelevant and time wasting. Leininger (1992, p. 394) recounts her somewhat frustrating experiences of trying to fund her first ethnnonursing study, revealing that the prevailing view from funding bodies was a lack of interest in such 'unscientific' projects.

Criteria/Paradigm	Empirical-Analytic	Interpretive	Critical-Social
Knowledge	Formalised knowledge generated from testable hypotheses. Knower is distinguished from the known. Observer is distinguished from the observed. Theory and practice are separate. Knowledge is universal.	Knowledge is shared. Based on culture, skills and practices perceived by individuals and interpreted through language. Knowledge is contextual.	Knowledge is not discovered, it is created or negotiated by communities. It is contextual.
Reality	Unitary and only understood by scientific method of inquiry	Multiple realities requiring multiple methods to understand them	Multiple realities which are problematic through distorted communication
Experience	A possession or trait of a person. Reduced to distinct observations.	Experience is dialogical. The 'now' is an amalgamation of our past present and future.	Experience is tied to social processes. Power, gender and hierarchical relations influence all experiences.
Truth	Only one, fixed truth which can be measured.	Multiple truths. Each situation or event is a refinement of preconceptions.	Multiple truths penetrated by value interests (social, political, gender, race).
Expected outcome	Prediction and control, technically exploitable knowledge.	Understanding at the level of ordinary language and action. Finding meaning and beliefs underlying the actions of others.	Emancipation. Radically improving human existence. Practical and public involvement in knowledge formation and use.

Table 2: Adapted from Allen, Benner and Diekelmann (1986) and Gunning (1994).

Sandelowski (1997) proposes that offering a range of balanced critiques and practices from within the qualitative framework, thus demonstrating to others that these research methodologies are useful and purposeful, is a way of voicing nursing's independence from the dominance of the medical paradigm. Notwithstanding any success of the implementation of various measures to illustrate a coming of age within nursing research there are other determinants that ostensibly halt nursing's progress towards establishing credence using new paradigm research. In her deliberations of the understanding versus efficacy debate, FitzGerald (1995b, p. 2) points to an imbalance of power within certain administrative bodies for health noting that medical personnel (as apposed to nursing personnel) largely control the financial and ethical decision making in health management as well as research. Issuing an invitation to rally together, FitzGerald (1995b) among many other contemporary leaders in the Australian nursing scene (see Parker 1991;

Pearson 1992; Koch 1995 & Walker 1997 for example) pleads for nursing researchers to let their voices be heard. Voices that celebrate different ways of knowing, through the utilisation of different paradigmatic stances that are more befitting the humanistic interests of nursing inquiry.

By examining the expected outcomes or central tenets of the three distinctive paradigms in the model presented (see Table: 2), the differences between their goals are elementary. The empirical paradigm supports scientific methods which purport to be able to predict and control findings using large samples or populations and employing statistical tests. Generalisations are made to even larger populations from the analysed data. On the other hand the purpose underpinning the interpretive position is to attempt to understand and make meaning. Methodologies that use thick descriptions as data are paramount within this paradigm. Moreover, in-depth and focused interviews with a small number of key people are better able to provide access to such descriptions. In using methods from this paradigm there is no attempt at generalisation. The data and consequent interpretations and understandings remain context bound and responsive to the researcher 'in dialogue' with the participants of the study. The final paradigmatic stance presented in this model is that of the critical-social. This paradigm responds to questions of how consensus of meaning is obtained, taking note of cultural as well as historical constructions which determine an individual's reality. Crowe (1998, p. 341) asserts that '... particular interests are served by any construction of meaning and those meanings which are privileged in any culture will reflect the dominant interests of power'.

Explicating, interpreting and articulating the dimensions of sadness for sixteen community nurses engaged in palliative care is research about being-in-the-world-of-nursing, and as the researcher I require that the methodology allows me to respond and value what it means to be human as well as appreciate the significance of dialogue and discourse. In particular, the use of phenomenology concerns itself with our way of being in the world and attempts to '... understand the "whatness" of ordinary life' (Munhall 1994, p. 4). Parallel with some phenomenological thinking is the process of hermeneutics. Methodologically both Heidegger and Gadamer embrace hermeneutics as the way of being-in-the-world. Hermeneutics as method proves an invaluable way of uncovering different understanding and so hermeneutical approaches are involved in informing this research.

Contemporary scholars who favour panexperientialism⁹ as important in understanding the human condition also inform this research, in particular the work of Charles Birch (1995). The embodiment of knowledge, cognition and experience is a focus of study for current cognitive scientists. In addressing the relationship between science and experience this study recognises that science has been a voice of authority in our culture. The proponents of cognitivism (Maturana & Guilloff 1980; Maturana 1988; 1988b; 1991; 1992a; 1992b; Varela, Thompson et al. 1992 & Capra 1975; 1982; 1988; 1997), rather than dismissing science as having no bearing on day-to-day experience iterate that cognitive science articulates a circular dialogue between science and experience. Inspired and guided by the works of the phenomenologist Merleau-Ponty this 'new' science of the mind provides a pragmatic link between the phenomenal world and the scientific culture (Varela, Thompson et al. 1992).

I am aware that readers of this chapter thus far could lay claim that I am being somewhat 'methodologically promiscuous' (Pearson 1998, p. 19). For many postmodern researchers however, there no longer appears to be a set of rigid boundaries that demarcate methodologies within each paradigm. Indeed, both Lowenberg (1993) and Schwandt (1994) contend that contemporary interpretive research is ongoing in its own evolution, responding in part to the influences of postmodernism, feminist and/or critical theories. As a *bricoleur*¹⁰ by intertwining four approaches to this research (phenomenology, hermeneutics, panexperientialism and cognitivism) I have been mindful only to mix methods *within* the interpretive paradigm, heeding Leininger's (1992, p. 395) warning that mixing methods *across* paradigms infringes their distinct integrity.

Even though this methodology focuses on the particularities of Heidegger, Gadamer, Birch, Varela, Maturana and Capra I must emphasise that the key word in this exposé of a research methodology is *informed*: In response to Crotty's (1996b) criticism of a selection of thirty nursing research projects published in the early 1990s, I am not striving to 'do' a particular methodology (phenomenology, hermeneutics or cognitivism); although certain epistemological and ontological outcomes will be realised¹¹. Rather, this research

⁹ Also known as psychicalism or panpsychism, panexperientialism is offered as an alternative to dualism which posits the reality of feelings and the subjective in general inasmuch as experience is fundamental to the basic entities of the world (Birch 1995, p. 2).

¹⁰ According to Denzin and Lincoln (Denzin and Lincoln 1994) (p. 2) a bricoleur produces a bricolage or pragmatic, changeable multimethod construction to seek solutions for research problems. Denzin and Lincoln perceive that qualitative methods are, by their very disposition, bricolages in formation.

¹¹ For example, the 'beingness' of being community palliative care nurses is perpetually explicated through the inquiry into the participants' lived experiences

embraces a 'plurality' of thought proffered by Heidegger by which he recognises that knowing arises in and from a multiplicity of dimensions of our everyday lives.

In his writings Heidegger renounces 'finitude' in all forms (inquiry, meaning and interpretation), which is an approach that Allen, Benner and Diekelmann acquiesce (1986). They in turn provide encouragement for an openness and willingness to embrace the concept of plurality in approaches to nursing research. While this research does adopt some ideas from traditional phenomenology (as guided by Heidegger) it does not attempt to reproduce 'authentic phenomenology' as prescribed by Crotty (1996b). In his critique of nursing researchers use of phenomenology Crotty (1996b) advises that most nursing researchers use what he describes as a North American phenomenology, a *new* phenomenology. For me however, a conundrum ensues from this assertion. As in researching ideas, and in true hermeneutical fashion, I believe that we practice a *new* 'ology' when advancing the methodological ideas of others. It is my intention that in this research I will not pretend to espouse a 'purist' approach. Indeed, I believe it to be eclectic and evolving in its methodological analogue within the interpretive paradigm, thus more in keeping with Heidegger's notions of contingency, plurality and temporality.

Careful reading of Heidegger's opus *Being and Time* reveals that his philosophical position embraces a plurality, not merely of methodology and method but also in his discussions of thinking, knowledge and truth. Dreyfus (1991, p. 37) characterises Heidegger as a *plural realist*—maintaining that 'for a plural realist there is no finite point of view from which one can ask and answer the metaphysical question concerning the one true nature of ultimate reality'. From this point of view the use of philosophical hermeneutics in this research will include an interpretation of the research process itself as much as the phenomenon in question (Lowenberg 1993, p. 58).

I am sympathetic however, to the pitfalls of 'blind faith' in selecting a particular philosophy and methodological position, as both Crotty (1996b) and Paley (1995; 1998) passionately condemn. Had I fallen into such a trap in this research I would not freely accede to a plurality of thought or methodology. I agree with Macann's (1992) comments in his discussion of the predicament of an uncritical allegiance versus an uncritical dismissal of Heidegger's philosophy. For me, Macann's (1992) premise augments well for each of the philosophers' works utilised in this thesis. Being in favour of neither uncritical allegiance nor uncritical dismissal he declares that:

Heidegger wanted his *Complete Works* to feature as a source from which philosophers would draw not *information* but *inspiration*, the kind of inspiration which would set them on their own path of thinking (p.5).

Rather than severing the two (inspiration and information) I lay claim that this research draws both information and inspiration from a selection of methodological dictums, whose historicity, contemporary applicability and usefulness for this and other nursing research will be further elucidated. However, before embarking on a critique of such methodologies I wish to address the concepts of 'context' and 'experience' as being pivotal to interpretive research.

The Primacy of context: the centrality of experience

It has been argued that nursing research spent its early years drawing from the empirical analytical paradigm using positivist methodologies (Parker 1991; Leininger 1992; Pearson 1992; FitzGerald 1995b). Following social and psychological scientists, nursing researchers have developed intricate statistical analyses for the purposes of predicting and/or controlling human behaviour—those very same behaviours that we find fascinating and at the same time propose to be unpredictable and uncontrollable. If the latter is true for nursing researchers then it begs the question: why continue to develop such intricate mechanisms? Is it because this type of inquiry (positivist) has long been viewed as the only valid 'scientific' inquiry? Or, is it a fundamental belief that individual experience is little more than 'hearsay' or 'anecdotal' evidence, and is therefore untrustworthy in mainstream social science? Despite the obvious contradictions highlighted by this path of questioning, many of these '... context stripping research procedures' (Mishler 1979, p. 3) remain dominant within the realms of social inquiry. Yet notwithstanding the clear 'ill-fittingness' of these processes some researchers have been caught in the language of certainty (proof), and the application of the scientific method to social science has been a source of disappointment to many social science researchers:

... the continued attempt to build general laws of social behaviour seems misdirected, and the associated belief that knowledge of social interaction can be accumulated in a manner similar to the natural sciences appears unjustified (Gergen 1973, in Mishler 1979, p. 5).

Dissatisfaction with orthodox approaches for social research has been the subject of Reason and Rowan's (1981) call for the development of 'new paradigm' research in which Heron argues against processes that diminish the self-determination of the human condition. He further contends that the ability of human beings to choose and offer meaning to their own experiences and actions is what characterises them as human beings. However, traditional scientific methods used systematically and quite deliberately in human sciences remove this idea of 'self-determination' in favour of a somewhat alarming view that people can be manipulated or exploited. It is precisely peoples'

experiences and how they give meaning to experiences that provides the impetus for this and other similar research.

Phillips (1993, p. 166) believes that a 'panoscopic' vision of researching the human condition takes into account the unpredictability and patterns of lived experience; '... in an infinite universe with open possibilities, helical lived experiences do not involve repetition and prediction, but, rather, innovative, unpredictable lived experiences that people create through knowing participation'. He further contends that, deterministic scientific processes are antithetical to a knowledge of lived experience. Rather, the enigma of lived experience is constantly unveiled innovatively, often unwittingly and most times during the mutuality of the research process.

New research methods are needed to understand the infinite wholeness of lived experiences. With panoscopic vision methods, prediction is not necessary, since one can experience the flow of energy in the relative present as patterns change continuously in the researcher-research participant mutual process (Phillips 1993, p. 167).

This idea of pandimensionality is proffered also by the eminent social commentator and researcher Charles Birch (1995). With an emphasis on 'event thinking' and relationships, Charles Birch's ecological model of philosophy pronounces that knowledge is not an object which can be reduced into component parts (no date, p. 4). Birch values subjectivity in the same way as empiric-analytic researchers appraise objectivity. He offers an alternative to dualism in the form of panexperientialism (1995, p. 2). Taking his cues from Whitehead (1966) and Searle (1992) Birch's principle is a belief in ourselves as existing experiencing beings, and integral to this experiencing is feeling. Birch (1995, p. 4) proclaims that:

The future history of the world will be determined by the feelings of people alive today and the extent to which their feelings are deeply influenced by the terrible and the noble events of the past as well as by the indifference that can lead to sorrow.

In agreement with Heidegger (1962), Birch (1995, p. 12) believes that we experience the world both ontically (as a world of objects through our five senses) and ontologically (as an inner awareness available only through existence). Yet it is the latter experience that is constantly pushed aside in favour of the former in mainstream scientific research. Birch suggests that much richness about the world is denied by negating the 'subjective' side of life and that it is in and through our complex relationships (internal and external to self) that our worlds (our reality) are sufficiently revealed:

To understand what they [people] are you have to understand them in terms of relationships and, in particular, internal relationships. They are what they are by virtue of their internal relationships. We understand the meaning of that best in ourselves. I am what I am by virtue of my internal relationships or feelings to other people, for example. I am not the same person today as yesterday. My internal relationships change me (Birch no date, p. 5).

Rather than favouring one against another (objective versus subjective) Birch concludes they are the two sides of the one phenomenon. He goes on to say that understanding our existence is a constant process of revealing and re-evaluating (like the hermeneutic circle discussed later in this chapter) our different layers of feelings that are infinite as long as we are existing (Birch 1995). It is as if our experience as a feeling-emotional-intellectual-embodied-whole is mustered from our multiplicity of past, present and future influences (akin to Heidegger's notion of totality of experience). In keeping with Heidegger's convoluted treatise which suggests that we understand because we understand, Birch (1995, p. 35) contests that '... all experiencing is feeling of feeling. Memory is a feeling of past feelings. Anticipation is feeling of feelings not yet concretely real in our experience'.

Kleinman (1988) elaborates the importance of feelings related to being ill, and the ability to access knowledge of them through conversational awareness of other people's experiences of their illness experience. Through his own admission of feeling impotent as to how to make contact with a child who was severely burned and had to endure daily removal of her dressings, he asked her to tell him about her experience. He questions, "how does it feel to have been so badly burned and to have to experience the awful surgical ritual, day after day?" Kleinman (1988) contends that their conversation was revelatory and therapeutic for both the patient and himself. Uncovering lived experience, according to the cognitive scientists (Stewart 1994, p. 142) has the potential to reach the very core of our being, of our understanding. As a mental construction reflecting our ontological reality understanding is shaped by and through a tireless dance of interaction between people and information: 'So my self shapes your self, which in turn shapes my self. We create our contexts, as our contexts create us' (Laughlin 1995, p. 1).

Therefore, in adopting Birch's views on feelings, and following Kleinman's example of the positive outcomes of lived experience research, it could be argued that this research about sadness, is about the relationship that each participant has with sadness through the totality of their experiences. Sadness then is in a constant motion of being defined and redefined as it is experienced. It is evolving not only through its relationship with the participants but also through the participants' relationships with me and my

understandings (past, present and future) of their sadness experience. It is within these somewhat 'muddy waters' of conversation that different expressions of the experience of sadness have the possibility to emerge, and then retreat again as a new cycle of relationship is explored through reflection.

The complex circularity of reflection is recognised by Merleau-Ponty (1962, p. x-xi) as a space that embraces the distinction between self and world as well as providing continuity between self and world:

When I begin to reflect, my reflection bears upon an unreflective experience, moreover my reflection cannot be unaware of itself as an event, and so it appears to itself in the light of a truly creative act, of a changed structure of consciousness, and yet it has to recognise, as having priority over its own operations, the world which is given to the subject because the subject is given to himself [sic] ... Perception is not a science of the world, it is not even an act, a deliberate taking up of a position; it is the background from which all acts stand out, and is presupposed by them: The world is not an object such that I have in my possession the law of its making; it is the natural setting of, and field for, all my thoughts and all my explicit perceptions.

When trying to understanding feelings such as sadness it is untenable to ignore our experience of sadness as our experience of sadness arises out of our world position about sadness which in turn arises out of our experience of sadness—a circularity. 'To deny the truth of our own experience in the scientific study of ourselves is not only unsatisfactory; it is to render the scientific study of ourselves without a subject matter' (Varela, Thompson et al. 1992, p. 13). Cognitive science purports that experience, and the scientific understanding of it '... are like two legs without which we cannot walk' (Varela, Thompson et al. 1992, p. 14).

By engaging in the world with each other, our espial experience is of questioning and it is this questioning, this search and re-search that propels us through life. So often we can become trapped in the pursuit of, or search for, knowledge that we suggest this knowledge is detached from existence because a specific answer is sought: a decontextualised truth. Maintaining the realisation that we are connected to every aspect of our world is antithetical to the Cartesian philosophy which continues to uphold the subject-object dichotomy, constructing the world in separatist dualisms such as mind or body. Exploration and clarification of the belief that knowledge, meaning, understanding and existence are interrelated was initially the pursuit of philosophers from the phenomenological movement.

Phenomenology

First described by Franz Brentano (1838-1917) and later developed by Edmund Husserl (1859-1938) phenomenology, as a method of inquiry, advanced the move away from the dominant logico-positivist paradigm grounded in Descartes objective reality (Gelven 1989). Phenomenology evolved as a reaction to scientists' beliefs that people's behaviour could be controlled in the same manner as natural phenomena (Field & Morse 1985, p. 27-28). Spiegelberg (1965) maintains that the phenomenological movement has three distinct phases; preparatory, German and French, each marked by prominent philosophers. The differences between these phases articulated well by Spiegelberg (1965) and is a precursor of my own beliefs that the phenomenological movement has continued to evolve. In latter times however, this movement has taken a hermeneutic stance that points towards adopting a post-modern turn.

In the first phase described by Spiegelberg (1965) Brentano's work takes centre stage, focusing on the ideas of inner perception and intentionality (Wilkes 1991, p. 232). With his unique approach to the metaphysical domains of logic, ethics and psychology Brentano is seen as the most influential philosopher of the later work of Husserl. Husserl became known as the 'father of phenomenology' in the early years of the second phase (Stumpf 1994; Wilkes 1991).

The German phase, marked by Husserl and Heidegger emphasises transcendence and existentialism respectively. Husserl maintains that the purpose behind phenomenology is to put aside all assumptions about the world and he does this by focusing entirely on 'letting the *facts* speak for themselves'. It is this pure descriptive phenomenology that Husserl (1970) calls transcendental and maintains that it must not be tainted with pre-conceptions. Consequently, central to Husserlian phenomenology is the concept of bracketing or suspending one's beliefs in the phenomenon in focus. Bracketing, according to Husserl (1970), refers to the researcher's ability to completely withdraw from their own bias regarding the phenomenon.

Also within this second phase, Martin Heidegger, a student of Husserl, believes that there is no such thing as an uninterpreted fact and that facts cannot be separated from their meanings. He prefers to '... let the *things* of the world speak for themselves' (Heidegger 1962). Likewise he pronounces that it is impossible to separate the researcher from the researched or the observer from the observed. Heidegger moves the emphasis away from epistemology to ontology and attempts to question what it *means to be* rather than the *meaning of being* (Gelven 1989). He, like several others before him, reverses Descartes maxim of 'I think therefore I am' to 'I am therefore I think'. Rather than viewing the world as a separate and somewhat passive entity, Heidegger (1962) unifies the concepts

of self and world. Rather than transcendence, Heidegger encourages emergence within the context of meaning. Wilkes (1991, p. 233) claims Heidegger's phenomenology has three central suppositions:

1. Human beings are self interpreting. These interpretations are not just possessions of the self; they are constituents of self.
2. To be human means that the kind of being one is, is an issue, ie. the person takes a stand on the kind of being she/he is.
3. The self is not a radically free arbitrator of meaning.

With these assumptions in mind, meaning is realised as embedded, limited and interpreted by language, culture and history. Knowing occurs, not from outside the situation, but from involvement within it. Theory and practice are therefore intertwined. In this study the sixteen nurses are asked to describe their experiences of sadness when engaged in palliative care. As self interpreting beings, their descriptions of sadness are ultimately descriptions of themselves as palliative care nurses. In relating their stories they explicitly and implicitly tell of their relationships with other¹² and how meanings are shaped by and in these relationships.

The third phase outlined by Spiegelberg (1965) is the French, and is marked by philosophers such as Marcel (1889-1961), Sartre (1905-1980) and Merleau-Ponty (1908-1961). Existentialism is reinforced in this stage, as is consciousness. There is always a consciousness of something. Again, distinctions between object and subject are made, yet they seem to be more allied to the Heideggerian sentiments of ontic and ontological¹³ than the Cartesian dichotomies which appear to dominate the Western world.

Martin Heidegger (1889-1976)

Born in the Black Forest region of Germany in 1889, Heidegger was first introduced to philosophy when he read Bretano's work which was given to him by the pastor of his local church (Stumpf 1994, p. 503). Educated in Constance and later at the University of Freiburg Heidegger began his academic studies in theology. However, after only undertaking four semesters of study he changed his major to philosophy largely because

¹² By other I mean all that is not 'self'. We are always in relationship with other people and other things.

¹³ Ontic means the entities found in the world into which we are thrown, and ontology primarily refers to the meaning of Being. However, Heidegger believes that we come to know the ontic through the ontological; that in finding meaning, the two cannot be easily separated (Heidegger 1962, p. 31).

of the influence of his teacher and mentor Husserl. After gaining two doctoral degrees, abandoning his Catholic faith, and following a tour of duty at the Western front in World War I, he became Husserl's assistant. In 1922 he was appointed to Associate Professor at the University of Marburg (Sheehan 1993; Stumpf 1994). It was during this time at Marburg that he worked on what was to become his most famous publication *Being and Time* (albeit unfinished) first published in 1927. It was only one year later that he succeeded Husserl as chair of philosophy at Freiburg University. Elected to the position of Rector of the same university from April 1933 to April 1934 Heidegger entered what was to become known as his most controversial period.

There are mixed opinions about Heidegger's behaviour, intentions and allegiances pre and post World War II, and while he was in residence in Freiburg (Dallmayr 1993; Sheehan 1993; Ward 1995 & Stumpf 1994). These different, often antagonistic views Holmes (1992) believes calls into question the ethical implications of using Heidegger's work in research, especially nursing research which concentrates on the well-being of people. It is therefore worth attempting to contextualise Heidegger within this epoch.

One way of portraying Heidegger during this period is as a nationalistic German who supported early National Socialist ideology as a viable strength to overcome the ill favoured Marxist revolution and a persistent threat of global communism. As a recent member of the National Socialist party Heidegger could well have been persuaded by his own idealism to seek to influence the fate of the German people from within the organisation. In a letter to the de-Nazification committee at the university post-war he claims 'to attempt from within National Socialism and while having a point of reference to it, to bring about a spiritual change in its development' (Feher 1992, p. 193). Dallmayr (1993, p. 47) contests:

For Heidegger, the Weimar and Hitler years were bound to be a time of agonizing [sic] soul-searching. Reared in a Eurocentric (and perhaps Germanocentric) culture, he must have been deeply unsettled and disoriented by the crisis and progressive decentering of Europe. His initial response was a rallying call—a call for the resurgence of the *Geist* [spirit] of Europe, for the reassertion of European hegemony in a matter that might tip the scales in the ongoing struggle for world domination.

Claims of Heidegger's anti-Semitism are difficult to prove or refute principally because of his own silence about his actions and secondly, there are disparate views within the literature about his attitudes, values and life in this difficult period. Some writers suggest that Heidegger took a pro-Nazi stance and claim he was responsible for the dismissal of the Jewish students from Freiburg (Ward 1995). Others argue in an opposing manner, proposing it was Heidegger who personally sought to protect all the books, including

those by Jewish authors, in the University of Freiburg library from being burned by groups of pro-Nazi students (Feher 1992).

With so much uncertainty surrounding Heidegger's situation I find myself questioning the ability to find some 'definitive' answer about his past. Given that my world view is one that yields there is no absolute truth I wonder for whose and what ends would such a revelation serve? Indeed, would it make a difference to this research to know why Heidegger's was silent in the post-war period about his relationship with the Hitler regime? These questions, like the issue, do not warrant facile answers, they are much more complex.

Yet Heidegger's silence *is* a fascinating contradiction which I fear will never be laid to rest by the critics, who in turn allege the issue is seemingly glossed over by the apologists (Holmes 1992). Sheehan (1993, p. 91) attempts to justify Heidegger's actions by sheltering in Heidegger's own philosophy:

Many of his most devoted followers believe that his intellectual work is in no way significantly related to, much less contaminated by, his support for Nazism, even though Heidegger himself rooted that support in his own very central notion of historicity.

Likewise, Heidegger's own words on keeping silent (perhaps a perceptive premonition) on the one hand offers little explanation for his own behaviour yet sets up beautifully that notion of a shared understanding where no words are exchanged. A sentiment I suggest, with which nurses are well versed:

Only in keeping silent does the conscience call; that is to say, the call comes from the soundlessness of uncanniness, and the Dasein which it summons is called back to the stillness of itself, and called back as something that is to become still. Only in reticence, therefore, is this silent discourse understood approximately in wanting to have a conscience, It takes the words away from the common-sense idle talk of the "they" (Heidegger 1962, p. 343).

Finally, it should be remembered that Heidegger, like most Europeans of the time was living through economic and social struggles that promised to destroy the foundations of life itself. Thus it may have been more comfortable to vow allegiance to a regime that pledged to not only re-establish order but restore it with nationalistic pride. To issue any sort of challenge to such an austere administration could have warranted life threatening reprisals from that authority. Pöggeler (cited in Dallmayr, 1993 p. 41) reiterates a tentative retraction in the form of having been witness to a personal testimony from Heidegger:

By stating forcefully at least in conversation that he was completely wrong in 1933 and that nothing could excuse this mistake, Heidegger also supported efforts to avoid such mistakes in the future.

However, Holmes (1992) does heed an appurtenant warning in his discussion of Heidegger's affiliations, questioning what those allegiances might mean for contemporary nursing. Yet he too is inconclusive about the philosopher's behaviour, especially his silence. As I have argued in another place (Chapman 1994, p. 38), I value Holmes' scepticism as a plea to guard against indiscriminate acceptance of Heidegger, the philosopher; yet I recognise and appraise the fallibility of Heidegger, the man.

After resigning as Rector of Freiburg University in 1934 Heidegger concentrated exclusively on his teaching until 1944 when he was conscripted to dig trenches for the German army (Mueller-Vollmer 1994, p. 214). Suspended from the university by the French militia between 1945-1951 during investigations of the Nazi regime Heidegger suffered a 'nervous breakdown'. In 1951 he was granted emeritus status, continuing lecturing until his death in 1976.

This potted biographical account of Heidegger's life does not reflect the enormity of his influence on twentieth century philosophy. His writings have impacted on the thinking of scholars world-wide and his works have undergone translation in several languages. Crotty (1996b) however, believes that such global adoption of phenomenology has led to its adaptation, and impoverishment especially within the North American scene. Outlining differences and discrepancies between the European and North American phenomenology Crotty (1996b, p. 2) denotes the latter as a *new* phenomenology. Notwithstanding my prior claim to the notion of some philosophical evolution in response to Crotty's *new* phenomenology, the following summary is largely an enunciation, explication and critique of Heidegger's hermeneutical phenomenology. This discussion is offered as supportive evidence for the usefulness of such methodology in nursing initiated research.

Heidegger's hermeneutic phenomenology

A relational view of the person is what distinguishes Heidegger's phenomenology from that of his teacher and mentor Husserl. Consumed with the meaning of Being, Heidegger, with one bold stroke, moved philosophy from an abstract philosophical perspective to a focus on everyday concerns. 'An individual is born in the world and responds to all his [sic] experiences by thinking' posits Stumpf (1994, p. 503). He adds further that Heidegger's mission was to ponder the depths of this thinking from the perspective of the

individual as a thinking existing human being. In one of his works¹⁴ Heidegger (1978, p. 370) issues a solemn speculation: ‘The most thought-provoking thing about this, our most thought-provoking age is that we are still not thinking’. ‘Thought is like a path, says Heidegger, a way into and through the world, a movement toward a clearing’ (Jackson 1989, p. 1). Heidegger corrects the tendency to think about humanity in the same manner as thinking about things: that is by defining them. He concurs that unlike things, people have ‘... a relation to their own being, because only people find themselves as “thrown into the world” and as having to choose how to be’ (Stumpf 1994, p. 504).

In his classic work *Being and Time*, Heidegger (1962) formulates this concept of relationship by using hyphenated language. Thus his linking of terms, such as Being-in-the-world, attempts to articulate the interaction of a person and their world. Heidegger names the existence that reveals itself to itself as *Dasein*. Indeed, *Being and Time* is devoted to the explication of *Dasein* not as a thing but as a way of Being-in-the-world. Much of the work is punctuated with tautological¹⁵ concepts that, in the process of unpacking, mirrors the very ontology on which Heidegger bases his philosophy. Heidegger believes that ‘phenomenology is the possibility of thinking’ (von Herrmann 1992, p. 310) and the only way to understand phenomenology is to grasp it as *possibility*. Heidegger’s phenomenology is concerned with the meaning of being—a *fundamental ontology*¹⁶ (Heidegger 1962, p. 32).

Heidegger further states that to question the meaning of *Dasein* assumes an awareness of *Dasein*. He calls this knowledge ‘*a priori*’ knowledge of existence. Taylor (1994b, p. 22) relates this concept to questioning in the research context and argues that ‘... to raise a question the questioner must have some idea of what to ask.’ In adopting the *a priori* argument Heidegger considers the world to be *a priori* and our lived experience is determined by our history and the laying down of all experiences which become part of the person and their world.

In *Being and Time* Heidegger (1962) uses the term ‘essence’ but not as a property that can be ascribed to a person or thing. Rather the ‘essence’ of *Dasein* resides in its existence

¹⁴ Heidegger, M. 1978, *What Calls for Thinking?* in *Basic Writings*, D. F. Krell (editor), Routledge, London.

¹⁵ For example, in reference to Heidegger’s concept of understanding he claims that we understand because we understand (see Heidegger 1962, pp. 185, 186, 189 & 385 for example). Also, Heidegger’s notion of the temporalness of being ‘*Dasein* temporalizes itself in temporality’ (p. 417).

¹⁶ The contemporary use of the word *fundamental* is much maligned. Thus when Heidegger talks of ‘*fundamental ontology*’ I believe he means the most basic or the primary of all ontologies.

and refers to a *way* of being for Dasein. In his critical assessment of the use of essence by Heidegger, Grieder (1992, p. 185) claims:

... it depends upon what Dasein chooses to be, upon possibilities it projects itself into; its essence is inevitable of concern to Dasein and inseparable from its selfhood; Dasein is said to become 'essential' in authentic existence and resoluteness.

In the light of Grieder's assertion above, this research concerning the experience of sadness seeks to examine the participants' descriptions of how they *are* sadness and therefore attempts to unravel the possibilities of how sadness presents itself to them. By attempting to enter the 'world of sadness' for each participant, the essential structure of *Dasein's* existence *as* sadness can be projected and represented through the three interlaced structures of understanding, mood and discourse.

Stumpf (1994, p. 506) declares that understanding '... is Dasein's projecting of the context of purposes and their interrelationships within which any particular thing derives its meaning'. Mood is the way the world exists for each person rather than an attitudinal description or response as is the popular meaning of the word. Caution needs to be taken therefore, in seeing mood as only referring to feeling. Mood locates how we come upon our milieu and 'understanding always has its mood' (Heidegger 1962, p. 182). Lastly, we are oriented to our world through language and we use language as discourse or talk to describe what comes into view in our immediate experience.

Heidegger's discussion of language changes from his early writing in *Being and Time* from 'discourse' to be known later as 'language'. Language is not just representational for Heidegger. It is more than words on a page, it exists as Dasein exists (Dreyfus 1991, p. 15). Yet in communication Dasein uses language as a tool to distinguish how we share our world; language as a 'tool' is a consequence of our thrownness into the world:

The way in which discourse gets expressed is language. Language is a totality of words—a totality in which discourse has a 'worldly' Being of its own; and has an entity within-the-world, this totality thus becomes something which we may come across as ready-to-hand. Language can be broken up into word-Things which are present-at-hand. Discourse is existentially language, because that entity whose disclosedness it articulates according to significations, has, as its kind of Being, Being-in-the-world—a Being which has been thrown and submitted to the 'world' (Heidegger 1962, p. 204).

Heidegger delineates three distinct ways of Being-in-the-world. These are the 'ready-to-hand', the 'unready-to-hand' and the 'present-at-hand'. Whilst these concepts are complex and convoluted, Taylor (1991, p. 39) offers some insights when she describes these abstractions in relation to nursing.

Ready-to-hand refers to equipment that is transparent, unnoticed, and experienced as an extension of the body, because of the way the person is actively involved in the situation. Conversely, equipment that is unready-to-hand is noticed, because of its breakdown, so that the person notices it. Present-at-hand refers to equipment distanced from the user, described as an object rather than the way the person perceives the situation. In as much as nursing is person to person work in everyday contexts, ordinariness in nursing could be seen as tantamount to ready-at-hand, in that the invisible nature of the ready-to-hand equipment provides for effortless action, which is attuned to the nature of the work for which it was intended.

Likewise our everyday language largely remains ready-to-hand. We use language unobtrusively, and in its ready-to-handness run the risk of sliding towards inauthenticity through 'idle talk'. However, Heidegger notes our mode of understanding and encountering entities in the world is through language: '... language alone brings beings as beings into the open for the first time' (Heidegger cited in Mulhall 1990, p. 176).

For Heidegger (1978), self and world belong to *Dasein*. They are inseparable, not two beings like subject and object, or I and thou. They come together in the unity of being-in-the-world. Heidegger (cited in Sheehan 1993, p. 78) proclaims:

Only in the resonances of one's own individual 'I' does a firsthand thing get experienced, only there does 'world happen', and wherever and whenever world does happen for me, *I* am somehow entirely there.

This meshing of self and world is, in existentialism, *intentionality* and according to Crotty (1996b, p. 40) '... means that human experience always points to something beyond itself. It is essentially related to the phenomenon—to the object of experience, to *what* is experienced'. A person is not just a being with an inner world to explore. Rather, they are a being-in-the-world wherein they are inseparable. As a free, self-conscious being-in-the-world, a person is destined to address the world, make sense of it and act upon it: to shape it even as they are being shaped by it. Both van Manen (1990) and Crotty (1996a) emphasise that mainstream phenomenology is to account for and reveal the world, not the person. Crotty (1996b) is at pains to stress in his treatise that the viewpoint of existential phenomenology is to see the world as it presents itself to a person not merely as a person has been taught to see it.

Nevertheless, Heideggerian phenomenology recognises that human beings are thrown into an already existing temporal world of traditions, relationships, practices and shared meanings (Parker 1991, p. 291). Our temporality sets up the possibilities of our becoming and we are constantly defining and redefining who and what we are according to our situation. Yet our changing understanding of being is not always a conscious choice and Heidegger (1962) claims we experience a 'fallenness' drifting easily away

from our authentic existence into inauthenticity. Stumpf (1994, p. 506) suggests 'a person's drift into an inauthentic existence is subtle but in every case it involves a tendency to escape from one's self by finding refuge in a public self'. Heidegger (1962) refers to this 'unconscious' inauthentic existence as 'fallen'. Thus the inauthentic self is consumed by the 'shoulds' and 'oughts' imposed by others rather than manifesting the self's own agency. This slide towards inauthenticity is illustrated by some participants in this study as they describe their experiences of feeling pressured by others, especially those in authority, to behave in a manner different from their authentic being-in-the-world-of-sadness. If they 'fall' into the expectations of others (behaving as directed) these participants could be said to be existing inauthentically.

Dasein too tends to become enveloped in the everydayness of being. We hide within our social roles and act out certain practices or activities of life that can move us away from our authenticity towards inauthenticity. As 'fallen' we tend to forget who we authentically are. Paradoxically the 'everydayness' is how we are being-in-the-world and needs to be appreciated as such. The everyday is the place from where we venture our authenticity, and so inauthentic and authentic become complementary rather than in apposition, which is unfortunately a common interpretation. Nevertheless, Heidegger (1962, p. 222) warns that self-forgetfulness heightens our pre-occupation and absorption with self, and *Dasein* can become 'entangled in itself ... sinking into the most exaggerated self-dissection'. This vicious circle brings little more than demoralisation, alienation from self, feelings of futility and a self unable to break free of its own destructive bonds.

The concept of 'being-towards' describes *Dasein's* temporal unfolding (Guignon 1993b, p. 225). *Dasein* is always ahead of itself, being towards some possible realisations of self. Heidegger (1962) says that *Dasein* is always being-towards-death. Not in the strict sense of facing death daily, although the participants in this study face the death of others daily and by vicarious experience it could be argued that their sense of their own finitude is heightened because of their work. This being-towards-death, suggests Heidegger, is a source of anxiety (*angst* or dread) of the presence of nothingness in our being. This nothingness reflects the inevitability that we shall die.

Our awareness of our presence in the world for Heidegger is hermeneutic in that we are always interpreting our interpretation of being-in-the-world. Interpretation is synonymous with understanding and the mode of being of *Dasein* itself. Heidegger's temporality of *Dasein* means that, that which shows itself to *Dasein* is in constant change '... and this constant change requires us to form particular interpretations' (Hoy 1993, p. 173). This constant change is indicative that we understand and skilfully cope in the world.

Heidegger believes that interpretation, the assignment of meaning presupposes some shared understanding. The intertwining of understanding and interpretation is, suggests Okrent (1988, p. 165), the fore-structure of interpretation. Within the fore-structure of each interpretation is a fore-having, a fore-sight and a fore-conception. A fore-having assumes knowledge of the entity which is to be interpreted. Fore-sight assumes a sense of how to approach interpretation of the entity and fore-conception assumes some expectation of what meaning is to be ascribed to the entity (Heidegger 1962; Okrent 1988; Dreyfus 1991). This presupposition, when applied to hermeneutics, raises the problem of circularity of meaning—no different interpretation can be forthcoming. Indeed Heidegger (1962, p. 153) considers:

... if we see this circle as a vicious one and look out for ways of avoiding it, even if we just 'sense' it as an inevitable imperfection, then understanding has been misunderstood from the ground up.

Heidegger's lesson then is not to leave the circle but rather, to be mindful of coming to the circle in an appropriate manner. However, if *Dasein* is considered to be hermeneutical then we are already in the hermeneutic circle, and therefore it is misleading to suggest that we come to it in the right way. One problematic suggestion is that a presupposition is based on assumptions that are not necessarily true. However, the fact that a fore-having is deemed to be either true or false has little outcome on a circularity which is vicious. Fore-having refers to the 'potential' within interpretation. Yet coming to the circle with an openness of fore-having allows us to turn to the things themselves *ontologically* rather than our everyday conceptions (Dreyfus 1991, pp. 200-201). It is precisely this ontological thrust that differentiates Heidegger's style from Husserl's manner of coming towards understanding, and Heidegger's recognition of the primacy of language to the hermeneutic event.

Hermeneutics

The science and art of interpretation, hermeneutics is purported to have emerged during the seventeenth century to help elucidate writings from the Scriptures or the works of classical authors (Grondin 1994, p. 4). Originally applied to four structures of society, theology, philosophy, jurisprudence and literary criticism hermeneutics was given an 'auxiliary status' within the established disciplines (Madison 1988; Grondin 1994). Grondin (1994, p. 1) however, traces hermeneutics to the patristic¹⁷ period, even to the traditions of the early Greeks. The term hermeneutic is often linked with Hermes,

¹⁷Patristic means, of or pertaining to the Fathers of the Christian Church or their writings

messenger of the Greek gods, 'and himself god of eloquence and cunning as well as of roads and theft' (Packer 1985, p. 1082).

Hermeneutics came into its own during the seventeenth century when worldviews began to change from the concept of duplication of one reality to interpretation of multiple realities and it is during this time that the Latin word *hermeneutica* emerged (Packer 1985; Hekman 1986; Caputo 1987; Reeder 1988; Descombes 1991; Grondin 1994). The etymology of the word 'hermeneutic' is fascinating: expression, explication and translation, the first two equally aiming at understanding while the last (translation) is often used synonymously with interpret. In modern hermeneutics the relationship between language, reproduction or interpretation of thought Grondin (1994, p. 23) advocates is a universal definition which claims to mean to make something better understood.

In the late nineteenth and early twentieth centuries modern hermeneutics has become linked with the human sciences, largely adopted by German historians and theologians such as Dilthey¹⁸, Droysen¹⁹ and Schleiermacher²⁰. It is Schleiermacher who makes the link between understanding (interpretation) and language, and Ast²¹ who first denotes what later came to be known as the 'hermeneutic circle'. Indeed they (Schleiermacher and Ast) could be said to have set the stage for the ontological phenomenological hermeneutical position of Heidegger and the ontological philosophical hermeneutical positions of Gadamer and Habermas (Allen & Jensen 1990, p. 241). In the contemporary analysis of *Dasein*, Heidegger (1962) argues that it is in the ready-to-hand mode that marks the grounding of all hermeneutic investigation. Packer (1985, p. 1089) comments:

[T]he ready-to-hand mode is in two respects actually the starting point for the hermeneutic investigation of human action. First, the ready-to-hand mode is the proper object of inquiry for such an investigation. Second, it is the primary source of a researcher's understanding of what ever she or he is studying.

¹⁸ William Dilthey (1833-1911) considering himself to be a methodologist of the historical school embarks on a critique of historical reason which he later abandons in favour of emancipating the human sciences from their shackle to the natural sciences (Grondin 1994, p. 84).

¹⁹ Gustav Droysen (1808-1884) although rarely mentioning hermeneutics in his limited publications thematises interpretation through appealing to the centrality of understanding in the historical sciences.

²⁰ Friedrich Schleiermacher (1768-1834) was a theologian and a Romantic. His concern with understanding incorporates exclusively pursuing an expression back to the original intention. 'The task is to understand the meaning of an utterance on the basis of language' (Grondin 1994, p. 158n).

²¹ Ast is reported to have said: 'the fundamental law of all understanding and knowing is to discover the spirit of the whole in the individual and to grasp the individual in terms of the whole' (in Grondin 1994, p. 65).

Thus the sixteen nurses' accounts of their day to day encounters with sadness form the initial texts with which I then engage in reflexive dialogue uncovering and explicating further understandings of the participants' experiences. These different interpretations are in no way complete or inflexible as the dialogue is always open, and each time the text is engaged in dialogue the entering point into the hermeneutic circle shifts (see previous referral to Heidegger's notion of coming into the circle). It is this 'going beyond' the original meanings, pushing the boundaries, identifying the gaps and contradictions in our everyday practices, that has been called the 'revelatory' aspect of hermeneutics (Packer 1985, p. 1089).

Hans-Georg Gadamer (b. 1900)

Born in Marburg, the son of a chemistry professor, Gadamer studied classics and philosophy at the universities of Breslau, Marburg, Freiburg and Munich. He received his first doctorate, on Plato, in 1922 and began teaching at the university in 1929 as a part-time, low salaried member of staff. He met Heidegger in 1923, serving as his assistant while they were both at Marburg. In 1928 he completed a second doctorate (again on Plato) under the direction of his friend and mentor Heidegger. Working briefly (1934-35) at Kiel he returned to Marburg becoming an 'extraordinary professor' in 1937. After teaching at Leipzig (1939-1946) and Frankfurt (1947-1949) Gadamer moved to Heidelberg where he taught until his retirement in 1968 (Gadamer 1994). He became professor emeritus in 1968. Upon retirement he was invited to spend semesters in residence at major universities in the United States of America (including Vanderbilt, Dallas, McMaster for example). Following retirement Gadamer lectured widely in the United States and Canada.

Following on from the previous history of hermeneutics Gadamer develops his 'philosophical hermeneutics'. His starting point is from a critique of Idealism and its Romantic traditions, as well as in response to the ideas about hermeneutics from Wilhelm Dilthey and Husserl. Perhaps as a rejoinder to the pressure at the time to develop a method exclusive to the human sciences, Gadamer (1975, pp. 8-9) argues vehemently against the idea:

The human sciences have no method of their own. Yet one might ask, with Hemholtz, to what extent method is significant in this case and whether the other logical presuppositions of the human sciences are not perhaps far more important than inductive logic. Hemholtz has indicated this correctly when, in order to do justice to the human sciences, he emphasised memory and authority, and spoke of the psychological fact that here replaced the conscious drawing of inferences.

Favouring the *je ne sais quoi* Hemholtz, rather than Dilthey, becomes Gadamer's 'silent partner' of hermeneutics as he embarks on his critique of the obsession with method in writing his opus *Truth and Method* (Grondin 1994, p. 109). Emphatic that philosophical hermeneutics is not a method Gadamer in his interview with Boyne (1988, p. 33) states '[Truth and Method]... is reflection about what is going on in using methods'. Effectively laying to rest problems he had with Dilthey's historical hermeneutics in Part One of *Truth and Method* Gadamer then unfolds his philosophy of hermeneutic experience which contrives to radicalise the human sciences.

Gadamer's philosophical hermeneutics

Like Heideggerian phenomenology, philosophical hermeneutics has its primary emphasis in realising understanding as ontological. Clearly following Heidegger in making language the essence of hermeneutics Gadamer's attention to historical *thrownness* is in agreement with Heidegger's concept of the person as a self interpretive being. Indeed Gadamer (1975 cited in Annells 1996, p. 707) notes that '... understanding and interpretation are indissolubly bound up with each other.' According to Gadamer, this interpretation is never finite, it is always evolving. Like Heidegger, Gadamer holds the view that:

The hermeneutic act of language and history maintains that it is in and through our traditions, our practices, our preoccupations, our historical perspectives and worldviews, and our specific concepts and ideas that we are able to constitute the world and objects in it. Tradition gives us a world, makes it present to us (Thompson 1990, p. 262).

Hekman (1986, p. 100-101) argues that Gadamer's work articulates three main components of Heidegger's approach: the facticity of being which Gadamer relabels the historicity of understanding; fore-structure or prejudice, and the hermeneutic circle. The concept of historicity articulated primarily by Heidegger is extended and developed by Gadamer and culminates in a theory of historical consciousness, and further legitimisation of the hermeneutic circle (Reeder 1988, p. 200). Gadamer suggests that we can feel a sense of belonging, or affinity to, a particular text or tradition that we wish to understand. Part of being drawn towards a particular question is according to Gadamer (1975, p. 268) '... an element in the act of understanding itself'. Thus in research, our alliance to a specific topic is in itself hermeneutic and in being so not only speaks of our own history but of the history of the particular topic. Gadamer (1975) describes this notion as effective-historical consciousness. We achieve this effective-historical consciousness through language and that language then assumes a character of universality. Reeder (1988, p. 200) further claims that we can then ask questions of the text and the text

supplies a response through a continuous and deeper philosophical reflection that consequently bridges the past and present horizons of understanding.

Prejudice, tradition and effective historical consciousness

Prejudices can be related to Heidegger's concept of 'fore-structure' (see previous discussion) and are considered by Gadamer to be conditions of understanding. Rather than displacing them in the summons towards 'objectivity' and/or 'certainty' Gadamer implores us to firstly recognise them, and secondly work them through interpretively:

The important thing is to be aware of one's own bias, so that the text can present itself in all its otherness and thus assert its own truth against one's own fore-meanings (Gadamer 1975, p. 269).

Neutrality in our understanding is of course unrealisable since it is impossible to step outside our own fore-meanings, or prejudices. Gadamer also notes that interpretations are themselves interpretations and full of prejudices. Hence the participants' stories are my interpretations of their interpretations of their experiences and thus laden also with prejudice. Risser (1997, p. 68) notes '[W]hat primarily hinders us in understanding the tradition that speaks out of the text is the tyranny of hidden prejudices'. However, these hidden prejudices according to Gadamer (1975) are legitimate and any effort to disengage them entirely is seen as conformity (see Heidegger's concept of 'fallen' as previously discussed) to the call of the Enlightenment for some absolute validity or authoritative singularity of meaning. 'The prejudices of the individual, far more than his [sic] judgments, constitute the historical reality of his being' (Gadamer 1975, p. 276-77).

In claiming '... we always find ourselves within a situation' Gadamer (1975, p. 301) notes that our historical consciousness is also hard at work determining the background of our values, understandings and judgments. Grondin (1994, p. 114) proposes that the concept of effective historical consciousness is 'subtly ambiguous'. On the one hand our consciousness is always affected by our history (from behind) yet, on the other hand '... a consciousness of being affected by history is primarily consciousness of the hermeneutic situation, that is, the situation in which we find ourselves' (Risser 1997, p. 79): the thrownness of our (historical) 'there being' (*Dasein*).

Gadamer's philosophical hermeneutics revolves around an 'ontological' version of truth. Truth appears in consciousness and in effect 'truth finds us' (Howard 1982, p. 124). Each time we come to a situation we are striving to find 'truth' (not necessarily a singularity), and each time we bring a different history (evolving from the past), apply a different language (built from previous understanding), search in dialogical conversation,

for a fittingness. 'One stands in truth, bears witness to it, only when the thing ... says what it means' (Risser 1997, p. 156). Gadamer (1975) also talks of 'right thinking' and 'right representation'. A somewhat bewildering choice of words for a person who believes that there is no singularity of truth. I support Howard's contention (1982, p. 145) in disputing Gadamer's use of 'right'. He argues that in his use of 'right' Gadamer does not mean *ideal* (in a Platonistic sense) but rather, a recognition, a knowing. Howard therefore returns to Gadamer's presupposition that no interpretations can be regarded as finally correct, welcoming an acceptability of a range of interpretations. Gadamer (1975, p. 281) however, does allude to a rejection of a total relativist view of truth in his discussion of temporal distance, which he considers '... lets the true meaning of the object emerge fully'. This petition could be misinterpreted as a plea for objectivity. Nevertheless, Risser (1997, p. 77) explains this quandary by propounding that it is through the continuing mediation between fading of error and illumination of new sources of understanding, what I call the positive possibility of prejudice, that a 'truer' meaning of the object emerges. Within the same argument Risser also reminds us that we cannot ever remove ourselves from the hermeneutical event.

While Gadamerian philosophical hermeneutics is postulated to move away from the ideas expressed in Heidegger's later writing, it is widely regarded as advancing significant parts of Heidegger's earlier work, in particular the hermeneutic circle. As a central construct of his philosophy Gadamer develops the metaphors of the hermeneutic circle, interrelated with the notions of fusion of horizons, and dialogue through language. The three concepts are intertwined and it is difficult to talk about one without mentioning its harmonious interplay with the others. However, in this thesis they are articulated separately for the purposes of clarity, validation and understanding of my interpretation.

The hermeneutic circle

Annells (1996, p. 707) describes the concept of the hermeneutic circle '... as a metaphor to explain the dynamic movement between the parts and the whole of the text within the seeking of understanding'. Heidegger gave hermeneutics, and the circle, ontological significance believing that all understanding is made from a given set of fore-structures which cannot be eliminated (or bracketed), only modified or corrected (Koch 1995). Gadamer identifies the primacy of the hermeneutic circle in understanding as a circle with no beginning and no end. He further suggests:

The circle, then, is not formal in nature. It is neither subjective nor objective, but describes understanding as the interplay of the movement of tradition and the movement of the interpreter (Gadamer 1975, p. 293).

In the context of interpretive research, the interpreter comes to the situation (the research question) with a projected meaning steeped in prejudice (anticipations or expectations of meaning). These first impressions of meaning that guide the reader to the text, yield to a meaning for the text as a whole; a meaning that is constantly revised in terms of what springs forth. This movement from interpreter to text and back to interpreter is never ending, nor does it have a finite beginning, rather its pattern is circular. By attempting to understand (a text) we are always projecting, and if we are aware of this mode of being then we will be open to letting the text speak for itself (the voice of the other).

Dialogue through language

The ultimate key to understanding for Gadamer suggests Hekman (1986, p. 95) is language. Understanding is a language event in which communication takes place. 'The linguisticity of understanding is the concretion of the hermeneutical consciousness' posits Gadamer (1975, p. 367). 'To Gadamer, the understanding of transmitted messages are not two processes but one and the same' (Annells 1996, p. 707). These messages are transmitted through language and Gadamer (1975, p. 345) purports that it is through language that we understand the world and as such, language is understanding:

To understand a text is to come to understand oneself in a kind of dialogue. This contention is confirmed by the fact that the dealing with a text yields understanding only when what is said in the text begins to find expression in the interpreter's own language. Interpretation belongs to the essential unity of understanding.

Like Heidegger Gadamer believes that language is more than a tool, it gives us a world carrying with it 'culture' and everything we understand. Hekman (1986, p. 111) believes that 'if language gives us a world, then the reverse is also true: our world gives us language'. I am acquainted with the world(s) of the community palliative care nurses in this study because of shared understandings brought forward by and through language. This language is situational coming from being-in-the-world-of-community palliative nursing and is different from say, being-in-the-world-of-neurosurgical nursing. Our shared language facilitates meaning and it is from this starting point of commonality that the process begins towards potentially unveiling different understandings.

The establishment of 'correct' or 'valid' meanings is a question of foundationalism within the interpretive tradition (Allen 1995). Allen (1995, p. 175) considers that nursing researchers, with their tradition in foundationalist suppositions reflected in positivist science, may experience difficulties moving to a theory that embraces anti-foundationalism. Gadamer however walks a fine line between foundationalism and anti-foundationalism warning that 'the discovery of the true meaning of a text or a work of art

is never finished; it is in fact an infinite process' (Gadamer 1975, p. 298). Thus for Gadamer, as with Heidegger, truth is an event which is both situated and momentary. Sparked by ongoing questioning, understanding is open to possibilities which are reflected in the languaged horizons of self and other.

The preferences of Heidegger and Gadamer towards questions of 'why and how' retain an openness, a sense of ongoingness that truths are in constant motion of discovery and rediscovery in and between the worlds in which we dwell. On the other hand the Cartesian style of questioning, causative in its orientation, seeks to find a single, fundamental truth. This single truth, this answer, seemingly provides a sense of certainty, order, and closure about the world in which we live. While this position may well appear comfortable for some people, it does little more than present the questioner with a truth that Heidegger (1962) contends is mask-like and illusionary. Inasmuch as certainty and closure temporarily achieve opulence they also halt the very dialogue, the very questioning that continues the search and re-search towards ongoing discoveries.

Fusion of horizons

According to Koch (1996, p. 177) Gadamer's horizon is '... the range of vision that includes everything that can be seen from a particular vantage point.' These horizons are not static or closed, they are always changing and their boundaries are set by time and prejudice (Hekman 1986, p. 105). This term 'fusion of horizons' is a metaphor for the coming together of different vistas. In interpretive research, a task of understanding is to show how these fusions have occurred. Illustration of these fusions of horizons is best achieved by a sensitive interpretation and re-writing of texts which are a depiction of the worlds of the interpreter and the interpreted. Through a constant movement between the interpreter and the interpreted, the researcher's discoveries and re-discoveries within the taken-for-grantedness of the life-world of the participant is facilitated. Each reading and re-reading of the text has the possibility to reveal deeper understandings. This 'crafting' of the text is artistically described by Reeder (1988, p. 202):

... it is helpful for the interpreter to act like an artisan between the life of the languaged text and the life of the author; that is, in a back and forth motion, tacking like a sailor does in a boat, towards a goal of understanding.

My stated familiarity with the participant's life-world(s) is suggestive of a willingness to move in unison with their world(s), shared common culture and language in order to bring forth a world, a world that through perception and emotion expands on our dimensions of understanding (Capra 1997, p. 278). By virtue of my own belief system,

shared background and fore-structure (prejudice), I will be unable to bracket myself from the experiences of the participants (facticity of hermeneutics). Rather through my historicity, I will attempt to continuously re-align myself with their world (by continually dialoguing with the texts—hermeneutic circle) in order to gain an understanding of the experience of sadness for a community nurse engaged in the delivery of palliative care.

Summary

Hermeneutic analysis is the relationship between the known and the unknown, between the phenomenon and its wider context and between the knower and that which is known—a circular relationship. Unable to separate ourselves from the meaning of a phenomenon our interpretations are an inexhaustible process with no clear definitive beginning or ending. This circularity and the apparent entrapment of knowledge is at the heart of inquiry for some contemporary researchers (Maturana 1991; Maturana 1992b; Varela, Thompson et al. 1992; Capra 1997). The following section of this chapter discusses some of their theoretical propositions towards a cognitive science.

Cognitivism and its applicability to researching experience

In accepting that all explanations are a conglomeration of pre-understanding and tradition the cognitive scientists seek to use these philosophical dimensions in a scientific process. Cognitivists believe that as biological beings, the process of knowing is itself a biological phenomenon (Fell & Russell 1994a). Challenging the linearity of traditional science Birch (no date) and Capra (1975) were instrumental in proposing a post-modern ecological model of science. They were not alone in their disgruntlement with the restraints of the traditional scientific method. Like-minded thinkers such as Bateson (1979) Maturana (1987), and Varela (1992), moved towards the establishment of a new biology, a biology of cognition, which became known as cognitive science.

The discipline base of cognitive science is not specific. It informs and is informed by various disciplines; linguistics, neuroscience, biology, psychology, anthropology and philosophy. Of late it has been associated with cybernetics and artificial intelligence and these contemporary issues have interested both Bateson (1972) and Birch (1995). Varela (1992), in his description of cognitive science, suggests that there are three successive stages of cognitive science, cognitivism, emergence and enactive. It is the third stage that is of interest to me in this research. Varela (1992, p. 9) states the term enactive:

[emphasises]... the growing conviction that cognition is not the representation of a pregiven world by a pregiven mind but is rather the enactment of a world and a mind on the basis of a history of the variety of actions that a being in the world performs.

Accepting the philosophical premises espoused by phenomenology and hermeneutics, cognitivism presents them in a pragmatic manner that makes them available to science. In addition, cognitive science is a science that also borrows, from Buddhist tradition, the notion of mindfulness. Mindfulness in this sense can be paralleled to Heidegger's (1962) authenticity. Of being present (aware) of our own experiences instead of wandering away from them, unaware of what we have just experienced:

Even the simplest or most pleasurable of daily activities—walking, eating, conversing, driving, reading, waiting, thinking, making love, planning gardening, drinking, remembering, going to a therapist, writing, dozing, emoting, sight-seeing—all pass in a blur of abstract commentary as the mind hastens to its next mental occupation (Varela, Thompson et al. 1992, p. 25).

Varela's 'abstract attitude' corresponds to Heidegger's (1962) notion of 'inauthentic everydayness'. Mindfulness reminds us of our disconnectedness from our experience. Being mindful/aware of experience can be developed by meditation. A practice that is steeped in the Buddhist traditions. Mindfulness however is an essence of the mind which has been temporarily obscured by our need to cling to thoughts and feelings of certainty. Yet these habits, submits Varela (1992, p. 26) are illusory and should be let go of, in order to allow the mind to know itself through reflection; a reflection that brings forth wisdom and maturity:

It is important to realize [sic] that such maturity does not mean assuming the abstract attitude. As Buddhist teachers often point out, knowledge, in the sense of *prajña* [wisdom], is not knowledge *about* anything. There is no abstract knower of an experience that is separate from the experience itself (Varela, Thompson et al. 1992, p. 26).

Reflection, in cognitive science is not a reflection *on* experience, as reflection itself is recognised as experience. It is the relationship of the mind and body (embodiment) in reflection that portends the possibility of bringing different meanings to the situation:

Meaning includes patterns of embodied experience and preconceptual structures of our sensibility (ie. our mode of perception, or orienting ourselves, and of interacting with other objects, events, or persons). These embodied patterns do not remain private or peculiar to the person who experiences them. Our community helps us interpret and codify many of our felt patterns. They become shared cultural modes of experience and help to

determine the nature of our meaningful, coherent understanding of our 'world' (Johnson 1987, p. 175).

These patterns are constitutive of ourselves rather than an objective reality outside of ourselves (Maturana 1988a). They are *of* us rather than being out there to be *had* by us. They do not exist independently of us. Yet to share our experiences we must explain them to others and explaining is not the same as experiencing. Like reflection, explanation is a different experience.

Cognitivism and language

Knowing from conversation, professes Maturana (1988b) is through the art of turning together (*con versare*). In this dimension, conversation is reflective of the notion of relationality proposed in my earlier discussion of Birch's philosophical position. Through this interaction, which Maturana describes as 'linguaging' we move towards our ontological awareness. Maturana claims as does Gadamer '... that we do not just use language, we are immersed in it' (Fell & Russell 1994b, p. 220). Linguaging then is seen as a structured patterning by which we continuously construct our realities by the telling of our experiences through experiencing. We are however limited by our language, and that we ever reach agreement about meaning is more a testament to reaching agreement than it is proof of the experiences we are describing. Thus meaning exists within us, '... it is context-dependent - meaning different things at different times, even for the same person' (Fell & Russell 1994b, p. 233).

The circularity of the discussion thus far could, for some people, point to the emergence of nihilism (nothing exists except in the mind of the person). This response however, assumes that to have nothing there must have been something. This something is for most people translated as objectivism. Thus objectivism and nihilism are connected. Nihilism '... is an extreme response to the collapse of what had seemed to provide a sure and absolute reference point' (Varela, Thompson et al. 1992, p. 239). Nihilism's source is objectivism and objectivity is a deep seated reflex that has grown from and of our need for stability and grounding in all that we do and say. To accept otherwise may send many people, especially those who remain coalesced to the Western scientific tradition, into an abyss where nothing can be grounded. Yet in this research I agree with Varela (Varela, Thompson et al. 1992) who says '... that a path exists only in walking'. Thus, it is within an ambience of mindful groundlessness that the temporal and ever-shifting interpretations of the dimensions of sadness for the participants in this research is unearthed.

Summary

In constructing a research project of this nature it could be argued that termination (for the sake of fashioning a thesis) of the process occurs when the researcher is satisfied with the depth of achieved understanding—the paradox of a temporary finiteness perhaps? Or more fittingly, a temporary pause in the charter of knowledge accumulation. Such ‘pauses’ or ‘waiting stations’ of knowledge are articulated in and through the literature, and it is worth considering a particular segment of this literature that illustrates the disport between nursing and interpretive research.

A brief consideration of interpretive research studies in nursing

Throughout this chapter I make reference to the increasing numbers of nursing researchers who utilise the interpretive paradigm as the philosophical foundation of their chosen research approach. In her monograph Taylor (1994b) attests to the usefulness of interpretative research in nursing, as nursing and nurses deal with the everyday occurrences of people. It is this day-to-day existence, suggests Taylor, that potentially holds a richness of phenomena, concerns and issues. Alongside Benner (1994) and other nursing researchers (see Allen 1995; FitzGerald 1995b & Koch, 1996 for example). Taylor (1994b, p. 5) values the personal and practical knowledge that is generated as people engage in their daily activities ‘... as participants in their social worlds’. Given also that nurses are at the cutting edge of interest in the human condition and meanings people attribute to their lives, it is apropos then that nursing researchers are seen to employ appropriate methodologies that reflect this concern with subjective experience.

Under the umbrella of interpretive research are four distinctive methodological approaches states Taylor (1994b, p. 8); grounded theory, historical research, ethnomethodological and phenomenological positions. Each of these aforementioned methodologies have differing epistemological assumptions and questions which drive their research methods and it is a critique of the last pose (hermeneutic phenomenology) and its relevance to research in end-of-life nursing care that forms the theme for the final discussion in this chapter. It is important here to stress that by selecting only hermeneutic phenomenological studies to review I am not suggesting the other three methodological positions hold no value. Rather, my choice is testament to the hermeneutical phenomenological position as being more in harmony with the methodologies that I have chosen to guide my research, together with a convincing debate surrounding the fittingness of phenomenology and nursing (Thorsen 1995).

On examination of the literature there appears to be an inherent difficulty in determining whether a nursing researcher has used Husserlian or Heideggerian phenomenology from the brief methodological discussions of their research as printed in the professional journals. Word limitations and publishers' intractable instructions to contributors may often prevent authors of journal papers and publications supplying an in-depth exegesis of underlying philosophies (FitzGerald 1995b). In short, nursing researchers frequently do themselves a disservice by publishing in nursing journals abridged versions of their research methodologies. Further deliberations with these authors can often reveal a far superior discussion of the complexities of their chosen methodology than the textual space within journal articles allows. In order to avoid the furore of critiques such as those proffered by Paley (1995; 1998) and Crotty (1995; 1996a; 1996b; 1997), nursing researchers who publish through the accepted refereed journals need to discover new ways of communicating their comprehension of these convoluted philosophical discourses (see Robertson-Malt 1998 or Walker 1997 for good examples).

Apart from reading the celebrated works and critiques of Heidegger and Gadamer, much of my own scholarship in using methodologies from the interpretive research paradigm, in particular hermeneutic phenomenology, has been enhanced by reading accomplished nursing researchers' interpretations and applications of these philosophers' methodologies (see Parse, Coyne et al. 1985; Benner 1994; Cohen & Omery 1994; Munhall 1994; Watson 1994). Additionally, I have read several theses at the level of doctoral studies (see FitzGerald 1995a; Walters 1992; Taylor 1991 for example) that utilise hermeneutic phenomenology as methodology. Nor can I discount the mastery of methodological concepts reflected in the work from Honours and Masters students I have known or guided (Vohland 1994; Breaden 1995; Hills 1995; Jones 1996; Meyrick 1997). However, by far the most influential enlightenment afforded to me to become familiar with the intricacies of various philosophies outlined in this thesis, has been through the friendship and scholarship of my peers from the Pearson 'nursing research school' of The University of Adelaide. In a forum conducive to sharing we were able to converse at length about matters methodological and philosophical.

Returning to the extant literature, and in agreement with FitzGerald (1995a) and others (see Bartjes 1991; Parker 1991 & Koch for example), Benner's (1989; 1994) work has been by far the most cogent in establishing interpretive research methodologies as relevant for nursing research. In her work *From novice to expert* (Benner 1984) and later Benner and Wrubel (1989, p. 57) in their publication *The primacy of caring*, conclude '... that a phenomenological perspective also more adequately captures the knowledge and notion of good embedded in expert nursing practice'. In their work, Benner and Wrubel use phenomenological aspects of the person, embodied intelligence, background meaning and

concern to illustrate what it means to be engaged in nursing practice and to care for patients experiencing their illness. Benner and Wrubel (1989) carefully take the convoluted structures of Heidegger's fore-meaning and Gadamer's effective historical consciousness and thoughtfully craft them into their conception of 'background meaning'. Reading their interpretations of these philosophers' works is for me, hermeneutics in action. I commend the manner in which Benner's work in particular has made the beliefs of these eminent philosophers, often couched in unfriendly language, accessible to nursing scholars. Expanding on the notion of care, Benner and Wrubel highlight five areas of nursing practice; health promotion, coronary care, oncology, palliative care and neurological nursing for their study. Concluding by focusing on what it means to care as a nurse, this work, along with Benner's previous publications legitimise the place of caring in the nurse-patient relationship.

In her publication *Interpretive Phenomenology* Benner (1994) pulls together a selection of scholarly essays and studies confirming the hegemony of interpretive research in nursing. In the preface of this book, Dreyfus (1994, p. x) acknowledges the input to discussion from nursing scholars in his own research methodology classes, asserting that through their involvement with interpretive methodology in the human sciences '... they [nurses] have found new ways of thinking about and articulating what they know in their practice'. He contends further that nursing researchers, in valuing all dimensions of the nurse-patient relationship, utilise interpretive methodologies (in particular Heideggerian phenomenology) '... to understand human beings in their physical and cultural diversity and not only as private, autonomous Cartesian selves' (p. xi).

Within this publication are two studies which capture some of the intricate ethical dilemmas that nurses face when caring for people who are dying. The first by Wros (1994) describes her study of the nursing care of dying patients and their families in a critical care situation, focusing on the moral aspects of day-to-day care as perceived by nurses working in intensive care units. The second, although written by a non-nurse Gordon²² (1994) examines an issue that is of particular importance to nurses involved in cancer care with Italian patients. This study explores the practice of disclosure or non-disclosure of health professionals and patients when a diagnosis of cancer is made.

Both studies stress the multifaceted ethical responsibilities of nurses and health professionals as they deal with conflicting opinions of what might be right or wrong in situations of caring for patients nearing the end of their life, and their families. The two

²² Deborah Gordon is an American anthropologist living in Florence, Italy. In this study her distinctly differing social practices (Italian and American) are well articulated as matters of conflict and confusion.

studies focus on diverse and differing situations yet both highlight the ethical positions of the 'moral good'. Wros captures the individualist's stance while Gordon offers a cultural perspective, nevertheless both authors agree that morality is revealed through culturally situated human actions.

Wros' (1994) study uses a combination of interview and observation. A similar method is used and described by other nursing researchers (see Taylor 1991 & Borbasi 1995 for example) in their phenomenologically-informed studies. Both the interviews and the observations (including field notes and the researcher's personal journal) become the text for subsequent interpretation. Wros describes the process of overlapping strategies in her analysis, eventually leading to the creation of '... paradigm cases and exemplars explicating the major themes and issues' (p. 258). In summarising her analysis, Wros (1994) indicates that expert ethical practices are embedded in everyday nursing in critical care and unless conflicting values arise these practices are largely unrecognised. However, in portraying the invisibility of ethical care Wros does not detract from the notion that nurses know they play a unique role in balancing what is 'right' with what is 'correct' for their patient.

By asking the question about the existence of experience: what does it mean to ethically care for dying people in critical care units, Wros explores the multifaceted relationships of concern in the lived world of the nurses who participate in her study. Through the interpretations that Wros continually creates and confronts in her hermeneutical analysis, many of the mysteries and paradoxes of moral distress that some nurses encounter when dealing with patients' suffering emerge. As 'agents of death' these nurses describe the inherent action of juggling responsibilities for their patients, relatives and friends of the patient, their colleagues including medical and allied health personnel and themselves (Wros 1994, p. 276). In explicating their complex responsibilities Wros perceives that the participating nurses are asking for due recognition of what they do when caring for critically ill dying patients (p. 275). Advancing Thomasma's (1994) petition for a 'relational ethic' in nursing Wros (1994) gives credence to nurses' abilities to fashion an ethic of care from the context in which they find themselves:

The involved, caring perspective of the nurse often brings forward situations that are not right, not in the sense of not adhering to principles, but rather in the sense of not fitting the values or particular demands of the situation. This involved stance propels and persists until a solution is found that fits the situation (Wros 1994, p. 276).

Gordon (1994) however, describes the Italian situation where ethical practices tend to follow the confinements of hierarchy rather than the flexibility of situatedness. Outlining

in his study the rigidity of medical practice and by implication nursing's response²³ Gordon traces the culture of concealment surrounding cancer in an Italian community. Like Robertson-Malt (1996), Gordon (1994, p. 286) exposes the ambiguity of language, especially the use of such medical jargon as brain death, carcinoma or tumour for example, that perhaps unwittingly negate the realities of a future for those involved. Hiding behind the language of a diagnosis, concealing the possibilities of a limited future is, according to Gordon, a choice that has to be made while considering the past, present and future experiences of the person; 'disclosure or nondisclosure must be "a caring practice" ... with inner standards of excellence, skills, and habits' (Gordon 1994, p. 313).

In both these studies Benner (1994, p. xviii) contends the researchers pay particular attention to their preunderstandings before they confront the silences, similarities and commonalities of the particular research text. Being guided by Heideggerian hermeneutic phenomenology these researchers demonstrate they enter the hermeneutic circle with the explicit intention of remaining open to the text that is before them, and the text that they subsequently create through analysis. Although each study hints at the possible answers to their research questions they illustrate an ongoingness of the exploration through further questioning and reflection (dialoguing with the text).

Conclusion

This research will seek to uncover the ontological meanings of what it means to be a community nurse delivering palliative care through the exposé of the dimensions of sadness and, in a typically hermeneutic formula, an understanding of what it is to be sad will reveal new understandings of what it is to be a community nurse engaged in the delivery of palliative care. Thus, it is through the explication of the lived experience of these community nurses which shall provide the research with the necessary data, because it is within lived experience that the 'Beingness' of sadness in being a community nurse will be exposed.

By revisioning these experiences and offering different interpretations of the dimensions of sadness, the given, well entrenched, embedded meanings of sadness are potentially thrown into disarray as changed, even divergent understandings are laid open for critique. This movement, this rhythm towards discovery is endless, it is never finished; it will perpetuate with my subsequent re-engagements with the text, and with your reading of the

²³ Gordon contends that nurses in Tuscany work under the authoritarian control of medical practitioners and health care decisions are made only by the physician.

thesis. By our relationship of engagement with our differing 'world' -views and the entities within it, we search and re-search our pathways through life. It is this search that propels us, this search that presents the potential for questions which awaken our knowing.

The rhythm generated within questioning is ongoing and hermeneutical, it is as life itself. We question through language, through conversation and it is through conversation and questioning that our network of worlds flourish and flounder, survive and expire, achieve stability and vacillate. Language and words are like hermeneutical strains moving between the text and myself. We do not live in well defined, well fenced, separate worlds²⁴, 'we live in webs of partially shared worlds' (Mair 1989, p, 257). Nevertheless, as we venture, in and through this study, into each other's worlds and the worlds of the participants it is important to remember that the interviews have permitted us only a partial 'glance' into the worlds of each participant, which are mirrored temporarily as text that are neither fixed nor static. The epistemological encounter is embodied in the ontological stance. Thus it is the synthesis of our separate being-in-the-world-of-the-text (fusion of our horizons) that will augment the meanings revealed by this research. Just *how* these meanings are brought forward through the research processes is expounded in the following chapter *Design and Methods*.

²⁴ Worlds here follows Heidegger's notion of world as apposed to Earth, and means worlds as lived.

Chapter Three

Study Design and Methods

It may be that unless we can learn to marry the true spirit of scientific endeavour (combining courage, persistence, honesty, sensitivity, attentiveness to hints and clues, intuition, and evidence) to that special kind of conversational courage whereby we allow ourselves to 'live in and amongst', we may be deprived access to worlds of reality that are specially rich for human understanding.

(Miller Mair)

Introduction

In research studies 'Design' is a word used to signal or draw attention to a plan, an outline or a sketch of the shape of things to come or work to be undertaken. The idea of design carries also some implicit notion of artistic endeavour—a personal creativity. Additionally, it could encompass intention and purpose behind the plans—design includes the conception of a future scheme. In choosing 'design' as part of this chapter title I wish to convey that I have appealed to both my organisational and aesthetic talents. I want to relate in this chapter how I blend the innovative and logical dimensions of completing a research project.

Stanley and Wise (1993) infer that 'method' chapters often display a misconception of what happened in the research process. Research processes are, they suggest, 'idiosyncratic and redolent with mistakes or confusion' (p. 150). They argue that descriptions of the research processes should acknowledge the humanness of the process. 'We insist that the presence of the researcher, as an ordinary human being with the usual complement of human attributes, can't be avoided' (p. 150). Pointing to the notion of 'hygienic research in which no problems occur' they submit that research is never without problems in its accomplishment and to say otherwise is misleading. They note however, that researchers have traditionally been taught to mistrust personal experience and present data that is presumably 'unclouded by values, beliefs or involvements,' (p. 153).

Implying that feminist research methodologies and methods move right away from these 'doctored' accounts of the research process, Stanley and Wise (1993) claim that feminism is producing and generating its own theory of what is research. Taking heed of their invitation to expose each action (warts and all) of the research, I have chosen to take a

middle path. I aim to do justice to the richness of the research process without boring the reader, rather than opting for an 'objective' mode of presentation which I believe it impossible to achieve. I acknowledge that:

There is no way we can avoid deriving theoretical constructs from experience, because we necessarily attempt to understand what is going on *as* we experience it. The research experience itself, like all other experiences, is necessarily subject to on-going 'theorising', on-going attempts to understand, explain, re-explain, what is going on. This is what consciousness is all about; this is what people do in new situations and researchers do no differently from anyone else (Stanley and Wise 1993, p. 160).

In this chapter I will therefore consider the pragmatics of this research—beginning with an explanation of how method arises from methodology and becomes the framework for seeking the experiences of these special participants. Subsequently, a map of the whole research process, incorporating the approximate time frames, shows how I move between the different processes of the research. A brief introduction to the participants follows this overview and outlines some of the ethical and practical considerations surrounding their choice to be involved in this research. The main thrust of this chapter however, is devoted to elucidating the specific processes I employ in the analysis of the situated phenomenon. In explaining my step-by-step utilisation of the computer assisted program NUD•IST, I will show how this, and similar packages, can be of value in organising the immensity of data in all forms of qualitative research. This chapter concludes with a discussion about my continuing struggle with the concept of articulating rigour within a qualitative stance. I offer some tentative suggestions for this research, submitting that these propositions may be transposed to other, similar interpretive research situations.

Methodology to method

My choice of methodologies that underpin this research have already been considered in this thesis. Yet it seems fair, when discussing the journey of this research, that some of those concepts be reiterated. In recognising the self as a self-interpreting being, researchers using the interpretive paradigm seek to re-search the experiences of those who live in and alongside a particular phenomenon. In choosing to be informed by the various philosophical stances as explicated in the previous chapter, I have located myself within the research, not as a bystander or innocuous interloper; rather, as a being whose being belongs with the participants in 'faith and sympathy' than from an attitude of suspicion (Reeder 1988, p. 205). I am claiming to embrace similar 'traditions' to those of the participants—being a registered nurse; working in a community setting; delivering palliative care to patients, to name but some. In addition, I am taking an existential position from which to view the possibilities of this research and as Reeder (1988, p.

194) suggests, hermeneutically journey in conversation with the participants through their individual and unique terrains of the research question. In order to do so I am using methods borne out of methodologies which, like the practice of nursing, embrace a multiplicity of voices and truths (see Reeder 1985).

In the previous chapter I argued that a methodology should be congruent with its paradigmatic stance. Guiding paradigms which are the feature for discussion in the previous chapter are the positivist, interpretive and critical paradigms. Research arising within each paradigm seeks to address research questions from different perspectives. The positivist paradigm asks questions which seek to control and predict and has been at the forefront of western thinking for sometime. Referred to as the dominant paradigm it sits well within a medical framework which focuses on cause and effect relations. As an alternative to positivism, the interpretive paradigm concerns itself with questions of meaning, seeking to understand. Methodologies which seek to describe and interpret use qualitative rather than quantitative data to elucidate their areas of inquiry. The final paradigm considered is that of the critical which has an emancipatory intent and seeks to illuminate alternative ways of viewing a situation.

The 'fit' of appropriate methodologies within a particular paradigm has been explained previously and similarly, it is not hard to reason that methods should be consistent with the chosen methodologies. Sitting within the interpretive paradigm phenomenology, hermeneutics and cognitive science guide this research, and in so doing a philosophical position which claims that there is no single, ultimate reality but rather an embodied, lived reality persists within this study.

As I argued previously, the idea of succumbing to the use of one method is antithetical to methodologies which lay claim to having pluralistic foci. Rather, the method(s) used in this research can be shown to articulate with the chosen methodological stance(s). The upsurge of the use of phenomenology in nursing research is suggestive that they (nursing and phenomenology) share similarities of focus (Rose, Beeby et al. 1995, p. 1127; Annells 1996, p. 712). Rose, Beeby and Parker (1995) claim that nursing values its humanistic interest and this trend towards holism equates with phenomenological tenets of considering wholes and parts:

... the way in which both nurses and phenomenologists collect data is an example of shared values, in that both place emphasis on observation, interviews, interaction and interpersonal relationships, to fully appreciate the patient's or participant's perception of events (Rose, Beeby et al. 1995, p. 1127).

Phenomenological methods which explore and describe human experience have been well documented (see van Kaam, Giorgi and van Manen for example). However, Koch (1996, p. 174) reminds us, as does Gadamer and van Manen, that 'there is no method, there is only tradition'. Apprehending overt relativism Koch appeals for philosophical, ontological and epistemological agreement out of which some tradition(s) arise(s) '... in which procedures are housed' (1995, p. 828). A particular tradition of the guiding research methodologies is the recognition of multiplicity in and of research methods. Tradition(s) in this sense keep(s) as the central tenet a notion of fluidity and a constant reminder that the chosen methods here are but some of the many ways of articulating the meanings of sadness.

I would also argue, that this tradition, fluid as it is, does itself set some parameters or boundaries over which the researcher knows not to traverse if consistency within a paradigm is to be maintained (see Leininger 1992, for example). These boundaries and the journey alongside them can be illustrated by Koch's (1994) image of a 'decision trail' in which the passing of the research process is articulated clearly, can be understood with precision, and evaluated for its suitability to the question at hand. I am not arguing here that boundaries cannot be permeated. Rather, that in this particular research my claim to congruency can be traced from my own assumptions, or traditions within nursing research and those of my chosen, influencing methodologies.

Mapping the research process

This research process follows a particular pattern which moves from the realised to the possible and forward to different understandings. It is circular in nature and configured in a dynamic relationship between myself as researcher and the participants; myself and the unfolding dimensions of sadness; myself and the matrix network of sadness as experienced by the participants. A difficult concept to unravel the research patterning is best explored by the process of mapping. Keeping in mind as Bateson (1972) proposes it is not looking at the map that is important but gaining some understanding of the terrain that is crucial in meaning making. Appreciating the complexities of understanding relationships of living systems Capra (1997) and Walker argue (1985) for the use of mapping to realise the intricate qualities of nonlinear processes.

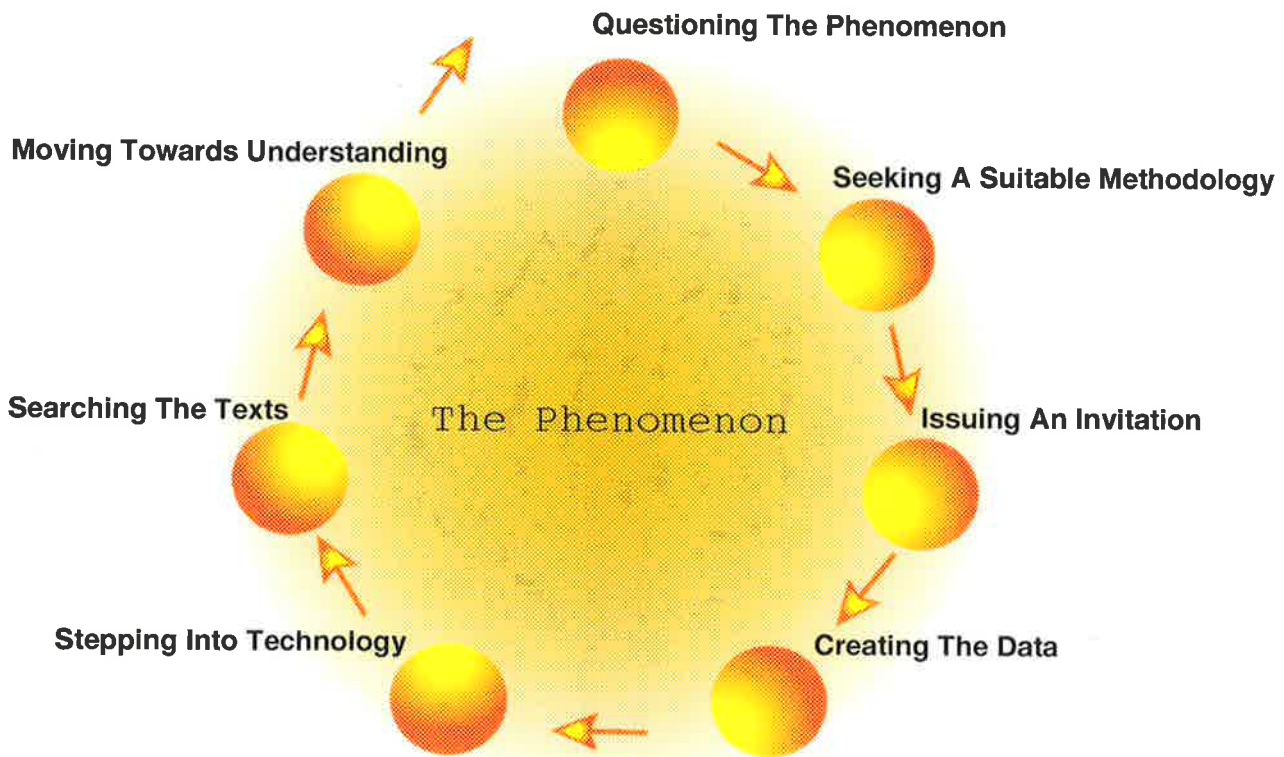


Figure 1: The research relationship cycle (adapted from Seamon 1993).

The circular design of the suggested model shows the unending process of this interpretation. In addition the practicality of the research is shown within the outlined stages in the following table (Table: 3).

STAGES	ACTIONS
1	questioning the phenomenon within the lived experience of palliative care nursing
2	seeking suitable, guiding methodologies - questioning the fittingness of the interpretive paradigm
3	issuing an invitation to the research - includes ethical relationships and, engaging with the participants
4	creating the data - transcription of the tapes; field notes; biographical details
5	stepping into technology: using NUD•IST as a data organiser and means for thematic analysis
6	searching and dialoguing with the texts & thematic analysis
7	symphysis, moving towards an understanding explaining the themes within the context of the research question.

Table 3: Explanation of the research model

Communication of research findings presented in this thesis is but a snapshot in time that hopefully provides an understanding of a dimension of the lived-world of a community palliative care nurse as well as a springboard for further research. The model provides the reader with an overview of the project from beginning to end and a time frame is superimposed over the seven stages which intimates approximately how much time was given to each research action.

TIME FRAME	STAGES
6 months	1-3
6-12 months	4-5
12 months	6-7

Table 4: Approximate time frame for each stage of the research process

Each stage however was not clearly delineated and movement between stages was inevitable: for example, I undertook to transcribe the tapes within two weeks of interview (stage four), while commencing interviews with other participants (stage three).

Issuing an invitation to the research

Sixteen Registered Nurses (RN) working in the community setting of a medium sized capital city in southern Australia were invited to be involved in the study. The following criteria applied to the selection of participants. Participants had to be:

- RNs working in the community and engaged in the delivery of palliative care;
- English speaking, and
- people who had experienced feelings of sadness in the delivery of palliative care.

Although I am not generalising from the findings of this research I am slightly disappointed that no male community nurse chose to be included in the study. In seeking participants for the research I spoke to two male nurses who declined to take part. There was no intention on my part to make any comparative analysis between genders. However, as nursing is both a female and male profession, I would have preferred to have one or two male community nurses participate in the study.

Three distinctive work location groups are identified amongst the sixteen participants (viz. Community Palliative Care; Community Nursing and a Community Oncology Service). Six participants are employed by the Community Palliative Care service. At first glance

this service appears to be concerned mainly with providing advice about palliation and supplying referrals to other, affiliated nursing organisations such as Community Health, Outpatient and Community Oncology, In-patient Palliative Care and associated health care agents. However, on speaking at length with these participants it became extraordinarily apparent that their role encompassed far more than an advisory service and that ‘hands-on’ care was a part of their daily routine. Although the participants in this group Wendy, Vickie, Louise, Zena, Tanya and Yvonne meet and pass each other daily on a superficial level, they come together on a weekly basis for in-depth discussion and case meetings. It is obvious from their camaraderie that they are outwardly supportive of one another.

The second group of nine participants are employed as community nurses from three areas which service the metropolitan and outer regions of the city. Pauline, Nadine, Monica, Joan, Helen and Frances are all employed by the one Community Health Agency servicing the inner city area. Their work includes home nursing and community liaison of which delivering palliative care is a regular and varied part. Kate is employed by the same agency yet she is based in a different location on another side of the city. Her area of practice also includes nursing in semi-rural locations. Kate’s work milieu is similar to that of Pauline and the others. Erica is employed by a different community agency which services yet another region of the metropolitan area. While not fully engaged solely in palliative care, Erica identifies herself as the person who cares for palliative care clients in that region. The final participant in this group—Sally—is professionally located in a predominantly rural setting just outside the city limits. Like the others in this group palliative care nursing is an important dimension of their daily nursing world.

The third group contains only one participant Rose who works in community oncology. Rose’s comprehensive experience in the areas of palliation and oncology contributes to her extensive knowledge of what it is like to be sad in her work. Knowing more than most about the experience I felt that her inclusion in the study would be of considerable value. Many years ago Rose was the sole provider of palliative care in the community. Together with a local specialist Oncologist, Rose implemented what they thought was ‘good palliative care’ for people principally suffering from cancer and who chose to stay at home and receive palliative care. Admitting that the care she gave in those initial days resembled nothing like the palliative care of today, she suggests both herself and the medical Oncologist were ‘pioneers of present day arrangements’. While her role today still crosses the boundary of active versus passive oncological treatments her stories of contemporary sadness experiences and those of the early stages of setting up the community service cannot be ignored. Rose is widely acknowledged by both the nursing community and the people she visits as a sincere, sensible and a ‘special’ nurse.

Prior to our meetings to discuss sadness in their work, details of the research were explained to each participant who was then given a plain language statement and requested to sign a form signifying consent to be part of the research (see Appendix I). All participants were asked if they had any objections to our meeting(s) being audio-taped. They were also informed that pseudonyms would be used, and as much as possible their specific role identification would be significantly blurred so as to make difficult their identity. A copy of the plain language statement and consent form was left with each person and they were informed that they could withdraw from the research process at any time without detriment to any previous or potential relationship.

Ethical approval and considerations

Interpretive research necessitates eliciting personal information from the research participants and Usher and Holmes (1995) advance that a balance between rigorous investigation and nurturing concern must be an aim of any research activity involving human participants. Interpersonal sensitivity and empathy as described by Kellehear (1989) and Lee (1993) lays the ground for avoiding the issue of an intrusive threat that some interviews may pose, especially when asking participants about emotionally charged events. Cowles (1988) proposes some ideas and systems for overcoming difficulties that might ensue when interviewing about sensitive topics. She advises that special attention should be given to the timing of the interview, noting that intense emotions from the experiences under scrutiny can be protracted, and participants might need some distance from the episode before an in-depth discussion about the event. This need for distance was reflected partly in Vickie's reluctance to engage in dialogue with me. When I initially approached her to invite her into the research her workload was particularly heavy. After making several appointments with her that were later broken, I decided not to add to her stress by repeating my invitation rather, I waited until she approached me with the suggestion of a date and time to meet. Also in relation to time Cowles (1988) affirms that a time limit be placed on each interview session because of the stressful nature of the topic. My interviews were set at sixty minutes duration and on the whole they remained within that boundary. There were however, two interviews when the participants stated they wanted to continue talking past the sixty minute limit. In my considered judgment of those situations I felt it was legitimate to extend the interview time.

In line with the University requirements and following sanction from the Department of Clinical Nursing's Research and Higher Degree Committee, ethical approval was sought and later granted from The University of Adelaide's Ethics Committee. As an act of courtesy each participant's immediate supervisor was consulted about the nature of the research. With their support I then felt comfortable in seeking each participant's

involvement in the study. Consideration was given to the vulnerability of the participants in that the stories these participants related to me had the possibility to be traumatic or disturbing. At all times the participants had control of the interview sessions in that they were able to discontinue the process at any time or withdraw from the research without any repercussion on either a personal or professional level. Resource personnel, in the form of a counsellor, was approached to be available and on-call for the participants should that need arise (Cowles 1988; Kellehear 1989). I am assured by the participants and the counsellor that no such encounter eventuated.

Completed consent forms, audio tapes, subsequent transcripts and narratives are stored, and will continue to be stored for a period of five years, in a locked filing cabinet accessible only by myself. Anonymity of each participant is guaranteed by the use of pseudonyms and minimal disclosure of personal details. Such details are used only to explain the social context of each participant.

At times our conversations took on an obvious therapeutic relationship which was often reciprocal in nature. In my conversations with three participants, extremely personal disclosures eventuated, and in retelling their particular stories (in Chapter Four) I made a concerted decision, albeit at times abstruse, as to which part of the data was to be considered public and available in this thesis and which was to remain private (Usher and Holmes 1995). However in saying this it must be noted that these personal narratives continue to inform my interpretations and will always remain part of the understanding I have of all their experiences. In making these choices I argue that I am actively discerning between data that fulfils the intentions of the research to reflect the meaning of the experience, and data that was released as a consequence of the trusting intimate relationships between these participants and myself. At times however, practicing such discretion was not an easy predicament and a blurring of the boundaries between what I considered private or public was evident. For instance at the end of each re-told story in this thesis a further analysis, reframed as a poetics, captures some of my personal feelings about the participant/researcher connections and relationship.

Care and responsibility are markers of my intentions with the stories entrusted to me from this research. Not only do these stories have the potential to shape and change the lives of the participants, but through listening and retelling their stories I was heedful that unwittingly I could become a character in their stories. This intensive relationship between the participants, their stories and myself requires thoughtfulness. These participants are 'real' people, explaining often painful events, and how I respond to their experience of retelling, initially in our conversations and later in my interpretations, is in itself laden with my own prejudices. Some of their stories were captivating and could rightly stand

alone in all their rawness and beauty. Indeed, in conveying meaning in this thesis the use of large chunks of the participants' own words is, as Bollnow (1982, cited in van Manen 1990, p. 114) informs, similar to '... the fulfilling silence of being in the presence of the truth'. Yet as a researcher my task was to interpret meaning from these stories and in doing so I kept at the forefront of my experience of the research my intentions to acknowledge an ethical duty of care to both the participant and the inquiry (Clandinin & Connelly 1994).

Engaging with the participants

Phenomenological data usually involves gathering '... retrospective descriptions of lived experiences' through storytelling (Parse, Coyne et al. 1985, p. 18). Estes (1992) believes that storytelling and story sharing is analogous to gift giving and receiving, in itself—a healing art. Nurses are experienced storytellers (Parker 1990; Boykin & Schoenhofer 1991; Sandelowski 1994). Stories of nursing situations move from the personal to the public, a necessary rhythm of nursing suggests Boykin and Schoenhofer (1991). They contend that '... nursing stories are rich data sources for research that is truly nursing inquiry' (p. 248). Narrative is the preferred pedagogy for facilitating understanding in nursing education sessions, shift change over, and describing changes in a patient's condition. Storytelling is therefore present in the art and science of nursing and is taking a rightful place as an acceptable method for data collection in nursing practice and research. As stories are told and re-told, the dimensions of understanding increase in complexity. 'Narratives reveal the historic and hermeneutic dimensions that define the lives and works of all authors' (Sandelowski 1994, p. 27). Walker (1995b, p. 156) contends that narrative and nursing research are suitable bed-fellows as 'telling our [nurses] lives as they happen to us is an extremely pervasive activity in our social world'. I believe that these sixteen participants were eloquent storytellers while I, content to assume the pose of an eager listener, felt privileged to witness their outpourings.

In listening and valuing each participant's story I have chosen what is to become visible (and invisible) in the texts and re-fashioned throughout this thesis. Questioning each participant and later questioning the text became my method of gaining deeper access into the rich data of the interviews. As this research considers the work of nurses with patients who, by the nature of their disease states, were already jeopardised, I did not wish to further compromise their situations by intruding into their space. A space that I later observed, through the participant's stories, as necessarily sacred and at most times reserved for immediate family, special friends and their nurse. Instead I opted for the sole use of in-depth semi-structured interviews employing appropriate questions (detailed later) that gently prompted for more information as I deemed necessary.

Benner (1994, p. 108) suggests that phrasing questions which are user friendly rather than in 'academic terms' allow the participants to remain in their everyday experience (lived experience) and gives permission for them to use ordinary language in their responses. This respect for the 'everyday' in discourse is discussed by Oakley (1986) who argues strongly that interviewing techniques in social science research have traditionally followed a masculine model where protocols of interviewing are held hard and fast. Deliberating further that there is a 'lack of fit' of these protocols when women interview women, Oakley (1986, p. 231) signals the need for change and a recognition of the worth of a non-hierarchical influence that is apparent in feminist interviews with women. In interviewing the sixteen participants the transition to friendship (Oakley 1986) with some of the women became clear. I have maintained a firm friendship with three participants and converse regularly about matters pertaining to the research as well as personal issues (Connors 1988).

The case for singular versus multiple interviews does not seem to follow a prescribed line. Benner (1994) and Taylor (1994a) advocate the use of more than one interview per participant thus identifying and revisiting '... gaps or blind spots'. Other researchers (Packard & Polifroni 1992; Pearson 1992; Parse 1997) purport that one session is enough to capture a participant's particular meaning of a phenomenon at that particular moment in time. Burnard (1997) however is sceptical. He questions how is it possible for a researcher to appreciate the complex dimensions of a person's 'life-world', related to a particular phenomenon, after just one interview. I agree that it is foolish to claim to know a person's life-world after speaking with them for one hour. Yet to say that you cannot know them is somewhat reflective of a belief in some static understanding of what is known, and not in keeping with the methodologies that inform this research. Silverman (1985) however appears to move towards some answer to this dilemma by suggesting that the data from the interview is not seeking some incontestable accuracy but a display of reality, a reality of that person's lived experience. Therefore, in response to Burnard's (1995) claims that storytelling is nothing more than a form of fiction Lucas (1997, p. 124) alleges, and I agree, that narratives as a method of data collection can be viewed as 'conversational events that take place in a certain context, where both participants have an agreed agenda, that is, to elicit an account of the interviewee's experience'.

Engagement with the participants of my study took place in a locality nominated ostensibly by them. The place of our meetings varied and included the participants' offices, my office at the University, the participant's home, or my home. Our 'dialogic engagement' (see Parse 1997 for example) usually commenced with the request "can you describe to me an experience of feeling sad when you have been engaged in the delivery of palliative care". A follow-up question such as "what does that [event] mean to you"

was offered if the participant did not clarify the meaning of the experience for themselves (Sorrell & Redmond 1995). Interjectory statements such as “can you expand on that aspect” or words of encouragement such as “uh uh” and “umm” formed much of my additional comments. In some engagements the participant and I held a conversations about particular aspects of palliative care and the associated feelings, sometimes exclusive of sadness. I recall there being much laughter in our exchanges which, given the nature of the question, may appear strange to the reader. Yet nurses use of jokes, humorous stories and laughter as a stress release is readily accepted by those engaged in caring for people who are terminally ill or dying (Cousins 1979; Fritz, Russell et al. 1984; Mallett 1993). As with all conversations other interests can emerge and take the conversation in directions that are not reflective of the initial question. In such an instance I would encourage a return to the initial question with another phrase or question primarily drawing attention to the fact that the conversation has wandered. Completion of our times together were generally heralded by a lull in the exchange or the participant saying they had no more to say about their experience. At all times I was cognisant of the participants’ emotional well-being, offering to cease the process if they were noticeably upset or crying.

Transcription from the audio tape to the computer occurred within two weeks of each session. Each transcription was offered to each participant for their comment and amendment if necessary. While one or two participants refused to take advantage of this opportunity to make comment, most offered invaluable suggestions proposing addenda or corrections (such as corrections to the spelling of new drug therapies or more information about disease processes) that did not alter substantially the initial descriptions proffered.

Stepping into technology: learning the value of a computer assisted data management tool

For sometime I struggled with the notion of using a computer generated program to make meaning (analysis) from the data. On the one hand my hesitation in using NUD•IST (Non-Numerical Unstructured Data Indexing Searching and Theorising) was borne of a seeming incongruence that its linearity had with the circularity of meaning making inherent in my approach to methodology and method. I did not want to appear incongruent or traverse paradigms in my research approach. On the other hand I was very excited about using NUD•IST, rewarding an intuition that the program could offer a unique and limitless way to store the large amount of data generated by the study.

The promise of NUD•IST; that is, recognition of categories, generation of ideas and exploration of meanings (Richards & Richards 1994) emerged as I began to manage the

large amounts of data that were availed by the participants' stories. Segments, as small as one word, of the text were able to be coded although in most cases the smallest segment coded and retrieved was a one-line sentence. For the most part, large 'chunks' of data were coded and referenced into an index, tree-like system. Often referred to as hierarchical (Richards & Richards 1994, p. 457), these *trees* '... represent the organisation of concepts into categories and subcategories, a taxonomy of concepts and index codes'. For me however, hierarchy was not an apt word to describe the arrangement of nodes within the trees, nor was it an appropriate way to describe the system of tree that developed as a result of my encoding. Rather, NUD•IST permitted me to construct several network systems within the one program that was easily adaptable to interlacing and interlocking emerging concepts and ideas as I began to theorise about the data.

Data is stored in NUD•IST by identifying a part of the tree to which a part of a transcript could be attached. Certainly at first glance NUD•IST appears to be a system whereby the whole is divided into parts and these parts can then be sub-divided and so on. I believe however the way in which I have used NUD•IST cannot be described as merely linear or reductive. The constant movements between the tape and transcript; the transcript and nodes; the nodes and memos; the memos and reports (the nomenclature associated with NUD•IST is explained further in Appendix III) and back to the transcripts are circular, hermeneutical and will be described in detail by the following seventeen-step method of data handling.

1. All numbered transcripts (1-16) were checked against the tape for accuracy and altered accordingly to produce a 'clean' transcription. With the computer open to the relevant document and a 'hard copy' of the document before me I began to listen to each tape. Where there was mention of a person's real name, hospital or ward name or place, I substituted pseudonyms or omitted such reference so these details could not be recognised. Pseudonyms were randomly selected and care was taken in this selection not to make any association with personal or professional friends. While performing these tasks I checked the transcripts for missing words and rectified such anomalies.
2. Each participant was then given a copy of their transcript to check for accuracy and to note any necessary changes or corrections (Jasper 1994). Mistakes such as diagnostic names, drug names and omissions in some transcripts were noted and changed. Again, all attempts were made to produce a clean transcription (no mistakes; no recognisable or identifiable names of place or person).
3. During this cleaning process (as instructed by Richards, a co-author of the NUD•IST package), each participant was also given a pseudonym according to the letters of the

alphabet working backward from Z. The participants were not re-named in the order of interview, nor in groups from where they worked, it was an arbitrary selection. It should be noted however, that each participant was asked to choose a suitable pseudonym but they left that decision to me.

4. Each cleaned transcript bearing the pseudonym was made into a document suitable for loading into NUD•IST program as raw data ('Name' raw—for example 'Sally' raw)
5. Each piece of raw data was then entered on to the 'Sadness' project and saved as a document ('Name' doc—for example, 'Sally doc')
6. At this stage a document memo (bearing the pseudonym of each participant) for each participant was made in which post-interview field notes were transcribed from my field note journals (fldnts). On most occasions these field notes were made immediately following each conversation with each participant. It is important to mention here that field notes too form part of the whole text, and are in themselves interpretations reflective of the relationship I had with these participants. 'What is told [in a field note], as well as the meaning of what is told, is shaped by the relationship' (Clandinin and Connelly 1994, p. 419).
7. A brief precis of each participant's career in palliative care was written in this section of the memo plus any significant nursing or personal anecdotes which seemed to be pertinent to the study. Such notations included the amount of time spent engaged in community nursing work, oncology nursing, palliative care in a hospital settings or involvement in funding applications for palliative care. Also, staff positions in the various health agencies were noted and their length of time in their present position was included in this data. Personal histories were recorded with full permission of each participant however, I was cognisant that revealing too much personal information could break the confidentiality and anonymity I had promised to preserve.
8. Confident that the on and off-line transcripts were the same and matched the tapes, apart from the imposed changes as detailed above, each line of each transcripts was numbered in accordance with most content analysis research methods (Burns & Grove 1993, p. 597; Berg 1995, p. 193). In this research each text line was represented by a text unit number.
9. Choosing only a small section at a time and carefully reading the transcript, I began the analysis by making notations in the wide margin of the off-line transcript. These notations of one or two words formed the name of the node (or tree branch) or child (sub-branch) to which that particular part of the transcript would become attached

(details of the theory of moving from wholes to parts are outlined in the following section of this chapter).

10. A summary of approximately twenty words was written to describe, in greater detail, the name of the node/child. The node/child had then a numbered piece of transcript stored for easy retrieval by making a report from the node/child (for example, a piece of transcript from Frances [11] relating to acknowledging the sadness of relatives is located at text units 9-11).
11. For each node/child a memo was formed immediately following the node/child identification. Within this memo the theory behind the node/child formation and its relationship to the piece of transcript to which it was attached was written. Additionally, the participant's pseudonym was detailed in this memo and a brief discussion as to the relevance of this participant's inclusion at this node site was made.
12. Before the next section of transcript was notated, I returned to the memo attached to the participant's document and retold their story encompassing aspects of the node(s)/child(ren) previously identified. This reflexive movement between the tape and the transcript, the transcript and the transcript memo, the transcript and node coding, the node coding and the node memo and returning again to the transcript memo was, I uphold, hermeneutical, that is moving from the whole to the parts and returning to the whole again. Each time I dialogued with the text I was noting, in the various memos, my interpretations of the text which in turn informed subsequent interpretations and creation of further nodes/children.
13. As the tree display became more complex I began to see patterns emerging and moved nodes to different locations accordingly. Thus bringing together those parts of the analysis that shared common focuses or interests. (Note: The NUD•IST program retains the original information of the tree, thus evaluation about whether the new location was more suitable was possible, and different alternatives could be trialed without disturbing or losing the original tree display).
14. At the end of each participant's analysis I made a hard copy of the participant's transcript memo which now retold each story (using my interpretations) and contained a list of the various nodes attributed to that particular transcript. Six of these stories are presented in Chapter Four.
15. In addition I made a report on the overall status of the nodes/children identified from the analysis and stored in the tree. For example at the completion of the first transcript

analysis there was a total of 20 nodes with 38 children (total 58). By the end of the analysis these numbers had risen to 45 nodes with 102 children (total 147—see Appendix II). The reports detail the node names, address numbers as well as the names allotted to the children of these nodes.

16. Node reports detailing summative descriptions of each node were generated regularly as the node numbers increased substantially throughout the analysis.
17. Following the analysis of each transcript I made a report summarising each particular node/child address, name and text unit numbers which identified specific details of transcript that I had attached to each node.

After every third analysis I renewed and reviewed the diagrammatic representation of the NUD•IST tree showing the position of each node/child in order to keep track of how the project was developing.

Aware of the other possibilities afforded by the NUD•IST program, such as string and pattern searching or intersecting one idea with another, I used these strategies to commence a search of all on-line documents for occurrences of the words; 'sad' and 'sadness', as well as determining the amount of text portioned to the participants in relation to my questioning or conversation. In spite of other dimensions of the program, I used it primarily as a cataloguing system and a space in which I could test out several theories of understanding the data.

Searching the texts: re-searching the research

While the previous seventeen steps is a meticulous discussion of the pragmatics of how I used the NUD•IST program I will now discuss how I hermeneutically dialogued with the text, as proposed by Gadamer (1976). The process of unfolding meanings from the data will be clarified. Moving backwards and forwards between the text and unfolding meanings was largely influenced by my fore-understandings of the context and questions I asked of each participant and the text. In turn these questions were framed by my own prejudices of engaging with this study. Questions such as, what is going on here? what is this experience like for this person? and others (as outlined in the following chapter) erupted as I challenged my own expectations of the research (as outlined in Chapter One). As stated previously the retold stories mark the first stage of analysis and are therefore in many ways a first level of interpretation. Nevertheless, staying within one level of analysis I found to be unachievable as the complex process of interpretation did not necessarily fit neatly into the different stages. Interpretative research is messy. The researcher is often caught in an endless sea of possibilities as different theories are thrown

in every direction from the data. Being simultaneously focused in differing directions, the researcher intertwines his or her experience with that of the participant(s) and finding a way through the 'forest' of events can be both laborious and stimulating (Clandinin and Connelly 1994). Mindful that my own experience of the research is reflected in the reconstruction of each participant's story I listened to all voices in the text, '... feeling with them, and distilling from them what is considered to be the quintessence of the circle of understanding' (Eberhart & Pieper 1994, p. 48). Following each story as re-told, I would reflect on its meaning advancing some key words and phrases that mark the beginning development of ideas. These rough stepping stones led me towards entering the more structured hermeneutical phase of this research. Each time I re-engaged with the text, new ideas or different aspects of older ideas came into view.

Eventually I became exhausted with the text, that is no new or different ideas were forthcoming. In positing the notion of an ending however—which could be seen as an absolute admission of reaching some finality—I acknowledge also the paradoxical nature of the temporalness of a research process. Clandinin and Connelly (1994, p. 416) posit that '... in the study of experience it is the researcher's intentionality that defines the starting and stopping points [of the research]'. Re-visiting the data at a future date could well elicit different ideas—I will be in a different life-world space at a different time and change is inevitable.

It is important, therefore, for us to understand the autobiographical quality of our own experience, the events and their temporal duration called up as we read and make meaning of the event. The same is true for you, our reader (Clandinin and Connelly 1994, p. 417).

This study is not the last word that will ever be uttered about sadness in the chosen context, nor will it be a definitive study about the nurses who willingly contributed their stories. Rather, this study is a snapshot of the participants' stories of sadness as palliative care nurses through my interpretations in 1997-99.

Symphysis towards an understanding

Presenting a phenomenon, in this case sadness, in all its contextual complexity is important to the interpretive researcher. Thematic development emerged from my relationship with the data. Constant questioning, such as asking the text what is this trying to tell me about sadness in palliative care? assisted me to unravel the multiple layers of meaning from these participants' transcripts. These ideas, generated from the data and steadily webbed with my own streams of consciousness formed a process towards unfolding my interpretations. Thus embarking on a journey of discovery (Roberts &

Taylor 1998) I shifted the data into patterns or groups of common themes which best reflected the interests of the research. Thinking creatively and lovingly, as Roberts and Taylor (1998, p. 319) suggest, I nicknamed these themes 'the four Rs' (Rhythm, Relationality, Resolution, Realisability) although in the final presentation of the analysis these 'nicknames' have been replaced with the major thematic names (Temporal Rhythms of Sadness and Kinship Sadness).

Returning to the musical metaphor outlined in Chapter One, these themes become *movements* of the symphony of sadness, pulling together meanings of being sad which emanated from these particular texts. Each theme or plot (Eberhart and Pieper 1994) acts as an organiser of significant events in each participant's story. Sometimes these happenings can be held together as shared experiences, at other times they stand alone, powerfully relating a unique experience of the phenomenon. By continuing to dialogue with the research text other conversations are stimulated. Conversations with the literature with other researchers or scholars, assisted in the clarification of meaning(s) interpreted from the text.

In crafting the writing of the research I was cognisant of van Manen's (1990, p. 132) allusions to style. He formulates that '... style shows and reflects what the author is capable of seeing and showing in the way that he or she is oriented to the world and language'. Writing is an expression of spirit, a manifestation of my experience of the world. However, by communicating my understandings of this research through writing a thesis I wish to emphasise that I am not 'concretising' my theories. They are not definitive, nor are they representative of a generalised expert denotation of the phenomenon in question. Rather, these understandings occupy a space which Walker (1995a) might term as a disclosure of 'living theory'. As van Manen (1990, p. 130) alludes:

Writing shows that we can now see something and at the same time it shows the limits or boundaries of our sightedness. In writing the author puts in symbolic form what he or she is capable of seeing.

Yet in seeking acknowledgment however, of this analysis as temporal and transitory I am not discounting the 'worth' of this research for as the saying goes 'beauty is in the eye of the beholder'. I recognise that the 'beholders' of this research may be many and varied, each bringing their own resources, creativity and personal judgments to the inquiry (Patton 1990). Thus whatever is written in this thesis will inform the conversational relationship between myself as the writer and you as the reader. You in turn will take this research on another journey, through other dimensions of knowing into your world, where the experiences here within will probably be re-interpreted. Endings then are

illusionary, for as each reader reads this thesis the research cycle begins again, it is ongoing, it is circular, it is hermeneutical.

Incorporated within all sections of the research process is the issue of validity. Evaluating research through critical appraisal, where the relative merit of a project can be shown to enhance a particular aspect of a discipline is necessary for the development of that discipline (Parse, Coyne et al. 1985). Validity of nursing research is no exception yet research into nursing issues, especially projects using new paradigmatic research methods, can throw forth issues of peculiarity that make traditional validation techniques at best inconclusive or at worst render the research unworthy. Reminding myself that ‘... research, like diplomacy, is the art of the possible’ (Patton 1990, p. 13), the following discussion considers some of these evaluation problems with particular emphasis on the characteristics of this research.

Rigour: pertinent and problematic

In using a methodology and methods that subscribe to multiple truths I suggest that it seems somewhat paradoxical to become steeped in a search for ‘absolute’ rigour (Hekman 1986; Walters 1995). Sandelowski (1993, p. 1) suggests the word ‘rigour’ is too rigid a term in qualitative research and moves ‘... us too far from the artfulness, versatility, and sensitivity to meaning and context that mark qualitative works of distinction’. She proposes that contemporary interpretive researchers would be better occupied ‘... with creating the evocative, true-to-life, and meaningful portraits, stories, and landscapes of human experience’ than trying to use a single set of criteria to test the rigour of all research. Guba and Lincoln (1989) advise the establishment of ‘trustworthiness’ in ‘qualitative’ inquiry. However, the interchangeable use of the term trustworthiness with rigour is problematic—at best, semantic game playing. What is at issue here are the dubious notions of truthfulness, internal and external validity and reliability, and their applicability to serve interpretive research. The complexity of evaluating interpretive research does not mean that accountability should be automatically nullified rather, by its own volition, evaluation becomes a matter of judgement (Sandelowski 1993, p. 2).

In general, scientific inquiry fails to recognise the part interpretation plays in the process of disclosing its truths. Appraisal of bias, validity and reliability conform to a set of rigid rules which lay claim to justify the research and the research process. Koch (1996, p. 178) argues for ‘believability’ criteria which are contingent on a specific research viewpoint. Several authors have heralded the need for qualitative methods to explore their own ‘... distinct framework for quality assessment’ (Andrews, Lyne et al. 1996, p. 442). In conformity with Guba and Lincoln (1989) Koch (1994, p. 977) embraces use of the

terms ‘credibility, transferability and dependability’ as suitable substitutes for ‘truth values, applicability and consistency’. Yet mere substitution does not appear to be a solid enough argument for change. What needs to be developed is a set of guidelines, rather than rules, that purposefully evaluate what it is that interpretive researchers have done in their research and the worthiness of further exposition of that research, and its development or appropriation to the particular field or discipline.

With these premises in mind I argue for the following terms as an expression of evaluation or contingency in interpretive research. The three concepts shown side-by-side in the table (see Table 6) are neither interchangeable nor substitutable. Rather, my suggestions for use within the interpretive paradigm can be viewed as signposts or milestones which edify the road towards plausibility, thereby reaching some consensus that the researchers interpretations, as FitzGerald (1995a, p. 273) muses, can be judged as ‘good’ or ‘better’ .

Scientific Paradigm	Suggestions for markers of research in the Interpretive Paradigm
Internal validity External validity Reliability	Harmony Plausibility Integrity

Table 5: Terminology used in the validation of research from the scientific paradigm and suggested terminology for assessing research from the interpretive paradigm.

Harmony pertains to the arrangement of the parts of the research in a sense of congruity. It is also suggestive of a creative endeavour in which each part, while having its own character, moves together in a unifying dance. In interpretive research engagements, the researcher and the participants move through a hermeneutic experience with themselves and each other, challenging their respective horizons and effective historical consciousnesses. Dialogue is continuous in these interactions. Harmonious chords strike at each turning point in the research journey and should be able to be heard and also recognised by the reader as they follow the researcher/participant interaction through the research processes.

Plausibility stresses a sense of sound judgement, of not being excessive, knowing the boundaries and an impression of fair-play. Applied to interpretive research, plausibility embraces this feeling of fair-play, of being principled in relation to the data. One of the criticisms of interpretative research is the possibility of straying from the participants’ meanings or plucking themes from the air which are more suited to the researcher’s

foremeanings rather than the participant's intended understanding. Gādamer (1976) addresses beautifully this problem in his discussion of moral intent. The interpretive researcher is entrusted with the participant's stories and from these undertakes to lay open different meanings of and for the participant in text. This newly formulated text is tantamount to speaking again in a new voice, a voice which coalesces the researcher's interpretations with the participants' descriptions (Risser 1997, p. 168). In relation to that voice, Benner (1994, p.100) states:

[I]t is expected that this voice is not a privatised, purely subjective voice but rather an embodiment and lived understanding of a world and set of local clearings created by social groups, practices, skills, history, and situated events.

Reeder (1988, p. 221) suggests that interpretive researchers become their own 'critical friend' and in a hermeneutical fashion '... make an evaluative judgment' regarding interpretation, moving forwards and backwards between the text and the standards and norms derived from our being-in-the-world. Logicity is also conveyed through use of the term plausibility, bringing forth the research for others to engage in making comparisons. However, I sound a note of warning here, as I am not suggesting that in comparing or finding similarities between the research in question and the evaluator's experience that interpretive research can be duplicated or repeated with the intent of finding the same outcome. Although not totally dismissed it would be highly unusual for such outcomes of research events to occur. As I have stated on many occasions in this thesis, interpretive research is context driven and time-bound.

The final criteria, *integrity*, accentuates the perception of honesty and confidence that the researcher has delivered an idea of wholeness to the research process. Interpretive research is multi-dimensional, understanding being as '... an unfolding process which rotates on itself' (Allen & Jensen 1990, p. 245). Integrity calls for each step of this unfolding process to be made known so that the reader can follow those decisions. Concepts such as Guba and Lincoln's (1989) 'audit trail' and Koch's 'decision trail' (1994) have emerged as traceable integrities of research processes. It is with a respected appreciation of Koch's notion of a decision trail that I believe my constant use of memos in the NUD•IST program reflects a readily identifiable trail of decisions I have made in interpreting these participants' experiences.

Conclusion

The study design and methods used in this research and presented in this chapter are informed by the guiding methodologies discussed in the previous chapter. The seven

stages of the research process have been articulated, reviewed and applied to this particular project. The chapter briefly discusses the application of NUD•IST, a computer package used for organising and storing the data. Elements of evaluation, especially in relation to qualitative research approaches have been considered. However, clearly the emphasis of this chapter professes that methods chosen for this research do not follow a pre-ordained guide. Rather, in keeping with the chosen methodology, a freedom to select those methods which best advantages a new look at sadness for community nurses engaged in palliative care was forthcoming.

Chapter Four

“Old Dogs and Tough Old Tarts”

*I cannot tell how the truth may be;
I say the tale as 'twas said to me.*

(Sir Walter Scott)

Introduction

In this chapter I have chosen to introduce in depth and by way of several commentated narratives, six of the sixteen participants who assisted me with this study. It matters to me that the reader, is provided with a similar opportunity as myself to encounter closely the richness of stories from these six women. It is important that some intimacy with my initial interpretations and subsequent challenges to the accepted views of sadness are shared, so that you may formulate an early appreciation and comprehension of how my understandings and meanings of the participants’ experiences developed in and from this initial phase of the analysis. As Gadamer (in Risser 1997, p. 3) posits, understanding takes place in all aspects of experiencing. Thus encountering these six short histories serves, at best to open the dialogue between the participants, myself and the readers of this thesis:

... the way we experience one another, the way we experience historical traditions, the way we experience the natural givenness of our existence and of our world, constitute a truly hermeneutical universe, in which we are not imprisoned as if behind insurmountable barriers, but to which we are opened (Gadamer 1975, p. xxiv).

Furthermore, in retelling these selected stories I begin to sketch a picture of the research, metaphorically laying the foundation stones of the research context. It is the question of sadness as it is experienced in an especial setting—community nursing/palliative care—that is the focus of this research. Keeping these experiences closely tied to their respective contexts by retelling each chosen story in full, a notion of ‘wholes’ begins to emerge and the risk of irredeemable fragmentation (that may occur if the sadness incidents are related only in their disparate parts) diminishes. These stories, told in the first person present tense, rather than the third person past tense, provide a sense of immediacy for the reader, analogous to being an active member of the conversational process.

In the action of introducing these people I have retold their stories of sadness which they so willingly shared with me. These stories are my descriptions and thus neophyte interpretations of their interpretations of their experiences. Throughout these chronicles I interpolate relevant sections of the participants' dialogue in an attempt to demonstrate my patterning, my interpretations in reconstructing the text. This new text marks the first stage of analysis in this research. This same process has been conducted with all the participants' transcripts and the retold stories are located in the 'memos' attached to each participant's document and the 'Reports' documents in the NUD•IST program (as described in a previous chapter). It would be impractical to share all the participants' stories in this chapter. However, in the subsequent chapters, when I discuss the data through differing perspectives (thematic analysis), I will explore the as yet untold stories together with a further exploration of those presented here.

The six people featured in this chapter were drawn from the three areas of practice in which the participants are engaged. It is important for me to emphasise that the process of engaging with the text, retelling each persons' stories, collating the significant words and phrases into nodes and creating poetics was undertaken for each of the participants. My choice of these six people was influenced in part by some prior knowledge of their personal characteristics, having shared differing qualities of working relationships with some of them. Having made these choices, I must quickly point out that I do not suggest the remaining ten participants are in some way deficient. Indeed, I respect and revere all the participants who assisted me in this study.

'Old dogs' and 'tough old tarts' are two expressions used by a few participants to describe how they might be construed by others within the small community where the research took place. While these idioms may appear discourteous, they and terms similar are an accepted element of the Australian vernacular. Australians' couch many of their terms of endearment in language more readily sanctioned as crude or irreverent²⁵. On the surface, these two phrases (old dogs and tough old tarts), may seem derogatory, yet, in the context of the discrete research conversations, they might be suggestive of the many years some of these participants have spent in palliative care nursing practice; or a perception that because of their many years in practice some of these participants have hardened feelings towards their work. However, using these phrases with a more affectionate twist, they could be explicated as being symbolic of erudite, efficient and

²⁵ The Australian everyday language contains similar jargon. 'Pommie bastard' for example, is a term that has a double meaning. It can be used to show either fondness or disdain towards an English person. Its meaning is governed largely by tonal inferences and the context in which the term is stated. The use of accompanying vernacular seems to have little influence on the overall meaning of the term.

insightful women whose life-work experience has somehow contributed to their seemingly composed demeanour. It is within the parameters of this latter interpretation that I introduce six of the 'old dogs' and 'tough old tarts'.

The six people

These six participants (Nadine, Pauline, Rose, Sally, Vickie and Wendy), practice nursing in the three areas where home-based palliative care occurs in the community. Vickie and Wendy work for the community palliative care service as specialist nurses. Their responsibility is largely consultative and between them (plus other nurses in the community palliative care team) they service both the metropolitan and immediate surrounding rural areas. Sally is employed as a part-time generalist community nurse in a rural region adjacent to the metropolitan boundaries. While her daily work enterprise encompasses caring for people with a variety of ailments, Sally maintains a keen and fervent interest in caring for people who are terminally ill. Nadine is attached to a metropolitan community health service and cares for a wide range of people within the inner city. She has a history of working in an isolated rural coastal community. She too has a special interest in patients requiring palliative care. Pauline presently heads up the community agency where Nadine is employed. Pauline has a wealth of experience in community nursing and maintains a small case load in her current administrative position. A few months prior to our conversation Pauline was diagnosed with an operable tumour. Almost concurrently her mother was diagnosed also with cancer and subsequently died. For most of her own illness and her mother's failing health Pauline continued working, taking sick leave to have her operation and recover, and compassionate leave when her mother died. Her first-hand knowledge of receiving palliative care nursing, together with stories from her own nursing experience, provides the study with plenteous data. Rose's main work emphasis is with community oncology services. A significant proportion of her work however is taken up by providing an oncology outreach service for patients receiving palliative care. Rose has been part of the community palliative care/oncology service since the inception of such services in this particular region of the state. At one time or another she works (or has worked) closely with all the remaining participants in the study.

Following my interpretation of a selection of stories from each person I have scoured the material and filtered out key words and phrases which form the foundations for building the themes presented in the following chapters. These words and phrases (language) were the rudiments of the computer-assisted analysis and form the preliminary NUD•IST nodes. Each box following each retold story presents these items. It is possible from

reading the information in these boxes to observe patterns emerging in the study. These patterns are then further analysed into major themes that form the subsequent chapters.

Language is not only the product of humankind it is also the process by which humankind can understand or make meaning of its existence. We cannot understand or even describe what presents in our immediate experience without using language (Crotty 1996b, p. 166). The idea that language is only representational of worldly images is limited to the empiricism espoused by Decartes, Galileo and Hobbes (cited in Polkinghorne 1988, p. 24). However, Wittgenstein and later Heidegger (in Mulhall 1990, p. 35) believe that language is not merely representational but entwined in our social constructions. Consequently, to Wittgenstein and Heidegger there is no such notion as a neutral language by which reality can itself be described. Polkinghorne (1988, p. 26) vows that '... we are then, caught in the prison-house of language with no way to break through to know extralinguistic reality in itself'. Words and their meanings cannot be separated, in the same way that language and experience are tied together. The nodes recorded at the end of each story not only describe aspects of the raw stories within each person's narrative but also give meaning to these stories. In her phenomenological thesis FitzGerald (1995a) uses the term 'impressive words' borrowed from Colaizzi (1978) to describe a collection of words that prompted reinterpretations and further analysis.

Despite the language-centric nature of this research, in wrestling with describing these participants' experiences, the words of Viktor Frankl came alive for me: '[W]hen we try to describe what presents itself to us in our very experience of it, we are lost for words' (cited in Crotty 1996b, p. 167). Nevertheless, these reinterpretations of the participants' experiences are not conjecture, they are a rebuilding of understanding brought about by consciously 'resting' within the data, moving towards Heidegger's (1962) notion of letting it (the phenomenon) speak for itself.

After each collation of NUD•IST nodes there follows a poetics of the experience of sadness for each participant. Borrowed from Mair (1989) a 'poetics of experience' is adopted from Aristotle's work on language, metaphor and poetry. Mair (1989, p. ix) declares '... [I] believe that we persistently boil down our experiencing to dull 'normality', while our unspoken selves long for a voice of more passionate precision'. These poetics answer that call to the passionate, born from an imaginative freedom of language rather than a desire to contain, dominate or control it. These poetics can be likened to Heidegger's (1962) *Gelassenheit* that Crotty (1996b, p. 160) describes as both '... letting go and letting be'. A state of dwelling by which the phenomenon of sadness in this particular context can be revisited, and its ready-made masks (vis-a-vis Mair's 'dull normality') lifted slightly allowing me to begin to listen to the edges of the symphony of

sadness that resonates before me in its own beauty. Notwithstanding the creative and imaginative tones provoked by these poetics, in this context they lend themselves also to become another analytical device. Together with the significant words and phrases they lead me down the pathway of discovery towards what the experience of sadness means for these community nurses when engaged in palliative care.

Vickie

Background and first impressions

It took some time to secure an occasion to talk with Vickie. She made at least three separate appointments to be interviewed, cancelling all of them at the last minute. At first I suspected that she did not want to discuss sadness with me, in spite of her earlier promises and seeming enthusiasm. Not wishing her to feel coerced I provided an opportunity for Vickie to withdraw from the commitment to be a participant in the study. However, she declined this offer of retraction, agreed to meet and finally kept the appointment with me to discuss her experiences (fldnts 1:21).

Vickie is a small agile woman who, when talking with me, constantly shifts her physical position, which upon reflection I interpret as her general busy approach to life. Articulating a deep commitment to palliative care Vickie describes herself as '*one of the old dogs*' (6: 37), a founding member of the original team who actuated community palliative care in the region where the study took place. A registered nurse of some thirty years, Vickie's interest in end of life care commenced while she was working in the bone marrow transplant unit of a major metropolitan hospital located in a capital city of another state. Subsequently transferring into community cancer care she was well skilled in the coordination of transitional (between hospital and home) services when she moved to where the study was conducted. On moving to this state she quickly secured a position as discharge planner for people requiring ongoing palliative care and from there moved into her present position, where she has been working for the past nine years. Her work in community palliative care is mainly consultative although she perceives herself to have a clinical focus rather than an administrative orientation to her work:

... but what we really needed was people working out there in the community in the palliative care area, so I tended to switch over and do more of the clinical work (6: 24-26).

Retelling Vickie's stories

In opening the conversation about sadness Vickie is quick to point out that people within the community almost always acknowledge that sadness is perceived by them to be a significant part of palliative care work. However, she claims there is a difference between her own and the patients' sadness:

... working in this area people tend to always say to you, God how can you work in that area it's so sad? Which makes you think yourself, well you know, am I a hard old dog or is it as sad [quizzical look] [Laughter]. And I think probably the reason that I've been able to work in this area for a long time is I've always been very clear about what is their sadness and what is my sadness (6: 45-51).

In her early days of working within community palliative care Vickie states she appeared to gravitate to caring for people who were diagnosed as being HIV (Human Immune deficiency Virus) positive and people with AIDS (Acquired Immune-Deficiency Syndrome). It was the recollection of this particular group of people that triggered for her these subsequent conversational memories of sadness:

I tended to look after all the AIDS patients that we had. And because of the um all the social problems that were involved at that stage, um, I tended to become more involved with the AIDS patients than I did, you know, than in my normal client load. And yes, so there was always an incredible sadness in the end of, loosing someone, you know being, having been involved with that person and not being able, you know I won't see them again (6: 56-65).

When approached to identify what, if anything, made these people significant for her, Vickie replies that she is uncertain, but suspects that it may be because of a number of reasons, the main one being identification with that person:

I've often thought about it. Is it because I was involved? And it wasn't every AIDS patient. No, it wasn't every AIDS patient. Ah and I've often wondered what is, what is it that makes someone different that I'm going to be involved with. Sometimes it's um, it may be a younger person sometimes. Sometimes it's just someone that you just suddenly click with and you think I really like that person you know um, there may be a lot of similarities in their life to your own life and so during the course of caring for that person you have to be constantly reminding yourself, listen you know, this could be you but it's not you. So, you know, be quite clear. But you know inevitably you'll sort of, um that sadness is you know, here is a young mother she's the same age as me, she's not going to see her children grow up, she you know, it's just putting yourself in her shoes (6: 69-85).

Recalling her most recent experience of sadness Vickie acquaints me of it with an recognisable air of reverence. She had recently returned from an overseas trip (with Rose, another participant in this study) having thought occasionally about three particular patients who were about to die. She outlines how one dying man was just "*an ordinary bloke*" (6: 114) yet someone who treasured his wife and children, appearing distraught at the thought of leaving them. Vickie's sadness expands to include his wife and family as she reflects on the chasm that was about to be left when the man died. One idea Vickie had about the development of her closeness with this family was their seemingly unconditional acceptance of her as a person. As '*ordinary people*' (6: 129) Vickie concludes that they responded to her ordinariness—her 'ocker' speech, her manner and her humour. As our conversation continued I could not help thinking about how the qualities Vickie notices in the family, especially the dying man, are like carbon copies of her own engaging personality—a salt of the earth person. When I communicate my thoughts to her she is embarrassed, yet humbly agrees with my observations:

Ysanne: *Umm so was it someone who accepted you as you are? ... as well as you accepting them the same way*

Vickie: *Yeah totally ...*

Ysanne: *So there was a bond?*

Vickie: *Yeah totally. We sort of spoke the same language too.*

Ysanne: *Sounds like this guy was the salt of the earth?*

Vickie: *Yes absolutely, yeah absolutely.*

Ysanne: *And that's how you come across to me.*

Vickie: *Ah Yeah, isn't that funny?*

Ysanne: *Yes I think of you as a sort of salt of the earth nurse (6: 157-175).*

The bitter-sweet memories come flooding back as Vickie recalls the family involvement in this man's death. Savouring the way in which his family went out of their way to create an appropriate ambience around his death bed, Vickie notes how they appeared to be attuned to the aesthetics of palliative care—an aspect of the work in which she too feels at ease and content:

I always felt, sort of very comfortable, at not always having to put on the airs and graces, no not at all, yeah. And I just, you know I just looked at them and I thought well, this is what palliative care is all about. I used to look at him, in the bedroom with you know the little flowers and all the nice little things around, which you might see in dozens of homes, but it was done with such care and such thought, you know, umm and also we could have a laugh. You know, there were also times when we could have a laugh, you know. I mean, his death dragged out in the last two weeks. I mean it was horrendous. I mean like he was just a skeleton of a man lying in the bed. But had been so beautifully looked after (6: 190-203).

For Vickie, sadness and serenity appear to go hand-in-hand in palliative care work and she recalls having been embroiled often in such positions, especially when dealing with children who are terminally ill. Both Vickie and Louise (another participant) share the caseload when children are the primary patient. Sharing a close working relationship with Louise, Vickie suggests they complement one another in the delivery of palliative care. Vickie's specialist background is in oncology and Louise's is paediatrics and together they make a good team. Nevertheless, during our conversation Vickie confesses that, while the care of dying children holds a particular appeal for her, for the most part she finds the death of any child particularly unfair:

And you know I mean I guess that's just the unfairness of you know a child. A mother having to bury, well you know, parents having to bury their child. And then I mean inevitably, being a mother yourself you think Oh God! (6: 214-218).

The demands on the community palliative care service and lack of staff to work all shifts, everyday, mean that community generalist nurses have to cover for the community palliative care nursing team on weekends. Vickie makes an 'off-the-cuff' remark indicating there are many mistakes made by these relieving nurses who are unskilled in the technological aspects of palliative care. While loading a syringe driver is not an intricate skill to be mastered she infers that many of the relief nurses do not have the knowledge to perform this craft proficiently. Vickie connects her sadness with such situations, poignantly etched with frustration, as she proffers it is the patients who suffer needlessly in such inefficiency, as they nearly always have to deal with superfluous break-through pain.

According to Vickie the nursing specialty of palliative care does not seem to be attracting suitably motivated nurses. She professes that some nurses are reluctant to give of themselves and senses they might be scared of involvement with dying patients. She pledges that the work is not all 'gloom and doom' asserting that most of the time she and her patients enjoy humorous exchanges. Vickie speaks admiringly of a position of privilege that community palliative care nurses find themselves experiencing when caring

for a person who is close to death. The openness, sharing and lack of barriers in this special nurse-patient relationship are symbolic for her. She fears that some newly graduated nurses want only to give the minimal care needed and do not wish to take time to get to know the person. She surmises that they may act in this manner out of fear, fear of loss of the patient, fear of confronting their own mortality, fear of the unknown. Clearly Vickie's sadness stems from a lack of confidence that recent graduates may not be able to appreciate the small pleasures and deep satisfaction that she acquires from her involvement with dying people and their families:

I think I feel, I feel sad sometimes about the quality of the nurses that we have that can't give that care that's needed. ... but, it's often sad sometimes when I look at nurses and I think, crikey look I've been doing this for 30 years and loved every day of it. You know, just give a bit more and you'll get a lot back. Because, when people say to you Oh God! how have you worked in oncology and palliative care, for all those years? And I say look, it's been wonderful! You know, I'm the sort of person that's not going to go into a job unless I get something out of it as well, I'm selfish enough to want something out of it. And I think, look I've been so incredibly privileged to work with people at that stage in their life because, particularly in palliative care there's no barriers, the barriers are all down by the time we get in. You know, I mean you share with everything, everything in their life that, you know there's no hidden secrets. And you think, I am so privileged to be involved in that part of their life and also, yeah, also to share that experience with them (6: 230-250).

Related to the issue of staff, Vickie quibbles that a minority of nurses begin a much desired career in palliative care unknowingly ignorant that some of them are unsuited to this type of work. She criticises nurses who commence palliative care work with their own unresolved grief on board, remaining in the service knowing they cannot really achieve good patient care because their own problems appear to interfere. Vickie remembers at least three people in the community palliative care team who left of their own accord having gained insights into their own unsuitability.

Working in a small team for Vickie means that each member has a greater opportunity to develop insight into each others limitations, or realise when situations in someone's personal life might be so overwhelming that their ability to deliver effective care is compromised. Vickie praises all members of community palliative care team in which she works for the collegiality that has developed over the years they have been together. She feels they sensitively care for one another and readily offer support for each other in an ambience of trust, politeness and humour:

I think to function, you know, to really function well, we have to know one another well and we have to be aware of one another's breaking points and we have to be aware with one another's stress. And yeah, I mean it has happened that there are people on the team that have had you know, difficult times and I think that's the time when we sort of, we come in and we say, listen, come on hand a bit over to us. Because you know that if you were in that situation, the same thing will happen to you. And I think if you know that, you will always help out. So that's sort of what really enabled this team to sort of function quite well as a small team I think, umm and a bit of a sense of humour too (6: 330-343)

During our conversations, Vickie speaks unfettered about euthanasia—an issue of some sadness in her practice. She gives a graphic account of Ivan, a young man diagnosed as being HIV positive who was referred to her care. He had returned home to die and in doing so not only had to confront his parents with his diagnosis but also his sexuality, unknown to them until his recent diagnosis. Vickie recalls that it was not an easy situation for either Ivan or his parents. In a heated argument between Ivan and his father, the father admitted that he 'hated' the boy, fell to the floor and died. Vickie sadly recalls the guilt that surrounded that situation and Ivan's ensuing three failed suicide attempts. Vickie's appreciation of the total situation and her abilities to use all her skills and wisdom resulted in Ivan dying a peaceful death at home. Unafraid, she confronted him about the issue of euthanasia and was convincing in her argument that she could not actively assist him. Instead, she spent time with him, ascertaining his fears, needs and wishes as he approached death. Vickie established that Ivan's most pressing wish was to attend his own funeral party. Contrary to societal 'norms and mores' Vickie works with him to organise this event. His gay friends attend from interstate and after the party she remembers that, in the afterglow of the celebrations, he was remorseful of his suicide attempts and relished in their failure. For Ivan the party enabled a triumphant meeting of his three families—his biological mother, the nurses from community palliative care and his adopted homosexual community. Recalling that after his third suicide attempt he could not forget the anguish on his mother's face Ivan indicated to Vickie that he could never attempt suicide again. He died two days after his celebrations, a peaceful, sanguine man. Vickie recalls:

You know, I mean he was just a different person. We were organising, we had the best flowers, we had the best food, just everything was fantastic. We'd ring up people and say okay bring along whatever you want to talk about, bring it along, let's go for it. So it was a Saturday was put aside. I mean at this stage he was just a skeleton, skin and bone and that he still had enough intellectually, his intellectual capacity was enough to know what [was going on] and because we had been planning this all week he was you know very, on the ball about what was going on. So we did and it was just fantastic. And people got up and talked about what he had meant to them in their life. People did come from two other capital cities in Australia and we drank champagne and ate the best food and everything else and that night I umm, I put him into bed and I said, great day! great funeral and he said, "I wouldn't have missed it" (6: 686-701).

Vickie reflects that only a small percentage of dying patients in her care have spoken with her in great depth about having her help them end their own lives. Although appearing clear in her previous responses to requests for euthanasia, she advances that she maintains an open stance on the contemporary euthanasia debate, admitting she has only nursed people with cancer and that patients with other diagnosis may persuade her that it might have some value.

The stories Vickie tells from her practice all, according to her, inform her knowledge, attitudes and values about many issues, including her own life. She surmises:

There's thousands of stories and it's their people that influence your life that, so that you practice your nursing in the way that you do.

Ysanne: *Well that's right.*

Vickie: And yet you might think, well why do I do this or why do I do that? Because in 1974 there was ... [Laughter and knowing looks]. And I mean all you can do is sort of pass it on to people and say well look, you know this is why I do this. That person still influenced my life ... (6: 738-749).

Recapitulating the story of a child Vickie shows how sadness in death can be perceived differently through a child's eyes. The day of this particular man's death is one she will remember vividly. The man had a young son aged five and on the day of his death Vickie and the family had been together, eating strawberries and drinking pink champagne. Vickie, the dying man and the family courageously stayed with each other until his death. She implies it was a day of celebration rather than distress. The following day Vickie visited the family (a post bereavement visit) and spoke on a one-to-one basis with the five year old boy. She insists that the boy did not show any signs of being sad. He recognised his father had died and told Vickie that he knew he was dead because he 'heard God's car

in the night'. The issue for the boy was not one of remorse or sorrow, rather he was intent on getting his father's tools to him (his father had been a carpenter) as the child was certain that his father could be of use to people 'up there'. Stunned and with tears in her own eyes, Vickie saw a glimpse of wisdom in the child's attitude—a sense of mystery yet a recognition and appreciation of his father's death. She remarks that the boy was not concerned with how he might feel or be in the next few months or years, rather he was focusing on the 'now'. And the 'now' for the boy was imagining his father in another place, in pursuit of continuing his life-work, minus the tools of his trade. This focus on the 'now' is a powerful lesson for Vickie who remonstrates that patients who need palliative care could do well to focus on what is happening in the moment, rather than waste precious time chasing elusive rainbows in the form of the many cures that are offered:

I mean I was overwhelmed when this child said it, but it made me think well, kids don't have that fear—this is my hang-up. ... They don't predict, they don't predict what they're going to miss out on next year. They predict what they're going to miss out on next week. And I often think that's a lesson that if we could teach our palliative care patients, that's what we try to teach them (6: 769-777).

Her recent overseas trip with Rose provided Vickie a unique opportunity to reflect on her work. It was during this time away from the community palliative care service when they engaged in conversation about how long they had been friends and the length of time they worked together in end of life care. Vickie realises that this particular holiday was the first time in many years she had spent an extended time away from working with the dying. Using the occasion to re-examine her own values she questioned her motives for continuing to work in palliative care. While Vickie spends her days off at her 'shack' on the beach, she reiterates how much she valued that extended period of time away overseas in which to reflect and re-evaluate her own position. Vickie claims that as part of her respite from practice, on her days off she deliberately avoids talking to her friends and family about death or dying. If she is confronted by media such as television or radio programs where death and dying is being discussed, she switches them off. Likewise, if a magazine she is reading contains articles about death she would rather put them down and not read them. Her time away from work is sacrosanct and keeping to her resolve of avoiding issues to do with death, is how she has been able to work with dying people for nearly thirty years. Additionally crediting herself with being able to say 'no' without feeling guilty to requests of taking on extra work, she acknowledges that this assertive behaviour has been a development with her maturity:

I thought well you know I'm, say I'm a very black and white person but, it made me realise when I was overseas, I thought no I don't think that I'm as black and white as I think I am. But umm, I think also you do have to look at yourself every now and again and think is this just all bull shit or do I really believe this? Umm, I think I'm very fortunate that, in that I have ways of debriefing myself (6: 395-403).

This situation of death avoidance is almost enigmatic—in the world of palliative care, where death is obvious, Vickie appears to effortlessly roll with its ramifications, its speculations and consequences. Yet, in her own 'life' there is no room, nor patience for death to feature. Questions exude from this conundrum—why does Vickie appear to have double standards? Why does she acknowledge death in her patients yet keeps it at bay in her own life? I suspect that answers to these and other questions posed from these initial analyses may possibly come to light through subsequent engagement with the texts.

Vickie believes she has worked during the 'best' years of nursing and feels sad when looking towards the future directions of nursing practice. In conjunction with her sombre view of the future she mourns the past, asserting that she is thankful for being a nurse during these and previous years. She contests solemnly that nurses today and in the future will be driven by economic rationalism rather than a committed care ethic. While Vickie confesses to being aware of rising health expenditure and actively instigates measures to reduce those costs, she makes a plea for some balance. She is fearful that nursing's future will be wrought with change for change sake rather than change for good reason. She criticises change saying that it takes her away from patients as she sees them as primary. Vickie bemoans that perhaps she might be viewed as a person who does not like change but that is not necessarily the case:

I mean there's always a bit of a joke in the team that Louise and I are sort of the old dogs, you know, it's hard to get them to change, you know. And umm, yeah they're right. I guess that with the age comes cynicism and I guess that I've seen so many bloody changes and I become very cynical about whether they're actually going to work. But if someone can say to me, listen if you change and do such-and-such, this, this and this will happen, then I'll do it. But if someone says look we want you to change just for change sake that's when I become difficult because it takes more of my time that I really want to spend with my patients. Because that's my joy, that is why I continue working, I just love my patients. I love, you know, the people. And it's not because you know, I love budgeting or writing you know, that's not my scene. [Laughter] But I accept that I have to do some of that. That I can't just go out and happily look after patients. I accept that, with that now comes you know, documentation, and this, this and this. But I hope that and I think it will, I feel optimistic enough to feel that, that, we had to change, the scales have gone completely over the other way and they'll come back into a level area at some stage

Ysanne: *It's not so long I don't think. That's an interesting sadness that one.*

Vickie: *I don't know if that's a sadness. I suppose it is a sadness, I suppose it is (6: 520-549).*

At the end of our conversation, Vickie confirms there is nothing erroneous in nurses being sad, so long as they do not dwell in sadness all the time and lose sight of happiness that can emerge from palliative nursing work. She emulates that nurses should trust themselves and their instincts as they engage in practice. Her stories too, reflect her own needs for equilibrium in what she perceives as a future, chaotic world. Yet she tempers this search for order with some regretful understanding that tradition, as she once knew it, might never again be achievable.

Preliminary NUD•IST nodes for Vickie's story

- (1) Sadness
- (1 1) Sadness/ Search text
- (1 1 1) Sadness/ Search text/ Whose sadness
- (1 1 1 1) Sadness/ Search text/ Whose sadness/ Their sadness
- (1 1 1 2) Sadness/ Search text/ Whose sadness/ My sadness
- (1 7 1) Sadness/ Failed expectations/ Frustration
- (1 10) Sadness/ Acknowledging
- (1 10 1) Sadness/ Acknowledging/ In colleagues
- (1 12) Sadness/ Why some?
- (1 14) Sadness/ As loss
- (1 14 2) Sadness/ As loss/ Personal relationship
- (1 15) Sadness/ In nursing practice
- (1 15 1) Sadness/ In nursing practice/ Missed opportunities
- (1 15 4) Sadness/ In nursing practice/ Unskilled practice
- (1 15 5) Sadness/ In nursing practice/ Futures
- (1 16) Sadness/ With family relationships
- (1 19) Sadness/ As reverence
- (1 20) Sadness/ As unfairness
- (2) Watching
- (2 1) Watching/ The relatives
- (4 1) Privilege/ With patient
- (5 2) Time/ case load
- (5 3) Time/ Time out
- (12 2) palliative care/ Beginnings
- (14 1) Knowledge of patient/ No knowledge of patient
- (17 1) Images and perceptions of palliative care/ From others
- (19 1) Sharing/ With the team
- (19 3) Sharing/ With relatives
- (21) Influences
- (29) Funerals
- (30) Conflict
- (32) Wise practice
- (33) Self-care

Table 6: Preliminary NUD•IST nodes interpreted from retelling Vickie's stories.

Poetics of Vickie's experiences

Humbleness and ordinariness mark the aesthetics of your sadness.
Be that sadness incredible or serene
it claims bitter-sweet memories,
everlasting and ever present in your relationship
with those in your care.

I find myself in step with you
as you pierce through the anguish, the enigmatic
and paradoxes of witnessing sadness.
Mourning the past and future simultaneously
is enough to confuse even the prestigious philosopher.
However, this conundrum clearly makes sense
to those in the know.

Marked by needless suffering, unresolved issues
and indifference, sadness continuously frustrates itself
and cynicism stealthily creeps into the conversation
and ever so gently those gut wrenching feelings are cleverly avoided.

But are they? What happens to all those feelings?
Do they disappear into some reclusive slop bucket
of fear and guilt
which at any moment can be up-ended
immersing you
in cumulative grief that sticks
like super glue making it impossible to move?
Or do you wait and tease out these sentiments with only special friends,
those humble ones who know the difference
between the sacred and the profane?
A bit of both I sense.

The salt in your tears grounds you,
and you become the salt of the earth,
the pillar of strength,
the reliable one.
Yet your frame is so small,
too small to wear
this princely burden.
But wear it you do ... and with pride;
your wisdom ready to confront that
which has no answer, that which is as uncertain as life itself.

Nadine

Background and first impressions

Nadine presents as a woman with a vast life knowledge and I am almost in awe of her confident air. A woman in her mid-life she has spent a few years working as a community

nurse in an isolated fishing town on the east coast of the state where the study was conducted (field notes 2:21). I relate readily to some of the situations she describes, drawing from my own professional experiences while employed as a community nurse in a coastal village of northern NSW.

Nadine began her training to be a registered nurse fairly late in her life. When she moved to the east coast she spent a great deal of her time fishing with her partner. A friend suggested that she would make an excellent nurse and advised her to apply and commence registered nurse training rather than 'wasting' her life fishing. She made an application and was successful in gaining a place at a nursing training school of a southern metropolitan hospital. For three years she commuted over a hundred kilometres (on her days off) between her home on the east coast and the hospital.

Following graduation as a generalist registered nurse she returned to the fishing town to work in the small local hospital. Gradually, over a period of twelve months she worked her way into community nursing and for seventeen years she was employed as the sole community nurse in the area. During the last five of those seventeen years she became proficient in nursing people who required palliative care. She was often relieved of her generalist community nursing duties so she could concentrate on caring for the people requiring twenty four hour palliative care. Many of these patients required Nadine to stay with them overnight (night sits). She would move into the particular patient's home, attending to their needs as required throughout the night. Nadine recalls:

... I used to work long hours but I mean it was easier for me than to send someone into my round from town umm... than actually... and keep me there in palliative care. Umm... so I had a lot of rural, rural experience with palliative care ... (10: 40-44).

Nadine recalls that she nursed twelve people requiring palliative care in this way, six of whom died while in her care. She purports that this type of 'intensive' nursing was not just patient focused but whole family oriented:

I quite enjoyed it actually, yeah. I don't know why, I really don't know why. But yeah it was, it's very whole family orientated when that occurs and yeah, you get very close to a lot of people (10: 54-58).

Nadine's stories appear to pour out of her being, as if they are being told straight from her heart. Her tears flow freely as she relates some very sad situations. She seems to me to be a person who is not afraid to show her emotions. At times however, I probe deeper into her stories to clarify my own understanding of what seems to me to be tormented situations. Currently working as a generalist community nurse for a metropolitan

community health centre, a major proportion of her nursing care is directed towards patients who need palliative care. Effortlessly, Nadine recalls three stories.

Retelling Nadine's stories

Willingly becoming involved with her clients and their families Nadine remarks that her sadness stems from that involvement. *I have no hesitation about getting in anyway emotionally involved with the family if that's what they require* (10: 87-88). Her first story discusses the case of a homosexual, who after being diagnosed as HIV positive, comes home (to the town on the east coast where Nadine lives and works) to die. He had been living overseas for eight or nine years and wanted to return to his family. At first Nadine suspects the family covers over his true diagnosis, saying to other people that he has cancer. However, over time the parents become more accepting of their son's illness and while HIV/AIDS was not overtly referred to, they did not dispute the possibility of such diagnosis when it was suggested. Nadine asserts that she learned much from that patient and his family as they openly expressed their emotions:

... that initial stuff was hard and and I think umm... he, he taught me a lot as far as umm... expressing what I felt umm... because of the way they are normally they're very expressive themselves, umm... and they're totally up front and honest umm... (10: 102-106).

Nadine recalls that the partner of this man had already died overseas and this loss of relationship and the patient's subsequent aloneness, as he faced his own mortality, was increasingly saddening as the time of his death approached. The potential loss of relationship was also a feature of sadness for the family. Our conversation progresses:

Ysanne: *Was his partner involved?*

Nadine: *No, no, his partner had actually died umm... in the... overseas so that was another trauma that... His partner died two years before so, yeah, of that so, yeah, sad! He'd had a sad time (10: 174-178).*

Making a general remark about caring for dying patients and their family she suggests that courage prevails within each person as they try to be strong in front of one another. Yet often, when they are alone with her, their feelings of sadness, depression and hopelessness are openly expressed. Valuing the trust they have in her and their shared relationship, she is overwhelmed frequently by family member's individual deep sadness:

... that if you're round at the time when families, especially families spend their time to be terribly terribly cheerful at all time and then, as soon as they're out of the room or with you it's where they're more likely to express their own sadness's. It's the same with the person that's actually dying too, they will, they spend their time saying you know, everything's fine, I'm fine, until their family go out of the room so. So usually in those cases you have two lots of people's sadness to actually take on board which yeah, and I think that's that's the struggle, which I've found a lot of the time (10: 123-133).

Using her car as her private sanctuary Nadine reiterates that it became part of her daily practice to express her own sadness as she drove from one town to another visiting patients requiring palliative care. She says:

I mean I used to have to drive from you know from one town to another. And you know you probably cry all the way home and then you'd be right, yeah. Then you'd have eight hours off then you'd go back, yes (10: 137-140).

Visiting patients needing palliative care on a regular basis she is witness to the gradual deterioration of people and claims that watching bodily functions fail triggers sadness within herself as well as for the patient and their family; *I mean that that's an enormous sadness anyway, because it can be... it just looks so cruel, towards the end (10: 157-159).*

Living and working in a small community it is to be expected that sooner or later nurses have to care for close friends: *'the next guy I nursed was a very good friend. So that was the hard... that was very hard'* (10: 192-193). Diagnosed and dead within three months her friend's illness rapidly progressed requiring that she stayed overnight with him and his wife for the remaining six nights of his life. Nadine expresses the intensity of her involvement:

I used to go... someone took over my rounds for the last five, five days and I just, I just did well probably more than one would do, working out of here or what ever. Yeah I'd go, I'd go and certainly sleep... I slept over the last five nights. And I come home in the morning after I'd got him organised and you know, go and have a shower and may be I'd sometimes have a couple of hours sleep, may be I wouldn't sometimes, and umm... then go back up and then I usually came back up, back down in the afternoon and then back up in the evenings so yeah, they almost had me there for twenty four hours yeah (10: 219-230).

The issue of a prior friendship between this patient and Nadine was of great concern to the nursing administration and a more senior nurse said frequently that she should not be caring for him:

There was a bit of kafuffle about me doing that because I knew them so well. [laughter] Like you know people... a certain sister in [name of major town] saying, you can't do it, you can't do it, you're too close, you're too close. And I said, look I'm going to do it. So I took a few days off (10: 234-239).

On discussing this contentious issue with the patient, Nadine relates that he could not bear to think of any stranger caring for him as he died. Their relationship was such that he felt comfortable discussing intimate details of his condition with her and he said that he could not do so with anyone else. Nadine said that she wanted to be with him when he died because of the very reason of their friendship. She did acknowledge however, that nursing a close friend can be extremely challenging. On several occasions the man hinted that he wanted to die, surreptitiously inferring that she might assist him through euthanasia. She remembers that sometimes she could not address his wishes by open discussion rather, she seemed to slip into placation mode or use excuses:

... yeah, there was lots of challenges in there and occasionally he would say, look I want to go today, I've had enough of this hanging about. Umm... and you'd sort of say well, you know, can't quite do it you know, God's not ready for you, you've got to wait a bit. And you'd have to get him through all those really depressed and down stages (10: 274-279).

In this particular situation Nadine's sense of optimism was often tempered with a sudden wish for him to die '*... and then you'd go out thinking, Oh God I wish he'd die, you know so... yeah, there's a lot of up and downing in that*' (10: 280-282). Although it was an emotional relief to her when the patient eventually died she recalls that it was particularly traumatic for her as she had no other health professional in the area to assist her through her own grieving process:

So that was very traumatic when he died and and most of that time I didn't do a lot of crying until he died and then I you know, I cried for about eight hours. No problem. But I think I was totally exhausted as well, yeah I couldn't even think about him for the next few days without bursting into tears. Up and down to the house. So that was very sad. Umm... not a lot, not a lot of people around to bounce that off then. That was the other thing.

Ysanne: *Because you worked alone?*

Nadine: *Alone. Yeah. So there was no work bouncing off people. I had, I had a very good friend up there who was not a nurse, but she was sort of, a bit of a bouncing person, as far as that goes. But she was the only one that when he died, he died at six in the morning and I came back down at eight, or whatever. No he died, no he died about four and I turned up at her place about seven so, and she knew it then and I was there for a while (10: 284-303).*

She adds that her grief was compounded as the whole town appeared to be affected by his death and there was nowhere to hide away from the reality of the event which appeared to consume the people and the town itself.

Moving to more recent experiences Nadine speaks about a gentleman she nursed a few months ago who was diagnosed as having cancer of the pancreas. She used to visit him monthly but following a relapse the frequency of her visits increased as his condition deteriorated. His relatives wanted him to die at home as they were aware of his fears of going into hospital and Nadine acknowledged his and their wishes. She recalls feeling very sad, crying often with the family as she nursed this man. Being with him three or four hours a day, everyday, Nadine concedes that she became a part of that family and grieved like a family member when he died:

I cried with them at times you know you come out and, because he was, he was sort of umm... I think that was about four weeks, no it wasn't it was about five weeks of, you know, you're there everyday for may be three to four hours yeah, so that was a long time. And we had people going in of a night. But usually if you've got a client like that I mean you just spend that amount of time with them yeah, yeah. So it was very sad when he died ... (10: 334-342).

While she does not attend many funerals Nadine implies that going to funerals is construed by the family(s) as a recognition of the bond(s) that develops between the nurse and the patient/family. She feels the family(s) cherish the presence of the nurse at their loved one's funeral. Also, funerals are understood as a rite of passage for Nadine, but she does not necessarily agree that this ritual signals a finishing of the relationship. Rather in attending funerals Nadine acknowledges a connection with the dead person and the nurse, frequently heralding the beginning of an ongoing relationship with the relatives:

... and it just shows that you know, there is yeah, there's that connection there and I think they, they appreciate it. And I don't think it helped me as such going to the funeral umm... I don't think it's like you know, oh this is finished now blah, blah and you know. I don't think that's part of it. I think from that, from going, my idea of going to the funeral was to realise that yes, I was still around umm... after he'd [they had] died you know ... (10: 367-375).

For Nadine there is always another patient who reminds her of those she has nursed previously. Thus she is constantly reminded of her prior sadness with others; '... but, but that horrible sadness umm... because you keep on going and there's somebody else, always someone else ...' (10: 380-381).

In the community area where she presently works Nadine professes that much of her sadness is witnessing the loneliness of people. The loneliness associated with being old, living alone, living in isolation are just three examples she meets on a daily basis:

Umm... in isolated people, isolated people who umm... especially in rural areas I suppose where may be you're the only one that visited for the week, you know. And that's what I notice when you get down here that there's a few isolated people but umm... that's their own, they elect to be isolated so umm... yeah, I think rural areas sometimes you feel a sadness when you leave someone (10: 424-431).

Our conversation ends with Nadine identifying paradoxes within herself. She says she cries when she is both happy or sad '... you [can] either burst into tears when you're sad or when you're extremely happy' ... (10: 471-472). As we come to the conclusion of our time together I realise that being with others at the ebb and flow of their grief is central to Nadine's sadness.

Preliminary NUD•IST nodes for Nadine's story

(1 1) Sadness? Searchtext
(1 10 2) Sadness/ Acknowledging/ In relatives
(1 14 2) Sadness/ As loss/ Personal relationship
(1 15 3) Sadness/ In nursing practice/ Others opinions
(1 21) Sadness/ As hopelessness
(1 22) Sadness/ As identification
(1 23) Sadness/ As a paradox
(1 26) Sadness/ As courage
(1 27) Sadness/ Re-visited
(1 29) Sadness/ Triggers
(2 1) Watching/ The relatives
(2 2) watching/ Friend die
(4 2) Privilege/ With family
(12) Palliative care
(19 2) Sharing/ With patients
(27) Car as sanctuary
(29) Funerals
(31) Challenges
(33) Self-care

Table 7: Preliminary NUD•IST nodes interpreted from retelling Nadine's stories.

Poetics of Nadine's experiences

Working in isolation, crying in solitude
You are the keeper of the light that spans the coast.
A light that searches
each tormented situation
bringing tempered optimism
to overwhelming, outrageous sadness

But you are alone and you must cope,
more often than not, you are their only hope.
So you become one of them
a family member,
and in their presence, in their closeness
you can placate, or cry, or grieve, or laugh;
in friendship—anything goes.

Yet you choose what you share,
you adhere to some unwritten rule
that guides your practice, that sets the boundaries.
And what is left you save for
what is publicly accepted;
the funeral, the wake or
the sad movie that you see just at the right time.

But it's not all gloom and doom.
There's the death that's relief,
a release from the suffering—
yours, mine, his and her's.
A sadness acknowledged
is a sadness shared.
Your kinship—an affirmation of your commitment.

Sally

Background and first impressions

Sally and I engage in conversation on two separate occasions. In both instances we talk for almost two hours. I think Sally is a loquacious woman willing to share poignant stories of intensity, peppered with both humour and reverence (fldnts 1:19). A middle aged woman whose career path spans countries as well as Australian States, Sally has an abundance of community nursing experience from which to draw her stories. Presently job sharing but working alone, Sally is a community health nurse for a large rural area in the centre of the state. Patients requiring palliative care are always found on her daily rounds. Many tears and much laughter emerged from our time together. I note that although the study focuses on sadness, the conversation brought into the foreground the notion of a banal paradox—laughter when confronted with tragedy. It is these conversations with Sally that make me realise sadness and happiness, rather than being two different sides of the same coin, are on the same side. Our conversation lulls from one to the other (sad/happy) with a unique ease and naturalness.

Confirming that her work in palliative care means that she can fully explore her nursing values at a grass roots level Sally finds also that working in palliative care gives her the

opportunity to practice those taken-for-granted nursing skills. Implementation of these skills can be quite challenging and difficult to achieve, especially when continually confronted with dying patients. Sally believes that palliative care is a rapidly developing nursing specialty area which constantly offers new challenges to her. She feels it is necessary to keep abreast with new developments, especially as her practice is located in an isolated rural area. She feels that the patients in this area should be open to the same opportunities for efficient and effective care as those located in the city. Sally coins the phrase 'tough old tart' to describe how she might be perceived by other nursing colleagues who do not have to cope with death of their patients on a daily or regular basis.

Retelling Sally's stories

While providing information about her background in nursing and palliative care in particular, Sally speaks about the death of her father. She was a very young woman when he died, just beginning her career as a health professional. The first dead person whom she saw was her father and like 'first deaths' for other nurses, the manner of his dying and his death made a lasting impression (Chapman 1994; Chapman 1998). Sally claims:

... the first encounter with cancer, which was when I was 18, was my father and he was the first person that I have dealt with cancer... nursed with cancer and the first person I had come across who died, so I have long entrenched memories of that and I can look back now without the grief that I used to feel (7: 15-20).

It is from this trigger of her father's illness and subsequent death that Sally's first story emerges 'I can tell you that as recently as yesterday I was very sad ...' (7: 81-82). Sally's immediate recollection of sadness in her work is expressed in her story of Joe and his wife Jill. Observing that Joe and Jill have been through some recent changes, she fears they have lost all hope for the future. Remembering their last meeting as powerful Sally asserts that Joe and Jill appeared to be suppressing their emotions:

... and I could see him... I was sitting next to him, on the chair next to him and his wife was sitting on the other side of the room and I could see through her smiles the tears coming up and I... and I felt gosh, the number of times I've had to smile through tears. So that made me... that sort of brought it back but then there was... he... he lowered his head and I then realised that he too was very sad and was trying to stifle his tears and sobs and we sat for a couple of minutes not saying anything but it didn't feel uncomfortable, but I could just feel that... that desperation um... and his wife cried openly ... (7: 114-126).

Like Jill Sally recalls that she has often smiled through her tears when engaged in caring for dying people in the community. Maintaining that Joe is quickly running out of time to

spend with Jill, Sally senses they are aware of time passing. Reflecting on the desolation of the situation Sally sees the beautiful home that Joe and Jill have created recognising that it is sad they are denied the time in which to be together in these lovely surroundings:

... my sadness has been there right from the word go. 'Cos I felt there's been nothing, we know that... his time was limited, very limited. Um... and just seeing that they've built up this modest but very comfortable and very lovely little home with a garden and he... he can't see anything now. He's just seeing that he's dying and I felt sad. Sad that I feel the people whose time is limited (7: 143-152).

Sally does not often share her own personal death stories with her patients but with Joe and Jill she makes an exception. Joe has cancer of the lung, as did her father, so when Joe suggests that no-one understands what he and Jill are going through, Sally tells him of her experience with own father. She confers:

It's that loss... that feeling that they sometimes show, he has shown it, yesterday, so has his wife, of despair, that is... that is tangible. You can... you can see it and you can feel it and... and... but knowing that no words are going to replace it and he did say to me yesterday, nobody knows how it feels until you get there and he said to me, others don't understand what you're trying to tell them and I did something that I don't usually do. I said, "I think I probably understand a little of what your family feel because I have been through that process when I was probably a lot younger than your... your children" (7: 162-172).

Joe seemed interested in exploring Sally's story with her and she believes that in sharing her story she and Joe have come to understand one another. Sally also feels that Jill can appreciate the similarities between their individual stories of loss and survive emotionally (albeit one is with a father and the other a husband).

Throughout our conversation Sally holds her hand to her heart as she recalls stories that remind her of her father. In pointing out this action to her she signifies that loss of the people in her care is a very important issue for her:

Oh yes, there are lots and lots of times when I've felt sad. ... I think I feel tremendously sad when... just a patient sadness and a family sadness and that... that feeling of hopelessness that they are feeling ... (7: 241-247).

Working with small communities Sally often sees injustices when people within those communities do not practice cooperation, collaboration or neighbourly concern. Sally tells the story of a middle aged woman (Faith) who was caring for her mother (Grace). Grace had been sick for sometime but a diagnosis of cancer had only recently been confirmed. Nevertheless, Sally was shocked that no-one in the community (ie. during her visits to

other patients living close by) had asked her about this woman. She reveals that most people she visits within small communities ask about others who are sick also, but this particular community had judged Grace and more or less abandoned her. From the same story she recalls the sorrowful plight of Faith who was the only carer for Grace:

To me I would have thought that illness broke down those boundaries and I felt very sad seeing the trauma that the daughter was going through because she insisted on nursing her mother at home and she didn't have that much help (7: 276-282).

Faith was unsure of Grace's drug regimes which were always being changed and she appeared to be angry with Sally when these variations occurred. Sally suggests it was grief and fear about the impending loss of her mother that contributed to the anger rather than any personal attack on the nursing staff. On one occasion Faith inadvertently gave Grace an overdose of Midazolam. Not wanting to demoralise Faith or lessen her already fragile confidence Sally tells how she negotiated with Grace's doctor, some seventy miles away, dosages and delivery of Grace's drugs which were more manageable for Faith.

Grace's two sons came to see the mother whilst Sally was visiting one day. She was touched by the concern of the boys. These sons were two large men who, by their size, strength and appearance, worked on the land. She encouraged them to help her with Grace's care and they willingly helped to lift and position Grace. When they asked Sally for a prognosis she told them that she doubted if Grace would live for very much longer. Through her sadness Sally recognised these boys as strangers to the situation of their dying mother, yet they showed enormous sensitivity when they understood that Grace's death was immanent. She recapitulates:

... then the boys came to help um... and just seeing these grown adult men, with kids of their own, and they were overwhelmed by what was happening and I... I encouraged them to help me because I wanted to turn her, and she was a heavy woman and I wanted to turn her and I was wanting to fix up the catheter and fix up the colostomy and it kind of diffused the situation by saying, "I need you to help me, I can't do this on my own," so that they felt an integral part of her care. But just seeing these lads trying not to cry and then, for me, the sad thing too was that that was the last time I cared for this patient because I was then going on days off, on holiday and... They asked me how long I thought their mother would live and really and truly thought she'd die in the next day or so. And I explained to them that I wouldn't be back in time. They both sort of shook me by the hand, which was quite unusual for... for lads of this calibre to do. It... it caught me and I had to swallow hard. And I thought... They... they can't this is their way of saying thanks for helping and it... it yeah, it moved me (7: 332-357).

Admitting that even though Sally feels deeply the loss of all patients, there has only been one occasion when she has cried openly with the relatives following the death of a person. She remembers how these relatives were somewhat shocked at her display of tears and notes that they told her she was not supposed to cry:

Um... well, because I work on my own all the time um... because of job share because... right. Um... there has been one occasion when I've done my grieving with the family and um... it just came. It's been the one and only time I've done it and um... Jane, the daughter, she came along and said, "You're not meant to do this Sally," she said, "It's meant to be us" Yes I suppose it is Ysanne (7: 363-371).

I too felt some sadness with Sally's judgement of the situation. For me, this avowal displays another mask that nurses are prepared to wear, which at best serves only to ignite the popular image of nurses being hardened to caring for dying people. Rather, the ability to cry with relatives is a kind of celebration. A memorial in sadness, recognising the loss of a patient who might well have become a close friend.

Similar to Nadine, Sally affirms her car is a sanctuary in which she does much of her grieving. She carries classical music tapes which act as convenient catalysts for crying. Working in a rural area she has access to beautiful countryside that she feels has healing qualities and she quite often pulls over to the side of the road to cry or just reflect on her own sadness:

I've got an hour's drive anyway and in that time I work myself.. myself through it and I use the music every day when I work. Um... I keep a lot of tapes. Oh, they're all classical and some of them are just that catalyst that if tears are gonna come they'll bring them. So... and... and I start.

Ysanne: *That's lovely.*

Sally: *Because I can't obviously drive down these country roads bawling my eyes out and I do it that way. I don't always. Yeah, I mean music helps relax us as we leave our sadness, which doesn't necessarily come with tears too (7: 378-392).*

Using her car, not only as a sanctuary for her grief but also as a repository for her reflections on work, she admits she would rather reflect in action as she drives from patient to patient and says she poses many professional questions as she travels.

The powerful emotions Sally describes when she thinks about patients dying encompass feelings of desolation, hopelessness and abandonment. These emotions are felt also by patients and the relatives and she claims she witnesses these emotions, sometimes feeling

them as they are exhibited. She suggests that she can see it in the peoples' faces, in their bodies—the way they move, and their actions; it is tangible:

Well, I can see it in them. Perhaps I do feel it um... you... you can't... you can't help but it doesn't make me dysfunctional, it doesn't mean that I can't, I can't, you know, go on and do things but there's just that overwhelming... and you can see it in their faces and the way they move, their actions. Um... after their... their displays of love for the person who's died and it grips me... makes me feel... yeah. I can't describe it to you. I just (7: 474-484)

Yet together with the recognition of these powerful feelings is the notion that there is some beauty being reflected from these situations of total desolation. For Sally, it is as if some equilibrium has to be found and usually this balance is provided by a feeling of love. Yet again the sadness/happiness dichotomy, rather than being at opposite poles appear to be travelling hand-in-hand.

Sally tries to facilitate 'good grief' with relatives noting that often she senses some unfinished business between the dying person and their relatives. She suggests to these relatives that they converse with the dying person even though they might feel it is too late or have the idea that the dying person cannot hear them. Trying to help grieving relatives reach a more positive outcome from the situation is a practice she has learned from experience and maturity:

... those that haven't had it good, a good relationship and... and you know that they're... they're trying to make amends in that very short time for what's gone on in the past and they're trying so hard and they're trying to come to grips with it and... and... and you're trying to say to them look what you're doing now is just wonderful, there's no greater privilege that you can do. There's nothing better that you can do than be here now and even though your loved one can't hear you... can't... isn't answering you, doesn't mean to say they can't hear you. Just let them ... just say... if there's something you want to say, just say it, I'll go out just say it. If you want to say your sorry. If you want to say that you've forgiven them for something you've been harbouring, say it. Don't feel that it won't be heard. Don't feel that you've got to part without that conflict being resolved. Just know that they can hear you and it's there and often that... as you say... that balance between that immense sadness that you've seen but it has brought some joy too, and even if there's death there's going to be mean yes, you've lost someone, but all that harbouring, and I've seen it, has been... has gone. So death, while it's loss has brought some gains too. So this person can go on and live hopefully reasonably well (7: 495-525).

Working in isolation Sally enjoys the times that she can relate to other nurses especially those from the community palliative care team. Sometimes the team may become involved at an advisory level and she likes to discuss new ideas or alternative modes of treatments

with them. However, sensitive to the needs and wants of her patients Sally suggests that if patients do not want members of the palliative care team to be directly involved with their care then she will abide by their wishes. Nevertheless, she does consult other nurses when she feels she lacks confidence or knowledge about a particular case. However, recognising that sometimes there are negative effects of working in the same community all the time, not everyone will want to be nursed by her and sometimes an outsider is welcomed. Knowing the patient and their family is an added advantage for Sally as she can predict when another nurse needs to be brought in.

Dysfunctional relationships within families in the small communities where Sally works is sadness provoking for her. Feeling like the 'meat in the sandwich' often she has to provide nursing care to different members of the same family. For Sally her sadness arises when family members with life threatening diseases remain distanced from one another, still harbouring grudges of many years. She recalls a recent experience:

Ahh you can imagine the street, like a T-junction. She lived on one corner and her son and mother-in-law lived on the other corner. They both had bowel cancer, they weren't friendly by the way. The one on the other corner was just a, you know, it was a lovely family relationship. It... it wasn't... it wasn't mirrored on the other side of the road. And one was watching the other I sort of, um... she said, " Why did she have a colostomy? I want a colostomy!" (7: 576-586).

Sally would like to achieve reconciliation between family members so they can be supportive of one another especially during an illness experience. Yet she fears this outcome may be entering the realms of idealism rather than pragmatism.

Sally is keen to relate Peter's story to me. This experience occurred earlier in her career when she was working as a community nurse in another Australian state. Peter was a young man with a brain tumour and was being nursed at home. His parents (Mr and Mrs Best) were in an unhappy marital relationship. Mr Best had a busy work schedule and consequently spent very little time at home and Mrs Best used much of her time entertaining officials and friends. There were two other siblings in the family, a younger brother and an older sister. The younger brother lives at home and the older sister is involved in sport and travelled extensively. The older sister is engaged and later marries.

Although Mrs Best showed a lot of love towards her son she was hostile towards the nursing staff who visited the home to care for Peter. Sally felt that she was imposing on Mrs Best when she asked for assistance or requested clean linen. Mrs Best made Sally feel unwanted. When Sally tried to question Mrs Best about her hostile attitude she vented her anger towards her accusing all the nurses of being voyeurs. Sally tried to facilitate calm in the relationship between them but Mrs Best became increasingly angry. On a

future visit Sally opened the discussion again but this time Mrs Best spoke of suicide. Sally alerted the local doctor and the director of the community nursing service. Sally fails to comment on whether these calls resulted in any treatment for Mrs Best:

I talked to her for a long time and went away feeling awful. And then a few days later in fact, she talked about committing suicide and she talked about putting her son in the car, getting him in the car and... and connecting the thing into the car. I can remember at the time, the GP not being very supportive but I do recall that when I left the house I was very disturbed ... (7: 691-699).

Peter died and Sally remembers the funeral. She notes that Mrs Best was desperately trying not to show any emotion, keeping her tears to herself. Sally recalls the funeral as being particularly emotive as Peter's school friends were coffin bearers and she remembers the sadness on their faces as they carried Peter's coffin from the church. After the funeral Mrs Best asked Sally about life after death. Sally was confused and challenged by this line of questioning, nevertheless I feel she was eager to find something positive about her relationship with Mrs Best:

... she worried about after Peter died what would happen to Peter and I... I have never brought religion into my nursing because, not that I don't believe, but my belief... I believe there is somebody or something but I'm not a theologian. But I did say... I did say... she put me on the spot. She said what would happen to Peter. She couldn't bear to think of Peter burning in Hell and I had to say that I wasn't a regular church goer. I did believe... I didn't believe that if there was a God that this would happen to him. How did I know. I said, "I don't know I merely know how I feel and how I've seen Peter." And she said "Do... do you believe that." Oh it was very strong and it was one of the most difficult... and it taught me an awful lot. It was very difficult because there wasn't just the grief, her grief of losing her son, there was the animosity and it made... it made us nurses feel reduced to the lowest common denominator. She had that ability to do that. Um... and there was... there was... she had this guard but only once or twice. A lot of the nurses just couldn't hack her. I mean, I didn't find her pleasant. You see, to me it was a challenge. I thought there must be some good in this person and it turned out that there was some good in her (7: 760-787).

Soon after the funeral Mrs Best visited her own ageing mother who lived overseas. On returning to Australia she was diagnosed as having breast cancer. Almost concurrently Mr Best, their daughter and new son-in-law were killed in a motor vehicle accident, leaving Peter's younger brother and mother as the only surviving members of that family.

Sally's sadness is linked to the tragedy of the whole situation. The hostility of Peter's mother fostering a frosty relationship between nurses and herself. The dysfunctional family also contributing to the hostility felt within the household. The unfairness of Peter's mother's illness being diagnosed so soon after Peter's death and the final blow of

the fatal accident. All the circumstances within that family were challenging to Sally and forced her to constantly look at her practice to consider how she could improve the situation:

I still... I...I still reflect on the family with sadness when I think of how everyone was lost. I... I often think of how much better it could have been, how much better because she... she dearly loved Peter, you could see that, but she hated us, oh dear she hated us. I often thought if only she could not be like that because it must affect Peter (7: 820-827).

When questioned further about other sadnesses, other than those linked to the death of a person, Sally mentions the frustration leading to sadness that she feels when there is a noticeable lack of knowledge from the attending General Practitioner regarding pain management or pain control for patients requiring palliative care. Fearing that she has to engage in the doctor-nurse game, sometimes with no or little effect, she is saddened to see the patient remain in great pain, often needlessly. Contending that some General Practitioners are egotistical Sally suggests they do not like to admit to nurses they might not be able to find a suitable solution for a patient's pain problem. To overcome such situations Sally would rather the doctor be affronted or rude to her than have to visit a patient who is in constant intractable pain. She laments:

I get very sad, potentiated by frustration when you are up against, and it has always been a General Practitioner who hasn't kept up those current trends and who you know isn't providing what could be the optimum in symptom control, or Pharmaceutical etc. And you're trying to pussy foot around without blatantly being specific "what you're giving isn't right". Don't keep on giving them morphine, there are other drugs you could be using and you know that the patient is suffering needlessly and because of the lack of knowledge and I'm not, don't get me wrong, I'm not saying I have greater knowledge, but because some of them... but they definitely don't keep up [with] the latest and current, they just keep on pumping more and more Morphine when you know that all that is happening is that they're becoming Morphine toxic. And the pain isn't being relieved. And their getting... their getting... patient's becoming... the patient is getting more disoriented and restless and the family is saying why can't you just... that I get frustrated and then they get sad because I did my utmost. I use every possible skill I came into by reporting to the doctor and saying can we look at this a different way... it actually amounts to game playing (7: 849-876).

Sally suggests to patients that they seek a second opinion but sometimes the patients have had a long standing association with the doctor and will not seek another's help. Sally believes these situations are tremendously sad for all involved. Sad for the patient who cannot have the pain relief they need, sad for the doctor whose ego prevents him (and they are usually male) from seeking her help, sad for Sally because she feels that not only is her wisdom unacknowledged but also other nurses, in similar circumstances, are

deemed not to have the knowledge needed to effect good palliation. While Sally concurs there is only one GP remaining in this category with whom she has dealings it is still needless pain his patients have to suffer and needless time wasting on her behalf. She contests:

There's living to be done and none of us know how much time he's got but it can be fruitful living. So when we have GPs and thankfully there are not many now, there's still one I have to cope with. But even if there's as much as a day there's too much time to lose and time is short to play around to not be able to say, okay you silly bitch I know you think you know better than I do but tell me what it is your going to say. Yes I'd rather he did that to me and I and I risk being slightly affronted at that, than not being able to admit that he doesn't know how to go about it, so then I have to play a game to get palliative care ... (7: 899-913).

Facilitating hope and wise practice is demonstrated in Sally's story of Jean, a woman who has advanced cancer of the liver. She recalls that Jean was discharged following an operation of a planned cholecystectomy but in finding far advanced cancer of the liver the surgeon left her organs intact and closed her abdomen. She was discharged into the care of her daughter who lived up the river in an isolated location. Jean was told she could not take care of herself and that she needed constant supervision so her daughter volunteered to care for her. On her first visit Sally recognised that Jean seemed depressed. Both the local GP and the Jean's daughter were concerned about her depression. Sally suggested to the daughter and the doctor that they hold off prescribing any anti-depressants as she wanted to assess further the situation. While talking to Jean, Sally observed that she was extremely depressed even suggesting that she had no viable future and suicide was an option:

I said just give us a chance to see how we go in fact um... talked to her got her musing what life was about, what was it worth, she saw there was nothing. I said, "OK what are you going to do then". She said "I just want to die", I said "OK why have you come here to be with your daughter." I was getting a bit impatient, cos it was a long way out. I said "you know you can get up and get dressed, and you can live." It was before Christmas, and I talked about Christmas and Christmas pudding and she said "Made the bloody Christmas puddings haven't I?" "You can still get up" I said, "you can either lie here and you can let what life's left drift past you, or you can get up and you can do something." She said "Lady, where's my bra?" (7: 943-960).

In this situation Sally took a risk in confronting Jean and by using humour and good communication skills facilitated a change in outlook. Eventually Jean became an active member of the family and towards the end stages of her illness she was able to take control of her care and direct her daughter to facilitate her needs. Sally was pleased that

she was able to effect this change but suggests that the doctor was not pleased with her as she had not followed his notion that anti-depressants should have been prescribed for Jean.

Sally also states that she spends a great deal of time, wasted time she calls it, trying to deal with doctors whose knowledge deficit in palliative care treatments are pronounced. She feels that some doctors are afraid to admit their deficits, or are reluctant to refer patients to a palliative care specialist as either way they are admitting defeat or failure publicly. Sally finds dealing with their seemingly fragile ego is a waste of her time. Clearly she does not suffer fools gladly. Time as an indefinite commodity is not one that palliative care patients can enjoy and Sally would rather direct her energies into facilitating good care than spending and wasting time on protecting doctors' self images. One way she has used to instigate a change of care from a doctor is to give him a pamphlet on palliative care research and new treatments and say that she has already given the patient a copy of the same article. While this behaviour might be construed as playing the game it had the desired effect of shaming the doctor into doing something different for the patient.

Sally suggests also that sometimes her colleagues attitudes and behaviours are construed as sad. She recalls again the story of Joe and Jill. Joe and Jill were on a limited income and Joe needed to have regular intakes of Sustagen which was proving to be very costly for Jill. When Jill explained the situation to Sally she suggested that Jill make application for the carers pension of \$54/fortnight. This small amount of money made all the difference to the family and meant that Joe could have the Sustagen that he needed without Jill having to borrow extra money from the family. Sally's colleague was horrified that Sally had suggested that Jill make application for these monies saying that the public purse should not be drained as it is a wife's duty to look after her husband. Sally claims that a similar judgment could have been made about receiving family allowance but both she and her colleague did not refuse this subsidy when it was offered. Sally upholds this judgmental attitude is not an attitude she would like to see pervading nurses' values:

I felt sad that she had that attitude. I mean God haven't we progressed beyond that? That's only one example of the attitude of palliative care colleagues that makes me sad. I think sometimes perhaps those colleagues who, and it may well be their defence mechanism that makes them do it, just go in and do what they have to do and nothing more. They don't see behind the task oriented perception of what their role is, they do their designated tasks and get out (7: 1057-1067).

The support from the nurses who work in community palliative care is highly valued by Sally. Using them to assist her with any of her patients' problems she trusts the relationship she has with the palliative care team and is able to admit when she does not

know something. She suggests that her maturity has helped her reach this point admitting that as a younger nurse she would not have had the courage to confess she had a knowledge deficit.

The palliative care team are another means of debriefing for Sally stating that when she debriefs with members of this team she does not have to go into great detail about the circumstances. Their familiarity with palliative care situations makes it easier for her to admit to her dilemmas. She feels that having to go into great detail to describe a situation to others often negates the very emotion that is problematic:

I can't..., I don't want to have to describe things. If I am going to have to unburden it I want somebody to be able to... to see... to see, so I don't have to go through the preamble of the situation so this is why when they, when the palliative care nurse is around you know you can just go wham straight into it (7: 1122-1128).

Aware of her own limitations Sally expresses that she might find some difficulty nursing palliative care patients who are very young children or someone who is of the age of her own children now. She states that she has only just come to terms with nursing people of her own age. Sally points to the reciprocity she feels when she does nurse someone of her own age and how it makes her more aware of the care she is giving to that person. She admits:

I have to say I've never nursed a child, a palliative care child. I don't know how I'd cope. Um... and when I nursed Peter, he's a lot older than my children. I don't know how I'd cope... dealing with someone of my children's ages or my husband's age. I can just about cope with my own age, I think, there go I for the grace of God ... (7: 1169-1176).

Sally has many stories of sadness in nursing practice and recalls a particular one associated with her recent practice at the local hospital. She acknowledges that many of the little practices that she was trained to do as a student of nursing appear to have disappeared and she fears that once these little actions fade that they will never be revived to their prior status of importance. She recalls that while working in the hospital she observed that patients were no longer orientated to the ward and that no time was spent sitting with the patient who was admitted for an operation on the following day to reassure him about his forthcoming procedure. She determines that nurses today do not openly communicate with their patients and do not spend time getting to know them and thus recognising when they have fears or concerns. However, she does acknowledge that contemporary nurses are well versed in assertiveness and asking questions about a patient's diagnosis. Interestingly Sally uses the term 'died' for the absence of these

nuances that are important to her and by suggesting a life cycle metaphor she infers that once they have disappeared from usage they may never return:

I couldn't believe how nursing had changed in the hospital. I couldn't believe the lack of care the lack of bedside manner I couldn't believe it (7: 1207-1209).

Yes I do get a bit sad sometimes, but then, and I'm not one to stick in the mud and say that things can be wrong because they've got to be wrong, but I fit some where in between the two (7: 1237-1240).

As a community nurse Sally claims that she has the best job in the State. Not only can she work alone and have some degree of autonomy but she works short hours as she shares her job position with another registered nurse. She is accepted by the community and is treated as part of the family by most of her patients and their families. She relates several stories about this acceptance and in doing so acknowledges the reciprocity in that she accepts the patients and their families and their distinctive nuances:

A few years ago I was working with an elderly person, who was eventually going to have to be institutionalised and I was just sort of treading carefully and I knew that she hadn't made a Will. So I, with her permission obviously, I organised for someone, for a lawyer to come up. Have I told you this? And that was nice and the lawyer said will you be witness to the will and I said yes. Because it would save me from having to bring someone else up and would cost her less money. So we were sitting there in this dreadful little 'humpy' and the dog was flicking it's fleas and they were getting on to my ankle. I already had graze marks on my ankle where I'd scratched and they'd gone septic. But anyway that didn't matter I'd scratched away. And the lawyer said to this old lady, "Excuse me, have you thought of who....", I did say to him don't speak in legal terms because she won't understand it. So don't use beneficiary or benefactor or any of that. Just simple it out. So he said, "Who would you like to leave your money to?" She said, "The sister." So he said, "Which sister?" "That one" [pointing to herself] So he said to her, "What's her name?" She said, "Buggered if I know". There are many of them [the patients] who don't know my name. They just call me Sister. Yes, you know, well he then thought I had been colluding so I said to him, "You better do this on your own", "I'll have to come back won't I?" He said, "You can't witness this". I said, "No and make sure I'm not in it either" (7: 1280-1322).

Her intimate knowledge of the patients and their family in her care is suggestive that Sally embraces each person as exceptional and individual, and uses this knowledge in caring for them in a unique manner.

In telling the story of Elsie and her family Sally recalls how she felt privileged to be part of the family's last times together. Flexibility and insights into her practice permitted Sally

to celebrate the end of Elsie's life with the family. In relating this story Sally demonstrates compassion in her sadness, love in the sadness of others and a sense of completion in her work with this family:

And Elsie was just delightful. She was one of these hard working, salt of the earth people whose demands were so small on the service and I was with her, oh it would have been about, I guess probably about three months and she was determined that she wanted to be at home. And her family were just excellent. Basic, good hearted, poor people. And they did every possible thing they could to care for [their] mum and she had a myriad of social, family/social problems. But they didn't seem to sort of intrude on the care that the family was giving her. But the thing that really hung with me about Elsie was how humble she was about about herself and about life in general and her needs were so small and all the time she was thinking about others. And the one particular thing that she was trying to hang on to get resolved was, one of her grandsons, who was then about ten or eleven, had had a very chequered childhood. Had been in and out of homes and had virtually come to Elsie to be cared for and then Elsie had become ill. And this little lad had a troubled face, I can still see it, he had a dark troubled face. And the thing that tugged at me was seeing the anguish of this child. Knowing that he thought, Oh at last I've got some stability and that stability was just slipping away from him. And this darling, darling lady she was... she had um... a very malodorous tumour and it's smell used to pervade the home, which was very simple, and it would hit you at the front door. And this darling boy, he didn't, he didn't even... it didn't strike him. He just, he just loved his Gran so much and yet at the same time there was that bit of harsh aggression coming up. You could see it. The defence. Don't take this away from me. Don't take Nan away from me. And she was struggling to stay and to help this lad. And I can remember one particular day, it must have been early spring time and she had, the primary carer daughter, and she had another daughter who had two little ones, who was in some sort of a relationship, it wasn't a very good relationship. Actually, yeah the second daughter was Liz and she was from her second marriage. But there was sort of step children all over the place. Anyway, they were all there and the sun was shining and the birds were singing and I said to Elsie, "Elsie, what would you like to do today?" And she said, "oh I'd love to go outside". "Let's go outside, I'll get the family to help" . And she said "if you could, would you?" And I can remember, we all rallied round and got her into the wheel chair, and I said "won't we need the mattress?" Because the only way she was comfortable was lying down. Anyway we pulled this old mattress outside on what bit of grass they had and we got Elsie on to the mattress and we got her a bolster and some cushions and she lay there, like a queen.

Ysanne. *Oh lovely.*

Sally: *And we all sat round and had morning tea. And the smallest grandchild was about eighteen months, I know she was a bit slow this wee thing. And we had this lovely lovely time in the sunshine and the boy, the little self-conscious grandson he was so troubled caring for his Gran, and shared in this. I think it was probably the last time we were all together (7: 1794-1867).*

Dysfunctional family relationships are another aspect of sadness for Sally and she tells the story of Bob Foote, a gentleman who was diagnosed with cancer of the larynx. He had been married twice and both his wives had died. He had only one daughter from his first marriage and their relationship was not good, there was hardly any contact between them. Sharing a good nurse-patient relationship she would assist him with his meals by making suitable foods, such as egg custards, as he had difficulty swallowing. During her visits she would whisk up the mixture and place it in the oven so that he could access them after she had left the house. Sally spoke of how he used to laugh and they would share in his small achievements and improvements he made to the home. One day when she visited, Sally found Bob in a poor state of health and ascertaining that he did not have long to live organised a bed for him in the palliative care unit at one of the hospitals. After driving him to the unit she telephoned Bob's daughter informing her of his impending death. His daughter visited but did not stay and Sally was concerned that Bob would die alone. Having to return home Sally asked the staff of the palliative care unit to inform her of any changes in his condition as she intended to return to the unit and stay with Bob as he died. However, the staff of the unit did not inform her of his deterioration and eventual death and Bob died alone. Dying alone is an issue for Sally and she acknowledges that it was more her problem than Bob's. She critiques herself admitting that she knows she is placing her own values on the situation but again, the reciprocity of the circumstances are highlighted in that Sally admits that she does not want to die alone:

... it was within the last twenty four hours of his death, of dying rather umm... he was semi-conscious then and his daughter was with him. I remember asking her are you going to stay with your father, and she had to rush off to work and I spoke to her saying he may well not be around for very much longer and giving her the choice. And she decided to go home and I stayed with him and I can remember saying to the nurses, "I've got to go 'cos I've got things to do at home but please, if there's any change," [because] I didn't want him to be on his own when he died, and I never got to him and he died by himself (7: 1968-1982).

Dysfunctional families hold other issues for Sally and she admits that she can feel the barriers some people place between themselves and their immediate family—the 'nothingness'. Conversely she states that she can also feel the love some people have for one another and reminds me of the first story of Jill and Joe and how Jill's love for Joe was apparent even through Jill's tears.

Some patients are referred to Sally through unusual channels of communication. She tells the story of Henry, the local greengrocer whom she noticed was not opening for business as usual. Remarking to another patient, Henry's neighbour, that she had not seen him around, the neighbour tells her of Henry's illness (small cell carcinoma) saying he was in pain. Sally goes to see Henry and informs him how palliative care might be able to help

him with his pain. Henry and his wife Maud agree that regular visits from Sally might be useful and she then negotiated a referral from Henry's local doctor.

Sally thought that Henry was anticipating his own immanent death and was very concerned about Maud's future. In relating this notion of anticipatory loss Sally concurs that the loss of personal relationships, that is patient and spouse, patient and nurse and nurse and patient's family is sometimes devastating to all concerned:

I think families... issues around families can cause a lot of pain and suffering for themselves, the patients and us (7: 2074-2075).

Sally recalls how time seems precious in the palliative care situation and that often much time is wasted in activities of collusion that do little to advantage the care of the palliative patient. She found that these situations challenging for her practice.

Sally returns to the sadness she feels when she witnesses the pain of grief in relatives of the dying person. Akin to Viktor Frankl's (cited in Crotty 1996b) interpretations she conveys that the pain is indescribable:

It's always very hard watching carers who feel so helpless when their family member's got pain and you can see they're at their wits end trying to do something. Or when you go in a morning and they're caught in it. I really feel sad (7: 2166-2171).

Speaking of the futility and hopelessness she feels when she has a patient to care for who refuses to accept a diagnosis she declares this non-acceptance hinders the possibilities for good palliative care:

The whole way through he denied he had cancer. He would say to me "what's wrong with me" and I'd say "what do you think's wrong with you". We go round and round in a circle and I'd even been there when the doctor's told him (7: 2150-2155).

Sally and I continue to talk about our shared feelings of sadness when patients ask the impossible, that is to take their disease away:

It's... it's sometimes my inability through lack of knowledge, through lack of experience to be able to help, to give them what they're crying out for. Umm... and that frustrates me and saddens me too. Perhaps it's beyond the realms of another person to be able to do, I don't know. What they want is for this illness to be taken away.

Ysanne: I was going to say what they want is something that you can't give.

Sally: *That's right and you can see their anguish. Do you understand that total anguish that people feel Ysanne? I guess you do. You've felt it yourself. That burden of grief. I can feel it myself. (long pause) Nothing is like it, nothing at all (7: 2175-2193)*

Believing that palliative care may not seem to be a pleasant activity for every nurse Sally claims she would rather be with a person who is dying than leave them alone. I feel this notion of Sally's links with the idea of reciprocity in that she wants to care for people in the manner she wishes to be cared for herself.

Sally's final story is to remind us both of her father's death and to compare the palliative care he received with the palliative care of today. She has some regrets that her father could not have the kind of care that dying patients receive today as she is constantly aware of how painful her father's death was. In returning to the experience of her father's death Sally comments on the paradoxical character of sadness. In acknowledging that she is sad she notes also a certain enjoyment in remembering who her father was and how his mannerisms are reflected in members of her family today. Her recollections of sadness are indeed celebrations of his memory:

It's almost enjoying remembering and in enjoying remembering the sadness comes in. Yes I think that's what it is (7: 2364-2365).

We talked at length about the death of parents and how significant personal losses are in life. Although much of our time together was spent recalling very sad events our conversations were punctuated with much laughter and I was constantly reminded that nurses are skilled in the use of gallows humour to off-set uncomfortable situations.

Preliminary NUD•IST nodes for Sally's stories

- (1 1) Sadness/ Search text
- (1 1 1 2) Sadness/ Search text/ Whose sadness?/ My sadness
- (1 3) Sadness/ As non-acceptance
- (1 5) Sadness/ Gut wrenching
- (1 7 1) Sadness/ Failed expectations/ As frustration
- (1 7 2) Sadness/ Failed expectations/ with community
- (1 14 1) Sadness/ As loss/ Anticipatory
- (1 14 2) Sadness/ As loss/ Personal relationship
- (1 15) Sadness/ In nursing practice
- (1 15 4) Sadness/ In nursing practice/ Unskilled practice
- (1 16) Sadness/ With family relationships
- (1 20) Sadness/ As unfairness
- (1 21) Sadness/ As hopelessness
- (1 23) Sadness/ As a paradox
- (2) Watching
- (2 1) Watching/ The relatives
- (3 3) Personal loss/ Family
- (4 1) Privilege/ With patient

- (5) Time
- (5 1) Time/ Running out
- (6 1 1) Difficulties/ Emotional/ Families
- (7 3) Hope/ Facilitating
- (8) Unable to help
- (9 1) Lack of knowledge/ Doctors
- (11 1) Game playing/ Doctor-nurse
- (12) Palliative care
- (12 4) Palliative care/ Comparing old with new
- (14) Knowledge of the patient
- (15) Wounded healer
- (19 1) Sharing/ With the team
- (19 2) Sharing/ With patients
- (19 3) Sharing/ With relatives
- (27) Car as sanctuary
- (28) Shoulds
- (31) Challenges
- (32) Wise practice
- (33) Self-care
- (36) Reflection
- (37) Suppressing feelings
- (38) Sensitivity
- (39) Knowing limitations
- (40) Reciprocity
- (41) Community nursing
- (41 1) Community nursing/ Part of the family
- (41 2) Community nursing/ Accepting the family

Table 8: Preliminary NUD•IST nodes interpreted from retelling Sally's stories.

Poetics of Sally's experience

happy-sad Sally,
many stories to tell.
each one a twisted tale;
love and hostility,
joy and anguish,
abandonment and hope,
humour and tears,
life and death.

and your father speaks with you.

contented-sorrowful Sally,
smiling through tears,
suppressing emotions,
sharing yourself,
with families,
with friends,
practicing wisely—
feeling their pain.

and your father feels with you.

blithe-rueful Sally,
watching, understanding but unable to stop
the wretchedness of the desolate,
the power of hopelessness,
the contempt of poor practice,
the senseless game playing,
the injustice of time,
the dysfunctional families.

and your father cries with you.

cheerful-unhappy Sally
searching for the positives,
propitiating good grief,
exuding compassion,
responding to the challenge
of failed expectations.
accepting the paradox
of happy-sad Sally.

and your father lives through you.

Wendy

Background and first impressions

Interviewed in her own home, Wendy made sure we had coffee and biscuits on-hand prior to commencing our rather lengthy conversation. Throughout our time together Wendy was cognisant of wandering off the point and took control of returning to the question. Occasionally she intimated that she might have been ignoring the question and suggested that the emotions arising from her stories were from time to time difficult for her to face or acknowledge. Recognising that she intellectualised many of the emotional issues I acknowledge that when discussing issues of management she became heated and deliberate in her tone (fldnts 3:19). Also, many of her responses were intricately tied to her role as a team leader and she appeared genuinely concerned about the other nurses in the team. Priding herself on being a good communicator Wendy admits to not liking situations when she gets it wrong. Nevertheless, she is not afraid to acknowledge that she does slip up occasionally.

Wendy began her interest in palliative care when she started working in the community setting of another capital city in another Australian State in the late 1970s. She was in-charge of a community nursing service attached to a major metropolitan hospital. Recalling there was a paucity of support services in the community Wendy infers that the

nurses she was working with then lamented their apparent lack of skills to deal with dying people. They also told of their own personal discomfort when caring for the dying (fldnts 3:17). However, at that time there was little education in death awareness and few people felt it was significant for nurses to examine their own feelings about nursing situations.

After moving to this State Wendy was working part-time in one of the hospitals in the city when a position in community palliative care became available. Although another part-time position it was in a newly formed service. The woman in-charge was a highly skilled palliative care nurse practitioner and Wendy realised how little she knew about palliative care from watching and listening to her. At that stage palliative care was only just beginning to emerge as a specialty. Wendy relates her comparative naivety and suggests that her learning about this highly specialised area began with this new job. She regrets not having realised earlier in her career that working with dying people was a highly specialised art in nursing.

Retelling Wendy's stories

When asked to describe situations in her practice when she was sad, Wendy (like Vickie) is quick to retort that she acknowledges there are distinctions between what is 'their' sadness (the patient/family) and what is 'my' (self/nurses) sadness. She says the '*world is full of sad stories*' (3: 140) but they do not necessarily influence our own personal sadness. Wendy asks the question, whose sadness is it? and speaks about the musings from a social worker who was sitting in on a team meeting session where stories about the patients and the associated feelings were being discussed by the nursing staff. After hearing a particularly sad story the social worker apparently remarked '*we must remember whose sadness this is or whose pain this is*' (3: 101). Wendy recalls that remark suddenly shocked her into realising that she did not have to take on board all the sadnesses and pain of each person's story:

... since then I've been incredibly aware that if we are going to provide um, a really high level service, we can't take on board the sadness of families impending loss and their pain, but that is not to deny that there are days I can see staff coming back in and I can tell they've been... it's been really quite torrid (3: 109-113).

However, in acknowledging that story telling is an important part of the process of debriefing Wendy still purports that expression of feelings were inappropriate behaviour in that team's meetings; stipulating that emotional responses although respected, were better left to be discussed on a one-to-one level between colleagues. The discussion at team meetings is more of an acknowledgment that the family are or may be about to

experience some very difficult times or that person is about to die, but the debate remains largely at an intellectual level.

Wendy's first story of sadness is about an incident when she was working in the community in another capital city. She was visiting an Italian family where the father (Giorgi) was approaching the end stages of his cancer and was near death. There were three children in the family, an elder son aged nineteen, a daughter of seventeen and a younger son aged about ten or eleven. One day while visiting the family, Wendy was talking with Giorgi, his wife and his sister when the youngest son (Paulo) came into the room. Wendy was introduced to him and they exchanged pleasantries and then brief conversations in Italian occurred between the Aunt and Paulo and the mother and Paulo. Giorgi asked Paulo a question but he did not reply, merely casting his eyes downwards in silence. Giorgi too looked downward and did not restate his question. There was an uncomfortable feeling in the room. Wendy was informed at a later time that the night preceding her visit Giorgi had called all his children into his bedroom and told them that he was about to die. There were mixed reactions from the other two children but Paulo became silent and did not make eye contact with his father again. Wendy felt very sad as she suggests that the scenario encapsulates the pain she has often since witnessed between parents who are dying, and children who may be non-accepting of their parents' impending death. She reports:

... it was a bit like theatre. It was a incredibly powerful. I could have choked and vomited and cried (3: 166-167).

... and it's never left me and I think was it sad... that was everything I mean to me now that encapsulated loss and life and families and sons and parents and fathers and um, but there was no berating of the child (3: 179-182).

Maturation, dry wit and black humour play major roles in dealing with sad scenarios according to Wendy. She is certain that effective coping strategies for the cumulative loss and grief in palliative care is essential for survival of the staff:

... so there's two things, one I intellectualise a lot because I'm there as a support [person] for the other staff it would seem. I would see most of them have developed skills in dealing with experiences that they come across. Ahh... we come across amazing scenes and black humour does come up in palliative care and there is no doubt the sharp wit is sometimes almost providing all along the edge. If someone was walking by and heard it it would be so dreadfully offensive and mostly black if it was out of context but it's really only part of dealing with the constancy of it. I do believe that it accumulates if we don't get frameworks in our life to deal with what we come across in loss and grief (3: 201-214).

As team leader Wendy comprehends her position to be one of support, the person to whom the staff can lean on and discuss problematic aspects of care if necessary. Wendy comments on Louise (another participant), whose specialty area is the care of dying children. She remarks that Louise can sometimes appear extremely engrossed and can seem a little flat in her communication with others. On one occasion Wendy made a comment to the administrative assistant, a non-nurse on the team, who replied that Louise's mood was affected by her caseload. That she (the non-nurse) always knew when Louise had a new child to take care of as she became increasingly silent and subdued. Wendy cringes that this observation was undetected by herself and that it took a non-nursing person to clarify matters for her. She watches the staff, especially new staff, and claims they appear to change how they discuss the various situations of care as they mature in their position. She believes that new staff focus initially on the emotional side of experiences and almost always position themselves in the situation of the dying person:

New staff dealing with young people tend to apply a... sometimes a reverence, sometimes an awe, sometimes a um... I suppose it's, you know, "I could be there myself", that experience. In the way they talk about them... (3: 354-357).

Anticipating death can be just as sad as the final loss of death itself. Wendy recalls a story of a man who had a high profile within the city community, who was diagnosed with a rapidly proliferating leukaemia. He was a person who took a great deal of interest in his condition, monitoring his blood levels and such like. When he was told of his poor prognosis and impending death, he was overwhelmed by the amount of nursing staff who made special visits to him to relate their sadness about his deterioration:

... and there is no doubt I feel for the loss of this man. I feel for the community, ahh I feel for his family, what a great loss he will be because he was such a dynamic and wonderful man to have and you can only make people feel better by having him around There's not many people who are so dynamic (3: 443-448).

For some patients, staying distanced from the nursing staff is preferable for them. Wendy recalls a scenario of a woman who was hospitalised and remained aloof from the hospital staff. She was fiercely independent and chose to keep her closeness reserved for her family. The staff became troubled and sad that this woman (Christine) would not allow them to become close to her and subsequently they almost abandoned her. Wendy feels this situation was tragic for the woman as the staff were more concerned about establishing an unauthentic nurse-patient relationship rather than focusing on the care this woman might need to help her through her rapidly deteriorating illness:

I would still consider, globally [the staff] were unskilled at dealing with her issues. They wanted to feel pain and sadness for her bad news whereas she wouldn't let them near her so they ignored her... and I don't feel sadness or anything, I don't feel any of those, I think, "How can we improve this?" (3: 459-464).

Acknowledging the sad and the bad Wendy tries to turn them around to focus on a positive outcome for the patient. She feels that those engaged in palliative care work within the community try to make negative events into something positive, possibly because of the nature of palliative care work (ie the popular assumption dying & death = negativity). Her detailed recapitulation of the story of Christine shows how 'a wisdom of practice' (3: 670) (wise practice) could have averted the situation when Christine felt disgruntled with her care in the hospital. According to Wendy, wise practice is demonstrated by; good communication and anticipation skills; a commitment and signification of being patient-focused in planning care; a willingness of nurses to use their own life knowledge and confirmation of facilitating patient-centred positive outcomes. For me also there are links to the sacred, the sanctified and the spiritual. Those with wisdom (wise nursing practitioners) pay credence to the totality of the person and hold sacred their meanings of life and their part in it (Knudtson & Suzuki 1992; Capra 1977; Bateson in Fell & Russell 1994a). Wendy questions the role of wisdom in practice:

I wonder if it is the wisdom, something of a wisdom of practice and a wisdom of life coming in, once you've had a couple of experiences and you think, "That wasn't very good for my Medicare health dollar," or, "Private Health dollar." It doesn't matter which one. They're almost in the same pot, almost, in the end, and there is that plus I think we... we must be aspiring all the time for improvements, and I just sometimes get a rude shock to realise that not just improvements and basics there that are missing ... (3: 670-678).

The nurse-patient communication and insightful awareness are not one-way streets and Wendy describes a sharing situation when a dying patient observed that she appeared sad. This reciprocity demonstrated in and through the woman's insights was an impetus for Wendy to re-evaluate some of her personal life goals:

I had a very interesting experience recently when I [laughter] went into this woman and she was err, she had a cancer of some sort and she was in fact in the last twenty six hours of life which I wasn't quite prepared for. She must have had a big bleed and died. Um... it was the day... the day before... I organised for her to go back into the major city hospital because she was barely able to get out of bed by herself. Which is a perfectly good reason why. But her daughter was over visiting. Her family was under great stress, ahh with her being at home but we've really supported her at home because that's what she wanted and then I said, "How... how much longer do you think this can continue?" and she said, "Oh Wendy, I don't know you whatever you say," I said, "Yep, all right, all right ohh I think you'll get one more day

but. Meanwhile with your family's you know, help and things,-" and but interestingly we'd had a couple of laughs but then she looked at me this morning, that morning that I went in and she said, "You're not a happy woman are you Wendy?" Arrhhh, struth [exclamation]. Absolutely. Some facing moment in my life and I said, "How do you think that?" and she said, "I've never been a fulfilled woman in my life, I can spot others. I just cracked up laughing. It was very funny I must admit I was feeling fairly ugh at the time, for some weeks but that was, that was as good as any. Don't worry about being a psychologist for debriefing, that was sharp and insightful and I thought, "What am I showing here," even though I didn't feel particularly not not happy and then you know, she was quite amusing. She sort of, oh she said, "Are you married dear?", and I was divorced, and she said, "The only way to be. We all are in this family too," and her daughter's over there giggling and she was giggling and she was really quite a character and I really like her. It... it... it did a couple of things to me because again someone says something at the right moment and you can take it on and do things. I think after that I started embarking more on exercise or at least sitting down and doing my journal, sorting out my life. What am I achieving? What am I doing? What are my goals that I might renegotiate and I've done that and I would consider she made me get a move on and do something like that.

Ysanne: That's lovely, isn't it? Because, I mean I can think about certain people who have been catalysts that I've nursed.

Wendy: Catalysts for your life?

Ysanne: For change.

Wendy: Yes. Yeah it's good isn't it... and yes, take it on with an energy and a interest, a commitment. Yes. Otherwise it just peters out again into mediocrity (3: 688-742).

Wendy's sadness with the profession extends to perceived problems at a managerial level. As funding is a central issue to the survival and growth of palliative care Wendy fears for the future of community palliative care should it remain solely under the financial umbrella of community nursing. Wendy asserts that this 'lumping together' of nursing services is detrimental to community palliative care. She speaks of funds being channelled away from research and development in the community palliative care area and given to the rural sector with little or no consultation with those most affected (ie. nursing staff in community palliative care). Wendy fears that nursing management is choosing to play an economic rationalist's game rather than looking to the demands and needs of an ever growing service area:

We're sort of just bundled in with community nurses. What's good enough for them. They're the major group, of course, for funding. Palliative care slips along the side. We're in no major reports that have come out of Government in the last couple of years (3: 752-757).

In contrast to many expectations and popular images Wendy contends that nurses working in palliative care have a better job than those working with people who have chronic illness. She voices that trying to give people hope or keeping them alive with a positive self image when they are facing a long and tortious road with chronic illness(es) is much harder than facilitating a good death. However, Wendy does concede that the public perception that palliative care is very difficult work is a source of constant feedback to her and the community palliative care team. Nevertheless, she purports that provided community palliative care nurses have sufficient skills to do their work they have the better job satisfaction:

... going back to palliative care, I think we're back to a very easy job. When I look at people dealing with the chronicity of problems, the plague, people. We come across some incredibly tragic stories you know, um... there was a suicide last year and another family member killed in an accident and this one ohh, came up with something young, doesn't matter what. They're all... It's all in there and they're all very tragic stories. Um... but we're in and out sort of over several months and yet the real challenge, the problem of keeping people, or giving them the power to feel good about themselves, about life, give meaning to them, I think that must be incredibly hard in... in the health sector that's trying to do that, whereas we're defined well we're sort of defined I think the role of palliative care is being demanded upon for much more.

Ysanne: and then a lot of people would sit in the shoes of chronicity and look at your work and say [I] can't do this.

Wendy: They do. All the time we get that feedback. But we do... do recognise that we think we've got the easy job. The plum job. So long as we've got the skills to deal with it. As long as we're innovative as well and promote the best of health I think would contribute to it. I have watched people not survive in palliative care (3: 807-831).

The need for stability within a nurse's private and personal life in order to cope with professional sadness is emphasised by Wendy. She recalls another staff member Jane, a part-time relief nurse, saying to her that if she had some upheaval in her own life she doubted if she would be able to cope with the stresses and strains, and the challenges that giving effective palliative care demands. Wendy tends to agree with Jane and argues that skilled selection of staff is important. Viewing the staff as a team and selecting people who show a preponderance to fit within with the team as well as looking to them to bring

new ideas and skills is often difficult to achieve. Wendy points to flexibility being an important component of success in staying in palliative care work. A typical day for the community palliative care nurse will include visiting dying people with dysfunctional families that are trying to overcome their problems; facilitating some families who do not have any idea that they are dysfunctional; counselling people who are extremely depressed and making bereavement visits, all of which impact on the nurse as a person. Deeming that if the nurse has a well developed networking system and a balanced personal life Wendy considers they can deal with the ever changing nature of palliative care work. That is not to say that all community palliative care nurses cannot experience their own private life traumas, indeed she speaks explicitly and at length about her own personal troubles. However, describing her personal system of debriefing as suitably established and having a tried and tested networking system Wendy purports to be able to deal with most situations unscarred:

... you're giving the whole time, and the demand on a personality I think with staff is, it's not just the single case of sadness that you'll come across, or pain. It is that you're stepping into a family here that are tearing each other apart and you're trying to not create further difficulties let alone rectify anything in the first week. But to start assisting somehow to the next family who have got no skills whatsoever and who don't know what to expect or anything else. Others who are expecting the wrong thing of you or the doctor, who are angry at the doctor, others who are depressed. So you're skipping from one to the next, to the next and then the bereavement [counselling] that we try to mix in with our work is incredibly hard because people are found in a great sense of sadness. Meaning goes out of their life. They've either cared for someone and suddenly they're in the grief state and many people are incredibly sad at that stage, and I think on palliative care staff, swapping every day, going from one to the other, to the other is very demanding and if they don't have a really good stimulating networked personal life, I think you can go under (3: 852-873).

Before becoming enmeshed in conversation about motherhood Wendy indicates that it was difficult for her to take on a new life role without having a suitable role model to follow. She contemplates that people who are dying (and their relatives) may be in a similar circumstance, not knowing how to behave, how to act, or how to be in their new life role of being terminally ill (an ontological mystery):

Oh what this mean, what am I meant to do, what's my role model? and also that made me quite aware then, at some point I suddenly connected to, people with cancer don't have a role model. They've got no idea how to behave or... or what it's like, so they've only got, "Oh Grandma died in agony." That must be what it's like. Yeah and there's no role model for dying and families don't have a role model for losing that person (3: 941-949).

Finally, Wendy reflects on how she is and wants to be in the world as a community palliative care nurse. She implies that there are those nurses who become hardened to the job and are, in her opinion, not well respected in the specialty. She claims she wants to be known as a person who cares for her patients and someone who is not afraid of striving for the best outcomes:

I think as we get older that um... maybe the sadness doesn't come because I think laughter can be quite saving for many people I suppose, I don't know. Maybe that's what it is, but I also look at some, what I would consider, fairly hard and ... and dry woman around about health as well. I don't want to be like that. I want to listen to people. I want to... I want to know that I'm providing the service and that we all are providing the service as a whole big team in health and that we must always strive for better and I think... I don't know why they're hard and dry but I don't want to be like that. I'd rather get yelled at a few times for doing it wrong, than just become hard and dry. That's what I'm like (3: 1006-1019).

Preliminary NUD•IST nodes for Wendy's stories

- (1 1) Sadness/ Text Search
- (1 1 1) Sadness/ Text Search/ Whose sadness?
- (1 2) Sadness/ Intellectualising
- (1 3) Sadness/ As non-acceptance
- (1 10 1) Sadness/ Acknowledging/ In colleagues
- (1 14) Sadness/ As loss
- (1 14 1) Sadness/ As loss/ Anticipatory
- (1 17) Sadness/ As black humour
- (1 18) Sadness/ Organisational
- (2 5) Watching/ New staff
- (3) Personal loss
- (5) Time
- (8) Unable to help
- (10 2) New knowledges/ Available to patients
- (11 1) game playing/ Doctor-nurse
- (12) Palliative care
- (12 1) palliative care/ palliative care as a specialty
- (13) Active vs. palliative Rx
- (15) Wounded healer
- (16 1) Happiness/ Laughter
- (17) Images and perceptions of palliative care
- (17 1) Images and perceptions of palliative care/ From others
- (19 2) Sharing/ With patients
- (20) Stability
- (24 1) Comparing? Oncology with palliative care
- (32) Wise practice

Table 9: Preliminary NUD•IST nodes interpreted from retelling Wendy's stories.

Poetics of Wendy's experiences

This is my sadness
and that is yours.
The lines are drawn and
I will not walk on your side
even though I suspect you will walk on mine.

As leader of the team
you appreciate the dry wit,
the black humour,
the demanding torrid time
that death and dying
so generously gives you and your staff.

And you celebrate
through empathy and closeness,
listening and maturity
all sadnesses, both personal and professional.
The wisdom of life
balancing and harmonising
relationships in and out of your field of practice.

As a wounded healer
you know the pit falls,
the empty spaces
where energies cage,
unable to breathe the air of consolation.
Wait!
In the distance you can hear the laughter
that will free the ties.

But not just yet...
There's another problem to fix...
another meeting to attend...
another paper to write...
another...
another...
another...

Rose

Background and first impressions

A nurse of many years Rose has been involved in cancer care services in the city since their inception. She presents as a woman with a vast amount of experience who relates her stories in a gentle manner, not appearing to be hardened by her experience (fdnts 2:19). Treating patients in her care as individuals she possesses extensive knowledge of their needs and of their eccentricities. For over twenty five years she has worked closely

with the medical profession to forge an effective and efficient oncology service within the local community. As the sole community oncology liaison nurse she retains a close working relationship with nurses within the community palliative care services. Covering an area of about half the State, Rose has established an outreach service for patients unable to attend the main public hospital for outpatient chemotherapy treatments.

When approached to be a part of this study, Rose readily agreed. In speaking with her it became apparent that the role permits Rose to cross and blur the distinctions between oncology and palliative care. Her involvement with patients and their families often extends over several years depending on their diagnosis and prognosis. However, through post bereavement visits and being an active and well respected member of the community, Rose has maintained friendships with many of the family members of her former patients. Having endured some personal traumas in her life Rose has a better than average understanding about what it means to be different and shows compassion, tinged with humour, portraying a sense of realism and pragmatism when describing her experiences of sadness (fldnts 2:20).

Retelling Rose's stories

Interestingly on asking Rose about sadness she replies by discussing the ongoingness of relationships between herself and the patient/families. She concedes that breaking the ties between herself and the family is often difficult and sometimes inappropriate:

it's important to have continuity of the nurse. It's important I feel to keep that one person involved right through with the patient and then the sad... some of the sadness comes of course, when you have been so involved with the family and... and the um... patient dies um... and it's very hard then to cut off from the family entirely. Um... so, you know, you still have a running relationship with the family for quite a few months and sometimes years. It's an individual... an individual um... thing you can't just say... like can't put a time limit on it like one month, six months or a year and that's a kind of rough idea but you know it never works like that (8: 26-38).

Anticipatory loss heralds as an important issue for Rose as she recalls recent feelings when attending the funeral of one of the patients in her care. Describing the intensity of her feelings, not for the person who died but for another patient who attended the same funeral, Rose became sad when she saw him. This person had a similar diagnosis and realising that he had to endure loss of quality of life in the near future as he approached his own dying trajectory Rose extols:

I was really upset because the fellow had died but what upset me more was, when I was... when we were coming out another one of my patients stood up and came out and he was blind from a first bone marrow transplant and so I got upset and crying, but I wasn't crying for the person who had died, I was crying for the patient who was alive (8: 49-55).

It is possible, Rose concedes, that many people might imply that because she has over twenty years of experience in this specialised field she might be hardened. Maintaining that she copes with the issues of cumulative grief she confesses that one loss usually triggers memories of other deaths. She perceives herself to be realistic when thinking about death of the palliative care patient, accepting that people cannot live forever and that death is a part of life. She presumes that for the majority of people who are terminally ill the death event is a close certainty. Whereas death for the majority of people is a reality of the future—a distanced event which can place itself in the realms of an illusion rather than a certainty:

Umm... you know because I've been working in the field for twenty five years, people think that you're immune to death and sadness and umm... grief.

Ysanne: *They could well get that idea.*

Rose: Yes and umm... you, you don't. You feel just the same gross thing and probably more, but you realise and you overcome that sadness because you realise that there is a time for people to die. And most of the patients are ready to die and the way that I prepare myself because I do discuss it with them ... I realistic enough to talk to them about their long term thing. And so when they do die well, it's very sad. It's like a little end of an era (8: 92-102; 104-105).

Rose's life experiences, including the deaths of her husband and brother, and other personal deprivations are deemed to contribute to her overall attitude to loss, dying and death, including her own perception of coping with death of the patients in her care. However, Rose uses the word 'coping' as a synonym for 'control' suggesting that every nurse should experience significant life events, such as giving birth or the death of a close relative or friend, in order to cope with death of patients. She says:

just occasionally it's overwhelming, you know so that I might go home and I ball (cry) all the way home. And then... but then you get home and you're doing things and it's not that you've forgotten, it's just your coping mechanisms have come into play. And I think that's something that the young I feel, with our younger girls, and I'm not, I don't want to sound like I'm saying all the young ones don't know, but they don't really learn to cope with it until they've had a lot of experience in their life, in their own life. I think that is the... I think having a baby and loosing

someone is probably the two important things on top of your nursing training, that you could learn from really (8:119-131).

Rose does not comment about nurses who do not have or are unable to have, for various and sometimes obvious reasons, life experiences of birth and death. However, she is emphatic that nurses involved in palliative care work should be empathetic rather than sympathetic and insists that patients do not wish a nurse to sit and cry with them and make rash statements such as wishing to take a person's pain away. Rose proposes:

I mean I've been with staff who have sat down beside the patient and said "I wish I could take your pain away" and cry. And that really is not what the patient wants. They want empathy but they don't want the sympathy of, you know, something that's impossible. You know there's certainly the empathy there that they need (8: 139-145).

Rose appears easily offended by public outward expressions of grief and describes a situation where she felt the behaviour was inappropriate. On seeking more information about this situation Rose concedes that she is more comfortable with private expression or a one-to-one situation where emotions are shared. However, she does accept that funerals are appropriate gatherings for the public display of emotions and admits to crying when attending the funerals of some of the patients.

Another example of sadness for Rose is highlighted by relapses in patients' conditions. While she acknowledges that periods of relapse can be part of the terminal illness trajectory she infers that for the most part the occurrence of a relapse is a stark reminder of the certainty of the impending death for that person. She proffers:

Apart from death there's also the sadness when people relapse. When they've actually umm... been through hell and high water and it may be only a few months or it may be a year or may be two years. Like today I've got a young girl who relapsed after having a bone marrow transplant. So you really, you feel that sadness but you can't... it doesn't take over your life. Umm... because if it did, number one, you shouldn't be in the field I think, but number two, you couldn't survive ... (8: 110-118).

Sadness and gladness can be experienced simultaneously at the death of a patient according to Rose. While she is sad that the person has died, she is also glad that their suffering has ended. This double edged emotion does not detract from her realistic approach to caring for terminally ill patients noting that for the most part patients will experience pain and suffering. She is fully aware that some oncology treatments will only help minimise that suffering, they will never reverse the situation of impending death. In spite of these hurdles she acknowledges that caring for terminally ill people is personally satisfying and a rewarding area of nursing:

I mean you're sad because that person's not here, but it's a relief for them, and even us, you know you feel, you get to a stage where, even though you're honest with them and that's what we really try to maintain is honesty without taking away all their hope but, it's, it's suddenly a load of your shoulders, I mean it sounds umm... personal but you know it's like a load off your own shoulders. And for the p... because you know also that the patient's now comfortable and happy wherever they are but it's not umm... it's not a devastating grief, it's not a devastating sadness. It's it's a thing you cope with within a profession you know and I mean people often say, well how do you cope? Or you must be used to it? But I really think it is just a time thing that you understand that you can't from the beginning you can't cure every person that you treat (8: 151-166).

... and from my own personal sadness I look back and I think well, you know, we really had some good times. I want something out of the job for myself. I don't mean monetary things but I really want to enjoy it and because I can... I think I do cope with umm... the grief and the sadness and that and then get on with it, umm... I see people fifteen years along, the spouse, you know and it's like we're still a friend even though you're not a friend as in, you couldn't be friends with everyone that obviously have died, but there's something there. And that's a kind of sadness and then there's... when you meet them in the street, their their sadness relates to you for an instant and then it's a passing thing ... (8: 179-191).

As our conversation progresses I sense that relationships are central to Rose's practice as she points again to the ongoingness of her relationships with bereaved relatives and discusses the notion of 'sharing in each other's grief' when she talks with them. Sometimes these relationships last for many years and she describes one particular friendship she has with a local Bank Manager and his children. Having nursed his wife several years ago, occasionally she might meet them when shopping. She values that he always acknowledges the part she played in his wife's care. For me, Rose articulates the joys of friendship in a close community which tends often to precipitate reciprocity:

Ysanne: I guess a lot of your sadness is then because they've gone out of your life or they were just nice people?

Rose: Yes well that's human nature! Isn't it? Is isn't really, I mean a lot of these people that I've met, I've met thousands, you know I mean I've kept a list for a few years but I've run out of space [chuckle] but you know you do, you umm... if you met them outside you'd like them too, if you weren't associated with, because they're nice people. You know, I mean I get little notes from people often you know. "I saw you at the supermarket but you didn't speak" you know. You know (name of Senator) wife died many years ago and if I'm in the supermarket and he's got any of his six, or four or thirteen kids he's got now, he always brings them over and says "you remember Sister Rose, she looked after mummy" you know and things like that. Again, now I think that's brave of him, as well. It also re-enforces perhaps you did something right and I'm not trying to be egotistical about it, it

just means you know, with all of their sadness umm... they remember your sadness too because when I've had problems they've come to me (8: 454-477).

However, working in a small community can be a negative experience. Rose notes that witnessing relatives deal with the initial diagnosis of terminally illness can be austere. This difficulty is made more apparent in a small community as more often than not the patient may be related to a staff member or even a personal friend. She advances:

... there's also the sadness of umm... of diagnosis because someone is always someone's mother or sister or brother or someone. They always belong to someone. And and in our community it's such a small place too that they often belong to our own staff or our own hospital members. You know so there's a sadness you feel for them (8: 340-345).

In spite of her love of palliative care there are areas of practice within the specialty that are problematic for Rose. Debriefing is one topic that she disagrees with vehemently, believing these sessions are often staged events rather than spontaneous outpourings of feelings. *'I have a real thing against umm... what do they call it? umm... debriefing. And not not in the principle, but in the fact that you go to it' (8: 261-263).* She fears that emotions can be neutralised if the person is asked to present themselves at a particular time for a debriefing or counselling session. Maintaining that strong emotions such as those associated with grief and loss are not easily turned on and off she suggests that allocating sessional time for the expression of such emotions cannot capture their full intensity or full meaning. *'I'm not knocking down the principle of that either. But they need it when they need it. They don't need it at two o'clock on a Friday afternoon' (8: 311-313).* Nevertheless, Rose does not believe these emotions should be suppressed. Rather that making a specific time to deal with them does in itself suggest that these emotions have to wait to be expressed. Rose would rather envision a situation where nurses are readily available to assist people instead of asking them to wait for an allotted time and space to vent their feelings.

Allied to the issue of debriefing Rose finds little time for the sentiment behind the organising of specific clubs for diseases or treatments. She criticises these clubs believing they achieve the antithesis of their aims. She voices their testimony is to normalise the situation for their members, claiming that society should be non-discriminatory. Rose submits the very establishment of clubs such as the colostomy club or the leukaemia club disassociates these people from the rest of the community. However, she realises many of her colleagues do not agree with her and she is willing to continue the debate:

But so I have a problem with colostomy clubs or any clubs. You know, twenty pale pasty faced kids running round the paddock with leukaemia I mean really doesn't do anything to me. I mean it isn't normal. I mean here we are in a world trying to say to our patients you know, you know to live within their own capacity, but you know and then to have a colostomy club and have a bar-be-cue and think about their bags after the bar-be-cue (8: 320-328).

Rose identifies the paradoxical nature of sadness when she remarks there is a 'joyous sadness' (8:440). She tells the story of a man (Reg) who called together six people who were instrumental in his care. Reg wanted them to join together while he gave thanks to each of them before he died. She insists that while the occasion was sad it was also joyous as Reg celebrated his thoughts for the six people:

I happened to be there when, when the doctor was there and he [the patient] was really really very sick and join... he wanted us to join hands 'cos he was I don't know religious, so we joined hands and he went round everyone and saying what, something to each of us, there was about six people all together. Well you can imagine. You know I mean here, and he says "when you come to heaven I'll tell you my 'Sister Rose' You know of me!" But it doesn't hurt you. That's a kind of joyous sadness, even though he died, he knew he was dying, he had it all sorted out you know (8: 432-442).

When she reflected on the care she had given Reg she felt comfortable that she had been able to give him what he wanted and needed. Rose comments that reflection on her work is important for her as it helps her cope with some of the sadness, and is an significant evaluation tool. She is able to discern what treatments are successful and which are not, and from these findings possibly inform her future practices:

He'd died the next day. So, I mean it was a real purposeful little interview but as I say it was sad but it was, it was beautiful really. You know I can appreciate that side of it. And umm... you know if you can't win doing anything more for the person then you reflect on what you've done and you feel comfortable with yourself, and that helps your sadness (8: 446-452).

Rose feels privileged being able to share the sadnesses with the family of the dead person. In sharing their sadness she believes that she also shares her own sadness:

I'm not very demonstrative, really, but, you know it is nice to put your arms around someone you know, and talk to them, or or don't say anything sometimes. Just to feel, you know take a bit of their sadness and join them really, isn't it? Join them and honestly a genuine tear or something doesn't matter, not that you can put that on. But you know you can really feel for people and I mean it hurts you yourself. Umm... they have to then go on with what ever their treatment is or what ever but we go on helping them. There's still that sadness there then too (8: 511-521).

Time is an issue for Rose as often she is aware that she could spend more time, or be more supportive with particular patients:

That you feel... that you would like to spend that extra time there and while I'm really lucky that I can spend more time... spend extra time with some people umm... there's never too much time. You know there's never... you can't spend too much time. Not as if you're there every five minutes but umm... well you could be there a little bit more often or just a little bit more supportive, a little bit more often (8: 559-566).

In discussing what constitutes palliative care Rose concurs that patients with cancer are not the only people who should be receiving palliation. She bemoans that people who are suffering from failing respiratory function, rheumatic disorders and CVAs²⁶ should also receive palliative care, and that the quality of life of people with chronic illness is just as compromised as those who are suffering from cancer. Idealistic in her notions of care provision she wants to do everything possible for all patients whose quality of life is diminished:

The only other thing is that I don't feel that cancer patients are any sadder or worse off than other patients, and and you know that really one thing I feel, when I give a talk I say well, you know cancer isn't the worst disease in the world. It's become a very emotive disease, but you know someone lying in a bed for twelve months having had a stroke, is that living?

Ysanne: *[in agreement] It's still palliative care.*

Rose: *The COADs²⁷ who breathe only on a Tuesday and Thursday when they puff into a machine for half an hour and go home and wait until the next Tuesday and Thursday, that's not living. So I think really that's um... an area that I really think should be, it's not fair for other disciplines in the way that cancer is so emotive. They might, a lot of people live shorter lives but they often... most of them live a better quality of life (8: 594-610).*

One of the rewarding aspects of Rose's job is to be able to give chemotherapy treatments to patients in their own surroundings. Sometimes she may be called to give treatments at work. On other occasions she may have to travel to a nearby rural town and give

²⁶ CVA or cerebrovascular accident is an occlusion by an embolus, thrombus, or cerebrovascular haemorrhage resulting in ischaemia of the brain tissues normally perfused by the damaged vessels (Anderson, Anderson et al. 1994) (p. 297).

²⁷ COAD or Chronic Obstructive Airways Disease is a pulmonary disorder and can be characterised by pursed-lip breathing, barrel chestedness, shortness of breath on slight exertion. It is an degenerative condition (also known as CAL - Chronic Airways Limitation).

treatments to working farmers. One story in particular which Rose tells in detail signifies the flexibility of the service she provides:

He... it was in the bush and you drove into his house and into the garden, it was like a secret garden. And here he was on this battered old li-lo thing with two arm chairs with the stuffing fall... coming out of it. And they had umm... a big Hydro wheel for a table and (name of another nurse) was with me and she had a... she had a sundress on and a hat, and she's sitting nursing a wombat. And there was the patient, his wife, his daughter, his mother-in-law and two friends and two kids, and we're all sitting round eating cucumber sandwiches under these pear trees while he's having his pump, his 'chemo' pump in. You know, so you know, that's a sadness to reflect on it but but but it was beautiful (8: 659-671).

Being flexible about the place of delivery of treatments is satisfying, juxtaposing happiness with the sadness of the illness experience.

For many of Rose's patients the time to cease chemotherapy can be fraught with sadness for both herself and the patient. Dependency appears to be the issue for Rose and she implies that sometimes the chemotherapy is clearly not benefiting the patient, yet they feel that without it their death would be closer. For some, Rose contends, death may well have come later rather than sooner had they been accepting of the treatment ceasing. She concludes it is highly likely that some patients may accuse her of stopping their treatments as they are unaware she is in constant contact with their treating GP. Rose contests that these episodes while sad are not hurtful sadnesses, not like the hurtful sadness experienced with the loss of relationship.

In many situations when dealing with bereaved relatives Rose will use humour to diffuse tense or awkward moments. These moments, she admits, usually centre on her feelings rather than those of the relatives. However, she believes that focusing on the good and happy times she shared with the dead person is of greater value to the relatives than talking about the pain and the distressing symptoms the person might have experienced. She concurs that speaking about the positive events in that person's life is being sensitive to the feelings of the bereaved:

... well if you're reflecting on that person's life or whoever... then you seem to bring up the better things or the funny things or the things... You don't dwell on the fact that he had well pain in the last twenty four hours of his life and was pretty miserable, you know ... (8: 749-753).

Finally Rose's view of sadness is postulated. She claims that sadness is spasmodic throughout the care process with dying patients. Sometimes the sadness is associated with the person themselves, or their relatives, or the situation, or the care they are or are not

receiving. Whatever the circumstances Rose believes that sadness is acceptable and definitely not fatal:

For me personally I really don't feel all the time overwhelming sadness, but there are times, there are times you let yourself go, in self-pity sometimes. It doesn't hurt you ultimately, it doesn't kill you (8: 812-817).

Preliminary NUD•IST nodes for Rose's stories

- (1) Sadness
- (1 1) Sadness/ Search text
- (1 1 1 1) Sadness/ Search text/ Whose sadness?/Their sadness
- (1 4) Sadness/ As acceptance
- (1 5) Sadness/ Gut wrenching
- (1 7) Sadness/ Failed expectations
- (1 10 2) Sadness/ Acknowledging/ In relatives
- (1 14) Sadness/ As loss
- (1 14 1) Sadness/ As loss/ Anticipatory
- (1 15) Sadness/ In nursing practice
- (1 15 1) Sadness/ In nursing practice/ Missed opportunities
- (1 15 2) Sadness/ In nursing practice/ Resistance to change
- (1 23) Sadness/ As a paradox
- (1 24) Sadness/ Coping
- (1 25) Sadness/ As celebration
- (2 1) Watching/ The relatives
- (3 1) Personal loss/ Patient
- (3 3) Personal loss/ family
- (4 2) Privilege/ With family
- (5) Time
- (12) Palliative care
- (12 2) Palliative care/ Beginnings
- (15) Wounded healer
- (16 1) Happiness/ Laughter
- (17) Images and perceptions of palliative care
- (18) Death
- (19 1) Sharing/ With the team
- (19 3) Sharing/ With relatives
- (28) Shoulds
- (29) Funerals
- (30) Conflict
- (36) Knowing limitations
- (40) Reciprocity
- (41) Community nursing

Table 10: Preliminary NUD•IST nodes interpreted from retelling Rose's stories.

Poetics of Rose's experiences

It's a rare bird
that traverses the boundaries
between the real and the rational.
Yet because you tread
where others fear,
there are no secrets hiding
no mysteries would dare allude.

I see a conservatism
that holds your wings
and keeps them safe,
entombed in an acceptable image,
an ordered zone, from which
you occasionally spring forth
to trifle with the rules.

A woman of values
intensity, survival.
Sharing involvement, compassion then loss.
The centrality of relationships
celebrates your sadness
then turns full circle
when parting realises tears.

Pauline

Background and first impressions

My first impressions of Pauline was that she is an extremely brave and strong woman. Coordinating a community nursing service in the city, and tainted by a recent family bereavement and self illness Pauline spoke freely of her personal/professional sadnesses (fldnts 3:21). A rapidly speaking person she delivers her stories as though there is not enough time for her to relate all their richness. A woman who packs diversity into her life, she frequently mentions that her experiences happened '*a hundred years ago*' (9: 34), intimating how quickly time passes in her busy world of community nursing. She recalls several experiences that she deems sad when she was in practice and cries openly during our conversation. She refuses the offer of stopping the session altogether although I did temporarily stop the tape when her grief prevented her from telling a particular story. I admired her strength as she spoke of the interrelatedness of her personal grief with patient situations that she experiences on a daily basis (fldnts 3:20).

Pauline's community nursing life began over seventeen years ago when she was invited to join the service as a weekend worker. Having no previous community nursing knowledge she was uncertain that her skills would be adequate for such a position. Nevertheless she accepted the part-time job confident that others (those who offered the position) deemed her to be competent. In these early days of community nursing palliative care was not a specialty and clients needing palliative care expertise appeared to 'muddle' through with nurses being their only source of advocacy when treatments needed to be re-assessed and changed. Often these times were marked by tensions between the community nurse and the treating medical officer. Pauline signifies with some frustration that a few doctors were known for their arrogance and reluctance to believe the community nurses when they would telephone them after hours to report a change in a patient's condition. She remembers one particular incident when a doctor, with whom she had no previous contact, 'grilled' her through a telephone encounter, almost suggesting that she had to prove her worth to him before he would listen to what she had to say. Known for her straight talking, Pauline refuses to play his game and succumb to his overbearing manner, managing to secure agreement that he would attend his patient who was in desperate need of a change in analgesia to manage his protracted pain.

Retelling Pauline's stories

Placed in the context of her recent bereavement, it is not surprising that many of Pauline's descriptions tend to highlight loss of relationality as the source of her sadness. Looking back over her early experiences Pauline remembers vividly times when patients questioned their own journeys towards death, seeking answers from her about when and how they will die. Then working at weekends only, Pauline wondered why they asked her these intimate and highly emotionally charged questions when they could have asked their primary nurse during the week. She intuitively feels that maybe her temporariness in situations attested to them asking such questions:

And I thought, is that because umm, it's someone new and different? And they could feel that they can unload that and it will be gone 'cos I mightn't see them again for another fortnight? (9: 50-53).

Breaking bad news was not a feature of many of her weekend visits to patients but she recalls that much of this early work was steeped in issues of trust, advocacy and demands on her to give some answers. Set in a climate of 'paternalistic doctoring', it is not surprising that certain community nurses, at that time, were identified by patients as people who could and would provide comment on issues of a difficult nature. Pauline recalls the story of Rita, a woman who was discharged home following an

oesophagectomy. Rita was cachectic, having difficulty with swallowing yet was sent home to her family with a prescription for oral antibiotics—an inadequate discharge plan by anyone's standards. On visiting, Rita requested that Pauline help her have a shower. The family suggested that a shower might be too tiresome for her but Rita insisted. Sensing Rita's request was bounded by ulterior motives Pauline agreed to help her to the bathroom. She indicates:

So we went in the room and she shut the door and she said, shut that other door so no-one can hear us. You know, and I laughed I said, okay and I shut the door and she said, okay what's going to happen to me, am I going to die? I said, yes you are. She said when? I said, I can't be sure but by the look of you it's not going to be too long. And she said, how long have I got? And I said, I don't know. She said, what about a guess? And I said, that's all it would be but I would say if you've got anything to do, do it this week 'cos you won't be here next week. Oh right-o, she said, what's likely to happen to me? And I said, you may have an obstruction, you may bleed, you may just not be able to breathe because of the mass in you. She said, Oh, all right then, she said, so I should take a lot more of that morphine that I'm knocking back. I said, yes if I were you I'd tuck into that morphine you're knocking back. And, so she said, okay run the water. So I ran the water and she said, now change my nightdress I've got no intention of having a shower, I just needed that information and I knew you'd give it to me (9: 98-118).

The shower was unimportant, Pauline had given Rita what she wanted, albeit a risky encounter. Rita died four days later. Pauline suggests that she senses when some people know already the answer to their questions of life and death and although she treads lightly with all questioners of this nature she determines that sometimes she may overstep the mark and she is left with some residual sadness. Rationalising that in these latter situations she is providing her own opinion, her own judgement, she affirms that many palliative care clients seek out nurses who are not afraid to discuss issues of time left to live.

Working as a community nurse prior to the advent of good palliative care and effective measures of pain control Pauline contends that many patients in her care suffered needlessly and their suffering was distressing and sad for her. She recalls the story of a young woman (Nina) who was eventually diagnosed with a secondary spinous melanoma after having been misdiagnosed with influenza for several months. A single parent with a child four years old Nina never experienced influenza and returned to the doctor with increasing pain and discomfort saying that she would not leave his office until she was satisfied with a diagnosis. After exhaustive tests Nina was found to have a primary brain tumour which was so advanced that chemotherapy was no longer an option. Over a short period of time her condition deteriorated. Pauline was still working weekends only and because of the work schedule visited Nina on a fortnightly basis. One weekend Pauline

was called to visit her and was taken by surprise at the extent of pain she was experiencing:

So I went down and this girl is fair, I've never seen anyone do it, hanging on to the wall trying to climb the wall from the pain.

Ysanne: *Oh no!*

Pauline: Yeah. So I rang the GP and said, this is absolutely terrible, this girl is in a lot of pain. And he said, give her some morphine. And so I gave her some and I gave her some and he said call an ambulance. The ambulance was late. Didn't get there very quickly and I gave her more. So I rang him and I just said, I'm just letting you know I've given her more and I said, if it doesn't stop in ten minutes I'm giving her more. He said, that's fine. So anyway it finally got there and I found that exceedingly distressing (9: 176-191)

While Pauline expresses regretfully that this situation occurred before the benefits of co-analgesia became known she does not minimise the sadness of the situation for her at the time.

Living and working in a relatively small community Pauline remonstrates that personal knowledge of a patient and their family enhances the quality of care that she is able to give. She is aware of the little nuances that may hinder or preclude care efficiency or effectiveness. Recalling the story of a woman (Deirdre) who '*liked to enjoy life*' (9: 237) she maintains that awareness and insight guided her through this difficult situation. Deirdre had had a succession of relationships with men throughout her life and when Pauline was visiting her she had a live-in partner Mark, some twenty years her junior. Pauline describes the man as '*fairly rough around the edges*' (9: 247-8) but in spite of his outward appearance and manner he was trying his best to care for Deirdre who was dying. She questions Mark about how much morphine Deirdre is requiring to manage her pain and asks him to write down the times and amounts of administration. She observed that Mark's limited education precluded him from writing so she guided him through a system of noting when the morphine was given. In spite of his limitations Mark was devoted to Deirdre who desperately wanted to stay at home and be cared for by him. Both the family and the GP were suspicious that Mark was unable to care for Deirdre yet Pauline disputed their claims and created opportunities for communication between herself, Deirdre and Mark. Through continued negotiation, support and trust that each person in this triad (Deirdre, Mark and Pauline) could effect good care, Deirdre remained at home to die. Pauline upholds that if the family and the GP had their way Deirdre would have been admitted to hospital against her wishes. Pauline is saddened by some doctors' attitudes and their inflexibility towards patient care.

Yet another example of sadness in practice that Pauline echoes is the story of Mrs Grant who admitted that she was not married to the man with whom she was cohabiting. As an older woman Pauline notes that this admission might well have been difficult for Mrs Grant as she was from a generation when cohabitation out of marriage was not a norm. Pauline assured Mrs Grant that she was not perturbed by this admission rather she was more concerned about the care that was being provided. On speaking to her defacto husband about the amount of Morphine Mrs Grant required, Pauline sensed that the man was unable to understand her instructions or the instructions on the bottle. It was then that Pauline realised the man could not read. After working out a suitable system for calculating the dosage of analgesia Pauline was confident that this man could manage the care of Mrs Grant. She emphasises that this experience, whilst sad, taught her a valuable lesson, never to assume that people in her care can read or write:

And it took me, I was almost at the door before it clicked that that, there's a reason for this man's body language. Umm, I couldn't believe that I was so stupid to have just assumed everybody could read. And then once we'd gone through it, he was quite happy with it, you know, that I'd finally cottoned on that he couldn't and that we could find a way around making sure he remembered it and how much to give her each time umm, yeah that was interesting, I remember that, I'll never forget that. 'Cos I've never assumed people read since then (9: 378-387).

Being in a position of leadership the issue surrounding a lack of accountability in some health professionals is a matter of sadness for Pauline. She vigorously claims that many health professionals are at odds to admit that they may have made a mistake. Intolerant of people who cannot admit to making mistakes she suggests that many mistakes occur in patient care and bemoans the unfairness of some of those mistakes. Placing value on those health professionals who risk their vulnerability by being open and honest with patients and their peers Pauline claims:

I don't have a problem if yes, you say to someone I'm sorry I mucked up. You're allowed a muck up. But don't make out you didn't muck up when you did. I don't have a problem with that (9: 337-340).

... there are hundreds, not, yeah there are a lot that get missed. Umm, I don't suppose, everyone's human, and I don't know how you go about that but that's very difficult when you're mucking around with people's lives (9: 344-347).

The loss of opportunities for the dying person is a constant source of sadness for Pauline as she relates the story of a man who felt he was dying before he could realise his dreams. At that time he had become a grandfather and was mourning in anticipation of the loss of seeing his grandchildren's lives develop. *'I almost grieved with him for what he had*

missed out on. His wife was great and very practical but he really felt as though he'd been short changed' (9: 416-7). In a similar vein she also notes that many dying people are not sad for themselves but are sad for those they are about to leave behind '*That sadness comes from the parting not from the dying'* (9: 444-5). Pauline finds it interesting that the dying person can make such a distinction.

Following the theme of relationality, Pauline declares her sadness in watching relatives cope with witnessing their life partner die. She remembers a situation of a young woman (Lesley) who had a mole removed some years ago and was informed at the time that it was benign. However, later it was found to be malignant and after a few months Lesley became very ill. When she visited a new doctor she recalled the episode of the mole being removed and the doctor investigated her histology report to find that it was malignant. By this time the woman had developed secondaries. With a young family and running a business from home, the husband and children coped well with the symptoms of Lesley's advancing cancer. Pauline tells how at times Lesley would telephone business associates and become incoherent over the telephone. However, her husband, aware of what was happening, used to secretly telephone these associates apologising for her behaviour. Pauline remarks on her own judgements being a little harsh when he told her of his fears that his whole life was changing around him. Pauline thought at the time that he was being rather selfish just thinking of himself but on reflection she felt that she had misunderstood him and that in fact he was preparing for his own future, a new life, a new beginning. She remembers:

Umm, and I thought yeah I'd missed the point of what he was trying to tell me about how it's not just there and he actually was preparing thinking about it and preparing for it and that was very sad to him because he said, we lived it full and I thought, yeah it is. Umm and it's sad for those kids umm, yeah very interesting point that he made that I missed until I thought about it, yeah. Umm, there have been some people that I've just sat on the bed with and cried. That's all there was to do (9: 551-559).

Sometimes grieving for patients who are dying can be overwhelming for Pauline. She freely admits to crying with people and contests that these infrequent outbursts of tears are difficult for some doctors to appreciate. She recalls a situation when she was working in a hospital when a young woman, whom she knew quite well, died of Myasthenia gravis²⁸, and Pauline openly wept at her death. A doctor told her that she must not cry as patients need her for support. She felt his comments to be slightly insensitive of her needs and

²⁸ An abnormal condition characterised by the chronic fatigability and weakness of muscles, especially in the face and throat, as a result of a defect in the conduction of nerve impulses at the myoneural junction (Anderson, Anderson et al. 1994) (p. 1028).

retorted that she felt very sad about the death. She also realises that cumulative death situations play a part in bringing sadness to the fore and notes a cognisance of the link between cumulative deaths and burnout:

Yes, you can't control it sometimes [crying] umm, what ever it is that strikes a chord with you umm, but you go off and most people cope with it (9: 579-581).

Returning to the theme of relationality she tells the story of Judy who was married to Jim, one of Pauline's patients. Jim was dying of cancer and Judy, who was also a community health patient having a history of protracted healing leg ulcers, repeatedly told her of the dysfunctional relationship between herself and Jim. As his disease progressed it became obvious to Pauline that Judy needed some assistance, especially at night as she was experiencing many sleepless nights attending to the needs of her husband. Pauline claims that not only was the relationship between Jim and Judy dysfunctional but also between the son and Judy. The son, who lived close by refused to become involved in caring for his father claiming he was too busy. Pauline notes:

... so, I actually went up and said look, would there be any way that someone could come and stay 'cos I didn't think that her husband, their dad was very, he was grossly unwell and that the doctor had said that he didn't have that long to go and I didn't know when it would be and he said I can't, I've got to go and get a load of wood (9: 643-648).

To compound matters earlier in the marriage Judy had 'pseudo adopted' a young boy who became like a son to her. Pauline suspected that Judy might have been his natural mother but maternity was never an issue as she appeared to claim him anyway. This adopted child lived some distance from the couple but agreed to come to live with them during Jim's deteriorating illness. For twenty years Judy had chastised Jim, saying that he ill treated her, which on occasions appeared to be true as her wounds would show. However, one early morning Pauline was called to the home and saw an ambulance parked outside. When she inquired as to what was wrong she was informed that Jim had died. On entering the house she could hear Judy wailing. On calming her Pauline suggested that she help her wash Jim and get him ready to be transported to the funeral home. Judy continued to cry and mourn her loss as if there had been no ill feeling between her husband and herself. She held on to Jim's head begging Pauline not to take him away. Pauline summarises the situation:

Yes so that was sad because, it was sad for this woman who really didn't according to her, for twenty years had told everyone what a mongrel he was and this, that and something else. But in actual fact having him there was better than not having him there. Or having him leave the house (9: 712-717).

Pauline also recalls that the following day's obituary notice read '(name of man) dearly loved by wife and son [including the man who went to get the wood]' (9: 710) and on reflection Pauline concedes he most probably was.

The remainder of our conversation focused on her own mother's recent death and the part she and her family played in that process. One devastating event in the middle of her mother's illness was the discovery of her own brain tumour which was successfully operated upon and removed. Throughout her descriptions I had a sense of a woman precariously balancing between life and death on several levels: working with palliative care clients as she watched her own mother die; being diagnosed with a brain tumour herself and not knowing whether or not to tell her parents; seeing the anguish on her children's faces as they watch their grandmother dying and their mother facing a future of possible physical incapacity or death. I find Pauline's experiences remarkable and throughout the narration of her stories I constantly marvelled at the capacity for the human condition to withstand the complex scenarios of sadness.

Preliminary NUD•IST nodes for Pauline's stories

(1 1) Sadness/ Search text
(1 7) Sadness/ Failed expectations
(1 8) Sadness/ As mismanagement
(1 8 1) Sadness/ As mismanagement/ Accountability
(1 14 1) Sadness/ As loss/ Anticipatory
(1 14 2) Sadness/ As loss/ personal relationship
(1 15 4) Sadness/ In nursing practice/ Unskilled practice
(2 1) watching/ The relatives
(5) Time
(5 2) Time/ Case load
(11 1) Game playing/ Doctor-nurse
(12 4) Palliative care/ Comparing old with new
(14) Knowledge of the patient
(18 3) Death/ Questions
(31 1) Challenges/ Requests for Euthanasia
(32) Wise practice
(35) Certainty
(37 1) Suppressed feelings/ Told by others
(38 1) Sensitivity/ With carers
(41) Community nursing
(42) Advocacy
(43) Learning from patients

Table 11: Preliminary NUD•IST nodes interpreted from retelling Pauline's stories.

Poetics of Pauline's experiences

You walk a tightrope of life and death with confidence
and compassion,
and strength,
and sensitivity,
and forgiveness.

Intimacy and respect pre-empt straight talking—
risky business this assertiveness!
Bouncing you
from person to person
and open expressions of sadness.
There is little tolerance
for those time wasting games
that take you away from
sharing their sorrows.
But with mirror-like certainty
their intractable pain
becomes your own.

Witnessing, questioning
your practice, their losses.
Their lives flow
like your tears
in and out of your public image,
your private hell.

Building the whole picture through the parts

These six very different stories form a collage of sadness. While retelling their stories and collating the significant words and phrases all help to passively attend upon the event of sadness, the next stage of analysis must disturb the foundations upon which the common meanings of sadness have rested. The basic tenet of the research approach taken here is to move these common meanings to one side so that different meanings can emerge. Thus in order to shake these foundations I engaged again with the text asking such questions as: What is going on here? What is sadness saying to me? What does this text reveal about the lived experience of these community nurses being sad when engaged in palliative care? What is being seen here? What is it about sadness that is coming through in these stories and how can this be captured? (van Manen 1990; Bartjes 1991; Parker 1991; Crotty 1996a).

While thematic analysis cannot capture the full richness embedded in the data it does serve to point to, or signpost an aspect of the dimensions of sadness as articulated by the participants in this study. As discussed in a previous chapter the nodes (forming sub-

themes) in the NUD•IST package were further grouped together and two main themes that subsume the experience of sadness for these community nurses engaged in palliative care emanate: they are: Temporal rhythms of sadness and Kinship sadness. These two interwoven themes structure the following two chapters.

Chapter Five

Temporal Rhythms of Sadness

*How sad and bad and mad it was—
But then, how it was sweet!*

(Robert Browning *Confessions*).

Introduction

Sadness for the participants in this study pervades their experience of being community palliative care nurses. The nature of their work is sad. They are viewed by others, both in and outside nursing, as being with people at one of life's most saddest moments. Consequently, the descriptions the participants shared with me about their experiences of sadness are, at times overwhelming. I came to understand their work as community palliative care nurses to be bathed 'in' and 'with' sadness. Yet the sadnesses they describe are also multifaceted, and occasionally indistinguishable from other powerful and intense feelings.

Sadness is portrayed by the participants as paradoxical, hopeless, inadequate, unfair, frustrating, overwhelming, humorous, celebratory, as well as through a process of identification, loss and failure. Divergent descriptions such as these reflect the context-dependent nature of sadness and in their very differences almost 'signpost' a passage through this research. For me, the participants vacillate between the familiar territory of sadness as socially represented and the unfamiliar terrain of expressing sadness as an embodied, lived experience. An experience that is at once temporal, rhythmic, dynamic and multidimensional.

Temporality is a multidimensional concept that signifies connections between the past, present and future, 'lived time', of Dasein (Heidegger 1962).

Because we are temporal beings, our ability to encounter things *as* such and such is also temporal. Dasein is thoroughly temporal, and thus Dasein's understanding is temporal (Dostal 1993, p. 154-155).

Temporality is the rhythm of our existence. Rhythm pervades everything that we experience. It is part of our daily physical activity; walking, talking, breathing and so on. Each living entity has a circadian rhythm of which waking and sleeping are the most visible. There are however, many smaller rhythmic dimensions to life; the ninety minute

light sleep cycle that alternates with dreaming sleep, each person's rhythmic heart beat and rhythms of brain activity, for example. These physical cycles, for the most part unconscious, are constituent of a to and fro movement, a rhythm of life.

In Bohm's (1951) portrayal of modern physics he determines that matter is never quiescent but always in a state of motion. He further attests that motion is an intrinsic property of matter, not something that is merely a force outside of it. Motion, Nicholson (1985, p. 61) argues '... is the primal source from which arise any number of different forms of energy'. The processes of human life can be realised as the pulses of this motion. From this standpoint life experiences can also be said to be in motion. When this motion itself experiences disturbance a sense of uneasiness can emerge:

... we may feel pulled apart, jangled, scattered, as though several conflicting rhythms were churning inside us as in turbulent waters (Nicholson 1985, p. 63).

It is precisely these moments of uneasiness, identified and expressed as sadness, that are the impelling force behind this research. Through my interpretation of the participants' stories I have come to understand their descriptions of sadness to be the living expressions of this temporality. Their unique *temporal rhythms of sadness*. A rhythm that is ever present but changing as the participants move from one context to another. It is also possible that the discordant rhythms may sometimes blur giving rise to a notion of multidimensionality of sadness experience.

Multidimensionality is not a new concept in theorising nursing. Watson, Rogers and Parse are three nursing scholars, who, in taking different pathways, recognise the co-existence of many different realities or dimensions within complex and diverse phenomena (Parse 1981; Watson 1985; Rogers 1994). Influenced largely by Eastern philosophy Watson (1985) discreetly points to this concept in her descriptions of the spiritual dimensions of the person. Rogers (1994) however, drawing on aspects of relativity theory and energy fields, suggests that human existence is pandimensional. Parse (1981), on the other hand, believes that multidimensionality refers to the ability of people to continuously choose from a plethora of options that are simultaneously available, in order to construct their personal reality. In a recent study Parse (1997, p. 81), for example, notes that the phenomenon of joy-sorrow is '... a paradoxical rhythm [that is] lived by all human beings'. A rhythmical pattern that is both outwardly expressed and inwardly embodied.

Journeying alongside others who are dying is the substantive work of nurses engaged in palliative care. Being with dying people therefore potentiates the possibility of 'angst' or dread towards death, and as such nurses and other health care professionals come face-to-face with the possibility of the reality of their own finiteness (Heidegger 1962). Thus, it is

not surprising for me to note that without hesitation, all participants in this study initially describe a sadness situation of death, rather than any other event in their work. This starting point was largely 'set up' by my questioning: '[C]an you recall an experience when you were sad as you went about your business delivering palliative care to people in the community?' Each conversation begins with obvious stories of sadness—sadness related to death, suffering and pain. Talking about sadness in this manner seemed to mark a boundary of expectation, theirs and mine, from which further discussion could be negotiated.

Each story, while different in context, shares commonalities and similarities. They each begin with descriptions that are couched in the language pertaining to common views of sadness. Events are delineated as 'hopeless', 'gut wrenching' or 'unfair' and for a while the participants appear comfortable dwelling with these descriptions. Descriptions that are familiar to the societal and political landscape of our society as they refer to common interpretations of sadness experiences. In being so familiar they remain, as Jameson (1972, cited in Desjarlais 1991) suggests, trapped within '... the prison house of language': our everyday language. When our discussion begins to move away from the socially sanctioned and expected views of sadness however, different, potentially contentious understandings of sadness 'as lived' have an opportunity to emerge.

Some participants speak of being able to experience two or more different feelings at the same time. The action of *smiling through tears* is one such example. When two participants recognise the interconnectedness of two distinct emotions as they engage in palliative care, they are caught between the experience of crying and the experience of smiling. Each response, when experienced on their own, is appropriate and powerful for the particular circumstance. So when experienced simultaneously their meaning, rather than being diminished, is potentiated. The phenomenon of melding two or more feelings together is not new. In *Scheler's Centennial Essays* (Frings 1974) the notion of interplay between different feelings in a person as an 'indivisible whole' is expanded. Giving the example of a martyr; one who bears pain as well as bliss, Scheler encourages that these disparate feelings do not wax and wane as attention switches from one to another, nor do they merge into one unified feeling. Rather, elements of both feelings are experienced simultaneously and described as such.

Situated firmly in the participants' descriptions of their practice, this analysis focuses attention on the participants' descriptions of their lived experiences, rather than on a semiotic analysis that might ignore the very thing (in this case sadness) that is expressed. This chapter represents various compilations of sadness worked through images constructed by myself and the participants when in dialogue. As Heidegger (1962) advances, we understand because we understand—we can only realise the unrealisable

through the already realised. Thus, I have structured this chapter to move from the known, common views of sadness toward the different, new impressions of sadness as lived and expressed within the participants' stories.

These familiar experiences of sadness are described in the usual negative terms: sadness as non-acceptance, sadness as loss, sadness as inadequacy, for example. While these descriptions signal unpleasant emotions for the participants, it therefore seems ironic that there is also a degree of contentment to be found in these expressions. As Heidegger reminds (1962) there is comfort to be found in what is familiar. In the main, people choose to be untroubled while interpreting and understanding their world according to the dominant ethos. I suspect however, that the comfort I recognised in the participants' expressions is indicative of a cultural familiarity with what sadness 'should be'. In many ways I found their expressions of the 'shoulds' to be analogous with Heidegger's (1962) notion of the 'they', and *Dasein's* preponderance to choose the familiar rather than examine new possibilities of meaning. From this position Heidegger proposes that, '... the average everydayness of concern becomes blind to its possibilities, and [consequently] tranquillises itself with that which is merely actual' (p. 239). Such deportment, Heidegger claims, is characterised by a lack of willingness to adventure beyond first impressions and what is seemingly presented and interpreted at face value.

In keeping with this preference for the familiar, much of the dialogue with the participants and myself reveals a discomfort when their sadness is expressed as something positive: that is, aligning with some fleeting belief in the existence of 'happy sadness' or 'sadness as celebration'. Not easily describable, these unfamiliar dimensions of sadness appear to sit on the periphery of our conversation, and subsequently on the edge of the participants' comfort zones. In describing their sadness(es) in unfamiliar ways I suspect from their interrogative tone that the participants were seeking assurance from me as to whether they should be expressing their sadness in these paradoxical ways. Perhaps they were doubting their own intuitiveness, or maybe they felt they needed me (the perceived expert) to say that they were 'correct' in their responses. Nevertheless, their unease to explore or own these unsanctioned expressions of sadness prove to be a sober reminder of Heidegger's proposition that we fall into the comfort of the familiar, rather than struggle with the discomfort of the unfamiliar. In spite of asserting, in most of my introductory statements, that I was not looking for one 'right' answer or one 'reality', the need to question me as to whether or not legitimate answers had been provided was common throughout our conversations.

Akin to the previous chapter I will identify each participant's speech by their pseudonym and code number representing each part of the transcript. Field notes too are itemised as depicted in a prior chapter. In addition, my research journal notes, notes I made while

coding and analysing each portion of each transcript, are entered as memos attached to each itemised node. These memos bear the same numbering system as the nodes used from the NUD•IST program, and will appear in the following chapters as pointers to my own journey through the research and research analysis. Thus, memo 1.14 is a reference to the memo made at the node 1.14 (sadness as loss: a comprehensive list of nodes is referenced in Appendix II). As each rhythm of sadness is proffered I will introduce the remaining participants in this study (those not identified in Chapter Four). I will not be offering the lavish personal descriptions supplied in the preceding chapter. These brief introductions, usually in footnote form, will merely situate the remaining ten participants in their respective areas of palliative care work, plus provide outlines of individual roles and responsibilities.

The participants' stories of sadness are narratives of exposure to their own vulnerability. They relate feelings of being perplexed, sometimes puzzled by the situation that is unfolding before them, sometimes not knowing what to do next. Their inability to move through a particular situation can have the effect of stripping them of their proven efficient and effective ways of negotiating the circumstance. They may feel naked, bereft of their coping strategies, unable to progress. Yet both they and I learn, through their descriptions, how in that nakedness a part of themselves sometimes changes. This change, may be an encounter with learning. We typically associate learning with the gaining of something, however, this is not so for everyone. For example, Monica²⁹ believes that with each sadness experience a part of herself is lost:

I've been quite sad about a lot of people. I think each one that you deal with takes a little chunk of you (12: 379-381).

Acknowledging Monica's feeling of loss I wonder what might be left of this nurse if she continually relinquishes 'chunks' of herself with every patient, with every death? Reminding myself that loss potentiates change, a concept expounded in a previous study (Chapman 1994) I contemplate further this issue. The loss that Monica, and others so readily elaborate, is not permanent. Rather it is a form of exchange, a removal of something, perhaps old but comfortable concepts which are then replaced with new ideas, and different ways of knowing. This ongoing regeneration for me is analogous to the hermeneutic cycle of life itself. This cyclic process is one that enables us to be open to

²⁹ An experienced nurse of twenty six years Monica has been drawn to community health work from a dissatisfaction with nursing within the hospital system. With seventeen years experience in community health and a love for palliative care I was initially disappointed with her seeming lack of response early on in our conversation. As the interview progressed she began to relax and became articulate in her story telling. When the interview concluded however, I left postulating that either she was holding back her emotions for fear of being overwhelmed or I had simply spoken with her on a 'bad day' (fldnts 2:16).

change, to different ways of interpreting what is happening. The familiar gives rise to the unfamiliar which then becomes the familiar, and so on.

“Whose sadness is it anyway”?

My conversations with the sixteen participants reveal that four (Wendy and Vickie, introduced in Chapter Four, and Erica and Louise) commence their discussions by verbalising that they need to be clear about whose sadness they are experiencing. Three of these four participants work together in the community palliative care organisation where demarcation of feelings had been the subject of one of their earlier team meetings (see Wendy’s story). As I speak with these four women I am struck by their need to assure me that they are clear about whether they are experiencing their own sadness, or that of their patients. Recounting Wendy’s reasons for the demarcation, and in thinking further about her poignant stories of sadness (see Chapter Four), I am not convinced that the distinction is as clear cut as she and the others argue:

And ah, into my psyche ever since then I’ve been incredibly aware that if we are going to provide a really high level service, we can’t take on board the sadness of families impending loss and pain, but that is not to deny that there are days I can see staff coming back in and I can tell they’ve been... it’s really been quite torrid (3: 95-113).

It is these ‘torrid’ experiences which construct many of the stories retold in this research. The turgid tone of these stories makes it difficult to identify whose sadness it is. Many of these stories cannot be so easily ascribed to different categories of ‘my sadness’ or ‘their sadness’. In their story-telling the participants cry, hold their heart, shudder, or exhibit facial expressions, which reflect for me their own pain (and mine) while we re-visit each situation. While Wendy, Vickie, Frances and Louise, throughout their stories, attempt to discern who owns the looming feelings of sadness, I begin to realise that achieving this distinction is not only unachievable, it is for the most part, unimportant and unnecessary (memo 1.1.1). To abrogate themselves from the sadness experience they are describing is, I consider, tantamount to seeing themselves as distant observers rather than participants in the meaning making of the sadness situation.

Erica's³⁰ story of Rita is another example of a participant's inability to clearly delineate between 'my' sadness and 'their' sadness. Rita, a personal friend, was pregnant with her second child when her first daughter was killed in a road accident. Rita's marriage was shattered and not long after the birth of her second daughter she and her husband divorced. Nine months later Rita remarries. James, an older man, idolises Rita and they have a child, a little boy. As a family they relocate after they are told that the eldest daughter, now twelve, has leukaemia. Rita and James spend time in their new garden, a form of distraction for them, when suddenly James collapses and dies. Erica responds to what she perceives as the torment of Rita's compounded grief:

It's so sad, she (Rita) had already had to make the decision when to turn the respirator off on her four year old daughter. You wouldn't think that one person could have a life like that (14: 627-630).

Sadness for Rita is coupled with sadness about Rita's circumstances. It is clear from her descriptions that Erica experiences a dilemma. She is unable to distinguish between sadness *for*, and sadness *about*, this particular situation. In a sense Rita's sadness becomes Erica's sadness and is intensified by the nature of the relationship between them. A concept that is developed in the following chapter.

Frances³¹, a community nurse who does not work with Wendy, Vickie or Louise relates her story of Kathleen. Kathleen is a young woman in her mid-thirties, separated from her husband, with a young daughter of eight. Having felt ill for some time she visits her doctor seeking relief from her nausea. Her local doctor prescribes a variety of treatments which are not successful in controlling her symptoms. Finally, and following several invasive tests, a diagnosis of malignant melanoma is proffered. Unfortunately, it is too late to instigate any active treatment as the cancer has metastasised. Kathleen is deemed to be in the end stages of her illness when Frances makes her initial contact.

³⁰ Working for a District Nursing Service located in the outskirts of the city Erica has a passion for palliative care. During our conversation she is very vocal about the misperceptions held by some members of the local community towards the role of nurses in palliative care. Angry that the community palliative care service, a separate body from community health and district nursing, appears to wear all the status and reputation for being the sole palliative care providers, she launches into a scathing attack of the community palliative care service as we begin our conversation. During our time together however, she clearly described her fondness for end of life care and became a little more subdued. Teasing out the sadness buried in her anger becomes challenging for me and by the conclusion of our conversation I left feeling that she was a little less vehement about her colleagues.

³¹ Frances' hours of work (weekends and relief positions) are such that she enjoys a fairly autonomous practice. A young woman and single mother she is engaged in self-growth classes based on Buddhism and Taoism principles. She is currently struggling with her conceptions of sadness and is following a pathway of constructing negative emotions, such as anger and sadness, as positive experiences. During our conversation I found that Frances and I had much in common, including a commitment to the use of complementary therapies in our nursing practice.

The first meeting is difficult for Frances. She too is separated from her partner, and having a young daughter, Frances cannot help but identify with Kathleen. Frances is aware of what she is doing, yet each time Kathleen brings up the issue of leaving her daughter behind after her death Frances wonders what she would do if the tables were turned. This young eight year old child has only recently undergone one separation (from her father) and now she is on the brink of another. Another separation that, for this child, will be so overwhelming, so devastating that Frances cannot bear to think of the consequences. In her wish to help Kathleen, Frances attempts to cope in the only way she knows how and so tries to distance herself from what is happening to herself:

I was focusing on her needs and feelings [rather] than my actual sadness and feelings (11: 215).

It is commendable that Frances recognises that she too has feelings and needs. The dominant discourse within nursing however, is that the effect of these powerful feelings must be held in abeyance for the sake of the patient or their relatives. Frances is well skilled in holding on to her feelings but at the end of the working day Frances returns home. Home to her own children where the sadness of Kathleen's situation again surfaces and Frances contemplates what life might be like for her children without her, without their mother. In reality, Frances is unable to truly distance herself from what is happening.

Working in palliative nursing the participants identified in this section of the chapter face a dilemma about their daily sadnesses. Is it their sadness, or is it my sadness? A constant questioning that is formed within their being-involved in each situation. The sadness of the situation appears to trigger sadness within the participant. Sadness however, does not act *on* the person. Rather, the being of the person is perturbed by their relationship to the meaning making of sadness (Maturana & Varela 1987). Sadness and the person are structurally coupled and its meaning a product of this relationship (Varela 1979). These participants are thus in conflict when they attempt to distance their sadness as belonging to someone else, perhaps from fear of feeling overwhelmed. It is a silent conflict that underlies their daily work. Another temporal rhythm of sadness that ostensibly remains invisible as they become involved in the 'doing' of palliative nursing.

“I wonder what might have been”: Sadness as loss

A character of being human is always Being-towards-the-not-yet (Heidegger 1962, p. 287). The future for Dasein however, is always death, and in palliative nursing this realisation becomes visibly apparent for the participants. Nevertheless, the participants in this study experience being human no differently to other people, and in being immersed in the constant knowledge of a patient's physical deterioration, they too experience 'angst'

or 'dread' about what *is* happening. In its certainty, death presents us with so much uncertainty. So much so that the participants in this study describe their readiness to enter into what might be described as a 'fantasy' of 'what might have been', perhaps with an intention of needing to reverse this uncertainty. Thus, moving constantly between 'what is' and 'what might have been' is, in itself rhythmic and temporal, serving to distract the participants from the sadness of the now, and so defying and prohibiting a resolution of 'what is'.

'What might have been' is a common catch cry from the participants in this study. Couched in terms of loss of potential, these participants wonder what possible futures could have been for many of their patients. Loss of potential is not necessarily attributed to the death of a younger person, although many of the participants recall such stories. Such loss by death Adams (1997, p. 48) reasons, makes us aware of life's fleetingness. In so doing he further contends that because death is such a lonely adventure, its untimeliness however, is sometimes an impetus for generating love.

Loss of potential however, is equally evident when chronic illness establishes itself within a family. Daily routines are disrupted, sometimes appearing to be sabotaged by the unpredictability of the effects of chronic illness. Living becomes limited as some people may cease work and become socially reclusive or shun activity (Mishel 1993). Chronic illness may also lead to changes in body functions and body images. The flowthrough of these alterations of self perceptions can torment the onlooker as much as the sufferer (Levine 1984). Locked in a deteriorating body the patient, and to some extent their carer, invariably apprehend a loss of future as they anticipate the impact that bodily changes have on the remaining life. Life with a chronic illness has the potential to be truncated. With constant reminders of the impact of death on family members, especially children, chronic illness can lead some people to shun, even terminate usual, familiar relationships resulting in a self-enforced isolation for the patient.

This loss of potential, as a result of a debilitating chronic illness, is aptly described by Helen³². Henry, once an educated man has developed complications of his chronic illness, leading to loss of speech, balance and mobility. Helen is deeply saddened as this once articulate man is now unable to readily verbalise his needs, and is rapidly losing other bodily functions to the point of being moribund:

³² Reluctantly, Helen discloses her stories of sadness. She freely admits that she does not want to cry during the interview as she is fearful that once started, her tears may not cease. Having nursed in both metropolitan and rural communities Helen has a soft spot for her 'palliatives' (her term of endearment for dying people on her community nursing rounds).

... well, they were both intellectual people so that took a lot away from their relationship. Umm... with the loss of speech, it was more, it was more a throat affect, so that he could not swallow properly and he would dribble (15: 162-166).

In our conversation Helen ponders over Henry's possible future life in retirement had he not been stricken by chronic illness.

Tanya³³ agonises about 'what might have been' for Jane and her family if only Jane's isolationist behaviour could be modified. Tanya attends Jane during the terminal stages of her illness—cancer of the cervix. Having been treated with radiotherapy and chemotherapy Jane has no hair, is severely wasted and cachectic:

... she had two young children. Her husband um... she kept at arms length because um... I don't know, I guess it was a fear of um... for both of them. It was a fear of loss and she thought that she was hurting them by being so close to them, and they would have to be without her so, I think that's the way she wanted it to be ... She was very much in control of her own disease and how she wanted to be cared for and um... and that she didn't involve us (the palliative care nurses) to a certain extent. ... it sort of saddened me in a way because her, the children and her husband was really upset that she was dying (5: 81-88; 101-105).

Tanya's sadness is twofold. While she recognises the reasons for Jane's behaviour Tanya feels sad when she sees Jane, her husband and children visibly wither as Jane nears death. Gortner (1991) discusses the impact on the quality of life that 'wasting syndrome' can have on a patient and their family. Feelings of guilt or frustration can be experienced by family members as they watch their dying relative presumably starve to death (Brant 1998). Overwhelmed by a perceived lack of control the patient, and often the family members, relegate themselves to a position of powerlessness. Tanya feels certain that if she can change Jane's perceptions of her illness then the family might be able to achieve a closer relationship. Yet, this unnecessary forced seclusion of Jane's has a domino effect of keeping Tanya from also 'getting too close'. Tanya's need to control the situation appears to be thwarted at both levels (memo 1.21).

Parental attachment to a future life for a child begins before the birth of that child and often remains with parents, and other key people, as that child proceeds towards adulthood. Changes to that anticipated future, either by death or chronic illness, can engender deep feelings of guilt within parents (Penson 1990). Western society has a universal expectation that children will be protected from death or serious illness by

³³ Tanya is a new addition to the community palliative care team and I will talk at length about her personal and professional background later in this chapter.

parents, or those who assume a parental role. Thus when chronic illness or death strikes a young child the parents/guardians are often convinced that society will blame them.

Keeping a brave face in adversity, especially when a child in the family is dying, is courageous and commendable. There are families however, where one parent cannot accept that their child is about to die. This lack of acceptance can make communication with that parent challenging and often upsetting for the nurse providing palliative care for the child. The Newbury family has four children; Leo, the eldest, Anna, Sue and Mary the youngest daughter. At the age of thirteen Leo is diagnosed with a brain tumour and Mrs Newbury expresses a desire to care for Leo at home. Enter Erica, who, over time, accepts Mr Newbury's actions of leaving the house, closeting himself in the garden shed, each time she visits the family home. Prior to his illness Leo's future had been decided. He was to take over the family business. Erica asks Leo's mother about her husband's behaviour and she confirms that he cannot bear to think about the impending death of his only son. The pain and trauma becomes overwhelming for Leo's parents and they separate. Erica's sadness regarding the loss of potential is two-fold: she is sad for the Newbury's as they confront daily the loss of their only son, as well as being sad for Mrs Newbury and her daughters who have to contend with the repercussions of losing their husband and father:

... and it was dreadful umm... I mean the child was only twelve, and the poor mum, trying to keep things going on an even keel the whole time (14: 489-491).

Mr Newbury vanishes. Erica believes he too is probably dead. Erica's sadness encompasses feelings of uselessness and hopelessness as she is clearly unable to reach Mr Newbury, a man in distress and great emotional pain, or change the circumstances for all involved in the situation.

As a carer who, in my opinion, readily assumes a vicarious parental role with some of her patients, Kate³⁴ relates her story of the two children and her sadness as a loss of potential for these young people:

³⁴ Kate is a community nurses with the inner city home nursing team. Her interest in palliative care nursing has led her to care for most of the palliative care clients in her case load area. A single mother herself she is fearful of the impact of chronic illness and the ease with which it can change a person's future.

I feel very sad about the situation some people find themselves in. I have got a family that I've had now for seven years in the service. And initially, dad and mum were alive and they were an Italian family and they came out here quite a long time ago and they had two children, a girl and a boy. And on the mantelpiece there are two photos of the boy about fifteen, the girl about ten, and mum and dad. And the girl's just beautiful, the little girl and the boy's just beautiful. The boy had a brain tumour and now is one of our clients. So I followed the family through. Mum died, dad died just before Christmas. Daughter became a schizophrenic and the son had a brain tumour. I have the son and the daughter living in that house in appalling conditions with the food piled up for three months. We get home help in every day but the house is a disgrace. She lies in bed and drinks all day but she doesn't want her brother taken away from her. She's on medication, I mean she really can't manage him but he can't go away. All the services have been put into place to manage them but I still look at the photograph of the two normal kids on the mantelpiece. And now that to me has always made me sad. And whenever I take a student there I say, you know quietly, come and have a look at the photo on the mantelpiece before you become a bit too critical about the chicken bones on the floor, the urine on the floor, the faeces all over the bathroom. Just have a look at the photo because it could happen to you (16: 366-395).

This story can, at first, appear sensational or melodramatic. It is however, an everyday story for Kate and other community nurses who in the course of their work have to intrude on the day-to-day life of their patients. In addition, by being instrumental in changing students' perceptions of disgust into sadness Kate's response is indicative of her need to change the situation, to make something negative appear different.

After visiting the Italian family Kate returns home and with a sense of humility ponders on how 'lucky' she is in life. Lucky to have her own home, her car and other materials things, but most of all lucky to have a daughter who enjoys good health. For me, Kate's story also highlights an *unfairness* that sometimes occurs when chronic illness or death buffets a seemingly 'normal' family, turning their day-to-day existence into disorder or disintegration (memo 1.14).

“It's not fair”: sadness as unfairness

Palliative nursing is abundant with the unthinkable and the unimaginable as untimely disease processes sometimes magnify into undignified and unresolved deaths (Saunders & Valente 1994). Quietly palliative care nurses work away at soothing the distress and turbulence within families as they face the unwanted death of their relative. In helping to resolve these situations of adversity some nurses are consumed by the injustices of the circumstance. In this study sadness as unfairness emerges as another temporal rhythm of sadness that repeatedly looms as part of their experiences, especially in circumstances of unexpected terminal illness.

Joan's³⁵ stories are replete with examples of sadness as unfairness. Attesting to having a set of principles that she uses when visiting dying people Joan emphasises that she prefers to focus on 'living' rather than 'dying':

Every time I get a palliative [patient to visit] ... some people may not approve but I actually sit down and say: Okay, look we've had some bad news, now what are we gonna do about this? Are you going to live whatever time you've got, or are you just going to lie here and die? And I mean, that's straight and um... then I say: Right, well I'm here to help you do the best you can and to keep you comfortable and pain free, and for you to be as honest with me as you can be, and I'll be honest with you (13: 386-395).

I have chosen to retell only one of Joan's stories as I believe this particular story forms a central theme of Joan's experiences of sadness. Throughout our conversation, when she relates other stories, she returns frequently to this story, adding to it, clarifying her thoughts about it and explaining the dynamics of the relationships she has developed with the people in the story. This story is not just an excellent example of the sub-theme—sadness as unfairness, it also reveals the *interconnectedness* between what makes her sad and the people connected to the sad event, which is a feature of the next major theme. While the following narrative is largely my reconstruction I will frequently punctuate Joan's story with her own words.

Lucy is only thirty when she dies and Joan cares for her up to her death. The cancer of the breast has metastasised and she has developed secondaries of the spine. Yet Lucy is a 'brave little woman', married to Charles who just adores her. Joan can see their love for each other each time she visits their home:

... she had a delightful, very devoted young husband um... who was doing everything for her (13: 18-20).

Joan nurses Lucy throughout her illness. On several occasions Joan feels that Lucy is close to death but somehow her spirit rallies, yet she remains very ill. Joan feels a sense of pride as she had assisted Lucy to increase her mobility around the home. However,

³⁵ At the time of our conversation Joan had been a nurse for forty two years. She had worked as a midwife, a researcher for the medical faculty, and was now employed as a generalist community nurse. She is so eager to relate her stories that she volunteers to be part of the study. After leaving a room in the community health centre where Monica and I were talking, Joan is anxiously waiting. Declaring that she has so much to tell me she asks if I am interested to hear about her experiences. I say that I am and motion to make another time for an interview whereupon she begins to tell me her stories. I have little time to find a private space for us to talk or switch on the tape recorder. Conscious of not wanting to arrest the natural flow of her narrative, I do not interrupt to ask her to read the plain language statement and sign the consent form. However, during our conversation I am able to reveal the aims of the study and steer the interview towards drawing out her wealth of sadness experiences. She willingly signs a consent form to be part of this study after our interview session ends.

Joan will not accept all the praise for herself. Charles plays a significant role in Lucy's care. Home renovations are essential for her to be able to move around the house. Among the many changes Charles makes is the installation of a spa bath, as he knows that water provides temporary relief for Lucy's pain. This agonising pain of bone metastases was for Charles, too severe to describe and too painful to watch Lucy endure.

Lucy and Charles live in a hilly suburb of the city. So hilly that it takes both Joan and Charles a lot of skilful manoeuvring to move Lucy from her bedroom down the winding narrow stairs to street level. But between them they manage to do so. Lucy wants to finish her Christmas shopping before she goes into hospital for the bone marrow treatment. Unbeknown to all it was to be Lucy's last outing:

I had her holding on to my arm and I must have been sort of terribly wary because they were very steep sort of hilly um... place and she said: Oh relax Joan, you know. Um... at which we both laughed and I sort of did relax a bit (13: 35-38).

While Lucy knows she might die during the transplant process she wants Charles to visit the specialist Oncologist so he can hear for himself the risks involved. But Charles is adamant, he does not want to see the Oncologist. He does not want to hear that Lucy might die. To him the transplant is just another treatment, one of the treatments with risks that Lucy has taken over the past six years. She has travelled to India to seek treatments from great Gurus. She has swallowed bitter shark oil and other complementary medicines hoping to find a cure for the cancer that seems to have spread so rapidly, so profusely.

Joan is concerned about making Lucy comfortable without letting her know of her own doubts about the success of bone marrow treatments. 'It is a devastating treatment' Joan postulates within, while trying hard to present an accepting manner and listen to Lucy's enthusiastic embrace of a possible remission. Joan cannot help but consider how she has been part of getting Lucy mobile and now she was going to hospital for a treatment that would again confine her to bed. Lucy has spent many months in bed and Joan believes it to be a retrograde step for her to voluntarily return to feeling so ill. 'Still, Lucy is very much in favour of this, and I must support her wishes' says Joan, trying hard to rationalise Lucy's decision within her own mind:

... what saddens me is that I really have got this hang up about... about... I would never want to look after somebody who is going to have a bone marrow graft again (13: 95-97).

Lucy is admitted to hospital for a bone marrow transplant. Charles has a bout of influenza and is unable to visit Lucy while her white cell count is so low. A day later she arrests and dies. She dies without seeing him, without feeling the warmth of his cradling arms. Charles is devastated as is Joan, and although she visits him daily for some time after

Lucy's funeral, her visits are as much for her own benefit as they are for Charles. Joan is Charles' link to Lucy. Joan knew Lucy's body; a tortured body whose memory stays within Charles. Joan knew Lucy's pain, the pain that Charles could not bear to witness, or did not ever see relieved.

The unfairness that Joan expresses in her story is echoed in society's wider view of deaths of young people, people with cancer, people who try to 'battle' against their disease. Yet, for Joan her sadness as unfairness encompasses much more than familiar clichés; stereotypical and superficial reflections that remain removed from the intricacies of the experience as lived. For her it is unfair that Lucy had to endure the painful and devastating procedure of a bone marrow transplant. It is unfair that Charles could not be at Lucy's side as she died. It is unfair that Lucy and Charles's tender relationship ended prematurely, abruptly. During our conversation Joan continues to reproach herself for not being able to change Lucy's mind about going through with the bone marrow transplant:

I mean she would have still been here and she'd still be able to walk up and down the stairs if she hadn't gone and had that treatment (13: 190-192).

... but it just still seems to me that I um... wish I had said, don't do it (13: 273-274).

The faith some patients have in the promise of treatments is misplaced, according to Joan, who speaks from the wisdom of experience. Her encounter with treatments, such as bone marrow transplantation and aggressive chemotherapy for patients with end stage cancer has been that these so called 'miraculous interventions' are injurious, fatiguing and ultimately shorten rather than lengthen life. Joan is not alone with her doubts. Relating the stories of seven survivors of autologous bone marrow/peripheral blood stem cell transplant, Jones and Chapman's (in press) account of a recent study reveals how the participants negotiated their chaotic journeys between life and death.

Joan's story in itself is tragic. Nevertheless, such stories are commonplace in the work of palliative care nurses in the community setting. Many of these stories however, remain untold. Working alone, sometimes in isolation, community palliative care nurses move from one tragic situation to the next with little time to share their grief for the people in the situations they encounter. Sadness accumulates, and much like cumulative grief needs attention before it is deemed dysfunctional (Garfield 1977; Bugen 1980; Kemp 1995).

Recalling the story of Mike, a man in his early fifties who has been diagnosed with prostate cancer, Pauline describes his (and ultimately her) sadness as unfairness. Having retired some three years before his diagnosis Mike had begun to build his 'dream house', a goal that he had worked for many years to achieve. Surrounded by his immediate family

(wife, children and grandchildren) Mike is disconcerted about the changes in his life that he will have to make following diagnosis and treatment:

He had worked so hard for so long... he loved this opportunity and he wanted to enjoy his grandchildren... and this was, this exciting enjoyable phase of his life. And I always felt, I almost grieved with him for what he had missed out on (9: 407, 411, 414-416).

The perceived unfairness of this situation, coupled with Mike's loss of future impacts on Pauline as she too has recently recovered from an illness which threatened to prematurely truncate her own life.

In the cases of Vickie, Tanya and Monica their experiences of sadness as unfairness are linked to either the death of children or the impact of parental death on children. Monica's story concerns the plight of an elderly woman whose daughter was dying of cancer. The dying woman has an eight year old daughter—Alice. Each day the elderly woman, Alice's grandmother, takes and collects her to and from school. During conversations with the grandmother Monica recalls how she comments on the unfairness of Alice's situation:

And she [the grandmother] said: I go and pick Alice up from school and I just think it's so wrong. I see all these young mothers with their children. It's so wrong that it's me picking her up. It should be her mum. I thought God, that's right. It's those little things (12: 417-422).

When a child is terminally ill or dies, feelings of guilt and inadequacy almost always emerge as the role of protector is 'snatched' away from the parents. Feeling abandoned themselves, parents often have to rally following the death of their child to make practical decisions about their child's funeral. Our Western society dictates that funeral events are dealt with quickly. Such practices can be bewildering for parents. Most parents expect to die before their children thus, to bury one's own child is not customary and can be a difficult subject to broach. It can be extremely distressing for the parents to witness their child's body being taken away. Firstly, to an undertaker and secondly, during the funeral ceremony. Many of the participants in my study are themselves parents, some having very young children. Vickie remonstrates that burying a child is tragic and unfair:

And you know I mean I guess that's just the unfairness of you know a child. A mother having to bury, well you know, parents having to bury their child (6: 214-216).

In a powerful exposé of mother's grief Cline (1995) describes the unimaginable and unthinkable terror of what it is like for mothers to lose their child. 'Because the natural order is to precede our child in death, it is the feeling that it is an 'unnatural act' which is

the most disturbing element' (p. 163). Death of a child invokes immediate and unparalleled changes to a family's structure.

Recalling the death of another young woman Tanya suggests that it is unfair when loving families are challenged by the hurt and anguish brought about by death. Rebecca shows no outward visible signs of dying. She is not cachectic, or wasted. And despite having aggressive chemotherapy she manages to keep her hair. Tanya visits Rebecca in the final stages of her life:

... and when I looked at her and she was unconscious and obviously in the very end stages, she looked like she was asleep. She had a daughter, who she left behind and yeah that was particularly sad (5: 114-117).

Tanya also remarks on the tragedy of losing a child, pronouncing that the death of a child, regardless of their age, is sad:

... if I were the parent of a dying child, I mean, even though she was thirty five, she was still their daughter and they... they were losing a daughter, and I picture myself in that situation. I think losing a child would be one of the hardest things you could ever... ever go through (5: 163-167).

Tanya's sadness goes beyond the unfairness of the death event and burial of a child. Her stories, like those of some participants are abundant with the concept of sadness as identification.

“There but for fortune...”: Sadness as identification

As community palliative care nurses the participants in this study freely respond to some patients in ways that could be appreciated as over-involvement (Morse 1991; Barthow 1997). Recognition of sharing similarities in life is a natural bonding that brings people closer together, cements friendships or even builds life-long relationships. Identification with a patient's circumstance, such as being a mother, or being in the same age group and having young school-age children are just some of the similarities the participants designate as sad. Thus sadness as identification is played out as another temporal rhythm that springs forth from the connectedness of the participants to some patients or relatives in their care.

The sadness of the dying person's situation seems to emerge when Tanya places herself in the shoes of the dying person—the other. At first glance this positioning could perhaps be mistaken for, or brushed aside as an empathetic response. While empathy is a sensitive and valuable response from a nurse I surmise that Tanya's descriptions epitomise and embody her own feelings about dying:

I guess in some situations you're actually coming to terms with your own mortality and that we can um... and not only your own but that of your family and how you would deal with that um... situation. Um... I mean, you can't help but do that even though you're working with dying people all the time. Um... you know... I mean some people you can just sort of look after and I guess the older people, even though some of those can be upsetting and sad but um... often when someone's older you accept it more readily and I guess its... a lot of that is to do with how a person is accepting of their own... of their own death... their own death. I think the sadness for me is... some situations can be incredibly sad but... I think for me it's been likening that situation to my own situation (5: 185-200).

The similarity of the situations that these participants identify with ignites their imagination and they ask themselves the question 'what if that person [the patient/relative] were me?' Along similar lines, Frances and Monica indicate that their patients may resemble members of their own family, or they may be living in matching circumstances to their own:

Leaving young families ... yes I have a young family (12: 52)

... people that actually you can relate to. Whether people actually are like your father or your mother or your grandmother or your um... yes so normally it's usually that you can fit them into your life situation I guess, and the children (11: 13-18).

And another case, a woman who had breast cancer and she died umm... leaving one child that they had. Umm... I wasn't closely involved with her but I did relate to her for... because she was about the same age as what I was, and the children. So I guess it sends you into revealing your own life and looking at what's happening in your own life and umm... and umm... how you would deal with that situation if that arose and, life experience I guess (11: 294-304).

When family circumstances, especially in bereavement, mirror the lives of the nurse Penson (1990, p. 164) claims that it is not always easy for the nurse to remain outwardly 'in control'. An expectation of most bereaved people is that the person assuming the role of the carer (nurse) will be able to keep control of themselves while they (the bereaved family) grieve openly. It is evident from the data in this study that in providing assistance to others, nurses may resent having to 'put on a front' and in doing so hide their own, often deeply painful, feelings. Frances verbalises how she works through some of those contradictory feelings:

... but I think it [sadness] comes out in other ways I guess. You know, like I probably end up feeling stressed and umm... may be angry or may be bury it underneath something else (11: 43-46).

When asked to expand on her descriptions of sadness as identification, Frances says:

... there was one, one lady that was quite quite recently actually, who had a daughter and she was separated which I have done as well, and um... just yeah dealing with her, her grief and her feelings I could relate to her quite well (11: 31-34).

Frances continues to relate the story of Kathleen (as outlined earlier) yet her descriptions are punctuated with almost paradoxical messages about sadness itself and what her responses 'should' be. In her self-development classes Frances' ideas about emotions are challenged to such an extent that she now believes that she views sadness in ways which are in opposition to most people. Her stories are fraught with her own struggle to free herself of anything negative, while at the same time she wrestles with her ability to openly acknowledge the sadness of her patients:

I feel sad you know. And then I do cry, right there and then. Its been quite a difference from that point of view. So probably whilst I was looking at Kathleen um... I was aware, aware of all her issues 'cos they were... a lot of them were quite similar to probably to what I would have been feeling in the same position as her. But I um... at the same time, sort of saw her need to be... treat her not as a sick person (11: 190-198).

'Sadness as identification' for Frances is not a static, debilitating experience. Rather, sadness associated with palliative care nursing is provoking for Frances. It is a chance for her to be forewarned of situations and alternative ways in which she might be able to respond:

I see what we experience whilst working with these sorts of people as a learning experience also, so it's valuable for us. "Cos we see, you know, things like, you know... Oh gee, I don't want to be doing this when I'm ra, ra, ra, or gee I must watch for that or... You can see issues in other people which maybe relate to you in some way (11: 242-248).

Youll (1996) notes that nurses are 'incredible' in their caring for bereaved people. This seemingly extraordinary position is addressed by Marck (1990) in her landmark article which discusses the phenomenon of 'therapeutic reciprocity'. Shared control, mutual responsibility and accountability are the hallmarks of therapeutic reciprocity. There is no doubt that therapeutic reciprocity exists in many of the relationships between some participants in this study and selected people in their stories. Joan and Charles, for example, enter into a continuing reciprocal relationship in which they are able to mourn Lucy's death. I suggest however, that an exchange or sharing in the context of sadness does not always lend itself to being therapeutic.

In the following chapter sadness as identification is elaborated within the discussion of the nurse-patient relationship and extended to include aspects of kinship sadness. For the most part sadness as identification is a rumbling temporal rhythm of sadness that when acknowledged can be marred with feelings of guilt for some participants. Guilt associated

with over-stepping the limits or boundaries of the nurse-patient interaction so frequently set in concrete by policies of policy makers who are not an integral part of the practice setting (May 1990).

“It shouldn’t have been like this”: Sadness as failed expectations or mismanagement

Sadness may well pose as an active form of appeal, implicitly or explicitly expressed, highlighting situations of mismanagement or apparent mistakes. Armed with the treatise to ‘... walk in the world of another’(Jones 1993, p. 504), nurses are nevertheless often reticent to question their contemporaries about perceived injustices, especially when reciprocal exchanges between colleagues can be seen as the ‘glue’ that binds people in kinship (Tousignant & Maldonado 1989). In the world of nursing, where it is expected that professional experiences can be shared, in part for supportive purposes, it can be difficult to articulate the sadness brought about by the perception that others have failed to deliver appropriate treatment. In many instances nothing is said directly to the person, although a culture of the ‘tea room whinge’ prevails. Participants in this study report that they practice selective mutism rather than risk being at odds with colleagues. Thus sadness as failed expectations or mismanagement is often an occult rhythm of sadness that appears to fester beneath the surface.

Nurses involved in providing palliative care often carry an idealised expectation of what they want to achieve in any given situation. Expectations that have largely developed from a palliative care history, based in hospice, which demands that the care delivered will result in outcomes such as a ‘good’ or ‘dignified’ death. This ideal however, does not always match the situation in which these community palliative care nurses find themselves. These nurses are with patients who live in less than idealised conditions. They may be surrounded by the effects of poverty, poor hygiene and inadequate housing. The rubric of ‘good palliative care’ in effect becomes a misnomer. However, some sense of palliative care nursing ‘idealism’ prevails. Consequently, nurses in this study often describe feeling sad when brought face-to-face with the concept of ‘failed expectations’.

Planning care for the patient and their family involves forward thinking, isolating priorities and goal setting. However in palliative care, goals are often unachievable and if they are, the time in which to accomplish such actions is truncated. Dying does not follow a well organised and predictable timeline, and what seems attainable one day may be thwarted by a sudden change in a patient’s condition, or the rapid onset of an immanent death. Reassessing or revaluation of actions for the family group may be shelved as the realistic goal posts appear to move with alarming speed. Often the lack of time, coupled with the urgencies and immediacies of care do not permit palliative care nurses to pass the

problem on to the person on the next shift. Patient centred care becomes the only possible focus for the palliative care nurse. The nurses in this study advise that it is a difficult balancing act trying to help patients set realistic, achievable goals within short timeframes. Moving the expectations of success from what is desired to what is practicable is one strategy that may help minimise the feelings of failure within the nurse (memo 1.7).

Relapse in a patient's condition can be a difficult period for Rose. She acknowledges however, that while this change in a person's condition is sad it should be remembered that in cases of terminal disease relapses are to be expected:

Apart from death there's also the sadness when people relapse. When they've actually umm... been through hell and high water and it may be only a few months or it may be a year or may be two years. Like today I've got a young girl who relapsed after having a bone marrow transplant. So you really, you feel that sadness but you can't... it doesn't take over your life. Umm... because if it did, number one, you shouldn't be in the field I think, but number two, you couldn't survive, and just occasionally it's overwhelming (8: 110-119).

Palliative care can be said to create a space in which to die, although at times, active treatment may occur up to the time of death. Long term palliation creates a space for the death journey to develop, supporting a movement towards some acceptance of the situation. On the other hand, active treatment up to the moment of death can often negate the unfolding of the dying trajectory (memo 1.8). Bridging the curative-palliative approaches to care is a contemporary issue that has received recent attention in the literature (Prior 1998). Much of the debate is centred around planned care where time is abundant, and to some extent disease processes insidious. In cases of rapidly proliferating cancers however, the time between diagnosis and death may contract to such a small window of opportunity that palliative care principles can be overlooked. Zena³⁶ recollects the story of a close friend. Fearing that her friend's care is being mismanaged she declares that she has not only failed as an effective advocate, but she has also failed in her role as an understanding friend:

I watched her very quick disease process. It was three months from the diagnosis of cancer until she died. But for me it was very hard and that was a very angry, gut-wrenching feeling because I had to be her friend, not her nurse. And I felt, looking back, she was mismanaged. I mean in some ways I think, because treatment

³⁶ As a transient member of the community palliative care team Zena speaks with me just prior to leaving for another state. With a background in community health nursing she had worked with the team on a number of occasions as a casual or holiday relief employee. A quietly spoken woman, she speaks generously about her sadness as a palliative care nurse. She likens each patient to a Christmas present, in that each time she visits a person she finds she will always receive something new and different from them.

continued until two days before she died that she never had the opportunity really to have palliation. She just moved through continual active treatment and to watch her, because she was very sick with the chemotherapy and radiotherapy, she kept... she was constantly sick. So, for three months she spent most of that time in hospital (4: 329-341).

Believing herself to be a change agent, a person who can legitimately make a difference, Zena's sadness is compounded when she cannot live up to her expectations of self. Zena experiences inertia, stemming partially from being unable to do anything for her friend, but mostly from the realisation that her expectations about care have not been met (memo 1.7.1):

... being a palliative care nurse, you always want what's best (4: 388).

I warrant however, that Zena is not alone in her story. The anguish she describes is indicative of many nurses who are caught within the paternalistic values that surround our health care system. It is often impossible for nurses to serve two masters simultaneously: the patient, and the treatment pronounced by medical personnel as appropriate. Like Zena, many nurses are thrust into a state of inactivity, fearing that 'speaking out' will be perceived to be at best, meddlesome, or at worst, whistleblowing.

Failure to achieve her professional hopes and dreams is a rationale of sadness for Monica. Usually triggered by an awareness of unfinished business, or the incompleteness of self-initiated resolutions, she often blames herself for failing to keep promises to the patients within her palliative care. Fuelled by the death of the person to whom she has made these assurances, and subsequently not honoured them, she begins to feel guilty about her perceived inadequacies. Realising she has high expectations of herself, Monica however believes that possession of such expectations is warranted in end of life care (memo 1.7):

I've had quite a few tears over the years I suppose. Umm... also if I felt that umm... guilty I suppose. Like if someone's gone into hospital I've been thinking yes, yes I will go and see them, and I don't get round to it and they die. I feel sad 'cos it's not finished (12: 75-80).

Having high expectations is not limited to some participants' views of themselves. Similar feelings of discontent are directed towards others involved in providing care to patients. The health care system in general, disappointment with responses from members of a community where a particular patient is domiciled, and the perceived limitations of new graduates are just some areas of concern identified by the participants in this study.

The inadequacies of newly graduated nursing staff is the target of Vickie's 'frustrating' sadness. Unclear about the difference between sadness and frustration she berates novice nurses for their inability to move beyond the negativity of death and dying situations.

Vickie suggests that there are many positive benefits for both patients who receive palliative care and the staff who work them (memo 1.7.1):

Umm, you know I think the other sadnesses that I feel. I don't know if this is a sadness that I feel, I don't know if this is a sadness or frustration, is that umm yeah [slowly and deliberately] I think I feel, I feel sad sometimes about the quality of the nurses we have that can't give that care that's needed. [Quietly and aside] Naar, that sounds a bit stupid but, it's often sad sometimes when I look at nurses and I think, crikey look I've been doing this for thirty years and loved every day of it. You know, just give a bit more and you'll get a lot back (6: 227-236).

The participants' ability to stay with patients who are suffering extensive and sometimes unyielding pain, demands that nurses engaged in palliative care assemble their compassion, humanitarian and ethical perspectives so they may effectively 'partner' patients and become a healing instruments in themselves (Just 1998).

I contend that nurses' abilities in developing profound relationships is as much a result of their many years of attendance at the 'university of life' (life experience), where their practical wisdom can be nurtured, as from skills gleaned from attending a recognised learning institution. I am not suggesting that all newly graduated nurses are not effective in end of life care. My personal experiences attest to the contrary. I am arguing however, that the expectation of being able to 'place old heads on young shoulders' is impractical, unrealistic and meaningless in an area of nursing that is replete with complex encounters. Practical experiences that, for nurses who do not embrace the concept of 'connectedness' (Chapman 1994), may seem forbidding, even laborious. This proposition is sustained to some degree by the calibre of most participants in this study. All of the nurses are experienced, not only in end of life or community based care, but also have significant, and sometimes relevant life experiences, that contribute greatly to the tenor of their nurse-patient relationships. However, a counter argument lurks behind these assertions. 'Old heads' can sometimes foster static practice, a situation of conflict described by many of the participants in this study.

The benefits of having experienced nursing staff on board in a palliative care health professional group are difficult to oppose. Their experience enables them to remain responsive to the many difficult and often complex situations encountered in this milieu. Nevertheless, 'old heads' may also be resistant to change.

A circumstance that brings considerable sadness for Yvonne³⁷. She suggests that some of her nursing colleagues do not value their own potential or that of nursing as a profession:

Umm... you see I mean talking about sort of sadness in practice, another way... I was looking at it yesterday and thinking about it umm... I see quite a lot of sadness in the fact that nurses are not taking advantage of what they can actually do and what is on offer at the moment. Umm... I see so many of my colleagues who are not taking advantage of the opportunities to promote themselves as nurses, as well as the nursing profession. Umm... I see them sort of stuck in old ideas and old models. Umm... and just not prepared and not able to get out of that (2: 442-450).

It is not only nursing colleagues that may be found wanting. In one of Sally's stories she recounts her interaction with a General Practitioner who she has to continually engage in the doctor-nurse game (MacKay, Matsuno et al. 1991) in order to deliver the kind of quality care that she deems is necessary for the patient:

I get very sad, potentiated by frustration, when you are up against, and it has always been a General Practitioner who hasn't kept up those current trends and who you know isn't providing what could be the optimum in symptom control ... and you're trying to pussy foot around without blatantly being specific (saying) 'what you're giving isn't right—don't keep on giving them morphine, there are other drugs you could be using' and you know that the patient is suffering needlessly (7: 849-859).

Sally asserts that she does not believe she has more knowledge than the doctor yet, because of her involvement in palliative care practices, the completion of a post-graduate diploma in cancer care, and her many years of experience within the same community, she does have an advantage of both local and specific knowledge that may be some cause of tension in their relationship.

Health care system failure, especially provision of or access to community funding that can facilitate the concept of a 'good death' is verbalised as a sadness by Louise³⁸. Frustrated and saddened by the budgetary constraints of the system, Louise submits that she would ideally like people to be able to choose how and where they die. She implies

³⁷ Recently graduated from a post graduate course that focuses on care of the cancer patient Yvonne is prolific in her descriptions of sadness, especially when she converges on her perceptions of sadness in the workplace. Yvonne is a woman in the mid-life who has progressively moved from community nursing to specialise in palliative care in the community setting. Her rapid speech makes it difficult for me to keep pace with some of her ideas however, on listening to her tape and re-reading the transcript I believe that Yvonne engages in a process of reflection-in-action as we converse.

³⁸ A middle aged woman Louise has a wealth of experience in community palliative care. Currently undertaking a Masters degree in palliative care she coordinates the educational staff development activities for the community palliative care team. With a flair for working with dying children she speaks without encumbrance about her experiences of sadness in her work.

however, that changes (decreases) in future funding for community palliative care services will dictate that dying at home may not be a viable option for many patients. She proposes that a lot of home care is reliant on the resilience of family members and so sometimes they need more help from community services than the community services are funded to give (memo 1.7.1):

I see situations where, perhaps with more services or money, I mean people could actually die exactly the way they want rather than perhaps be admitted to hospital or into a nursing home or... Maybe that's fairly naturalistic and not very realistic but you know, you've got again old people who are with us about six to eight weeks of their life and they've got to be in an institution when they'd much rather be at home. If they could have more help at home, but that's just not, not available, so their choices are just not there. That can be sad (1: 220-231).

'System' problems, suggests Vachon (1987), are long lasting and outlive many palliative care patients. She further elaborates, somewhat tongue in cheek, that if all the palliative patients were miraculously cured overnight, the system problems would most likely remain. Subsequently, system problems may only compound the sadness already experienced by the palliative care nurse, and the stress of dealing with dying patients may decrease the level of tolerance for sadnesses generated by system problems—a 'catch 22' enigma.

Louise mentions an example of a ninety four year old man who wants desperately to stay in his artist studio and potter around until he dies. He becomes so ill that he is unable to be left at home. Placed into a palliative care unit, he is cared for by expert nurses. He is not however, in the environment of his choice. He is not in the place where he wants to die. Yet there is no immediate family to care for him and the community services are unable to generate enough funds to provide the twenty-four hour care necessary for him to stay at home, so he remains in the hospice:

He was a delightful, delightful man, incredibly talented artist. His whole life revolved around his art, even up to a few weeks ago, was quite prolific in most of his drawing. But over the last few weeks he became so frail, he couldn't stay at home alone, and so he's been in the palliative care unit, beautifully cared for, but he can't potter out to his little workshop, even though it might have been only five, ten minutes a day. But that was his life... It's still sad to think that somebody's... he's lived such an incredibly, fruitfully productive life. In the last few weeks really he's (been) denied that access or form of access, even if he couldn't do it (1: 237-246; 251-254).

Balancing the needs of the patient against the available resources can be a constant, but covert source of ethical and moral dilemmas for the palliative care nurse. A cornerstone of good palliative care practice is communication (White 1998a). Communication that occurs, not only between nurse and patient but also within the multidisciplinary team as

well as at various political levels. Without significant representation from nurses, engaged in palliative care work at the grass-roots level, in the policy decision-making forums, the needs, wants and desires of those receiving palliative care can be effectively whitewashed in favour of a system that answers to the call of some other master such as economic rationalism.

The final sadness in this sub-theme is again expressed by Sally. Working in a small rural community she is saddened by a powerful ostracism displayed by one particular group of inhabitants:

One of the things that saddened me was that normally within this community people ask how's so and so and very few people asked me (about a particular patient) because she wasn't a particularly nice person... person within the community. I didn't have any problems with her, but anyway. It made... that made me sad too, the fact that people can put (others) into compartments and can judge umm... judge whether or not they give empathy, and caring. To me I would have thought that illness broke down those boundaries and I felt very sad seeing the trauma that the daughter was going through because she insisted on nursing her mother at home, and she didn't have much help (7: 266-282).

It is not enough, in Sally's opinion, for relatives or the nurse to shoulder the impact of caring for the dying person. In small and sometimes isolated communities support from 'outsiders' can be the only support mechanism available for the dying person and their family. When it is not forthcoming, as in Sally's example, the sadness of the situation intensifies, adding to the distress experienced by the carer. Feelings of isolation and aloneness compound the sadness which Sally can also readily identify within herself. Without support from others these negative perceptions of self may manifest themselves as helplessness and hopelessness. The complexity of crises that may advance from end of life care can ultimately seem insurmountable.

This particular temporal rhythm of sadness moves beyond, yet impacts heavily on, the nurse-patient relationship. A relationship that is made with the promise of professionally fulfilling and sustaining outcomes for both nurse and patient (Barthow 1997). Yet these participants discern that sometimes these outcomes are blocked by individuals or a system that fails to 'deliver the goods'. Health care personnel whose practice is steeped in recovery-oriented treatments can compound the problem and perhaps inadvertently set the scene for failure. There are no easy solutions to such situations and the temporal rhythm of sadness as failed expectations or mismanagement, as a clandestine posture, serves to explicate the quandary.

“I feel lost!”: Sadness as hopelessness

Feelings of inertia expressed in the previous sub-theme carry over to the sadnesses identified as hopelessness in this section of the analysis. Needless to say this particular rhythm of sadness is not always present in the palliative nursing milieu as it stems mainly from feelings of failure when a therapeutic relationship is not achieved (Barthow 1997). Inability to function as an effective palliative care nurse because of unfamiliarity with the multidisciplinary team processes, total despair of witnessing a dying situation, or the predicament of not being able to contribute any meaningful actions of care as an illness progresses are all forms of sadness as hopelessness for some participants.

Tanya contemplates her role as the newest member of the palliative care team. She states that the team has conflicts, although infrequently, when she feels defeated by the realisation that she is unable to ‘fix’ the disharmony:

It [team conflict] doesn't happen that often. There are some things of course, we all say things and do things that someone else doesn't agree with. It's sad for me, knowing that you cannot do anything to help (5: 437-440).

A marked feature of our conversation together is Tanya's apparent need to control or fix situations. This compulsion is somewhat paradoxical when considering the professed flexible nature of palliative care (Hodder & Turley 1989; Parker & Aranda 1998). Palliative care is riddled with uncertainty where definitive answers are antithetical to its nature. There is however, a need within some individuals to control the uncontrollable. With respect to death, Heidegger (1962) asserts that our ‘angst’ is almost subliminal, yet we go to extraordinary lengths to seek some sense of order in the disorder that surrounds it.

The hopelessness experienced by Sally is verified in her stories of being witness to a patient's death. Their hopelessness becomes her helplessness as she inwardly reaches out to the families yet physically holds back, not wanting to halt their grieving or their crying by placing her arms around them. She realises that the despair and hurt is also indicative of the intensity of the love they feel and want to share with the patient at the moment of death:

... a family sadness and that... that feeling of hopelessness that they are feeling and that oh... I really felt it, this, yesterday, and you must have done Ysanne, that like a part of you has gone and I can see that in them, and you... you want to be able to say... and words just don't fill up that void when they've got that awful emptiness (7: 245-251).

... its hopelessness, it's the total despair that they feel and... and you can see that, that lifeline being cut. It's as though they've been going along suddenly the... the lifebelt's been taken away from them (7: 463-468).

... and you can see it in their [the relatives] faces and the way they move, their actions. Um... after their... their displays of love for the person whose died and it grips me... make me feel... yeah. I can't describe it to you (7: 480-484).

When there is nothing else that can be done for a patient, and the care given belies even the best that palliative care can offer, is when Nadine feels the most sad. Like Sally she describes the pain of witnessing both outward and inward deterioration of a person's body:

... the cruelty of the disease, actually watching that particular person. Umm... just physically I mean. That, that's an enormous sadness, anyway it can be... it just looks so cruel, towards the end (10: 156-159).

... he was just skeletal, you know umm... got to the stage of incontinence and everything, still mentally alert, umm... all the time, all the way through. Umm... you know there were skin lesions, all those things that are very displeasing, umm... which all broke down. Yes so, he was very unpleasant to look at umm... at that stage, and he was aware of that (10: 164-170).

Suffering manifests itself in patients with cancer in ways other than pain (Just 1998, p. 58). The dimensions of suffering are created by each individual according to their life experience and prior knowledge of what suffering means to them. Physical and spiritual losses are what most people interpret as suffering in cancer care. However, fear of suffering itself may impact on the pain of suffering and fear has been shown to increase pain perception (Just 1998). Nurses involved in delivering palliative care are skilled in discerning the difference between pain associated with the spread of disease and pain expressed as suffering. Nevertheless, when pain (from whatever source) is deemed intractable by both the patient and the health professional, not even an acknowledgment that there is nothing that can be done will lessen the feelings of sadness as hopelessness.

This gut wrenching, raw sadness manifests itself for Zena when she feels useless in the situation where nothing can be done for the patient and the outcome of the disease or dying process is unclear:

For me, the gut wrenching, the sick feeling, the anger, they really tear at your heart. You can just feel your insides being ripped apart. It's a definite emotional feeling. It's an absolute. It's hard to describe. It's just that gut wrenching feeling and it's the situations where I can't... I feel inadequate that I can't do anything about what's happening to this person (4: 160-166).

Nevertheless palliative care nurses continue to 'stay' in these hopeless situations, sometimes employing a kind of 'compassionate silence' (Just 1998, p. 64) in which the patient and their nurse are honoured for their strength and resilience. This connectedness (Chapman 1994), this bond, signals to patients and their relatives that the palliative care nurse will not go away, will not leave them desolate and alone, when others are becoming conspicuously absent.

“I've got a sick sense of humour”: Sadness as black comedy

Although this study identifies sadness as its main discussion point I am astonished by the frequency with which the participants recess into humour as they relate their responses to some of their stories. Often used as a release the black humour described by the participants is not the usual gallows humour reflecting an attempt to minimise or gain a sense of mastery over the circumstances in which they find themselves. Rather, it is a timely interlude that places incomprehensible possibilities into a more manageable perspective. Wendy recapitulates:

Ahh... we come across amazing scenes in palliative care and there is no doubt the sharp wit is sometimes almost providing all along the edge. If someone was walking by and heard it would be so dreadfully offensive and mostly black if it was out of context but, it's really only part of dealing with the constancy of it (3: 205-211).

Wendy's overt description of how the staff in the palliative care team utilise humour to relieve their own stressful situations is supported, albeit scantily, in the literature (Mills, Reisler et al. 1976; Katz & Sidell 1994). The use of humour in nursing is a well established ritual 'for normalising a terrifying situation' (Sherman 1994, p. 128). I agree with Goleman's (1996) belief that laughter provides a sense of creativity to finding solutions for a problem, as well as helping people to think broadly and notice relationships that might otherwise have eluded them. We can all appreciate the way in which humour reduces stress, provides a way to relieve tension, anxiety, hostility and sometimes anger. As a defence mechanism humour may distance the person from a stressful situation, creating a space, possibly to gain a different perspective or insight, or providing temporary relief from the intensity of the problem. Monica identifies humour as her way of achieving some semblance of balance in sad situations:

I've got a really sick sense of humour. And I think a lot of nurses have (12: 148-149).

Many of Sally's stories, some not involving sadness, feature the 'characters' whom she regularly encounters on her daily rounds as a community nurse. Housed in rural and remote communities these folk are obviously special for Sally. Her stories of their peculiarities are overflowing with humour. These humorous stories emerge throughout our conversation, perhaps as a conscious, or unconscious diversion from the intensities of her other stories of physical suffering and emotional pain. So often terminal illness is revered as being above laughter and humour. For Sally, nursing people in a small and close knit community who have a terminal illness needs her involvement as a whole person. A significant part of Sally's demeanour is her friendliness through laughter. Notwithstanding her recognition of the pain suffered by terminal patients, Sally seems able to locate a special time in her practice when she and the person, or their family, are able to lift themselves out of despair by a joke, or a funny incident:

A dear, dear old chap, he died last June last year. His birthday was close to mine so I always used to go out for lunch and he always used to say "Sis, it's your shout" and I'd say, "It's my shout" and we'd get to the pub and we'd have a meal, and he never let me pay. So last year it was my shout, so I said "It's gonna be my shout!" but he died just before his birthday so it never was my shout. I used to have to go in the garden with him and check the raspberries and check the chooks and this day I said to him "Where did you get that bantam from?" And he said, "Don't know, free loader he is". I said, "But you don't normally have a rooster?". He said, "No". So I said, "is he any good?" And he said, "He's no bloody good!" So anyway a few weeks later I said, "see that little rooster, any joy?" And he said "too bloody right!". I said, "How does he get up on the chooks?" and he said, "They scoop a bit of dirt out and they lie down and he hops on". So I thought well, fair enough. I said, "You'll be having chickens soon". The next week I went there, opened the 'fridge door and there on a plate was this little corpse, bantam... the bantam rooster. I said, "Why did you do that?" He said, "Too bloody randy!" I said, "Well what are you going to do with it?" "I'm gonna eat it" he said, "are you staying for lunch?" (7: 1709-1739).

As the participants tell their stories, the humour that is released is inclined, in part, to offset the intrinsic tragedies of their stories. Additionally, these humorous interludes tend to bind the participant and myself together, promoting a sense of kinship whereby we can both recognise the fearfulness attached to some of the sadness occasions.

Changing the expected discourse of death from one of morbidity to something exciting, perhaps comic is, according to Cline (1995, p. 321) '... an attempt to lift the taboo around death'. Changing the ambience however, does not ignore or dilute the powerful negative emotions that may accompany any loss. The temporal rhythm of sadness as humour can transform the standard approach to suffering and death, through creating a space of comfort in which spiritual searches and enrichment of the lives of the bereaved and the carers can be inaugurated. Humour in the face of death is also described as a release and

'... a great leveller in that it treats us all alike and confronts us with the fact that there are no exemptions from the human predicament' (DeSpelder & Strickland 1992, p. 26). In this study, sadness as humour is used as a momentary device to relieve the emotional pain or defuse some of the anxiety attributed to terminal illness or death.

“We salute you”: Sadness as reverence or celebration

In the following chapter the participants will speak of their privileged encounters with patients receiving palliative care. Before revealing these accounts however, it seems suitable to relate the penultimate and powerful sub-theme of the temporal rhythms of sadness, namely sadness as reverence or celebration. Integral to many of the relationships between the participants and their patients is a concept of admiration. The participants describe paying homage or honouring patients or their relatives for their courage to face the often difficult circumstances that surround them during their palliative care and journey towards death.

For Vickie it is an ordinary man who *'tugged at her hearts strings'* (6: 127). According to Vickie he is *'... just a bloke, one of life's battlers'* (6: 115). She remembers knowing him for about ten months:

When I first met him he was umm, quite shy, and umm, he'd been in a lot of pain and he was distraught about his diagnosis because he was going to leave his girls. His wife and his girls. And he just struck me as being a lovely fella, you know. ... And to say it was his ordinariness sounds awful, but there was nothing outstanding about this guy but he was just a thoroughly nice person, you know, that had probably never done a nasty thing in his life (6: 121-125; 128-131).

The concept of ordinariness as it relates to nursing is described by Taylor (1994a, p. 34) as 'notions of nurses and patients within caring relationships' and is reaffirmed by Pearson's words from a 1988 graduation ceremony :

Most of us [nurses] are engaged in the process of helping people every day, often without any conscious awareness of 'being helpful'. The foundation of genuine helping lies in being ordinary. Nothing special. We can offer ourselves, neither more nor less, to others—we have in fact nothing else to give (cited in (Taylor 1994a, p. 33).

Vickie recognises her patient's ordinariness because she can equate with him as a person. She genuinely becomes close to him, and feels 'at home' in caring for him in her non-possessive manner. There is a sense of humility in Vickie's remembrance of this man. A humility that also concedes the difficulties that are apparent in his dying. A humility that captures admiration for the man as he faces death. Yet to those outside nursing, the

ordinariness of circumstances such as the one Vickie describes can often be perceived as extraordinary.

Kübler-Ross' (1978) work *To Live Until We Say Goodbye* is abundant with stories from 'ordinary people' who are dying. Like Vickie, Kübler-Ross gained insight into the lives of dying people, listening, not to the interpretations of health professionals and others, but to the thoughts of the dying people and their concerns about dying. Vickie, in her unique manner of being an 'ordinary nurse' is able to achieve a closeness that leads her to understand when the man in her story is about to hit 'rock bottom'. In her appreciation of the circumstance, Vickie is able to walk alongside him rather than distancing herself from his worries and concerns about his family after his death. Omission of negative judgmental statements are rare within relationships however, in the connection between Vickie and the patient in her story, her appraisals are abundant.

Appreciation of sadness as courage to be revered is also reflected in Kate's story of Sarah. Sarah's husband has cancer of the lung and is being cared for at home with the assistance of the community health team to which Kate belongs. Kate is given a referral to an elderly lady with end stage cancer of the bowel. On arriving at the woman's home Kate ascertains that this lady is Sarah's mother. Upset that Sarah now has to care for her mother as well as her husband Kate praises Sarah's ability to cope with the impending loss of two significantly important people in her life:

... the daughter [Sarah] makes me feel so humble in that she does everything. Everything for her husband and her kids and her mother who lives next door. And she's probably one of the... it's the most supportive network I've ever met ... Sometimes what I see as good in other people, good in inverted commas, make me feel sad. There are some people out there who are amazing (16: 503-507; 517-520).

Not all family courage however, is deemed authentic or beneficial by some participants. Nadine, implies that the concept of erroneous courage is neither honourable or creditable to any of the people concerned with the plight of a dying person. Although she understands and appreciates that some family members, and indeed some dying patients need to 'put on a brave face' in front of a dying patient or family, she also admits that, as the person who listens to both the patient and their family she is the person who usually bears the brunt of their unexpressed sadnesses:

... families, especially families spend their time to be terribly terribly cheerful at all times and then, as soon as they're out of the room or with you, it's where they're more likely to express their own sadnesses. It's the same with the person that's actually dying too. They will, they spend their time saying, you know, everything's fine, I'm fine, until their family go out of the room. So usually in those cases you have two lots of sadness to actually

take on board which yeah, I think that's that's the struggle (10: 124-133).

Working in palliative care it is difficult to ignore the spiritual dimensions which emerge as part of nursing work (Harrington in progress). Kübler-Ross (1974) expounds that medicine and faith must work together, especially in end of life care. However, she adds that 'one must not exclude the other' (p. 162). Truly religious people, Kübler Ross (1974, p. 163) suggests, find it easier to face death with peace of mind. Nevertheless there are exceptions and Kate's story about Gerry recalls her respect for his capacity to be equanimous even though his lack of religious beliefs is seemingly foreign to her.

Kate initially calls on Gerry twice a week. At the beginning of his disease—cancer of the lung—he is ambulant and while Gerry does not need palliative care at that stage Kate visits him to assess the progress of his disease and to purposefully begin to form a relationship with him and his wife. Gerry lives with his wife. They do not have any children. Kate remembers their conversation:

And I didn't quite know whether he was putting on a front for me. If everything was as rosy as he made out. I went into the bathroom one day and he had a shower and he had a shave so I guess I thought it was a personal sort of time ... and he said "I'm not frightened you know" So I went "oh"[thinking] what will I say here. I felt the tears running up in my eyes and I said "umm... what do you believe happens?" Thinking to myself, how is it that you are behaving like you are. I've never met anybody who is so accepting and so lovely to everybody. There's no anger, no denial, there's no anything that I've read in the text books. Why haven't you got it? And he said, "Well I don't believe in God". And I went "Oh". And he said "Well there wouldn't be" what were his words, "wouldn't be a God, because of all the bad things that happen in the world". "But" he said, "I don't mind, it doesn't matter" (16: 219-235).

Kate comments further that she is confounded by his belief, or rather lack of belief, in a higher power and that she even commends him for having such staunch convictions. In a sense Gerry is defining his own spirituality which does not involve the usual aspirations of faith (memo 1.26). Kübler-Ross (1974, p. 162) asserts: '[it] is not what you believe, but *how* truly and genuinely you believe'. Thus for Gerry his unbelieving serves as his truth, and it is his conviction and courage in this lack of faith that summons sadness within Kate, a sadness she values and respects:

... and I felt terribly sad because that brings up feelings within us obviously about our own beliefs. And he was so strong and staunch about that you know. He didn't mind dying. He wasn't scared. And he did die at home. And actually he died about two days after that (16: 236-241).

Remembering the loving and caring that families give to the dying person are, according to Joan, reflected in some of the obituaries that she regularly reads in the local paper.

While Joan suspects some of the opinions expressed in these endorsements may be fallacies:

... you read through them and you'll see periodically, without, practically without fail, you'll see this great screed of names and things and you've known that they've been real sods and they haven't indic... you know, shown any compassion or concern at all for the person umm... and then you'll see the little one, where quietly there's been total devotion and self sacrifice. I find it unbelievable (13: 456-463).

Many of these sentiments are a source of sadness for her, yet a sadness that is frequently tinged with reverence and appreciation.

“It’s okay to feel like this”: sadness as healthy and healing

The last sub-theme of this section is almost a return to an interpretation of sadness as sanctioned by the wider society. Most participants overtly authorise sadness as part of palliative nursing work. In believing that sadness also builds a sense of closure in bereavement the Palawa people embarked on a assignment to retrieve the bones of their ancestors. ‘... [T]he spirits of the Old Ones who had returned, roamed among the people, embracing us all, subduing us with a healing sadness’ (Lehman 1997, p. 231). In our conversations Kate and Frances also describe sadness as healthy or healing.

Sadness for Kate is an integral part of her work as a nurse. She endorses the idea of outwardly demonstrating sadness (crying) in front of patients or their family. A conduct also ratified by Kübler-Ross (1974, p. 106):

Yes, I have cried with my patients. Sometimes I have tears in my eyes when I sense this is my last visit with a patient I have cared for for a long time. I do not feel that it is unprofessional to have tears in your eyes. It is not a question of not having worked through enough of your own feelings; it is rather a question of how much you are willing to share your own humanness.

To cry or not to cry when feeling sad in the company of a patient and their family is an issue for Zena. While she agrees that crying is a natural release and response to her sadness she is encumbered by the thoughts and attitudes of others who openly disagree with nurses showing their emotions. Zena is caught between what she wants to do and what she thinks she ought to do:

I mean sometimes you shed a few tears. That's good and umm... I often shed tears. At funerals I'm pretty hopeless but I'm getting there (4: 611-613)

Believing there are many types of sadness, Zena describes her concept of ‘calm’ sadness. The type of sadness that occurs when all parties involved in the care of the dying patient

accept the consequences of what is happening. Yet, in spite of the ambience of acceptance in these moments Zena, conscious of the love that surrounds such situations is also aware of how easily that love can turn to a deep sorrow when a patient dies:

... they share a lot with you, the family. So that's sort of sad, seeing the love feeling of not being able to see them again. It's sad to see the family as they're grieving. But it's a very quiet type of sadness (4: 146-149).

Concerned that there may be nurses who work in palliative care who do not express feelings of sadness Kate ponders:

I find that it's [being sad] really healthy because I'd be pretty worried if I thought that we were working in the area that we do work in and we didn't feel sad at some time. And even if they didn't ever tell anyone else, or did have a cry in their car, or they did feel momentarily sad about some situation they'd found themselves in in somebody's home, I'd be a bit worried. I think it's a pretty important part of our work (16: 634-642).

Sadness is identified as a healing emotion by Frances. In her spare time Frances is completing a course that considers emotion as the basis of disease and she has worked through some of her own negative emotions, such as anger, believing that release of the blocked energy can invoke a healing response:

I see it [sadness] as a umm... as a healing thing, more so than a..., more so than a negative. I actually find that when I deal with sadness now I can actually see beauty in it as well, you know, see an actual healing of sadness and umm... the expression of sadness is not something which is a negative, as is something which is um... positive in lots of ways (11: 99-105).

So for me now like, it was just like yesterday I was feeling sad, I burst into tears and then I thought well, this just feels so great. Like this is beautiful. So I actually see the other side of it (11: 157-160).

In her own search for poise and stability Kate appears to be in agreement with the teachings of the Dalai Lama (cited in Saron & Davidson 1997, p. 87) who claims, among other things, that equanimity is not necessarily restful. Instead, conscious equanimity is a state that can happen once a pervasive sense of compassion is realised (memo 1.33).

Conclusion

In this chapter I have re-told many of the participants' experiences of sadness. For me, these experiences embrace more than a simple description of what makes them sad. By telling their stories their sadnesses are already contextualised. Thus sadness is not, and

cannot be objectified. The 'what' of sadness is embedded in the participants' practices, the people they meet and the places they visit.

Sadness in these stories is embodied, and thus integral to their experiences. The participants are not just sad about, or sad for something or someone. In telling their stories they become the sadnesses they describe. This incarnate sadness, assumes many guises; anger, frustration, guilt, humour, hopelessness and happiness. Comprehensive of their work, a rhythm of sadness is ever present, and in so being, sadness is dynamic, temporal and ever changing. Sadness and experience cannot be separated. In sharing their experiences of sadness the participants distinguish many aspects of themselves, as well as orchestrating the many rhythms of sadness.

Elucidating the musical metaphor evoked in this thesis, for me the participants have described their sadnesses as rhythms made by the 'tympani' within an orchestra. An orchestra who in this thesis plays a symphony of sadness. Ever present, these base rhythms take on differing tones, pitches and intensities. Some sadnesses are loud and brash like the sound of a snare drum; such is the rhythm of sadness as hopelessness and uselessness. Other sadnesses, not so overt, give forth soft, sometimes inaudible sound, similar to the brush work on a cymbal; sadness as reverence is perhaps a good example. These rhythms of sadness colour the whole symphony and in their temporality they become the sonorous undertones that pervade the entire composition.

Throughout this chapter I have alluded to a sense of connectedness that these temporal rhythms of sadness have with the people (in relationship) from which they emerge. The following chapter, entitled 'Kinship sadness', offers some insights into the nature and quality of relationships experienced by the participants in their work as palliative care nurses.

Chapter Six

Kinship Sadness

*A Sacred Kinship I would not forego
Binds me to all that breathes*
(Boyesen)

Introduction

The temporal rhythms of sadness arise from, are intensified and sustained by, the ‘melodies’ held within ‘kinship sadness’; melodies that arise from the networked relationships that the participants in this study make with the people they encounter during the course of their nursing work. To me the ‘melodies’ in this thesis are the participants’ descriptions and my subsequent interpretations, of how sadness emerges within and from a relationship, a kinship formed between the participants and other people they mention in the study. ‘Kinship’ in this thesis is used metaphorically, developed from and out of ‘scientific’ and ‘anthropological’ meanings of the term. Meanings such as familial, affinal, connection and shared history are parts of a non-genealogical kinship relationship that exists between the myriad of people involved with the participants in their everydayness of palliative care nursing. The people, identified by the participants, include: the patients; their relatives, friends or lovers; nursing colleagues and other members of the community palliative care team, and the participants’ immediate family/friends (memo 19). In their relationships with others the participants and those with whom they relate form a community. A community which is, in the case of this study, bound together by invisible threads of sadness.

According to Nicholson (1985, p. 25) a sense of community or kinship in theosophical terms is ‘... not an ideal to be achieved, but a reality, an expression of the unity which pervades all life at every level’. The notion of a ‘universal kinship’ first articulated by Moore (1916) describes the existence of a homology between all living things. Steeped in zoological concerns Moore’s thesis was controversial, as at the time of his writing, the superiority of the human species was a taken for granted assumption. Ideas about human beings having a shared relationship with plants and animals were mocked or ridiculed. In spite of opposition from a large section of the scientific community Moore persisted in developing his proposition and the notion of a ‘universal kinship’ from a scientific perspective was seeded. Understanding universal connections is integral to the beliefs of

the Zen Buddhist tradition. Vietnamese Zen Buddhist master Thich Nhat Hānh³⁹ relates a beautiful story (entitled Interbeing) about how connections between human beings and nature can be understood:

If you are a poet, you will see clearly that there is a cloud floating in this sheet of paper. Without a cloud, there will be no rain; without rain, the trees cannot grow; and without trees, we cannot make paper. The cloud is essential for the paper to exist. If the cloud is not here, the sheet of paper cannot be here either. So we can say that the cloud and the paper *inter-are*. ... If we look into this sheet of paper even more deeply, we can see the sunshine in it. Without sunshine, the forest cannot grow. In fact, nothing can grow without sunshine. And so, we know that the sunshine is also in this sheet of paper. The paper and the sunshine *inter-are*. And if we continue to look, we can see the logger who cut the tree and brought it to the mill to be transformed into paper. And we see wheat. We know that the logger cannot exist without his daily bread, and therefore the wheat that became his bread is also in this sheet of paper. The logger's father and mother are in it too. When we look in this way, we see that without all these things, this sheet of paper cannot exist. Looking even more deeply, we can see ourselves in this sheet of paper too. This is not difficult to see, because when we look at a sheet of paper, it is part of our perception. Your mind is in here and mine is also. So we can say that everything is in here with this sheet of paper. We cannot point out one thing that is not here— time, space, the earth, the rain, the minerals in the soil, the sunshine, the cloud, the river, the heat. Everything co-exists with this sheet of paper (Hanh 1995, p. 95).

The conceptualisation of the universe as an interconnected web has been colonised in Western thought principally by the explanations found in Bohm's (1951) quantum physics. Bohm's theory, it has been suggested, was a catalyst for modern constructivists' ideas (Capra 1982). From an ecological viewpoint, central terms of a concept of kinship such as 'interconnection' and 'oneness' are supported by eminent constructivists including cognitive biologists (Maturana & Varela 1987; Varela, Thompson et al. 1992), anthropologists (Bateson 1972) and physicists (Capra 1997). The notion of 'interconnection' however, is a difficult concept for many people to grasp as our Western society has invested in the counter theories of objectivity, individualism and separation. Yet, as this thesis has already illuminated, there is another way of reflecting upon ourselves and our world(s). An alternate mode of knowing that does not separate the knower from the known, the subject from the object:

³⁹ Thich Nhat Hanh, has been a Buddhist monk for over forty years. Also a poet and peace activist he founded the School of Youth for Social Service ("the little peace corps") in Vietnam. He was nominated by Martin Luther King Jr for the Nobel Peace Prize in 1967. Unable to return to Vietnam following an overseas tour which began in 1966 he received asylum in France. He lives in Plum Village, a small community in France, where he teaches, writes, gardens and assists refugees worldwide (Hahn 1995, p. 135).

We constantly share and interact with each other on all levels. Though each of us is a unique individual, we make up one humanity, our divisions into groups and nations are less fundamental than our oneness. Through history we have identified with larger and larger units—first family and tribe, then leagues of tribes, city-states, nations, at first small, later including super-powers (Nicholson 1985, p. 30).

This idea of connectedness is not new but it is often unfathomable in a world that activity practises and embraces the concept of dichotomy: an either or stance. In nursing for instance, we have held on to the distinctive notions of nursing as an art or as a science. Very few nursing leaders have embraced the reality of the connectedness of the two to form a creative energy that in turn bridges art and science (Rose & Marks-Maran 1997). Following the idea of a universal linkage, the knowledge that these participants have about sadness comes from what they know about themselves in relationship with other (their patients and in this research, myself). Also, through dialoguing in and with this thesis we (the participants through my reconstruction of their texts, myself as author and interpreter, and the reader) are in a conversational relationship, partaking of ‘kinship sadness’ as reinterpreted by each reader. It is important here to remember that by conversations I do not mean conversation as object. Conversation, as previously articulated, relates to the notion of *con versare*, or ‘turning together’.

On the other hand traditional anthropological kinship models reflect various laws or codes including: the Parentela Orders found in Judaism and Classical Athens; Civil Law which dates from Ancient Rome, and Canon Law. These principles and rules, which primarily govern succession to property, emerged in the late Medieval period. These somewhat austere conceptualisations of kinship have largely remained unchallenged, possibly because they assist to stabilise social relations within certain segments of society (Farber 1981). There is nevertheless, another way of thinking about kinship, and that is as a metaphor of social structure in terms of spatiality. Kinship can be described in relation to its ‘proximal’ component—physical distance, socio-emotional distance and genealogical distance (Schneider 1968).

Interpretation of kinship from a spatial dimension is well understood in nursing. It has long been appreciated amongst nursing theorists that nurse-patient-relative relationships can be of a similar quality to the close and personal relationships that may flourish within families. The qualities of this relationship have, deservedly, attracted voluminous discussion in the nursing literature. Nursing theorists, (Peplau 1952; Travelbee 1966; Paterson & Zderad 1988; Watson 1985 & Benner 1984 for example) feature the nurse-patient relationship as their foundation stone from which their theories spring forth. In taking differing perspectives they provide diverse and interesting interpretations of ‘what

is' composite of the nurse-patient relationship. For many of these nursing theorists care and caring systems are central themes of the nurse-patient relationship.

In terms of caring networks, kinship is a term inclusive of the spiritual, emotional, social and physical support of others. The common, accepted meaning of kinship however, embraces a familial message and can also be interpreted as such in this thesis. The people described by each participant are brought together by a common goal or theme, that of palliative nursing. As either recipients or givers of care all the 'players' are immersed within a 'community' of palliative nursing. In addition, many of the nurses in this study suggest that by the nature and intimacy of their work they are often considered by the patient and their relatives to be included as part of their family. Kinship in this instance extends beyond the immediate family to incorporate the nurse, therefore, members of this newly formed extended family recognise each other as 'kin'. Allan (1979, p. 140), appraising of the links between friendship and kinship, suggests that '[t]he more non-kin are thought of and labelled 'true friends', the more the symbolism of kinship is used to describe them'. Not all nurse-patient-relative(s) relationships however have a 'kinship' quality. Nevertheless, in this study the relationships from which the different anthologies of sadness emerge have been described by the participants as 'special' or 'unique'. Indeed, Sarvimaki (1988, p. 465) maintains that '... nursing consists of interactions between unique individuals with unique experiences, and always takes place in unique situations'. And it is from within an understanding of the participants and their patients/relatives as forming a 'kinship community' that the stories about 'kinship sadness' spring forth.

In Chapter One I recalled various 'interaction' constructs of nursing theorists such as Peplau (1952) and Travelbee (1966). However, these same nursing theorists tend to focus on an 'ideal' of nursing rather than the 'experience' of nurses. Paterson and Zderad (1988) are quite possibly the first nursing theorists to describe the work of nurses through the dialogue of nurses themselves. Using phenomenology and existential philosophy they state that '... nursing is an experience lived between two human beings' (Paterson & Zderad 1988, p. 3). Concerned with the lived dialogue of both nurse and patient Paterson and Zderad (1988, p. 23) focus on the '*plane of between*'. Giving the example of 'comfort', they acknowledge that a nurse has an experience of giving comfort and a patient an experience of receiving comfort. However, while each person experiences something within themselves Paterson and Zderad (1988, p. 14) profess that they also experience '... something of the between, namely the message or meaning of the comforting/comforted process'. Further clarifying the notions of 'being with' as favouring a qualitative stance, and 'doing with' as facilitating a more quantitative position Paterson and Zderad (1988, p. 14) suggest that the former (being with) requires nurses to

be 'open to the here and now of the shared situation', a form of intersubjective lived dialogue where the voice of the nurse is as important as the voice of the other (patient/relative/colleague).

In this thesis I have come to understand the nature of the relationship between the participants and others as a form of compassion, in part stemming from their realisation of sharing an awareness of suffering. Being responsive and entering into the space of another's suffering and not going away is the backbone of some 'kinship' relationships. Much is shared within the relationships described by the participants in this study. Sharing and honouring their partnerships (Just 1998) with their patients, the participants sometimes become instruments of healing for themselves as well as others.

While feeling slightly uneasy about 'unpacking' the notion of kinship sadness, given that I have argued earlier in this chapter for creating and maintaining some semblance of universal wholeness, I present several compartments (melodies) of the concept, namely kinship sadness discerned, reflected, shared, witnessed and released. I hasten to add however, that by describing the actions of kinship sadness in this manner I am presenting different dimensions of sadness rather than an objectification of what it means to be sad for palliative care nurses. In this fashion the distinctive dimensions of 'kinship sadness' are reminiscent of the temporal rhythms of sadness (Chapter Five), in that they may be experienced individually or simultaneously, and form parts and wholes of the sadness experience for the participants in this study. In each explication of kinship sadness I am cognisant of the participants' whole stories. Like holograms, these parts (thematic interpretations) provide glimpses of the whole, and conversely by being 'in conversation' with the whole, the parts become visible.

Thus far I have spoken of the notion of 'kinship sadness' as being present in every interaction between the participants and their patients/relatives. I would not however be reflective of the data if I was to leave you with this supposition. In our dialogue together some of the participants questioned themselves, and most subsequently explained, about why they were sad in some situations of their work and not others. While recognising that Western society, in the main, has adopted an epistemology of separation, represented by a duality of 'that' and 'this' Bateson (1979) cautions that in talking about the world as being made up of separable parts is largely a seduction of language, which in turn leads to a way of describing the world out of notions of difference rather than acknowledging the interrelationships between 'this' and 'that'. Thus the distinctions in this chapter are offered, not in an attempt to sort or divide, but to emphasise that any attempt to separate is, in itself, another connection (Bateson 1972; Flemons 1991).

“Why some people and not others?”: kinship sadness discerned

It could be argued that posing a question of ‘why some and not others’ is antithetical to the central tenet of this thesis. I doubt that finding an answer to the question ‘why am I not sad in some situations?’ will change the circumstances where sadness is integral to the relationship. Conversely, finding an answer to the question ‘why am I sad in some situations?’ will not inform the initial question posed. Yet the need to differentiate, compare and contrast is an integral part of our culture and processes. Thus, I have decided to include in this thesis, some discussion of the distinction. The ‘why’ was not so much a search for an answer but a means of extending the participants’ meaning making and of experiencing a deeper understanding of sadness. By engaging with four participants’ descriptions of their practice (Yvonne, Vickie, Tanya & Helen) where the ‘why’ question became the focus, I moved beyond my thoughts of the futility of the question, and in so doing caught glimpses of the richness of kinship sadness to be described further in the sub-themes of this chapter (memo 1.12).

Before talking with Yvonne she describes how she contemplates our time together and in that moment of pre-reflection she realises that what ever she tries to rehearse will dissipate from the time of her pre-reflection to when we were scheduled to meet (in her particular case, eight hours of her working day). Letting go of what her responses might be she ponders on the question of ‘why some and not others’:

... it's been quite amazing, I don't quite know why some people actually make you more sad than others (2: 227-229).

In relating her stories Yvonne did not address the question again yet, she describes her ‘love’ of palliative care as being attributed to the opulence of her relationships with the people (the patients and their families or friends) whom she meets. She speaks of satisfaction in being able to make a difference with some patients, and of intuitive responses, many of which she is not conscious at the time, but that are deemed important and valuable by the people she visits:

... it's really the people. Part of it that I think that umm... yeah I know I am making a difference. Umm... I'm not making a difference so much is for me but I have found that umm... I have made a difference for them. And quite, the most significant times have been when I thought well, I don't see that I've been doing anything in particular, I feel I really just, I probably felt that I haven't been doing enough, but you get the feedback that you have done, you've made a very important contribution (2: 116-126).

In one of her stories Yvonne emphasises that it is the people who make the experience significant. Frank, a seventy six year old Polish man, had a large proliferating tumour of the lung. He was married to Doris (her second marriage) a registered nurse who trained several years before Yvonne. Yvonne describes Doris as '*one of the old fashioned sort of registered nurses*' (2: 150). Yet as a mature woman herself Yvonne can identify with some of the 'old fashioned' practices valued by Doris and they develop a friendship. So much so that Doris, surmises Yvonne, almost hangs off her every word:

... she felt as though I had some sort of inner knowledge of what was going on with Frank (2: 184).

Prior to Frank's unexpected death Yvonne had spent time with Doris and Frank helping them reminisce about their life together. They spoke about the times they had spent travelling and what had been happy for them when Frank was well. Although Yvonne claims that she had no idea that Frank would die suddenly she observes her own capabilities and prophetic insight of knowing when the time is right to do the right thing (memo 26). A practice that Paterson and Zderad (1988) might call humanistic nursing:

To me, a nurse is a being, becoming through intersubjectively calling and responding to her suffering, joyous, struggling, chaotic humanness, always trying beyond the possible while never completely free from ignoble personal human wants (Paterson and Zderad 1988, p. 56).

Being in-tune with another, whether sadness is a part of the process or not, is pivotal to Yvonne's practice as a community palliative care nurse. Thus for Yvonne, the question of why some situations seem sad and others do not, remains unanswered if viewed from the context of sadness alone.

When patients require palliative care and choose to stay at home is when Helen, a generalist community nurse, feels her most significant sadness. Helen stays with her dying patients when they are in the end stages of their terminal illness, becoming an extension of the family unit. Embarrassed by the outcome of one patient's death she recalls how she became the person who needed comforting:

And I didn't think I'd have any hassle with this [the death of the patient] until I went in to see him, and that was the end of me. And she [wife of the dead man] was the one who ended up comforting me. She was the one who put the arms around me, and I just... I just found that a bit, a bit strange that I should be the one being comforted (15: 67-72).

Posing the question herself about why this particular situation was sad for her she affirms that it is the quality of relationship with some people that sets the stage for her emotions:

It's just a closeness that you build up with some people (15: 77-78).

At least half of the patients requiring palliative care from Helen do not remain at home to die. Many are admitted to the city hospice, some to the surrounding general hospitals. While Helen recognises her own pain when she witnesses terminally ill patients leaving their home, this pain is off-set by a hope that the patient's choice to be admitted to an institution to die is firstly, their own, and secondly, made with a hope that the staff in the hospice/hospital/nursing home would be able to provide an appropriate ambience for that person's death. Thus for Helen, witnessing the death of a patient requiring palliative care with whom she has shared a friendship, a meaningful relationship, is fertile ground for her sadness (memo 1.10).

On the other hand, Tanya's rationalisation of why she feels sad in some situations and not others is not easily explained:

I don't know why... why I feel the way I do, but I'm just trying to sort of umm... work out why... why is one particular situation sad for me and not the other (5: 151-153).

In a previous chapter I have described how Tanya distinguishes her sadness as identification with young, female patients needing palliative nursing. Her sadness is also exacerbated by the knowledge of parents, at any age, having to bury their children, and situations of untimely deaths. In struggling for an answer to the question 'why some and not others', I was aware that Tanya was perhaps searching for a sense of 'grounding' in her practice world. A practice world that is replete with uncertainty, complexity and at times confusion:

Umm... well I suppose I turn sad by being in a position of feeling hopeless. Umm... and you're looking after a patient and you don't seem to be getting anywhere (5: 57-59).

These four participants act of reflection tends to make pregnant their self-initiated question 'why some and not others' and Vickie's response is couched in terms of recognising meaning in nurse-patient relationships. At first glance it might be argued that her responses raise issues of identification, transference and counter-transference (Morse 1991). However, as she continues to talk I become aware that she is already analysing her own behaviour believing herself to be in a connected relationship with the particular patient:

I don't know why it's different. I've often thought about it. Is it because I was involved? And it wasn't every AIDS patient. No it wasn't every AIDS patient. Ah. And I've often wondered what it

is. What is it that makes someone different that I'm going to be involved with. Sometimes it's um, it may be a younger person sometimes. Sometimes it's just someone that you suddenly click with and you think I really like that person you know. Umm, there may be a lot of similarities in their life to your own life and so during the course of caring for that person you have to be constantly reminding yourself, listen you know, this could be you, but it's not you. So, you know, be quite clear. But you know inevitably you'll sort of... um that sadness is you know... here is a young mother, she's the same age as me, she not going to see her children grow up, she's... you know. It's just putting yourself in her shoes (6: 69-85).

The personality 'click' is, according to Morse (1991), a first stage assessment mechanism that nurses use in negotiating nurse-patient relationships. Establishing common ground, mutual appeal and requiring special needs are three further qualities Morse (1991) identifies as characteristics of a connected relationship. I understand Vickie's identification with a patient to embrace all three qualities suggested by Morse, and more, as is evidenced by her stories retold in Chapter Four.

This study and my previous research highlights that there is no firm demarcation line between what is a connected relationship and what could be identified as over involvement according to the model outlined by Morse (1991). Each relationship between the participants and the patients in their stories are unique and very different from each other. Vickie's sense of connecting with one family may not be the same as what she shares with another family. Yet both may be classified, using Morse's criteria, as 'connected relationships' and some as 'over involved'. For me, Vickie's situation emphasises that classification does little more than attach a label to a situation. For me, it does not explain or make meaning from that situation. Vickie is nevertheless clear, that it is from a sense of identification, connection or involvement when sadness in her work is made apparent. That connection however, is not a necessary sequelae of a relationship established over a long period of time. A sense of sharing, connection or kinship may occur in the passing of a moment.

“I've been in your shoes”: kinship sadness reflected

Some participants describe their own personal illnesses and loss or grieving situations as contributory to being able to place themselves 'in the shoes of the other'. Turning towards themselves in our dialogue Kate, Rose, Pauline and Sally pay attention to their own personal sadnesses. This notion of turning back on one's own experience is understood by social constructionists as reflexivity (Steier 1991). The participants' self-referenced sadness experiences inform their social constructions of sadness as palliative care nurses. The personal is the professional, and the professional is the personal, it is a circular process (memo 3). From their standpoint of describing 'lived sadness' rather than from a

detachment of 'observed sadness', the four participants retell stories of their own sadness from out of the commonalities they share with the people for whom they care.

In turn, through a reflective process of recognising their own sadness experiences the participants use these experiences as markers from which to inform their professional selves about the sadness experiences in their work as palliative care nurses. In telling their own stories they shift positions between their personal and professional relationships, move back and forth between conversations of their personal and professional experiences, melding and shaping them into an elaborate mesh of sadness.

Three weeks before our conversation the mother of Kate's best friend died. Kate recounts the story from the telephone call she receives from her friend early one morning. Her friend, Clare, a General Practitioner, was holding her dead mother's hand when Kate arrived at the hospital. Kate had known Clare's mother for many years. She and Clare had spent a lot of time together in their youth. They grew up in the same city, went to the same schools, watched the birth of each other's children. They have been firm friends since childhood.

In spite of their friendship Kate could not grieve for Clare's mother when she first saw Clare at the hospital. Not immediately anyway as Clare needed her to be the strong one, the organiser, the listener and the clarifier. With an appearance of control Kate helped Clare make the funeral arrangements. At all times Kate was alert to not taking over, not assuming the responsibility for Clare's decisions. It was Clare's mother who had died, not Kate's, and Clare would have to live with the decisions made at this chaotic time. Hard decisions to make, thought Kate, when grieving the loss of your most significant role model as a woman. A situation of recent experience for Kate, as her own mother had died in tragic circumstances just a little over twelve months ago.

After the funeral arrangements were made Kate's thoughts turned to Clare and what she could possibly do to acknowledge Clare's grief; to show Clare that she had some inkling about what she was going through. Kate suddenly had an idea. Some years ago they used to run together to keep fit:

I looked at her and thought she was just going to crash. And I said "let's go for a run?". And she said okay. And we went up into the bush at the top of (name of suburb). We went for a run. And I looked at her and she said "this is great". She didn't say anything else and that was all I needed to know (16: 687-690).

Kate's choice of activity was peculiar to her knowledge of Clare and her knowledge of herself. Running for both Clare and Kate was a way of letting go, and in this occasion a way of letting go of their individual, yet shared, sadness. A sadness in and of kinship.

Kate continues to spend time with her friend, and by listening and accepting Clare's sadness Kate not only sanctions Clare's grief but also creates the space for her own grief to be acknowledged, a grief associated with both Clare's mother and her own mother's death. Their shared sadness adds another dimension to their kinship.

All experience arises in the present, does its dance and disappears. Experience comes into being only tentatively, for a little time in a certain form (in the case of this thesis as the many dimensions/forms of sadness); one form ends and is replaced by a new form, moment by moment. Describing her many experiences of sadness Rose recalls sadnesses experienced from her own personal life (memo 3). Having endured a permanent, physical deformity since birth Rose is sensitive and responsive to sadness associated with her own loss:

I've experienced a lot of bereavement in my own life too, and I am sure that helps me cope with the sadness of other things (8: 108-109).

Pointing to the many connections she makes with others in their sadness Rose illuminates for me that through experiencing tormented circumstances in their personal lives, nurses can gain some insight(s) into the anguish and suffering of others:

... somewhere along the way I changed from that person that worried to the other person, and I think that's how you help, help the, with all these other kinds of umm... crisis really, that you're able to [know] within yourself. Yes I think your past experiences really come into play to make you able to cope. And as I said it doesn't make you any less sad, but it's being able to cope with the sadness that's important (8: 236-242).

While none of Rose's patients have Rose's disfigurement, she can appreciate others suffering and sadness by acknowledging a 'sameness' about their descriptions of feelings. Rose's familiar responses to her own suffering (sadness) is triggered by others who appear to be also suffering. Her own problems and sorrows, as in Buddhist beliefs, become the very place from which she can discover her wisdom and her strength to give to others.

A respect for others, and valuing that experience as individual and unique is recognised, revered and evidenced by Sally's story of Joe and Jill (for a more detailed account of this story see Chapter Four). On the day before our conversation together Sally kept an appointment with Joe, a person suffering terminal cancer. During her visit Sally recognises that Joe is becoming increasingly melancholic about his death that seems to be approaching rapidly. He makes a comment to Sally that nobody knows how he and his

wife feel. Sally knowingly responds, thinking about her own father's death and her feelings of loneliness and isolation:

... and he did say to me yesterday, nobody knows how it feels until you get there and he said to me, others don't understand what you're trying to tell them. And I did something that I don't usually do, I said, "I think I probably understand a little of what your family feel because I have been through that process when I was probably a lot younger than your children". And he started to ask me about my father and how old I was and how old my father was and what he had died of. And in fact my father died of lung cancer too and he asked about it, about pain because this chap's got pain and we were trying to get it managed and umm... I didn't like going into my father's pain which was... I could never forget that (7: 167-179).

In feeling comfortable to be open about her own pain and suffering within a professional situation Sally's sense of kinship with the patient, with the patient's illness and with the suffering felt by the patient's family, is articulated (memo 3.3).

The shared situation does not necessarily have to correspond, it is within the response that kinship dwells and is nurtured. Such affinity is the basis of most Australian Aboriginal social order (Radcliffe-Brown 1971; Falkenberg & Falkenberg 1981). Kinship is understood in Australian Aboriginal culture as coming together in strong solidarity regardless of genealogy. Nevertheless, Radcliffe-Brown (1971) does establish a genealogical reasoning to the notion that most men within a tribe are known as 'brothers' despite disparate differences in parentage. In deference to Radcliffe-Brown, Hammel (1965) rebukes the relevancy of genealogy as inherent in kinship, submitting that as a concept kinship is an 'affinal' relationship. Sally's declaration of affinity towards her patient and his family not only reminds Sally of her own personal sadness about the loss of her father, it transports her from the trauma of seeing her father die in pain to the realisation that pain control nowadays has the possibility to be effective.

In Chapter Four I retell some of Pauline's stories and in concluding I mention briefly that she has suffered her own personal sadness, the death of her mother and her own life threatening illness. It is from these personal, frightful experiences of sadness that I gain a strong sense of Pauline's kinship for others in her care. In particular, one story about her mother's illness speaks loudly of Pauline's values for wholistic care in terminal illness: of going that extra mile for her patients.

Her mother's condition had deteriorated making nursing her at home impractical and impossible for Pauline's father. When visiting her mother in hospital Pauline was stopped at the ward desk and told by the in-charge nurse that her mother was becoming aggressive, outspoken and saying 'nasty things' to the staff. Pauline asked the nurse what

the staff had done about this change in her mother's behaviour. 'Oh nothing' replied the nurse.

On visiting her mother Pauline notices that she is pulling at the bed clothes and wriggling in the bed. After trying to communicate with her mother she determines that her mother is in pain. Pauline promptly telephones the physician, suggesting to him that her mother's condition has changed and that he should visit the ward to make a reassessment. The doctor retaliates by accusing Pauline of interfering with his diagnosis and assessment, adding that her mother has rights and that Pauline has no business in suggesting a change in treatment. Unperturbed by his accusations Pauline again strongly requests that the physician visits. Later that day her mother is commenced on morphine mixture as required.

Unfortunately Pauline's mother died within twenty four hours of the change in treatment and she reflects that had the staff (nurses and the doctor) been attentive in their care her mother might have died in more pleasant circumstances. Pauline's sadness in this situation is expressed as not being in control and she recognises herself in the sadnesses of other relatives who are also witnesses of their parents' deaths:

There are always other people's parents and you see how devastated their children are and how some cope with it better than others. And I think to myself, you don't have any control over this [the nature and manner of their parent's death] (9: 963-967).

Aware of the complexities in dealing with health professionals who are reluctant to listen to what the patient or the relatives are saying, from her own story Pauline understands the sense of powerlessness that can be the experience of others (memo 3.3).

The theme, 'kinship sadness reflected' is understood to be a recognition, sharing and an affinity with responses to sadness events of others. Recollection of painful, personal experiences from the participants' lives signal to me the participants' willingness to enter into a deeply involved relationship with patients and relatives in their care. Reflexive kinship sadness is what I have come to believe as a complex web of the participants' stories about their own sadness juxtaposed in 'conversation' with the sadness they experience in their work as palliative care nurses. Telling personal accounts of sadness the participants in this section construe their experiences similarly, and in so doing aspects of their lives are braided together in kinship sadness.

“I watch and I wait”: kinship sadness witnessed

The delivery of nursing care has, as a principle, commitment to other people (Sarvimaki 1988). There are nevertheless many situations in nursing when ‘doing’ something to enact this commitment is inappropriate, unwarranted or impossible. In these situations nurses’ expressions of care may remain silent and, in such circumstances, so too do nurses’ sadnesses. Nurses become silent witnesses to the pain, turmoil and travesties of their patients’ journeys towards death, and the relatives road towards resolving grief and loss (memo 3). Being a witness has, for many of the participants in this study, a spiritual edge, and this notion will be explicated through the following analysis and descriptions of their experiences.

The strength of the relationships between nurses and others is not time bound. In some cases the participants talk of a short, intensive relationship that has to form quickly as the dying person is first presented to them in the final stages of their terminal illness (memo 5.1). Louise suggests that late referrals to the community palliative care service necessitates concentrated interaction that can be emotionally draining for all concerned:

Because you frequently see people in the end stage of their dying process you actually tune in fairly quickly to where they're travelling. So you may have to cover in twenty four hours what you would prefer to cover in two weeks (1: 466-471).

Reminding herself of her personal trauma with an incident when a gentleman who had moved from interstate was referred to the service and died within thirty six hours, Louise describes it as ‘like being hit by a bus’ (1: 507). In her communication with this family there was no certainty except his death. She had to constantly move the goal posts from talking about length of life in months and weeks to days, hours and minutes. This intense involvement is unfortunately not a one-off situation. For Louise, late referrals, and the accompanying intensity seem to be an increasing pattern in her work. Becoming in-tune with the dying person is her main interest in these situations, and while she is cognisant of the sadness in the situation she is also aware of the sadness for the family:

Umm, it happens, it happens fairly regularly. We do get late referrals ... you do have to do a lot of travelling [metaphor for being with the person] to do in that time and that's your objective, that journey. So that's pretty sad and sometimes heartless really (1: 496-497; 499-501).

Louise also describes her sadness when dealing with family who survive the death of a loved one. Watching their grief she too experiences the sadness of the situation, the sadness of being left behind, acknowledging the unavoidable emptiness:

I can think of one old couple, I think they met when they were fourteen and they were in their eighties [when he died] and I know they just, ah the... wife was left. I mean she just couldn't realise a life without him (1: 130-133).

Being alongside relatives when they have to make difficult decisions about caring for their loved one is as much part of community palliative care nursing as caring for patients (memo 2.1). Often relatives make promises to the dying person that over time they may have to negate or change. In Helen's case, her sadness abounds when witnessing carers' exhaustion:

... watching carers run themselves into the ground when they've got usually elderly people that they're caring for ... but you know the carers, the elderly, even elderly or older daughters and sons who are looking after a father or a mother. And it's their life, but you know there's more to it that this, there's almost an injustice (15: 244-252).

Helen describes her sadness as hopelessness when she witnesses families having to place their mother or father into institutionalised care. She indicates how such situations can place intense strains on relationships.

Monica concurs with Helen stressing that there is often a lot of pressure placed on relatives to care for the dying person at home. Restating that many carers make assurances they cannot keep in the long term, Monica signals that carers can often feel trapped. Watching the sometimes tortuous decisions that families need to make is sad for Monica. In describing their agony she notes that for many people the feelings of guilt are not easily released:

They take it all on board, stuff they should just let go. And it's trying to get that through to them but it's probably the way they've lived their lives (12: 248-249).

Stressful circumstances in family relationships invariably lead to uncomfortable situations presenting themselves when others visit the home. Yvonne describes witnessing such uncomfortable family situations, and her sadness as hopelessness, in being unable to do anything to change the present, and perhaps future circumstance. Sylvia, a patient of Yvonne's was in the end stage of her disease. Yvonne was making arrangements for Sylvia to be transferred to a city hospice when she remembers that Sylvia has an estranged daughter. Mother and daughter had not spoken for several years. The anger between them had never been resolved and Sylvia's daughter, Janet, has no knowledge of her mother's present, declining quality of life. Sylvia's husband Bruce respects his wife's wishes and does not want to upset her by secretly telling Janet about Sylvia's illness. Sylvia is adamant that if Janet comes to see her she will turn her away. Sylvia dies

without reconciling her differences with Janet. After Sylvia's funeral Yvonne asks Bruce if he has made contact with Janet but he has not as he is still abiding by Sylvia's wishes. Caught between wanting to inform Janet herself and respecting her patient's dying wishes Yvonne suggests to Bruce that he might make a telephone call to his daughter. After a few weeks Yvonne hears that Janet learns about her mother's death from a mutual friend of the family who lives overseas. Janet is very upset. While Yvonne can equate with the pain of loss that Janet is feeling she also notes:

But you can't do anything about it. You have to step back, you know. People live the lives that they live. Umm... but I felt yeah, I felt sad for this woman (2: 692-694).

Abiding by the often foreboding rules of partition that can emanate from family feuds or holding on to life-long values that are in conflict with other family members can interfere with healing family rifts. One of Vickie's stories (re-told in Chapter Four) expounds the effects of non-resolved hatred surrounding homophobic beliefs of one family member's capacity to accept a contentious diagnosis (memo 2.4). Such deep-seated convictions can sometimes be tempered and possibly overturned as Nadine relates in her first sadness story (see Chapter Four for a full description of this story). A young man who is HIV positive returns home to a small community to die. Nadine speaks about her sadness as she watches his parents deal with the realisation that their son is both 'gay' and HIV positive. While both parents come to grips with their own feelings they still feel as if they have to publicly lie about their son's condition, especially to friends and neighbours within the small community in which they live. In a few words Nadine articulates her sadness for the family:

... the HIV guy that died and he actually had come home from the UK to die so, and he died in a small rural town. Umm... with a diagnosis that wasn't very socially acceptable. So there was a lot of sadness in that family and I was sad for them because they had been... yeah hadn't seen him for eight, nine years. So they got a terrible shock when they nursed him at home, but they wanted to. Umm... there was a lot of hidden stuff there too because... he had cancer and that was it and that was what went out to the community at the time (10: 89-98).

Speaking reverently about the part that families play in the care of people who are terminally ill, Nadine continues to talk about her sadness as she watches their involvement:

And I think that a lot of sadness for the family's at that point because of the work they do, you know. [I have] huge empathy for twenty four hour care which we don't quite give so, oh we do at the very last stage but there's a long time before that yeah (10: 187-191).

Also relating the impact of terminal illness on family members Pauline recalls how she feels powerless and sad for some relatives. She describes the behaviour of Lesley's son and twelve year old daughter as they face their mother's impending death (for a more detailed account of Pauline's story see Chapter Four). Lesley and her family (husband and two children) were a dynamic family before Lesley's illness prevented them from enjoying their usual outdoor activities. As Lesley became too ill to work or look after the children her husband willingly took over. The children had differing responses to their mother's illness. Nicholas, Lesley's son appeared less troubled by his realisation that his mother was going to die. On the other hand, Leanne, Lesley's daughter, became depressed, *reactive depression* according to Pauline (9: 517). Pauline's sadness in being a witness to this family's circumstance is reflected in her description:

He [the patient's husband] took the kids on. They, one of them, was a sad, she was like a sad girl, sad, sad, sad! Umm... and I always wondered what she'd have been like if that [her mother's illness] hadn't happened. She was obviously very quiet and kept her sadness. The boy just went about his ways as though he was taking the dog for a walk, no matter what happened, you know. Yeah, but that's all right, that's how he coped. I mean they all cope differently. But she just looked sad all the time, this girl (9: 488-496).

For Pauline, the boy in this story was unreachable. All she could do was watch and wait and hope that some opportunity would present itself so she could intervene and possibly help facilitate the child's grieving process.

In most participants' stories funeral attendance is described as part of a process of acknowledging their own grief (memo 29). In one of her stories however, Rose describes how when she attends the funeral of one man she feels sad for another man (Eric) who happens to be attending the same funeral. Eric has the same disease as the man whose funeral they are attending. Rose's sadness is not for the person being buried but for Eric whom she has not seen for some months as she has been on long service leave. While Rose was away, Eric had finally lost his sight. Rose describes her feelings when she first sees Eric again, some months after he has lost his sight:

Umm... just to see this pa... [patient] and he was as white as a sheet. He had a... he looked lovely. He had a, he looked like 'bananas in pyjamas'. He had a pin-striped suit on and he was white from here [points to neck] up with a real thick neck and this bald head and these black thumb nails. Oh, it was just awful to see him and I just, you know your heart just, oh dear. And I was thrilled he was there, because it was another patient, and but I, and you know it was really, really just so sad (2: 381-389).

Rose ponders further as to whether Eric is fearful of dying as he suspects that soon his own health status is about to change. As she considers his plight she is reminded of all the other people she has cared for who have either died or deteriorated:

And I was wondering to myself, I wonder if he was saying [about the funeral] I wish it was me ... So then I drove away from that service balling my eyes out you know. And then, and then 'cos every other issue comes up, because it's, you've broken down that barrier yourself. Umm... and but you know you come to grips again with it. And it's not, I honestly don't think it's hiding the grief. I think it's coping rather than not facing it (2: 398-405).

Families in grief, and witnessing their invisible connections is a source of sadness for Sally (memo 6.1.1). Henry is a local vegetable grower who has small cell carcinoma. He was referred to Sally by another patient, a practice that often happens on Sally's rounds. Henry was having difficulty managing his pain and had not opened his greengrocery stall for some days and was missed by members of the local community. Sally makes contact on an informal basis with Henry and his wife Maud. They negotiate that Sally will 'keep an eye' on Henry as she goes about her daily rounds. Sally telephones Henry's General Practitioner, establishing a more formal basis for her visits. Unfortunately Henry's pain becomes intractable and he is admitted to hospital for reassessment of his pain management. Maud visits Henry at the same time that Sally also visits. She describes her impressions of their relationship:

You can feel that love, it's there. ... And I was watching his wife yesterday. They'd been positive about it, up to last week. He was in bed when I got there, just resting. And I went in, had a chat with his wife sitting on the bed. And just that bond between them and every so often her eyes would fill up and she'd keep on smiling through these tears (7: 2004; 2011-2018).

Sally's stories interpreted as 'kinship sadness witnessed' are powerful. Describing family pain as being similar to a raw, open wound she adds:

Oh just seeing their, that anguish that... it's almost indescribable. Watch the pain of the relatives and they're sitting there holding a hand and you know, it's so sad (7: 2203-2206).

Dying of cancer does not always mean that patients become cachectic or lose their hair. Yet the lack of alteration in bodily appearances does not diminish the emotional pain of watching someone you love slowly die. In her appreciation of 'kinship sadness witnessed' Tanya describes the case of a thirty five year old woman with malignant melanoma who dies without a visible blemish on her face. Tanya's anguish for the woman's parents is brought forth:

and when I looked at her and she was unconscious and obviously in the very end stages, she looked like she was asleep ... she was looked after by her parents so... umm... they were losing a daughter but they were a very close loving family. ... my feelings for the parents was incredibly, incredibly sad (5: 114-116; 130-132; 208-209).

Witnessing the dying process and the effect it has on the family is a tangible sadness for the participants in this study. 'Kinship sadness witnessed' connects the nurse with those family members who are also feeling sad. Recalling her story of an 'ordinary man' (see previous references to this story in Chapters Four and Five) Vickie declares that she reaches out and touches the sadness of others:

Yeah and umm I guess it was watching the way that that family cared for him and seeing how hard it was for them to separate at the end. That caused, you know, the feeling of Jesus it's not fair! You know. And that that I suppose, was a sadness that I felt. It's a sadness that I felt for him. It was a sadness that I felt for his wife and his kids and what-have-you (6: 133-138).

Many of the participants in this study comment upon witnessing the 'passion' of family members' love for the person who is dying. Describing sadness as either harsh or quiet Zena remembers the love that some parents gave to their dying daughter. Suggesting that the dying situation was calm and quiet Zena recalls how privileged she feels witnessing the passion and love between the family members. The young woman in the story was divorced, also she had a small child of her own. The young woman's parents moved in to her home and cared for her and their young grand-daughter:

... I actually was there when she died on the night. They rang me and I came, and that was very sad watching the family in, well halfway through the grieving process already. But it was an acceptance, it was a sort of quiet sadness. ... They wanted her to die at home. She wanted to die at home. Her daughter had spent lots of times in bed with her, cuddling her. And it was sort of sad but very accepting sort of time for all of them. And they were pleased that... that it worked the way they wanted it to. It was still sad, it was, the still having to seeing other people grieve (4: 123-127; 130-135).

The quiet acceptance of dying and death evidenced by some families is not without unhappiness, asserts Zena. However, those situations where families cannot accept that death is happening is when Zena describes their pain, and hers, as gut wrenching—'you can feel your insides being ripped apart' (4: 161). Often unable to help family members through this highly emotionally charged process Zena silently watches:

You see them really suffer. You see the pain they have to suffer and I think that's when I feel sad. I feel sad that I probably don't, not able to help this family ... Families who... who won't come to terms with it. They allow other things to get in the way of achieving what could be quite a, you know, a good experience (4: 235-237; 228-231).

Watching and waiting with people who are dying, or relatives who may be in distress is described by the participants in this study as witnessing sadness. Yet it is a sadness that is shared through the close-knit relationships formed with the people in the stories. 'Kinship sadness witnessed' emanates from a compassion in an awakened heart (memo 1.10.2). It is a compassion that does not need feedback or recognition from those with whom it is silently shared. 'Kinship sadness witnessed' for these seven participants is a compassion that is reflective of an affinity: an affinal relationship that displays authentic human companionship, in which the participants react vigorously and lovingly to those people who are in need and in their care.

"I know how you feel": kinship sadness shared

'Kinship sadness shared' is an extension of 'kinship sadness reflected' and 'kinship sadness witnessed'. It emerges from a spontaneous compassion that embodies a concernfulness for others who share the world of palliative care with these participants. It is double-edged in that 'kinship sadness shared' in this thesis is described through the participants interactions with firstly, the people in their care, and secondly, the colleagues with whom they work.

"I've lost someone too": kinship sadness shared with patients and relatives

From their expressions of 'ownership'⁴⁰ and of being in an involved relationship with patients and relatives, these participants are survivors of the death and dying event and liken their experience to that of grief and loss as experienced by the dying or dead person's relative. Even though nurses are usually not members of patients' immediate family, the strong bonds that develop between the participants and the patients/relatives

⁴⁰ In our conversations the participants talk of 'my' patients or 'my' clients. In the context of palliative nursing care however, the people that the participants identify as patients are described from within a kinship relationship, not a detached acquaintance. They have become, in many instances, good friends. In the main nearly all the participants have nursed the patients identified in each story from an initial referral to the event of their death. Thus it is not surprising that the language used by the participants takes on a flavour of ownership, of being involved with someone from life to death.

can trigger sadness. The nurse-patient relationship has meaning and any change in the patient's condition, or their death, becomes significant (memo 1.14.2). Joan professes:

There's this entity who has had an impact and it's gone. So there's gotta be sadness always, but you can't not feel (13: 430-432).

Similarly, for Helen her relationship with patients, especially palliative care patients, means that sadness is always part of the interaction:

It's just a closeness that you build up with some people. Umm... I guess I probably fill up [tears in her eyes from being sad] with any, I guess with any palliative [patient] I fill up a little bit. When I'm actually with the body (15: 77-80).

Sharing in people's lives in an intimate fashion is what bonds the palliative care nurse with a patient. Zena contends that because she shares such a deep level of intimacy with dying patients she cannot help feel their loss when they die:

Us palliative care nurses, we become involved with that person and it's a loss to us with that person as well. We... you miss... you miss them. There's a lot of people that you actually miss umm... because they've shared such an important time in their life with you and they'll share the most intimate things with you which is a privilege (4: 137-142).

Validation of self, acknowledgment of being human, and confirmation of being accepted, as previously discussed, are particular to kinship relationships. Within relationships formed between some participants and the families they visit, there is a recognition of each others sadness and many describe being sad when grieving with the relatives of the dying person. Joan's story of Charles and Lucy, retold in a previous chapter, is an exemplar of Joan's involvement with a family. Joan remembers her relationship with Lucy and Charles as 'easy' and 'natural':

They were lovely and they sort of were very relaxed in front of me. ... I went on holidays and I sent them a card from overseas and they were really touched by that. You know, they sort of... you sort of get involved. I mean I'd sit on the bed and she'd be munching a packet of biscuits. (13: 50-51; 141-146).

For some time after Lucy's death Charles would go out of his way to make contact with Joan. On one occasion while driving in the city he saw her getting into her car after visiting a patient and drove onto the footpath so he could talk with her. For me, Joan's descriptions of their ongoing involvement was a recognition that both Joan and Charles need each other to grieve for Lucy.

In her role as a community oncology nurse means that Rose has the possibility to experience enduring relationships with people suffering from terminal illness. Possibly visiting people up to their death she upholds that it seems natural for her to develop ongoing relationships with patients and their families. As a consequence she finds difficulty in breaking away from this close relationship once a patient has died:

Some of the sadness comes of course when you have been so involved with the family and... and the um... patient dies umm... and it's very hard then to cut off from the family entirely. Umm... so, you know, you still have a running relationship with the family for quite a few months and sometimes years (8: 29-34).

These close, intimate relationships that community palliative care nurses develop with their patients and families means they may sometimes share happy times together during the nurse's visits. When patients are in the end stage of their disease the community palliative care nurse will often call in to see the patient and spend as much, and sometimes more time with the family, talking about the patient's impending death and facilitating the family's grief response. Grieving for the loss of friendly intercourse with dying patients and their families forms part of Vickie's sadness. She remembers:

And umm... yeah, and there's also the fact that I miss seeing them each week. Not just seeing him [the patient] but seeing his wife. It was a nice place to pull in and have a cup of coffee and feel comfortable and that I could be myself and was accepted for being me and the way I spoke and everything else (6:149-153).

I always felt, sort of very comfortable, at not always having to put on airs and graces, no not at all, yeah. And I just, you know, I just looked at them and I thought well, this is what palliative care is all about (6: 190-193).

'Kinship sadness shared' is an embodied experience for some participants. Sometimes hard to describe, the sharing of sadness with a family is a corporeal encounter for Sally:

You can see it and you can feel it and... and... but no words are going to replace it (7: 165-166).

Crying with relatives or a dying person is an expression of 'kinship sadness shared' for some participants. Monica for example says that she has shed many tears of sadness and helplessness:

Crying with people, I done that a few times, quite a few times (12: 183).

Expressions of sadness however, are not always welcomed. Feeling overcome by her sadness Sally recalls one episode when she allowed herself to openly weep with a relative. After telling her story Sally also questions the appropriateness of her tears:

Umm... there has been one occasion when I've done my grieving with the family and umm... it just came. It's been the one and only time I've done it and umm... the daughter, she came along and said, "You're not meant to do this Sally". She said, "It's meant to be us".

While all of the participants speak of at least one encounter when they have become involved with a family, in some conversations in this study there is a palpable air of hesitation about this involvement. With others there seems to be a degree of penitence attached to their disclosure. To me, they appear to be almost apologetic for allowing themselves to become close to a dying patient or a member of the family. By negating a part of ourselves Heidegger (1962) suggests that we are acting in the 'they' (in the inauthentic) rather than just 'being'. In our day-to-day activity Heidegger suggests, we unquestionably engage in social practices of a 'world' into which we have been thrown (we act inauthentically). This 'world' becomes so familiar to us that we think of it and our practices with a sense of comfort and certainty. Thus changing these practices poses struggles, anxiety and uncertainty for many. By becoming authentic, by taking action, Heidegger (1962, p. 406) proposes we are able to see what a situation demands:

What is needed, then, is a way of recovering a sense of the openness of the possible and of our own responsibility as individuals in articulating and bringing to realization [sic] the worldly contexts in which we find ourselves. And that means being able to experience our predicament not as a mere set of "circumstances" (*Lage*) subsumable under universally valid (and hence anonymous) principles, but as a 'situation' where the choice demanded of us is defined by the concrete characteristics [no matter how momentary] of the context itself. To become an authentic individual is to achieve the kind of clear-sighted, committed resoluteness that first "gives itself the situation, and brings itself into that situation" by defining how things are to count in relation to one's stance (Guignon 1993a, p. 31).

The action of being authentic disrupts our complacency allowing us to achieve clarity and a sense of purpose that is realised out of the relationship of self with other (people and situations). Yet remaining inauthentic can at first seem a sensible option, especially when that option means the person avoids personal distress and/or anxiety. It is not that obvious a choice however, as Heidegger (1962) reiterates we 'fall' (slide unconsciously) into inauthenticity, not knowing for the most part that we are there.

Yvonne's dialogue illustrates the power of the inauthentic. She accepts that she is sad when a patient dies but struggles with the 'appropriateness' of acknowledging publicly,

her feelings. She challenges the 'shoulds' and 'oughts' of 'acceptable behaviour' for a palliative care nurse but in the main does not trust her own feelings, and often submits to the rules of behaviour as constructed by others (memo 28). The following three excerpts from Yvonne's transcript illustrates her continual struggle. Yvonne, a recent graduate with a Postgraduate Diploma related to Cancer Care, began our conversation by describing her impressions of the 'old days' when acknowledgment of the nurses' feelings was taboo:

... you weren't supposed to show your emotions, especially not as a nurse. Umm... you weren't supposed to become really close to the patient or the patient's family because that was showing umm... over emotional involvement and that was supposed to be a sign of weakness, and you're supposed to be as strong as steel (2: 50-56).

Later in our conversation Yvonne reveals her sense of connectedness to patients and their families:

But you do become... or the family, you do get that involvement that yeah, the family to meet some of that grieving. You're certainly not grieving on the same level as they are, but it's a process I suppose that you go through with them that helps you with... Well, doesn't matter how short it was with that person, the involvement you've had with them, you can get very close to them (2: 369-376).

Nevertheless, even after describing poignant experiences of sadness she questions her involvement. The stereotypical behaviours of stoicism and detachment are not easily shed for Yvonne:

Getting back to that old stuff I said in the beginning, you know, the good nurse doesn't become involved with the family or the patient. And you [meaning herself] have that big barrier. I still think that I've got some of those old dregs that have umm... you know, it's indoctrinated in you so firmly and it's very very hard to umm... shake off sometimes (2: 383-390).

It is hardly surprising that this conflict exists as nurses have been constantly and consistently taught that to be emotional is wrong; because if nurses are emotional then they cannot be rational. A similar conflict persists today, albeit less vitriolic and pervasive in its petition. Several contemporary nursing authors suggest that nurses need to exercise some 'balance' between emotionality and rationality (Morse 1991; Ramos 1992; Barthow 1997). While I do not doubt that there are situations where a middle road can be taken I also believe that to ignore strong feelings can leave us at risk of sliding into mediocrity where neither way of 'being' serves any purpose. Both emotion and rationalism are qualitative statements about behaviour. Maturana believes that as animals we 'naturally

use reason to justify our emotions' (Fell & Russell 1994a). He also suggests that we understand others through recognising subtle differences in the 'emotioning' of ourselves (Fell & Russell 1994b, p. 235). Thus to negate our own 'emotioning' may be tantamount to losing our ability to understand others, and by a process of reciprocity, also understand ourselves.

The theme of 'kinship sadness shared', in situations of relating to dying patients and relatives is fraught with contention. From listening to the participants there is some meaning for them by involving themselves with others, especially in the context of palliative care (memo 19). Yet there are many in nursing who lean favourably towards a behaviour of maintaining some 'professional distance' between the dying person and themselves. Nevertheless, the participants in this study acquiesce with the participants involved in a previous study (Chapman 1994) claiming that through connecting and sharing each other's sadness there is a potential to develop a rich understanding of one another.

The participants also speak of another relationship from which their sadness can be recognised and appreciated, a kinship with their colleagues. 'Kinship sadness shared' with colleagues is the next sub-theme to be discussed.

"In the same boat": kinship sadness shared with colleagues

The sixteen participants in this study all work in community health services and in the course of their professional work may have to call on each other for advice. Some participants are also friends, and in our conversations talked of the value of that friendship in terms of sharing and caring for each other (memo 19.1). Rose and Vickie both name one another in their conversation when retelling stories of sharing their sadness. Rose speaks of 'being in-tune' with Vickie and Vickie talks about 'walking the same path' as Rose:

You know I often go out with Vickie because we are both on the same wave length. She's got her expertise and I have mine, but we have worked together for so many years and we actually say the same words, we're really quite in-tune together (8: 44-47).

Do you know Sister Rose? Well see our sort of nursing career goes back to sort of virtually the same time, we started about the same time. We've gone very similar paths. We have very similar attitudes. We talk a lot (6: 346-351).

The most common circumstance for sharing sadnesses with colleagues as described by the participants is in the collective space of debriefing. In a structured debriefing session the people concerned with a particular case or event can have input into the conversation.

Recognising that palliative nursing may have lasting effects on nurses as well as patients Joan realises her own need for regular sessions where she can meet other community health nurses who have been involved with the same cases:

So we're there, hanging in. I mean, we hang in there, that's part of what we are, but it doesn't mean that you walk away. People sort of say things like "how can you bear to do this?" But you don't really walk away unscathed, do you? ... we do debrief with each other and that... because fortunately we often know... more than one of us knows the client and you can debrief with that quite a bit (13: 232-236; 243-245).

In a similar vein Monica accedes :

... debriefing I think, just talking about things. That's lots of support (12: 159).

And everyone else is going through the same experiences. All of us has each other around. It's also handy, like I work weekends and umm... of a weekend it's a much smaller team, there's about four or five working at one time and most other team members would know that person as well, so that helps. When someone else knows the person you can really talk about it. And all be sad together (12: 389-396).

Understanding one another and being able to share because they are part of a professional team is a commonplace response of the participants in this study (memo 1.10.1). Having worked in several different areas of community health Zena considers herself lucky to be part of a community palliative care team. As they are a very close-knit group of people who usually know each other's patients and have some knowledge of what each person might be feeling Zena suggests the team understands her needs:

I think, you know, I'm lucky that I can work with a palliative care team that are supportive and really understanding of... of the needs of one another (4: 747-750).

Sharing with other members of the team is not only accomplished within a formal setting. Zena alludes to less sententious activities where she can get together with her colleagues and talk about her sadness:

... the other thing we do is sometimes we all have lunch together or... or do something like that to, sort of, share (4: 772-773).

All health care teams have their unique ways of working together as well as expressing and dealing with their difficulties. When a new person joins a team there are often concessions to be made by both the new person and members of the existing team. In addition, as new knowledges come into being and as each member accommodates the resultant changes teams themselves also evolve. Acknowledging there are pitfalls in teamwork Louise is grateful she works with a team of people who are prepared to share their emotions about their work. She feels confident that she can speak frankly to other staff:

We've got a very good broad team. It's not perfect, we've got issues about ownership but generally speaking it's quite good. And everyone knows everyone else and the focus is very much outcomes for the person who needs it (1: 366-370).

Later in our conversation, Louise adds tenaciously:

You've got to be able to talk to your colleagues (1: 578).

Not all participants agree that debriefing sessions are an ideal situation for sharing sadnesses with colleagues. Rose retells her experience of a debriefing session that she attends, describing the behaviour she witnesses as inappropriate and not conducive or supportive for her to share her feelings in a purposeful manner:

I went to one. We sat round the room after a young girl had died and it was really sad. And the people were Greek and it was a very volatile, emotional time. And we sat around the room and everyone had to say what their involvement was. By the time it got round about three [people] there was all this inappropriate behaviour and you know from people who didn't really have much to do with the person. You had to say what you, what you did for that person and how you felt. But to me, it was, it just, they'd have been better off to go to the pub really (8: 266-276).

Not all the participants in this study work in a designated team. Sally is a lone professional for much of her working day and most of her sharing-with-others happens via the telephone. She is grateful however, for any opportunity to share her feelings about her work and describes a recent event from her practice when a member of the community palliative care team came to her assistance:

When it got a bit heavy a few weeks ago, one of the palliative care nurses came and I really appreciated having her there, just taking some of that load away from me, and we were able to sort of, bounce things off each other and... and I was beginning to feel bitter about some of the feelings I was having, hopefully they didn't show to the people, but afterwards, umm... that... that yes, she was feeling them too, so it was shared (7: 1094-1104).

As a team coordinator of one of the groups having palliative care as their main focus, Wendy acknowledges that new staff often need careful observing for any signs of becoming overtaxed by the nature of their work. Suggesting that although it may seem to others that she is sitting back and paying no attention, Wendy says that she keeps a close watch on new staff and notices that some of their reactions remind her of herself when she first started in palliative care work (memo 2.5). She adds that in sharing her own past reactions with the new staff they feel less alone and less overwhelmed by the work. For Wendy, her first experience in palliative care was one of gentleness and learning.

The opposite however, is true for Pauline. Her initial experience with community palliative nursing was, in her words, overwhelming. Initially working weekends only Pauline ostensibly worked alone. On one particular morning she had six clients to visit who were all at an end stage of their individual terminal disease. Feeling that she was the only person caring for them she shouldered the responsibility for their care. Concerned by the burgeoning circumstances she telephones the community health service and speaks with the coordinator, also a nurse. The coordinator, by listening and 'really' hearing Pauline's sadness, she is able to appease her concerns:

I can remember that first time years ago when I had those six clients who really bothered me [made her feel sad]. It's the first time I'd ever worked in community health. And I rang up and I said "Right, that's it! I'm not having that any more! I don't think it's on!" And the woman [coordinator] said to me "God, I'll have to do something about this". And I said, "well I wouldn't have rung if I didn't want you to". And she said, "it's because at the weekend you get it all." They are seen by many different people in the week because they are on several people's rounds. But at the weekend they are concentrated into one person's round, yours" And after that I was fine (9: 584-599).

The presence of a sympathetic listener facilitates Pauline's anxiousness. Pauline surmises that as her coordinator is also a nurse she does not need to know the minute details of the situation. Listening to Pauline's tone of voice and anxiousness she knows, almost in a moment, what she needs to do to defuse the situation. Finely tuned listening skills are, in part, borne out of being able to move directly into the situation, validate and respect the person's feelings and give them the space they need to talk. In her own practice, listening carefully and responsively is a skill that Pauline also highly values.

'Kinship sadness shared' between some participants in this study and their colleagues, also reflects a sense of close, authentic human companionship that helps give meaning and purpose to their lives as community palliative care nurses (memo 19.1). Through sharing their sadnesses with others these participants are able to move through some of the more negative connotations of sadness towards a sense of resolution. It is important to

remember however, that not all participants speak about their relationships with their colleagues as being able to provide a suitable circumstance for sharing their sadness. Some prefer to release their feelings within their own family situation (memo 19) and discussion of this action of kinship sadness forms the final sub-theme of this chapter.

“You must let go”: kinship sadness released

Giving of themselves compassionately in their professional lives some participants wait until they return home to release their sadnesses, the sadnesses they describe as ‘overwhelming’, ‘gut wrenching’ or ‘indescribable’. Others create a safe space within their cars, a sanctuary in which they can reflect upon and sometimes release their feelings of kinship sadness (memos 27 & 33).

‘Kinship sadness released’ for Sally almost always happens while she is travelling from patient to patient. Working in a rural setting Sally often has to travel several kilometres between patients’ homes. Her car is home to a wide selection of classical taped music which she has playing through her car stereo system during these long journeys. Sally describes how her music and the surrounding landscape often help her to release her sadnesses:

I work myself... myself through it [sadness] and I use music everyday when I work. Um... I keep a lot of tapes. Oh, they're all classical and some of them are just the catalyst that if tears are gonna come, they'll bring them. So... and... and I start [to cry] (7: 379-384).

Aware of the inherent dangers of crying while driving Sally adds:

Because I can't obviously drive down these country roads bawling my eyes out, and I do it that way, (aside) I don't always. Yeah I mean music helps relax us as we leave our sadness, which doesn't necessarily come with tears too (7: 388-392).

When Sally returns home in the evening however, especially after a particularly sad day, she describes how her husband can intuitively sense her sadness:

... my husband has this innate sense and with this last case because it was very late when I got home, and he doesn't say... he doesn't say anything. Um... he knows not to ask umm... he knows not to ask and he's likely to say "Want to go for a walk?" (7: 394-397).

Touching base with her familial 'kin' (spouse), Sally is able, through walking together, to release the kinship sadness of work. Also preferring to engage in physical activity rather than sedentary pastimes to work through her residual sadnesses Sally adds:

... I can work through the sadness with physical exercise, through music, umm... not through reading because it tends to come back in again umm... getting out into the bush (7: 399-403)

Like Sally, Nadine describes how when working alone it is difficult for her to release the kinship sadness she feels when caring for people in small communities, especially since one of Nadine's patients was also a friend:

I didn't do a lot of crying until he died and then, you know, I cried for about eight hours. No problem. But then I think I was totally exhausted as well. Yeah I couldn't even think about him for the next few days without bursting into tears (10: 286-290).

Also working alone in a rural, coastal area Nadine has similar experiences to Sally. She describes how she too uses her car as a sanctuary:

I go away sometimes and drive out and cry. I mean I used to have to drive from, you know, from one town to another. And you know probably cry all the way home and then you'd (I would) be right, yeah. (10: 135-139).

Among the participants in this study only one (Tanya) verbally shares with her spouse the explicit details of her sadness. Tanya describes herself as being very fortunate in having a very supportive husband with whom she can freely discuss aspects of her daily practice:

I've got a very supportive husband who listens to what I tell him and I can talk freely at home anyway (5: 307-8).

Outlining other activities in which she engages, she adds that she prefers to develop strategies at work to deal with her sadness believing also that dwelling on work issues, especially those of a difficult nature, can be detrimental for palliative care nurses:

I try not to dwell on work too much and I don't think you can work in palliative care if you're... well not for any length of time, if you do that. If you can't, you know, um... close off. You just have to. You have to have the ability to do that otherwise you would be a wreck. Yeah, I think you have to have clear strategies of your own in dealing with sadness at work. Umm... and I do a lot of exercise, and walking and breathing in fresh air and walking the dog along the beach and the water's not far away so I do a lot of that walking with the dog. Umm... I have other personal interests like sailing. I have a very active daughter who plays a lot of sport. So I do have... I don't go home to an empty

house. That's very much a part of it, of being able to deal with it (5: 310-323).

Taking responsibility for their own self care appears to be a commonality of practice within this group of participants. Also within this group of people there are nurses who tend to focus on, or care for, particular groups within the community. Vickie for example, works mainly with people who are HIV positive or who may be dying from AIDS related diseases. Louise works with children who are terminally ill. Louise indicates that when she feels she cannot work effectively, especially she is carrying too much sadness, she will take time away from her work:

... and then I start to look at, okay what's been happening over the last few months. We've been really busy. I've dealt with a few children and there's lots of issues for them and when I can't deal with it I've put it aside. And then I think well you have to really. You know it's hard to take a break. So I'll take a week or two off over the next few weeks (1: 85-91).

Adamant that she would never involve her own family by sharing details of her feelings Louise describes some of the alternatives that she has found useful:

... dogs are wonderful. I usually take it [the dog] out for a walk. They don't answer back and it [the action of walking the dog] gives me time to think. Think about and umm... I usually resolve it [discomfort with work practices or feelings]. I get into sort of mental journalling. I process it [discomfort with work practices or feelings]. If I've got someone in pain and I've done what I can do. [I ask myself] can I do any more? Shall I do it different next time? Same with sadness. And umm... then I leave it. Sometimes I wake up at midnight and think about it again, but that's okay (1: 569-577).

Similar to Louise, Vickie releases her sadness by removing herself from reminders of the situation by leaving town. By escaping to another place that is isolated from other towns and telephones, Vickie can absorb herself totally in activities that are completely alien to her work. She stresses also that palliative care nurses must learn to be aware of their own limitations and learn to say no when they are beginning to feel overwhelmed by their sadnesses:

And if I've had a pretty awful week, I've got a little cottage down the south coast. I adore the beach, I just love it. I find that walking from one end of the beach to the other and sort of thinking about it, talking through it etc. I can you know, close it off. I just can go down there for sort of you know, two days and that's like recharging my batteries, you know. And I've always been aware that in this area you need to be able to do things like that. You need to be able to do nice things for yourself, and you need to be very honest about what you will take on and what you won't take on (6: 403-413).

As I discussed in the introduction to this chapter, making distinctions about private and professional attitudes to sadness serves not only to distinguish 'something' from 'something else' but also to re-signify their connection. In this section 'kinship sadness released' is described by the participants as a process of 'letting go'. This release however, in turn creates a space, a clearing. In this clearing the self can re-engage with the same situation but see it in a different light, or engage in a new situation supported by new knowledge learned through the experience of previous situations. In this sense, release and connection are coupled.

Conclusion

Kinship is constituted of human emotions that move constantly in and between polarities of affection and hostility, altruism and meanness, benevolence and violence, happiness and sadness and so on. In the contexts described by the community palliative care nurses in this study I have come to understand kinship to be the lived realisation of loyalty, respect, acceptance, understanding and compassion. This chapter has moved through several dimensions of kinship sadness as interpreted from the conversations I had with the participants in this study about their immediate experiences of sadness. In keeping with the musical metaphor alluded earlier in this thesis these dimensions can be seen as the different melodies running through the symphony of sadness.

Probing deeply into their experiences I came to realise that these participants' sadness is an embodied experience of compassion for others in their care, their colleagues and others they meet in their world of palliative care nursing. It is a mindful, spontaneous compassion that is liberated through an unconditional state of kinship.

It is not serendipitous that this chapter appears where it does in the analysis section of this thesis. I have consciously placed this chapter following a discussion about the temporal rhythms of sadness to remind me, and the reader, that the two themes interconnect. It is from and within relationships with others that the participants' sadness can ebb and flow in the complexity that it is. Being responsive to oneself and others as sentient beings is skilful as well as compassionate; and it is this skill, in the form of wisdom, that is evidenced in the practice of the participants involved with this research.

The next and final chapter, guided by explications braided throughout this thesis, will conceptualise multidimensionality, paradox and complexity as a tripartite thesis of this study.

Chapter Seven

Complexity, Paradox and Multidimensionality: an interlacing trinity towards understanding

We are floating in a medium of vast extent, always drifting uncertainly, blown to and fro; whenever we think we have a fixed point to which we can cling and make fast, it shifts and leaves us behind; if we follow it, it eludes, flips away, and flees eternally before us. Nothing stands still for us. This is our natural state and yet the state most contrary to our inclinations. We burn with desire to find a firm footing, an ultimate, lasting base on which to build a tower rising up to infinity, but our whole foundation cracks and the earth opens ...

(Virginia Woolfe)

Introduction

This research has been a process of conversations between myself, sixteen other women and our conversational journey as text. Through our interactions and sharing I have come to realise that understanding 'sad' or 'sadness' purely as terms to mark an event is inadequate. From being engaged in this inquiry I now know that the labels 'sad' or 'sadness' are too small and narrow to reflect the magnitude of the experiences I have witnessed with the participants through our conversation. Yet, in our everyday world, we use words such as 'sad' and 'sadness' as if a common, one dimensional comprehension of the phenomenon is all that exists. Nevertheless, by the process of this research I have illuminated and confirmed my earlier suspicions that being sad and sadness are experiences that are not universal.

As the participants' meanings of sadness emanate from a process of cognition, which in turn arises out of contextualised bodily sensations, it is hardly surprising that I have found multiple meanings of sadness as a result of my textual analysis. I have already stated that as a consequence of this research my understanding of sadness has broadened to include the multiple realities of sadness as described by each participant. But there is much more to my understanding. Sadness for me, in the context of the sixteen community nurses in this study, is not one phenomenon. Rather, it is an event that in itself is multidimensional. So powerful is the realisation that sadness is, in itself, multidimensional that my confidence to argue against any assumption that sadness is a

universal concept is now obsolete. Thus my original intention of describing sadness as a phenomenon has partially failed. What I have been able to do however, is to describe the multiplicity of events that the participants in this study signal as being significantly sad for them. From their descriptions of personal and professional elements of their lives these participants have allowed me to see sadness in different levels of complexity. By gaining access to the participants' descriptions of their practice, I have been able to come to understand the intricate and non linear dimensions of sadness that co-exist in and arise from affinal everyday relationships: descriptions that are at once transparent and paradoxical, multiple and singular, simple and complex.

Through conversation with the participants I have come to realise that within the complexity of their experiences, paradox and multidimensionality cleverly collide within each temporal rhythm of sadness, and in an ambience of kinship. The temporal rhythms of sadness also encapsulate the ebb and flow of sadness; its many and varied faces, and the underlying pulsating feeling of a stalwart, yet sometimes mercurial presence of the participants as they went about their business of palliative nursing.

Through interlacing the multiple interpretations of these descriptions of sadness I suggest that the participants unwittingly disclose their own unique, idiosyncratic yet pragmatic understanding (practical wisdom) of their sadness experiences. An understanding that I have also come to appreciate helps to sustain and nourish these community nurses to stay alongside their patients. From their stories I can also sense how difficult it must be to remain within a situation when both they and their patient, or the patient's relative(s), are at their most vulnerable. The nurses in this study appear to be energised by their sadnesses and instead of fleeing from their feelings, they work with them. Becoming one with their own experiences, by *embodying* their feelings of sadness, these participants are able to engage in compassionate actions, actions that are inseparable from wisdom (Varela, Thompson et al. 1992).

Nevertheless, a question that has haunted me throughout this study is that if the experiences of sadness are as tragic, contemptible and poignant as the participants describe, why then do they choose to stay in the practice of palliative care nursing? The answer lies in part in the question itself and, in the realisation that the kinship formed between the participants and their patients, relatives and peers is central in providing some insight into my recurrent question. Within the ever changing yet incessant rhythms of sadness, the relational aspect of sadness partially illustrates how and why, for most participants, they choose to stay in the business of palliative nursing care. Always in the process of 'being-with' someone or some thing these nurses define and redefine these

ongoing relationships with most acknowledging that even within the sadness they can, or have the possibility, to make a difference.

Caught within the web of this relational theme I also found the participants' expositions of 'wise' practice. Stemming from the links they form with their patients, coupled with their own creativity as nurses, their accounts of wise practice explain by example how a unique relationality can be realised. Thus these two very strong themes of temporal rhythms and kinship also interrelate. At times they braid together and in their resultant complexity, a further two dimensions of the experience of sadness emerge, namely, paradox and multidimensionality.

Paradox

In describing their lived dimensions of sadness the participants move in and out of an awareness of sadness that is at times paradoxical. Sadness as happiness, as humour, as celebration are three of the common paradoxes found in this study. Moving between these polarities (sadness and happiness for example) I have come to understand that sadness for these participants is also a rhythmic tension between the opposites they describe (happiness, humour and celebration) and the 'accepted' interpretations of sadness that have been laden upon them by society. This tension however, serves also to remind us that we live in a state of constant motion, rhythm and discovery. Prem and Ashish (1969, p. 80) contend that '... nothing is ever in a static state of rest, but is forever changing and passing into its opposite': opposites that are at once contradictory and reciprocal. Thus for some participants sadness is happiness is sadness, a paradoxical circularity. Within this paradoxical circularity there is something to be revealed other than the immediate contradiction and thus the identified sadness polarities are worthy of further examination.

'Laughing and crying surge up from the depths of life bound to feeling' (Plessner 1970). These words serve as a reminder of the eastern philosophy and law of Yin/Yang which in its explication of complementary opposites, one extreme becomes the other (Nicholson 1985). We cannot know happiness without also knowing its partner, sadness. It is within this paradoxical play that the temporal rhythm of sadness as happiness is seen to pierce the palliative nursing practice of the participants in this study. The following poem by Francis Frangou (1987) *Happy Sadness* portrays a similar paradox within a different context:

*I try to write but I am sad.
But I am sad from happiness
not from sadness.*

*I miss you from happiness
I don't miss you from sadness
Because sadness is happiness
If sadness comes from the people you love.*

*I miss you because I love you
I am sad because I miss you
I am happy because I am sad.
Sadness is happiness
Happiness is love
And love is sadness.*

Clearly, this poem is obviously not about death and dying. Rather, it is about loss, loss of love. It reveals how this loss of love could quite possibly be located within a context of grief. In some of the participants' stories sadness does not consume them. Rather, sadness and happiness blend together as a complementary emotional response to a given situation. In these circumstances sadness and happiness emerge as similar faces on the same side of the coin, rather than taking opposite polarities. As Wolinsky (1994) postulates, they may be opposing, however, they are made of the same matter and are, therefore, not in disharmony with each other.

Helping a person achieve pain control or symptom control even though their prognosis may be short or often poor, brings joy and excitement in the nursing work of the participants in this study. A common catch cry from other people outside nursing is that the participants must feel constantly depressed working with people who are dying. However, it is often being able to balance the small 'wins' against the immense losses that helps the participants lift their own sadness. Thus joyfulness alongside sadness in palliative nursing provides a sense of balance. The participants, like us all, 'live' the paradox of complementary opposites. Sadness and happiness share a similar energy and there is an attractiveness in sadness when these emotions interfuse.

Irrespective of how the notion of paradox has interested scholars for some time, studies of paradox as lived are sparse within the literature. Nevertheless, the concept of living paradox in nursing is highlighted in Rogers' (1994) theory of the *Science of Unitary Human Beings* and adopted by Parse (1981) in her theory of *Human Becoming*. Mitchell (1993, p. 44) in an account of Parse's theory defines the concept of living paradox as '... a rhythmical shifting of views, the awareness of which arises through experiencing the contradiction of opposites in day-to-day relating of value priorities while journeying to the not-yet'. The participants in this study, as travellers alongside their patients, moving towards the 'not-yet' of death, journey a rhythm of paradoxical sadness. The rhythms of happy sadness, humorous sadness and celebratory sadness constitute the ordinary and

commonplace ups and downs of everyday experience for nurses who work in palliative care.

In reactivating the musical metaphor threaded through this thesis, paradoxical sadness can be paralleled to the melange of drums found in an orchestra. Some are loud, others soft: most play a syncopated beat, an ever changing rhythm that may complement rather than antagonise the symphony's theme.

Multidimensionality

The multidimensionality of sadness reveals itself on many levels; these levels are circumspect and subtle in their differences. While I have identified certain patterns of sadness for these sixteen participants (sadness as loss, hopelessness, celebration etc) these patterns are not predictable for future palliative care events. Tiny little changes in factors influencing life dynamics bring forth dramatic changes in human experiences and what once appears as simplistic can emerge as complicated. Within this complexity however, is a movement towards patterning; an interesting development of chaos theory. Pattern, structure and process are all interdependent dimensions of the chaotic nature of experience (Capra 1997).

In this hermeneutical research I came to realise that an ultimate meaning of sadness could not be articulated. Rather, through 'dancing' with the text multiple meanings of sadness emerge in an ever changing and continuous movement. Meanings that are at once context dependent and time bound. Meanings which also share a possibility to be extinguished in any given subsequent moment. A simple understanding of sadness in the context of palliative nursing is like trying to hold on to one grain of sand in a shifting dune. As soon as a meaning is grasped it yields to something different. Yet in their evasiveness these sadness experiences appear as real as the events they describe: events that appear as a hologram reflecting the sadness within them as a constituted whole. In presenting a textual description of this hologram I am reminded of Parker's (1997, pp. 12-13) plea for balance between nursing as an art and as a science:

... nursing may be studied in a rigorous manner, using a wide variety of valid reliable methods. This 'nursing' may be defined as the skilful art of integrating personal, aesthetic, ethical and empirical knowledge into the unique and ever changing situation within which the nurse, patient and significant others find themselves.

Not only can sadness be a convoluted series of circumstances surrounding events in palliative care, it can also be an ethereal experience brought about by interaction with other experiences that are unique to each individual. While Louise's circumstances of sadness

may be similar to those of Wendy's they are, at the same time, different ethereally from the experiences of Wendy. Thus the participants' individual experience of life in turn reveals their individual meanings of sadness.

The multidimensional levels of sadness are reflected also in the levels of interaction between each community nurse engaged in palliative care and their previous experiences. The participants' stories allude to these multiple dimensions in their descriptions of their daily events of palliative nursing. In one of Nadine's stories (see Chapter Four) she describes the quality of her sadness(es) that arise from her interactions with the dying patient. Yet, at the same time, she acknowledges a different sadness; a personal sadness as the man who is in receipt of her palliative care is also a friend. Parallel with these same experiences she is aware of her nursing colleagues' antipathy towards her desire to stay overnight with the dying man; a sadness experience that she appears to squash, along with her own feelings of grief. Nevertheless, she points to the reality that these same feelings have the potential to arise at some later date, more especially when she is alone, perhaps when driving to visit another patient. From this one small glimpse of Nadine's sadness experiences it is possible to glean some insight into the multi-layering of sadness moments for this community nurse.

Similarly Tanya, a less experienced palliative care nurse, but equally experienced community nurse, recognises her sadness when giving care to a young mother who has children the same age as herself. As she embodies this sadness; sadness as the potential loss of a wife and mother, Tanya is immediately taken to her own family circumstance and tries to imagine how she would react, or how her family might cope if she were to be in the shoes of her patient. Moving between her present experience of sadness and some future prediction Tanya, in trying to explicate some understanding of her sadness, engages in a hermeneutic dance; a dance that continues when I re-engage with the text of the conversation between Tanya and myself. I cannot deny that my own engagement with any part of the text is devoid of feeling. As I read and re-read this particular story I am reminded of my own feelings of sadness that I experienced as a palliative care nurse giving care to a young woman who would soon die, leaving a husband and young children to cope with her absence. Thus sadness as potential loss becomes a circular interpretation. My experience is distinguished by Tanya's experience which reminds me again of my own experience, and so on. As Guba and Lincoln suggest (1989, p. 145):

A construction once formed is likely to maintain itself ...
Constructions are self-sustaining and self-renewing. Constructions,
like other forms of knowing such as theories, are able to 'wall off'
contravening evidence, by their very nature.

This use of prior knowledge to understand is a central principle of hermeneutics and engagement in the hermeneutic circle is apparent in the participants' descriptions of how

they make sense of their sadness. When Erica recalls the sadness(es) of her friend's husband(s) she is immediately reminded of the untimeliness and injustice of death. Similarly with Tanya, the unexpected death of a patient brings her sadness; a sadness that is both explained and bounded by her vulnerability in being a palliative care nurse. Being vulnerable however is not restricted to one participant in this study. Most of the community nurses at one point in our conversations comment upon the relationship between being sad and being vulnerable.

Like Tanya, Kate's response to her sadness is one of unfairness: unfairness attached to death of the young; unfairness of those who will grieve; unfairness that she too will be caught in this web of sadness as she has become a kindred spirit of her friend. However, sadness as unfairness takes on a slightly different dimension when revealed by Joan. While she acknowledges the unfairness of Lucy and Charles' plight (see Chapter Five), she also brings forth her own personal dilemma (and possibly that of many other nurses) of trying to be attentive and supportive when listening to patients who gain comfort in appraising medical treatments that may be deemed to be inappropriate or have the potential to reduce their quality of life. Inappropriate advocacy by nurses is a controversial topic debated by Watts (1997) who suggests that as nurses extend their professional education they will become critical of the 'status quo' and begin to challenge so-called 'accepted practices'. Joan's sadness is complimented by her knowledge of Lucy's impending death, her anticipatory knowledge of Charles' (and her own) grief, her suspicions that the bone marrow transplant will not be of value and a realisation that Lucy's faith in this medical promise may be misplaced. In one small moment Joan's sadness has increased four-fold and yet as she then continues to give palliative care she tries to remain sensitive and appreciative of Lucy's decision.

While the questioning of their nursing practice is a constant feature of the participants' stories, it is within this questioning that their sadness(es) emerge and expand. Yvonne's questions about herself and her abilities to be an effective and efficient palliative care nurse implode on her views of palliative nursing that in their very nature are sad. Yvonne's preponderance with clinical competence and her constant disappointment and resultant sadness that the future of palliative care nursing will be deficient of care, in essence forms the core of her stories. Unable to see past the present economic stressors and downsizing of personnel and resources Yvonne mourns the future of palliative care in the community. Her sadness(es) is inextricably bound by her interpretations of what palliative care nursing should be, as well as what it is. I suspect that this doom and gloom response to the future of community palliative care influenced Yvonne's recent decision to move out of this area of nursing and take up a position in another state as a senior administrator in a health related profession.

As discussed in a previous chapter 'kinship sadness' can also be viewed as multidimensional. The process of giving palliative care extends well beyond the patient in need of that care. As professed by palliative care nursing specialists (see Saunders 1978, 1990; Penson 1990 for example), a palliative care nurse functions within a team and thus has the potential to share the sadness of its individual members, as well as having the responsibility to care for the family/friends of the patient. All the participants in this study have told similar stories of their experiences of caring for others, either colleagues and/or relatives/friends. The sadness(es) arising from and of the kinship relationship are at most times reciprocal, impacting on each participant in different ways. The subtlety and intricacies of these differences are again reflected in the participants' experiences and retold in their stories.

The artistry of community nursing is captured in part by the '... healing webs and caring communities' (Watson 1999, p. 232) fashioned by the interaction of the nurses in this study with those in their care and others within their immediate community. All participants exhibit their adroitness in constructing sadness by signalling that relational sadness has many faces. Armed with the contentious knowledge that 'good nurses don't cry' both Helen and Frances challenge themselves about their own outbursts of emotion as they feel sad that a patient's premature death has truncated their individual relationships. Monica on the other hand, turns her sadness outward when considering how palliative care and its most probable outcome, death, impacts on family relationships. Witnessing fractured family dynamics Monica's sadness(es) alternates between her feelings for the situation as a whole and what she fears may be happening within the family.

As discussed in the chapter 'Kinship Sadness' relationality in community palliative care is not restricted to patients, their immediate family or friends. Sally's stories, for instance, are replete with excellent examples of her communication with people in her community. It is clear that subliminal feelings of sadness arising from those interactions are almost always close to the surface of the relationship she is describing. Sally's occupational, relational sadness however is constantly juxtaposed by her sadness surrounding her father's death; the personal becomes the professional and the professional becomes the personal. Sally is not the only participant in this study to meld the professional with the personal. In their healing work most of the participants blend their sadness(es) into a positive or creative energy moving towards what Watson (1999) determines is a sacred space, a spiritual experience.

Some issues in presenting a completed symphony

In order to evoke and enhance meaning in this specific research I have explored many stylistic aspects of language and have used metaphor and poetry to illuminate my journey. The following sequence is a description of a hologram of sadness: a hologram thrown forward from my interpretations of the sixteen participants' stories. Use of holographic exemplars to describe nursing work Watson (1999) suggests could be a new model for nursing where the interconnectedness of all things is recognised and celebrated.

In writing this final chapter I struggle with the concept of finality and by inference the idea that sadness, even for the sixteen participants in this study, can be defined as an entity. Therefore in describing this hologram of sadness I am at pains to reiterate that this description is but a momentary picture that I made while engaged in the analysis phase of this research. Now, by placing these metaphorical descriptions before you as text and later as poetics, I am inviting you to stand still with me as together we fleetingly reflect on the sadness events for these sixteen participants.

As we engage in this contemplation, the being and doing of community palliative care nursing, constitutive of intuitive, caring nursing practice, will reveal multiple meanings of sadness for these sixteen participants. I feel confident that while some of these meanings of sadness will be sustained over time, many will disappear into the ether, perhaps to rejuvenate in another place/time, perhaps to die forever. Yet in their short and somewhat precarious lifespan they are meanings that are reflective of critical and creative thinking, moral and intuitive knowing, wise and caring practice, held together in a mesh of relationships.

Viewing the hologram

As has been revealed throughout this thesis the sixteen community nurse participants ostensibly work alone. Yet are they alone? In their daily routine they share, in an ambience of kinship, an intricate lace-work of both fragile and forceful emotions. Emotions that, while emanating from others (patients, relatives and colleagues) appear to be reconstituted and relived within themselves. A gamut of emotions which are in themselves all worthy of separate study. For this thesis however, sadness was chosen as a central focus. Through this point of convergence, sadness became the conduit by which the participants' palliative care nursing practice was laid open for scrutiny, understanding and celebration.

As the participants stories unfolded we became aware of the innumerable relationships in which they engaged as they undertook their day-to-day nursing practises. Palliative care

nursing practises that by their definition have endings, namely dying and death, as the eventual outcome of care. This study has illuminated that nursing someone to death is, in a sense, the greatest professional paradox of all. Through their stories however, we are frequently reminded that while life's ending is the substance of their practice, these cumulative endings do not translate only into something that is being taken away. On the contrary, as we have observed from their stories, the participants frequently discuss their involvement with patients from a position of privilege that creates an unusual ambience in which the relationship is nourished and appreciated. Within this position of privilege the participants share sadness events that, for the most part the vast majority of people within society would wish to remain hidden and unacknowledged. I am reminded however, that the persistent invisibility and concealment of nursing work with people receiving palliative care is one of the reasons why I undertook this study. Together with my previous research (Chapman 1994) the travesties, tragedies, pleasures and paradoxes of working with dying people can be brought to professional and public arenas for discussion, acknowledgment and appraisal.

This thesis also shows that amidst the suffering of others, stories of courage, change and challenge that masquerade as sadness are also freely related by each participant. The complexity of sadness within these stories makes problematic the 'ease' with which these participants view sadness. Loss, for example, is seen as both tragic and auspicious. Death is an experience of the future that is both welcomed and feared within the same moment. Relationships that were once dysfunctional become coupled and connected as the participants effect change within a patient and their family.

As much as their position of loneliness can be said to be illusory, especially when they enter into strong kinship relationships with others, aloneness from human contact is recognised by the participants in this study as a welcome interlude. Time alone becomes a special time when they can ponder upon, or be in conversation with, their very private world of reflection. This study nevertheless alludes that these processes are not always undertaken in solitude. As is apparent from this study, the participants invariably relate intricate details of their regular and sustaining encounters with nature. It is as if the environment that surrounds them each day also assumes the persona of a supportive friend: a friend who ceaselessly and generously listens; one who never makes judgements, no matter how ravaging or desolate the narrative.

This thesis discusses the literal embodiment of sadness by the participants in this study. They become sadness and as they move between people in their care they acknowledge, appreciate and applaud the varied and multifaceted sadnesses that are embedded in their practice as palliative care nurses. As described in the previous two chapters the

participants' sadnesses emerge and dissipate in a moment. Sadness as loss and sadness as happiness for example, can converge within a participant and in a moment project a new meaning of sadness that links positive with negative, despair with pleasure, certainty with uncertainty.

This thesis has brought together my interpretations of the participants' stories of sadness and from these poignant pieces I have no desire to generalise my findings to other community nurses engaged in palliative care. Nevertheless, I do wish to say something about how this study might inform and influence future palliative care nursing in the community. Sadness in this area of nursing work has perhaps a more intense impact on the individual than any other branch of nursing. Sadness is not a simplistic, one-dimensional experience. Rather, it is a complex web of multidimensional, paradoxical experiences that for the most part remain hidden behind and within a compassionate mindfulness of these skilled practitioners. Community palliative care nurses, by working closely with patients/relatives in their own home, transgress the usual health care boundaries that can be realised as protective when positioned within an institution. When nursing in the community it is often difficult for practitioners to escape from the harsh realities and sadness(es) of care. There is no space in which refuge can be taken; no treatment room in which to hide. For most of the participants in this study their only haven of sanctuary is their car. It is often in this small metal box that extreme feelings are acted out or talked over. In the main, these stories of emotional pain are seldom told and hardly ever appreciated by colleagues or others within the community they serve. By awakening us to their stories these participants have already engaged in some inner healing. Providing opportunities for practitioners to talk freely about their multidimensional, paradoxical and complex sadness(es) facilitates a connection to a new creative energy that is both universal and sacred.

Poetics in this thesis, as Carper (1978) suggests, is used as an expression of aesthetic patterns of knowing. By articulating the experienced whole through poetry I have constructed my own holographs which in turn capture some of the mysteries of the participants' experiences. By re-telling their story through the use of poetics, I have created another vantage point from which to view the lived world of a particular participant. In my use of poetry to both introduce and conclude this thesis I have accessed and brought alive some of the complexities, paradoxes and multidimensionalities of the participants experiences that may not have been explored in the text. Poetry is, in itself, complex and multidimensional. By writing poetry I am able to gain entry to '... an ever-changing consciousness ... of this ever changing world' (Holmes & Gregory 1998, p. 1192). Poetry creates the spaces in which multidimensionality can flourish. Thus it is in celebration of, and keeping alive our perceptual sensibilities, that I offer the following

poetics *Daily Travels* as my own reflections of the day-to-day experiences of the sixteen participants in this study.

Daily Travels

On my daily travels, remaining invisible to most,
I explore dark caverns of emotions
discernible only to me as I move in and between the spaces of care.
Yet as a witness to pain and suffering I also hurt.
I hurt for those whose time here
is shortened by cruel blows.
And as a witness to loss I also anguish.
Anguish for those who remain
lost in aloneness, severed in parting, barely alive in dying.

On my daily travels I move between relationships.
Time becomes deceptive, illusive, vanishing
beyond boundaries set down by others
and of life itself.
Dying and death have no measured time.
Dying for one may be death of another, thus
I am caught between and beyond them.
Only the rising and setting sun marks
my time and space within this puzzle.

On my daily travels I dance with decay and demise.
Dying opens my care
yet death does not halt it.
Each death taking a part
of me yet each dying gives me
something to be cherished, nourished and returned.
Returned to those who wait,
returned to those who launch themselves
on life's last excursion.

On my daily travels I am alone with my thoughts.
They cannot be shared,
except perhaps with the birds and the bush.
The sturdy hills—a keeper of secrets;
the meandering river—a vessel for tears;
the car—a confessional, a place of reflection,
a room for renewal. Sometimes music restoring
my soul—promptly and with prudence.
Sometimes silence reordering my priorities, my survival.

On my daily travels I converse with the loved and the unloved,
neither are without despondency.
For the loved cannot bear the thought
of wrenching from others, and
the unloved rip themselves apart
harbouring judgements of yesteryear.
Amnesty, freedom and liberation denied for fear
of exposing self. Isolation becomes an
easy trap to inch into—solitude an enchanting promise.

On my daily travels I observe injustice and virtue
working together illuminating life's lessons.
A family in crisis becomes
a family united. Potential loss of future
heralds challenges and new opportunities.
Ideas once valued—now contested, can yield
different understandings.
Degrees of comfort constantly questioned,
momentarily answered, then thrown again into chaos.

On my daily travels I am sadness.
Moving rhythmically in and between complex
relationships with myself and others.
I am sadness—celebrating the loss of those who have passed through my care.
I am sadness—consoling self and others in our losses.
I am sadness—foreseeing the wisdom of future practice.
I am sadness—rejoicing in the certainty of death and the uncertainties of life.

Afterword

Before finally leaving this thesis it is fitting to consider future possibilities arising from this research. Similar to the present and ongoing debates about nurses and caring I have come to realise that nurses do not hold a monopoly about sadness in the work of delivering palliative care. As a specialty, palliative care has long been proclaimed as a multidisciplinary practice. Thus it would be useful and informative to doctors and allied health professionals who are likewise engaged in such care to replicate this study for those specific groups of health care personnel. A similar suggestion has been recently articulated to me (Hunt, R. Dr 1999, pers. comm., 22 June).

For nurses and nursing however, this study also announces the possibility of viewing community palliative care nursing in a different way. By celebrating the interconnectedness of all things this research emphasises a spiritual dimension of nursing. Not just the recognition that nurses should become involved in spiritual matters for those in their care, but a recognition that nursing is, in itself, a spiritual activity. In making this claim I feel this thesis, with its emphasis on the connectedness of all things, its accent on

rhythmic relationships and belief in esoteric, limitless ever changing realities heralds the emergence of what I have termed a 'nursing theosophy'. In brief, my explanation of nursing theosophy is a philosophical belief that captures a religious (universal) intent of nursing, providing a special insight into the multifaceted energy that is nursing. Clearly this concept is too convoluted to be released or discussed within the confines of this work. It is perhaps a focus for another study that for the moment remains a quiescent overture for myself and/or others to envision within a future possibility.

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Appendices

Appendix I

CONSENT AND PLAIN LANGUAGE STATEMENT FOR PARTICIPANTS

WORKING TITLE OF STUDY: SADNESS IN END OF LIFE CARE: A HERMENEUTIC STUDY WITH COMMUNITY NURSES WHO PRACTICE PALLIATIVE CARE

Investigator: Ysanne B. Chapman RN

The purpose of this study is to reveal the lived experience of sadness for community nurses who practice palliative care. Information will be gathered according to the wishes of each participant but mainly in the media of audio-tape.

The stories you tell me will be tape recorded and we will discuss what it is to be sad in your work as a palliative care nurse in the community. These tapes will not be shared with anyone else and when I have transcribed them I will send you a copy of the text for your own interest and validation.

The topic of your stories has the potential to be very sensitive and may arouse unpleasant feelings associated with loss. Should the situation arise that you become distressed during our session(s) together, I will undertake to cease recording and also give you the option of withdrawing from the research. Additionally, you are also free to withdraw your consent and terminate participation in this research at any time.

If you have any questions regarding the research with the working title 'Sadness In End Of Life Care: A Hermeneutic Study With Community Nurses Who Practice Palliative Care' please contact Ysanne B. Chapman of 12 Winding Way, Belair, SA 5052 (41 Pirie Street, New Town Tas 7008) or by telephoning 041 950 9951.

I (the participant) have read the information above and have been given the opportunity to ask whatever questions I desire and all such questions have been answered to my satisfaction. I agree to participate as a volunteer in the above named research, realising I may withdraw at any time. I agree that research data collected for the study may be published, provided no real names are used.

Participant

Date

Researcher

Date

CODE ASSIGNED TO PARTICIPANT BY RESEARCHER _____

Appendix II

FINAL LIST OF NODES AND THEIR TITLES ASSIGNED TO DATA WITHIN THE NUD-IST PROGRAM

1	Sadness
1 1	Sadness/Search text
1 1 1	Sadness/Search text/Whose sadness?
1 1 1 1	Sadness/Search text/Whose sadness/Their sadness
1 1 1 2	Sadness/Search text/Whose sadness/My sadness
1 2	Sadness intellectualising
1 3	Sadness/As non-acceptance
1 4	Sadness/As acceptance
1 5	Sadness/Gut wrenching
1 6	Sadness/As inadequacy
1 7	Sadness/Failed expectations
1 7 1	Sadness/Failed expectations/As frustration
1 7 2	Sadness/Failed expectations/with community
1 8	Sadness/As mismanagement
1 8 1	Sadness/As mismanagement/Accountability
1 9	Sadness/As misrepresentation
1 10	Sadness/Acknowledging
1 10 1	Sadness/Acknowledging/In colleagues
1 10 2	Sadness/Acknowledging/In relatives
1 11	Sadness/As disenchantment
1 12	Sadness/ Why some?
1 13	Sadness/Competing values
1 14	Sadness/As loss
1 14 1	Sadness/As loss/Anticipatory
1 14 2	Sadness/As loss/Personal relationships
1 15	Sadness/In nursing practice
1 15 1	Sadness/In nursing practice/Missed opportunities
1 15 2	Sadness/In nursing practice/Resistance to change
1 15 3	Sadness/In nursing practice/Others opinions
1 15 4	Sadness/In nursing practice/Unskilled practice
1 15 5	Sadness/In nursing practice/Futures
1 15 6	Sadness/In nursing practice/Team conflict
1 15 7	Sadness/In nursing practice/Team changes
1 16	Sadness/With family relationships
1 17	Sadness/As black humour
1 18	Sadness/Organisational
1 19	Sadness/As reverence
1 20	Sadness/As unfairness
1 21	Sadness/As hopelessness
1 22	Sadness/As identification
1 23	Sadness/As paradox
1 24	Sadness/Coping
1 25	Sadness/ As celebration
1 26	Sadness/As courage
1 27	Sadness/Revisited
1 28	Sadness/As loneliness
1 29	Sadness/Triggers
1 30	Sadness/Questioning
1 31	Sadness/As healthy
1 32	Sadness/Burying

1 33	Sadness/As healing
2	Watching
2 1	Watching/Relatives
2 2	Watching/Friend die
2 3	Watching/Patients
2 4	Watching/Uncomfortable situations
2 5	Watching/New Staff
3	Personal Loss
3 1	Personal Loss/Patient
3 2	Personal Loss/Friend
3 3	Personal Loss/family
4	Privilege
4 1	Privilege/With patient
4 2	Privilege/With family
5	Time
5 1	Time/Running out
5 1 1	Time/Running out/Not making a difference
5 2	Time/Case load
5 3	Time/Time out
6	Difficulties
6 1	Difficulties/Emotional
6 1 1	Difficulties/Emotional/Families
6 1 2	Difficulties/Emotional/Patients
6 1 3	Difficulties/Emotional/Self
7	Hope
7 1	Hope/New treatments
7 2	Hope/Better outcomes
7 3	Hope/Facilitating
8	Unable to help
9	Lack of knowledge
9 1	Lack of knowledge/Doctors
10	New knowledges
10 1	New knowledges/From nurses
10 1 1	New knowledges/From nurses/Better outcome
10 2	New knowledges/Available to patients
11	Game playing
11 1	Game playing/Doctor-nurse
12	Palliative care
12 1	Palliative care/ Palliative care as a specialty
12 2	Palliative care/Beginnings
12 3	Palliative care/Futures
12 4	Palliative care/Comparing old with new
12 5	Palliative care/Complementary
13	Active vs palliative treatments
13 1	Active vs palliative treatments/Option not given
13 2	Active vs palliative treatments/Combination
14	Knowledge of the patient
14 1	Knowledge of the patient/No knowledge of the patient
15	Wounded healer
16	Happiness
16 1	Happiness/Laughter
17	Images and perceptions of palliative care
17 1	Images and perceptions of palliative care/From others
17 2	Images and perceptions of palliative care/From public
18	Death
18 1	Death/Changed ideas
18 2	Death/Unresolved
18 3	Death/Questions

18	4	Death/Effects of
19		Sharing
19	1	Sharing/With the team
19	2	Sharing/With patients
19	3	Sharing/With relatives
20		Stability
21		Influences
22		Goals
23		Study
24		Comparing
24	1	Comparing/Oncology with palliative care
25		Uncertainty
25	1	Uncertainty/Job
26		Making a difference
27		Car as sanctuary
28		Shoulds
29		Funerals
30		Conflict
31		Challenges
31	1	Challenges/Requests for euthanasia
32		Wise practice
33		Self care
34		Control
35		Certainty
36		Reflection
37		Suppressing feelings
37	1	Suppressing feelings/Told by others
38		Sensitivity
38	1	Sensitivity/With carers
39		Knowing limitations
40		Reciprocity
41		Community nursing
41	1	Community nursing/Part of the family
41	2	Community nursing/Accepting the family
41	3	Community nursing/Establishing contact
42		Advocacy
43		Learning from patients
100		Rhythm
150		Relationality

Appendix III

EXPLANATION OF NOMENCLATURE USED IN THE NUDIST PROGRAM

The following glossary is taken from the User's Guide for QSR NUD•IST (1996).

Terminology	Meaning
Node	An index category containing a title, optional definition, editable memo and reference to parts of the data documents. Nodes are connected to each other to form 'trees' of categories and subcategories.
Text Unit	The smallest subdivision of data from a document. In this study the smallest text unit is one line of the data document. Each text unit is numbered from 1. Thus each line of all the documents are individually numbered. Thus any reference to a numbered line in any of the participants' transcripts can be traced back to the original data.
Raw File	A text only file that is used as the source of textual data for a NUD•IST project database.
Memo	A text only file that is associated with a particular node or data document. Memo's are a useful space in which to describe the node, theorise about the node and make notes to be used in a later analysis.
String Search	A search of the NUD•IST system (raw files) for all instances of the exact sequence of characters. In this study the following words: sad, sadness, sadnesses, saddens, my sadness, your sadness, their sadness were presented for string searches.