The Lived Experience of Nursing Dying or Dead People

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A Thesis submitted in total fulfilment of the requirements for the degree of Master of Science (Social Ecology) (Hons)

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Candidate's Certificate

I certify that this Thesis entitled 'The Lived Experience of Nursing Dying or Dead People' and submitted for the degree of Master of Science (Social Ecology) (Hons), is the result of my own research, except where otherwise acknowledged, and that this Thesis (or any part of it) has not been submitted for a higher degree to any other university or institution.

Signed: .................................................................

Date: 17 October 1994 ............................................
This Thesis is dedicated to the memory of my parents, 
Elsie Margaret and Thomas Frederick Chapman. 
Their love for each other and love of life remain cherished 
in my heart.
Acknowledgments

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Abstract

This phenomenological study describes the experiences of twelve registered nurses who have nursed a dying or a dead patient. These registered nurses come from a variety of backgrounds, not only personally, but also educationally and socially. The study primarily focuses on these registered nurses’ most significant experience with death in a professional capacity. Twelve registered nurses were invited to share their stories by means of taped interviews and/or written narrative which attempted to discover the underlying meaning of their experiences. However, in relating their stories, many of the registered nurses wished to describe other death experiences which were of significance for them.

The study is grounded in Heideggerian phenomenology and analysis of the transcripts revealed the emerging essences of connectedness, aloneness, questioning and accepting. The study further reveals that these essences align themselves to the four fundamental existentials of spatiality, corporeality, temporality and relationality as described by Merleau-Ponty (1962). Additionally, these essences are related back to the principles of Parse’s (1987) theory of Human-Becoming and provides some insights for nursing practice when caring for the dying or the dead patient. Some discussion on how these insights may be related to contemporary nursing practice in Australia is highlighted.

Each participant’s transcript is followed by a poem which intends to capture the essence of their relationship with the situation(s) they have shared with me. These poems are my personal gift to these registered nurses who so willingly and freely entered into sometimes tortuous recollections in order to find meaning. Without their risk-taking this Thesis would have remained a dream. Their unconditional inspiration has been a prime motivation in developing this dream into a reality.
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Prologue
This prologue presents my initial death experience and subsequent significant personal and professional death experiences. Its aim is to provide an insight into my social context. It is an invitation to share the lived-world-of the researcher.

BACKGROUND TO THE STUDY

The idea of researching the lived experience of nursing the dying or the dead originated from my work as a senior lecturer in nursing at the University of New England. Since the late 1980s, sections of the nursing community have increased their interest in undertaking further studies in the care of the dying. My background and experience in palliative care has assisted me to introduce a strand of studies in palliative nursing for undergraduate, post certificated registered nurses and postgraduate students and revise the program about death, dying and bereavement offered to pre-registration students. Prior to the revision of the program many students made comment on their first or significant experiences of nursing the dying or their involvement with caring for a dead body. These experiences were often traumatic, as were my own, and I began to wonder if these significant death experiences made any difference to nursing the dying or the dead. Nursing the dying encompasses palliative nursing of acute care patients who suffer sudden death, or long term chronically ill patients who may die. It may appear unusual to research nursing the dead. However, it is well known within the nursing community that nursing does not cease with the last breath of life and there are certain nursing rituals undertaken after a person has been pronounced dead.

MY INTEREST IN THE TOPIC

My passion for understanding death and dying has evolved out of my personal and professional development in the area. In the early 1980s my personal life had been in unresolved turmoil from cumulative loss, and since my father’s death I had been in the process of developing an acceptance of these personal losses. It was to be a spasmodic development, compounded by divorce and movements from home of my children. More recently, during the writing of this Thesis, my mother died. On reflection, my life has been an evolution of learning experiences.

My professional life too has moved me through several death experiences, some of which I will share in this Thesis. In my early years as a registered nurse I
avoided working in areas of clinical practice in which patients were more likely to die. I became an expert practitioner in operating rooms, intensive and coronary care and surgical nursing. I had been conditioned in the medical model school of thought where the preservation of life was paramount and death was viewed as a failure.

My initial death experience occurred in 1966 during my hospital training period. It was a bitter English winter. The snow lay like immovable slabs of white concrete slowly melting where it came in contact with the once vibrant colours of the autumn scene. I started my daily routine with a cautious slide down Belsize Park Road towards Chalk Farm Station and the inevitable crush on the ‘tube’ train towards the city. How I hated the smells on the train; cheap perfumes blended the plethora of body odours. Stale alcoholic breaths and aromatic tobaccos mingled with the heavier and overpowering stench of the underground network itself.

I felt so insignificant as I travelled with the millions pouring into London for their ‘daily bread’. Three months had passed since I left the peace of the Thames, the quiet river banks, my trusted friends and my parents’ home. These were three months of preliminary training towards completing requirements for my chosen profession. I had learned to make beds—not just empty ones—theatre beds, occupied beds, fracture beds and split beds. I had gained skills in washing walls and lockers, scrubbing bed pans and lining up endless bottles in spotless store cupboards. Two weeks’ experience on my first ward and I was now able to wash patients, give them bedpans without embarrassment (mine or theirs) and take and record their observations. Was this nursing? Staff nurse roared at me continually, “You’ll never make a good nurse, you can’t make beds fast enough.” I questioned her criteria for the makings of a good nurse and was reported to the ward sister for insubordination.

The pan room became my sanctuary. The molten metal shone from hours of hard rubbing with powder cleansers and tears. The view from the pan room was less than inspiring. The hospital was old and was held together by a network of rusting, leaking pipes. Steam burst from them as if yelling some obscenity or protest; lagging loosely clad around the pipes as they shook in their duties of their daily business, shunting the waste away. The London skyline, bleak and ever grey offered little relief from the torment of staff nurse’s wrath.
Monica had been a patient in the female medical ward for two weeks, arriving the
day after my commencement date. She was most tolerant of this novice as I
admitted her to her bed. This was Monica’s fifth visit to hospital within that
year—1966. She was only fifty-four, but her medical condition made her appear
at least twenty years older. She was a large lady, quite tall and had bulging eyes,
rather like a bull frog. Her face had a purple tint as she found it hard to breathe;
however, her warm and patient nature contributed to the bond that we formed
during those weeks. Staff nurse said that she was a difficult patient, whatever that
meant, but I enjoyed looking after her. She was confined to bed, thus she needed a
lot of attention. Also, her bladder had weak muscles and she needed to use the
bedpan more often than the other patients in the ward. We had lots of fascinating
conversations during bath times; she had been a nurse during the war and related
her stories with lots of sadness and a little humour.

Somehow that particular day was different. Monica was not her usual self. She
said very little during her bath in spite of my constant chatter. I could see she had
some slight irritation with all the noise in the ward and my own babbling, so I
asked her if she would like to keep the screens around her and maybe have
another sleep after her wash. She looked relieved and said that sometimes she just
wanted to be alone with her thoughts and this was one of those times. I made her
as comfortable as possible, placed the buzzer in her hand in case she needed
anything and left her to her privacy. I hurried to my next patient. Staff nurse was
on the war-path and I couldn’t face another confrontation about not finishing my
patients’ beds in time for matron’s round.

It was possibly twenty minutes later when the buzzer rang in rapid succession. I
looked down the ward and saw the light outside Monica’s screens. Intuitively I
knew that Monica needed a bedpan so I darted into the pan room on my way to
her bed. As I opened the screens she sat bolt upright and in a distressed voice said,
“Quick nurse, a pan!” I assured her that I had one and helped her onto it. Almost
immediately she slumped back and groaned. I looked at her in amazement as she
went purple and gasped for breath; her eyes appeared to pop out of her face as she
fixed her stare on me. Terror and fear hit my abdomen, my knees began to shake
and my hands fumbled for the buzzer; we both needed help. I pushed the back-rest
in so I could lay her flat and gave the buzzer three sharp hits. Within seconds staff
nurse and two senior student nurses were at my side. They shouted orders at each
other as Monica was stripped of her nightdress and placed on the floor. Where
was her privacy now? I stood motionless and watched the nurses, still shouting,
pound her chest and give her mouth to mouth resuscitation. I wanted to scream, I wanted to cry, I wanted to run. Nothing would happen. Staff nurse was yelling, the senior nurses were yelling, but I couldn’t hear them. All I could see was Monica’s face, now black, her body mottled, her eyes still transfixed.

“Well, she’s dead,” said staff nurse as she hurried past me towards the telephone. “You had better get everything ready to lay her out nurse,” she bellowed in her usual matter of fact manner. Dead, Monica dead. I heard the words but the thought would not connect. I could see this lifeless body lying at my feet, yet I refused to believe that Monica had died. How could she die? She was my favourite patient, we had shared so much together. Why would she want to die right now? A burst of energy propelled me into my safe place, the pan room, and I began to weep.

“Ever done this before?” staff nurse said as she pointed to the trolley with the equipment in it for last offices. My lack of response must have relayed the answer as she said, “Well, you’re going to have to do it sometime, so you may as well do it now. By the time you get organised the hour will be up,” she added sarcastically. “What happened, staff?” hardly able to choke out the question. “Probably a pulmonary embolism,” she retorted. “They always go like that, on a bedpan. Don’t they teach you anything in that school? One of the seniors will help you.” She left the pan room in her usual brisk manner, the starch in her uniform crackling as she brushed past me.

For once, staff nurse was right. It took me an hour to assemble all the equipment for last offices. A senior student put her head around the pan room door, asked if I was ready and told me the routine of what we were about to do. Monica was back in bed, her eyes closed, her hands placed across her chest and a white sheet was pulled up to her neck. Ridiculous thoughts rushed into my head. I didn’t tell her about my night at the theatre last night. I didn’t tell her about my plans for my days off. I didn’t say goodbye. We washed her and dressed her in her favourite nightdress. I wanted to talk with her. I wanted to hear her stories. Now she was dead and I would never have that chance. I placed a rose inside her hands and covered her face, now pale, yet peaceful. The senior nurse was called away and I retreated to the pan room to dispose of the equipment. Steam belched out of the pipes on the other side of the hospital. My friend had died and I cried.
“Pull yourself together,” staff nurse bellowed in my ear. “There are other patients to look after. It’s not professional to get so upset. Go and make up that bed. There’s a new admission coming.” Is she the epitome of a good nurse? How can she be so unfeeling? Can’t she just leave me alone for a while? I wonder if she ever cries? I wonder if anything ever touches her? Perhaps it’s me, perhaps I became too attached to Monica? So many questions and no-one to trust to answer them.

“I heard you had a death,” said one of my peers. “Yes,” I replied sadly. “What was it like?” she asked in a ghoulish fashion. There was lots of talk in the tea room about Monica—graphic descriptions of how she died and many theories about the cause of her death. I closed my ears and retreated to my own pain. Who could I talk to? Was this what nursing was all about? As I returned from the dining room I saw the ward sister sitting at her office desk, the starch in her uniform holding her back in an upright position. We had exchanged very few words since my arrival to her ward: a formal greeting as we listened to her report each day; a few words of retribution; and asking permission to leave the ward for lunch or off duty. She was a woman of few words. As I stood in front of her, hands shaking behind my back, she peered at me from over her half moon spectacles and asked what I wanted. Timidly I asked if I could speak with her about Monica’s death. “Not now, nurse,” her Irish brogue made her sentences lilt at the end. “If you have any problems, see staff nurse.”

I encountered death several times during the following three years of my training. Each time was just as painful and each time I ignored my feelings. I was determined to be a ‘good nurse’ and ‘good nurses’ didn’t cry. I had learned my lesson well. New students would come and go and be in conflict about death. I was a senior now and I knew all the answers. I would mouth the words about getting on with the job, not allowing feelings to get in the way and being professional. I joined in with the laughter and the jokes about death experiences. I had become a real nurse!

Seven years later, and half a world away from England, my first child was stillborn. My labour was short and very intense and my only comfort was an enrolled nurse who sat with me and gave me encouragement to deliver my dead son. He was placed in a wicker basket and quickly removed from the labour ward before I could ask to see him. The registered nurses on duty at the time said it was fortunate that I didn’t see him and I believed them. Death had visited my front
door, yet I refused to acknowledge its rite of passage. He was buried in an unmarked grave and I left hospital with an armful of flowers. The weeks prior to my post natal check-up I walked the streets avoiding women pushing prams, unable to contain my tears as my breasts moaned with the weight of the milk that my baby should have sucked. The obstetrician advised me to go ahead and embark on another pregnancy as soon as I felt emotionally stable and gave me some pills to dry up my breast milk.

Fourteen years ago my father and I were enjoying our moments together after a difficult relationship in my childhood. I had come to love him and accept him as a beautiful, warm person and he no longer considered me to be a four year old. We were holidaying together on the mid-north coast, playing games with my sons, talking about his life as a child, fishing off the rocks and taking long walks along the beaches. He was not a man in good health but had a desire to live until the year 2000. We often made plans to explore Australia together, touring by car, pitching the tent, living the experience—an exciting dream.

The holiday was our last time together. He had a cardiac arrest and died in my arms. I was unable to save the one man I loved and trusted. My wealth of experience in cardiac nursing left me incompetent in the moment that I needed it most. The pain of his death was so powerful that it brought all my death experiences flooding back. I had reached saturation point with accumulated grief. The process of working through my personal and professional death experiences was complex, poignant and often depressing. There were times that I felt the tears would never stop. My counsellors were as numerous as the techniques which they used as the years of embittered responses erupted from my belly.

After separating from my husband and subsequent divorce in 1983, I moved to the far north coast of New South Wales. I lived in a small fishing village, bounded on the west side by a tidal river and on the east, the glorious ocean. It was situated fifty kilometres from the nearest major town; I had found my ‘Mecca’. For three months I basked in the warmth of the north coast autumn, walked for miles along the pale sand beaches, strummed my guitar beside the banks of the river, wrote poetry and settled into my new life as a single parent. I reflected on the losses associated with my divorce and, being unemployed, had the time available to gently massage the emotional wounds to emerge as a peaceful but courageous woman.
My life of leisure was halted by an offer of employment as the local community health nurse. It was a new position and I was ready for the challenge. It was a chance for me to be creative in my approach to nursing and it was my first venture into community health activities. As well as the usual duties of a 'district nurse', I was given 'carte blanche' to develop health related community programs, specifically reflecting the needs of the local, permanent residents. However, it was the delivery of basic nursing care that cemented my feelings of getting in touch with what I call 'grass-roots' nursing.

As time progressed I formed a unique bond with my clients and their families. I became an adviser, an educator, a counsellor and, more importantly, a friend. It was difficult at times to claim time for myself, but the people of the village soon learned to accept Ysanne, the nurse who would drop everything and attend to their needs, and Ysanne, the very private person who needed space to be alone. My personal life followed a convoluted pathway; my emotions mirrored the route, yet I felt balanced and energised.

My inner and outward war with death and dying changed as a result of one very special experience. I attended the home of Ben, a man who was dying of mesothelioma, the end result of exposure to mining asbestos. He was married to Priscilla, a woman several years his junior. They had raised a large family and were enjoying the fruits of their labour in their grandchildren. The process of his dying was long and tortuous and fraught with the agony of acceptance of the ultimate by both himself and his wife. To me, they were lucky to be able to have the time together, knowing that death was not far away. I remembered my agony and that of my mother when my father died so suddenly. Ben and Priscilla had time to deal with unfinished business and could make plans for Ben's death and life afterwards for Priscilla. Convincing them that this situation was a more favourable position to be in was no mean feat. Nevertheless, they began to communicate and I felt a sense of satisfaction with having been able to facilitate that process. When it was time for Ben to die, he called for me and asked me to telephone for an ambulance. He did not wish to die at home, nor did he wish to die in front of Priscilla. Priscilla accepted Ben's wish to die away from home and she held on to me as we waved him goodbye in the ambulance. After the ambulance left we sat together for almost an hour and wept. We talked very little except to agree that we were both very honoured to have known Ben in our respective special ways. The telephone rang and I answered. Ben had died in the ambulance, on his way to hospital.
As a budding poet and a lover of the art I have read many poems which have brought alive the feelings associated with my life experiences. In writing this Thesis, poetry has become a significant adjunct to the lived experience stories told by each of the participants. In the following poem, Marjorie Pizer (1983) encapsulates my sentiments about Ben’s death:

I had thought that your death  
Was a waste and a destruction,  
A pain of grief hardly to be endured.  
I am only beginning to learn  
That your life was a gift and a growing  
And a loving left with me.  
The desperation of death  
Destroyed the existence of love,  
But the fact of death  
Cannot destroy what has been given.  
I am learning to look at your life again  
Instead of your death and your departing.

My work exposed me to several death experiences similar to that of Ben’s, in that I had become closely associated with the people and their families. With each occasion I became more comfortable with my feelings, able to express them in a free and uninhibited way. Was this the result of maturity or had I become more accepting of my own immortality? I had certainly matured. I no longer depended on a man to affirm or confirm my life actions; the responsibility of self and my children rested comfortably within me and I not only felt in control of self but also capable to deal with the negative emotions which arose from my life-work. I made mistakes in my life as a single mother but rather than dwell on them and sink into depression, I used them as a learning experience. I turned the negative into the positive and began enjoying life without feeling guilty. I thought of my own death many times. Being alone, without a full-time, live-in relationship or permanent partner, I developed a pragmatic approach to death. I was no different to anyone else; I possibly would die, hopefully later than sooner and my children would have to adjust to a new life with someone else, just as they were currently adjusting to their new life with their mother. My own life was exciting, challenging and had direction. The future held many options and I feared none of them, including death. I had found an inner peace, not in the form of any recognisable faith or religion, rather a deep and satisfying ‘knowing’ and appreciation of self.

Three years later I felt that it was time to move on. An immense amount of inner healing had taken place in that little village; now I was ready to face the city
again. I was successful in gaining a position as a senior nurse educator at a hospice in Sydney’s inner city. Again I had chosen a career path of great challenge. The AIDS/HIV epidemic was just emerging and I was in a position to develop learning packages and resources for the staff, in preparation for admitting AIDS patients to the hospice.

My journey in palliative nursing had begun. I had made a ‘round trip’ in my career: from the acquisition of basic nursing care practices in my training days to the technology of coronary care, operating theatres and a basic premise of saving lives at all costs. Now, I was choosing to return to basic nursing and caring for the dying. However, this time the experience would be different. Along my unique and powerful pilgrimage, I had accommodated within myself an inner, intuitive appreciation of the meaning of ‘caring’ and the various dimensions of creating its ambience within my work.

Besides designing and conducting workshops, courses and other education packages, my work at the hospice involved a great deal of involvement with the students working at the patients’ bedside. Although the staff in the palliative nursing area were supportive of the students, sometimes the workload of the more experienced nurses prevented them from offering sensitive instruction to a student. As the memories of my initial death experience stayed fresh within my mind, I wanted to avoid leaving students without support and guidance. Thus, the staff of the education centre, that is, myself and a junior registered nurse, were called upon to facilitate the students’ grief.

Students at the hospice were training to the level of an enrolled nurse and had little or no theoretical input on which to base their interactive processes with a dying patient. The orientation program provided some insight into dealing with a dying patient and, for some students, this was enough. For others, however, dealing with a dying patient and their relatives was both a terrifying and traumatic experience. I was determined that none of the students should endure a similar experience to that of my own first death of a patient.

Consequently, in these situations I placed a greater emphasis on the experiences of the nurse rather than the death itself. I am not saying that the patients’ needs were not met; the staff on the particular ward were more than able to meet their needs. Rather, my priority was the support of the nurses as they nursed the dying
or dead patient. The hospice philosophy encouraged the nursing staff to participate in all of the rituals associated with the dying and death of the patient in their care. Students and registered nurses attended ‘last rites’, celebratory ceremonies of comparative religions, for example, the Buddhist chants and funerals, however unorthodox. Staff were allowed ‘time out’ from the ward area immediately following the death of a patient to reflect on, or express, their grief. It was inspirational for me to find a nursing philosophy in action which valued the nurses’ ‘rites of passage’ vis a vis those of the patient.

My learning about death and dying continued long after I left the hospice. Consolidation and internalisation of feelings and attitudes towards mutual sharing of knowledge are fostered and nurtured within my present working environment in the School of Health at the University of New England. My links with death and dying education are twofold. Firstly, I have developed a unit in palliative nursing which is offered to students in the undergraduate and postgraduate degree courses. The university offered this unit for the first time in 1990 and there have been over one hundred and fifty registered nurses who have undertaken the unit to date. Secondly, I have a continued involvement in teaching pre-registration students about palliative nursing and approaches to death and dying in a variety of clinical settings. During the annual death and dying workshops we share many stories. Some of these stories are in the form of poetry and already have been committed to print. I look forward to continuing the publication of these works in future years.

Sadly, my mother died earlier this year before she could read this Thesis. The poignant experience of her death is tempered by thoughts of her leaving her tired body and being re-united with my father. In life and in death, my parents are two of my teachers.
Chapter One
Introduction
THE PURPOSE OF THE STUDY

This study has been largely influenced by my own significant experiences with death in the clinical setting and the knowledge gleaned from recent students that similar traumatic experiences are still prevalent despite the availability of educational programs for health professionals in many aspects of care for the dying or the dead. As a registered nurse I acknowledge that much of our work has a strong bias towards wellness and a focus on the living. However, not all patients live, and some patients are placed in our care because they are about to die.

As patient advocates, nurses are involved in identifying and anticipating patients’ needs. Fulfilment of these needs in the dying process is just as important as satisfying those which facilitate the process of living. In understanding how we, as nurses, facilitate these needs we must understand our patient, but, more significantly, we must understand ourselves. Frequently the relationship between ourselves and the patient goes beyond the dimensions of the socially constructed nurse. We may assume many roles. As well as a nurse, we could be a confidant, a counsellor, a teacher, but, more importantly, a friend. Most of the time it is impossible to distinguish between the many collaborative ‘selves’ we bring to the nurse-patient relationship. The multi-dimensional aspects of who we are and the way we are in the world impacts on how we perceive our worlds of nursing. Thus, to understand or make meaning of nursing and, in this case, nursing the dying or the dead, we must look beyond our own experience and discover the experience of others.

Therefore, I became interested in exploring the lived experience of other registered nurses in their significant encounters with nursing the dying or dead patient. I was hopeful that the study would illuminate a myriad of both positive and negative responses and provide some insight into what it means to nurse the dying or the dead. The study was not designed to give a ‘recipe book’ approach to nursing. It does not pretend to deliver answers to specific problems. Rather, the meaning of the experience is intended to arouse and, hopefully, enlighten nurses to improve their practice of nursing the dead or the dying.

CHOOSING A RESEARCH METHODOLOGY

I began my struggle with methodology whilst defining my question. My ideal was to find a suitable methodology which was innovative, creative and insightful and
followed the loose but expected social ecological theme. The methodology also had to encompass a valuing of the storytelling process, a focus on meaning making and an internal theory which acknowledged the interrelationships of people with their environment. The concept of constructivism was appealing, yet for me lacked a feeling of ‘newness’ and, to some degree, demanded some ‘directional’ input as the researcher. Perhaps ‘directional’ is not the most appropriate word here but after reading Kelly (1955) and how his theoretical model has been applied I felt that some of the meaning making had been taken out of the control of the co-researchers and permitted the manipulation of the studies by a named main researcher rather than a collaborative response to the research question. There had to be something better! Some process which allowed the participant to direct their own contribution to the research and in so doing share with the researcher the significance of their own experiences.

Nursing research, although still going through a stage of infancy when compared to other disciplines, has been heavily influenced by the logico-positivists. The historical links with medical science and the so-called ‘dominant paradigm’ have not served nursing well. Nursing is more than the implementation of prescribed orders. It is a profession which has people as its central focus and the understanding of people as its core. I have a belief that nursing work is truly immersed in a social ecological framework, yet it has still to enjoy exposure to a more qualitative stance within its research. New paradigm research has opened the doors for nursing to move away from the positivistic position and explore a newer stance through the interpretive and socio-critical paradigms. Thus, the search began again and I looked long and hard at the interpretive paradigm for a method which could form a bridge, a linkage, between the old and the new. In short, I did not want to throw the baby out with the bath water.

Part of my own academic commitment is input into a unit of study on nursing theories. I have been involved in this unit for the past three years and have had a continuing interest in understanding how nursing theory informs nursing practice, which in turn informs theory. This dialectical response is claimed to have been born out of the development of a more socio-critical stance and the adoption of this paradigm, in part by the nursing scholars of the 1970s, such as Patricia Benner, Jean Watson and others. I stress the ‘in part’ nature of adoption, as most new nursing scholars would classify their work within the humanistic framework, rather than the socio-critical.
Parallel with my own interest in expanding my knowledge base of nursing scholars was an increasing interest in chaos theory and its relationship to nursing. The idea of patterns emerging within the complexity and unpredictability of the world of nursing and the world in which we ‘are’ and continue to ‘become’ led me to try to uncover the life-works of Martha Rogers, a nursing scholar whose work baffled me and caused me some distress in understanding. Rogers (1970) calls her theory ‘The Science of Unitary Man’. However, I began to slowly uncover some meanings behind her work and it was during this journey that I came across the works of Rosemary Parse (1981). Talking with my ‘on-site’ supervisor, an acclaimer of Parse’s work, helped me in my discoveries. He described Parse as the only true nursing theorist, in that she has developed a research methodology which is based in and of nursing whilst the other so called theorists rely heavily on their exposure to the social sciences to formulate their theoretical frameworks.

The fundamentals of Parse’s theory include: the person relating to the environment; the person constructing in their world with others; and the person achieving understanding of the freedom ‘to be’ and ‘become’ in an increasingly complicated world. These assumptions emerge from the principles and concepts developed by Rogers, and Parse admits that her work is influenced by some of the existential philosophers and proponents of phenomenology such as Husserl and Heidegger (Parse 1981). Parse calls her work the Theory of Human-Becoming (formerly Man-Living-Health). Yet another, perhaps less obvious, criteria for finding a suitable methodology was my need for some degree of comfort with methods arising out of the methodology—methods commensurate with my belief system at this time of cooperation and collaboration and one that could be readily identified as informing nursing work.

My initial exposure to Heidegger was through the work of Benner and Wrubel (1989) and, more recently, my introduction to Parse (1981). After reading the work of these two nurses, I became increasingly interested in Heideggerian philosophy as a philosophy of everyday life. Reading Heidegger’s work (1962) and proponents of his work (Gelven 1989; van Manen 1990) awakened my interest in hermeneutics and the powerful, yet apparently simple, nature of gaining meaning from listening to others tell their stories. Much of the phenomenological research in nursing has been concerned with the nurse-patient interrelationship, with the patient being the central focus. This study has the nurse as the central focus, yet surrounding these nurses are multi-dimensional facets of the
interrelationship with their patients and the influence of life experiences, education, attitudes and values on the perception and actioning of the nursing these nurses deliver.

It has been said that nurses are great storytellers. A non nurse listening to the stories of nurses’ life-work could experience a whole gambit of emotions but to another nurse these stories may be a method of finding commonality, or meaning to their work. The weaving of a story and the action of telling it moves the narrator beyond the experience they are describing. This movement correlates with Parse's principle of cotranscending in which she argues that the person has the potential to become aware of what is possible and to choose from the future (1981). Within this principle the concepts of powering, originating and transforming underpin the movement from what was, what is and becoming the not-yet (FitzGerald 1992, p. 6). Parse says that the process of transforming change gives way to the creation and recognition of chances. She (1981) also believes that 'persons are the experts in their own lives,' thus, storytelling would seem an ideal method for gathering both individual and collective meaning. Parse likens her perspective of people to stories.

Thus, it became clear to me that hermeneutic phenomenology, based on Heideggerian philosophy, was to be my choice of methodology for this study. Additionally, Parse’s work would provide me with the necessary linkage I needed to make with nursing practice. I approached several registered nurses who were visiting the university for nursing studies residential schools and invited them to be a part of this study. In explaining my research some of them were very enthusiastic to share their stories; others were reluctant for fear of revisiting traumatic events. After explaining my interpretation of their participation in the study, twelve registered nurses agreed to share with me their stories.

**EXPERIENCING THE STUDY**

As a registered nurse I have built up a network of colleagues in the profession, some of whom were interested in participating in the study. Additionally, as a senior lecturer in nursing within the School of Health at the University of New England, I had continuous contact with many registered nurses who were undertaking studies in nursing or nursing related subjects. I came into contact with most of the students undertaking undergraduate or postgraduate degrees and would frequently meet with a small number of students to discuss research issues
of mutual interest. During these discussions I briefly talked about my own research and asked if any of these students were willing to participate. Several registered nurses came forward and said they were interested and I spoke to each person individually and outlined my expectations of their commitment to the study. Some of the people who expressed interest declined to be involved because of time or distance constraints; reasons given were limited time at a residential school to conduct interviews, or their place of residence was in another state or territory, making it too difficult for me to travel to conduct interviews.

Some participants were concerned about being interviewed and preferred to firstly, write down their experiences, then receive my comments and engage in dialogue with me at a later time. As time constraints for these registered nurses were high in their priorities and the writing of narrative was consistent with the methodology it was agreed that some participants would utilise both methods. Some participants were concerned about speaking into a tape recorder and after some initial hesitation became quite fluent in their storytelling. I assured each participant that their written stories and/or taped conversation would be kept in a locked cabinet in my home study office and that immediately following transcription and analysis I would keep the tapes and/or written stories safely locked for a period of five years and then destroy them. I also assured each participant that I would use only pseudonyms in the study to preserve anonymity and confidentiality.

I cannot ignore the relationship between myself and the participants which was strengthened as a result of engaging in this study. The collaborative nature of the research and identification with some of the participants' experiences left me feeling that most of these registered nurses needed to tell these stories as a release. For some, this study provided them with the first opportunity to ventilate sensitive and sometimes painful recollections of their stories in a safe and trusting environment. This recognition gave me a real sense of satisfaction and appreciation of the intrinsic value of interpretive methodology in conducting research.

**GENERATING MEANING**

I listened to the taped interview and commenced the transcription as soon as was practicable. In some cases this was immediately following the interview; with others, it took up to one month. My word processing skills being limited enabled
repeated listening to each interview. This close scrutiny of each interview assisted me to identify emerging themes and differences between each participant. With the participants who wished to initially write down their experiences, I copied their stories into the word processor and returned my responses via an audio tape. They in turn replied by tape and these responses were listened to and typed into the word processor along with their initial written responses. Each participant expressed a wish to read the completed Thesis. As this was an impossibility at the time of interview I assured the participants that I would maintain communication with them through the process of the research. When each transcription was finished I sent each participant a copy for validation and personal interest. Whilst validation with the participants is not dictated in phenomenological research, I felt a sense of security in undertaking this process.

Although there are a variety of computer analysis packages available I was unfamiliar with their usage. Thus, essence extraction and analysis were performed manually using a combination of listening and reading the transcripts and a colour coding manual method of identification. I considered that the frequency of listening to and reading the transcripts of the interviews fostered my interpretations of innuendo and emotion which complemented each story.

Preliminary explicit and implicit essences were formulated from the relating of each story. van Manen (1990, p. 90) speaks of themes as ‘... metaphorically speaking they are more like knots in the webs of our experience, around which certain lived experiences are spun and thus lived through as meaningful wholes’. Thus, essences are intransitive and describe aspects of the structure of the lived experience. These initial essences were then woven into the four ‘fundamental lifeworld themes’ or existentials of spatiality (lived space), corporeality (lived body), temporality (lived time) and relationality (lived human relation) (Merleau-Ponty 1962, cited in van Manen 1990, p. 100).
EXPLANATION OF KEY TERMS AND STYLES USED IN THE THESIS

1) Key terms

**Phenomenology**—A philosophy as well as various research methodologies recognising that there is no such reality as objective reality and that all reality is subjective. As a research methodology, phenomenology attempts to describe the ‘lived experience’ using language, without changing the meaning of that experience.

**Husserlian Phenomenology**—Edmund Husserl is considered to be the ‘father’ of phenomenology. He refers to his own methodology as ‘eidetic reduction’, that is, an attempt to describe, through memory imaging of the experience of conscious acts, the way the world is. Husserl differs in his approach from Heidegger in that he requires the researcher to bracket or suspend pre-conceptions thus overcoming subjective bias.

**Heideggarian Phenomenology**—Heidegger was a student of Husserl and like Husserl he believed in letting the facts speak for themselves. However, the major difference between Heidegger’s approach and Husserl’s approach to phenomenology is that Heidegger refuted the possibility of a value-free interpretive research. He views the researcher as being-in-the-world of the research question and recognises and accepts the researcher’s presence and influence on the research process.

**Hermeneutics**—The term comes from the Greek verb *hermeneuein* which translated means ‘to interpret’. It is a method of uncovering implicit and explicit meanings and has been used extensively in the interpretation of the Scriptures.

**Lived Experience**—The unique meaning for people experiencing their lifeworld.

**Existentials**—The name given to the fundamental thematic structures which pervade the lifeworlds of each human being. For the purpose of this research ‘existentials’ refer to spatiality, corporeality, temporality and relationality.
Ontology—A curiosity or consideration of what it means to be or exist. Heidegger has called ontology the ‘phenomenology of being’ (1962, cited in van Manen 1990, p. 183).

2) Styles used in this Thesis

Interview, conversations and story are used interchangeably to symbolise the collective nature of the information gathered from each participant.

Words written in the font Zapf Chancery are transcribed verbatim from the interviews with the participants.

Pseudonyms have been used for all participants and for identifying patients whom either I or the participants have nursed. The choice of pseudonym in these cases is merely a representation of gender.

The first person ‘I’ has been used extensively throughout this Thesis to portray the extent of my personal involvement in this study.

Professional terminology has not been defined; however, wherever possible an explanation of nursing terminology is provided within the text of the 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. This style has been guided by the ‘Style Manual’ as produced by the Australian Government Publishing Service (1988, p. 38).
ORGANISATION OF THE THESIS

The Prologue provides the reader with an opportunity to engage in the lived-world-of-the-researcher.

Chapter One provides an introduction to the research, and explanation of the common terms used in and organisation of this Thesis.

Chapter Two gives an overview of the research methodologies which ground the study.

Chapter Three reviews the literature on nursing the dying or the dead. In this chapter some critical analysis of the extant literature is undertaken and the researcher’s contribution to the literature is discussed.

Chapter Four explores the phenomenological methods used in this study.

Chapter Five introduces the stories of the twelve participants with some preliminary commentary from the researcher. Each story is concluded with a poem to honour each participant and give gratitude for their involvement in the study.

Chapter Six embarks on the presentation of the common emerging essences of the research and weaves the phenomena of connectedness; aloneness; questioning; and accepting into the four existentials of spatiality, corporeality, temporality and relationality.

Chapter Seven concludes the study by noting how research findings provide insights into nursing practice with dying or dead people and offers some possibilities for further research.

The Epilogue concludes the Thesis by providing some self-reflection by the researcher on the research process.
Chapter Two
The Research Methodology
In contrast to Chapter One, this chapter assumes an academic focus. In attempting to explain the methodological underpinning of this study it is essential that a comprehensive view of the chosen methodology is provided. Whilst acknowledging the sometimes difficult language and concepts in this chapter, I feel it is essential to enter into the world of phenomenological methodology and grapple with these complexities. van Manen (1990, p. 3) provides some impetus to rise to this challenge, ‘... almost anyone who is seriously interested in human science research can benefit from an examination of its methodological dimensions’. In writing this chapter, I was conscious of my need to explain these sometimes tortuous complexities in clear and unambiguous terminology.

This study is concerned with the meaning of experience, thus the philosophical and methodological foundations underpinning the study are grounded in phenomenology. Phenomenology as previously mentioned is both a philosophy and a research method (Field & Morse 1985, p. 27; Gelven 1989, p. 37). This chapter will describe the development of phenomenology, in particular, Heideggerian phenomenology, and distinguish it from Husserlian phenomenology. It will consider Heidegger’s (1962) own theory of death and discuss in detail the four fundamental lifeworld existentials as used in this study. Furthermore, it will examine how phenomenology has been used in nursing research and the contribution of phenomenological research to nursing practice. Finally, this chapter will describe the American nursing scholar Rosemary Parse’s (1981) theory of Human-Becoming.

**PHENOMENOLOGY**

Phenomenology can be described as an interpretive methodology, seeking to find meaning in the lived experience of others (Taylor 1994; Field & Morse 1985; Pearson 1989; Gelven 1989). Phenomenology was first described by Franz Brentano in the late 1800s and later developed by Edmund Husserl (1859–1938) (Parse, Coyne & Smith 1985, p.15) as a method of inquiry which revolutionised the move away from the dominant logico-positivist paradigm grounded in Descartes objective reality (Gelven 1989). The logico-positivist paradigm attempts to control, manipulate and predict the world by stating that knowledge can be deduced by objectivity and control (Pearson 1989, pp. 98–99). The positivist paradigm is still considered to be the dominant paradigm of western thought and certainly has its place in the consideration of cause and effect relationships and most quantitative research analysis. However, the very nature of
objectifying human behaviour initiated the response for the development of another way to view the world and the foundation of other philosophical views or paradigms. Phenomenology evolved as a reaction to scientists believing that people’s behaviour could be controlled in the same manner as natural phenomena (Field & Morse 1985, pp. 27–28). Gadamer (1975) purports that ‘... the preoccupation with objective method or technique is really antithetical to the spirit of human science scholarship’ (cited in van Manen 1990, p. 3).

The differences between human sciences and natural sciences are well described by Wilhelm Dilthey (1976) with the former being characterised by ‘mind, thoughts, consciousness, values, feelings, emotions, actions and purposes, which find their objectifications in languages, beliefs, arts and institutions’ (cited in van Manen 1990, p. 3). Natural science studies the objects of nature and the way in which these objects behave (van Manen 1990, p. 3). Natural science uses methodologies congruent with controlled experimentation, detached observation and quantitative measurement. Thus human science and, more specifically, phenomenology aim at unravelling the meaning of how human beings exist in the world.

The issue of rigour in interpretive research cannot be judged by using reliability and validity as with quantitative research analysis. These criteria are appropriate for data with measurable characteristics. Guba and Lincoln (1981) suggest that the criteria of credibility, auditability and fittingness are perhaps a more appropriate judgment of qualitative methodology. Credibility refers to a recognition by other researchers of the structural description arising from the lived experience and is enhanced by the ‘... explicit articulation of the researcher’s perspective of the phenomenon prior to engaging in the data collection and analysis’ (Parse 1988, p. 294). Auditability relates to intersubjectivity. Other researchers should be able to follow the pathways from the raw data through the levels of abstraction to the structural description of the lived experience and in so doing arrive at a comparable interpretation to that of the researcher. Fittingness is described by Parse (1988, p. 295) as being ‘... satisfied if the findings of the study fit into contexts outside the study situation and if others appreciate the findings as meaningful’. I would argue that phenomenological analysis of the lived experience does not seek to fit the meanings attached to these lived experiences in any other context. Nevertheless, it may be possible to find some commonalities between the found meanings within a study and the meanings of people’s lived experience in a similar context outside the study.
Phenomenology differs from other human science methodologies such as ethnography, symbolic interactionism and ethnomethodology in that it distinguishes between ‘appearance and essence’ (van Manen 1990, p. 184). Merleau-Ponty (1962, p. vii) says ‘phenomenology is the study of essences’. It asks the question ‘what does it mean to have that experience?’ Instead of producing empirical evidence or theoretical observations or accounts, ‘... it offers accounts of experienced space, time, body and human relation as we live them’ (van Manen 1990, p.184). It concerns itself not only with the ontic but also the ontological. The interpretation of the action is as important as the action itself.

The phenomenological movement as described by Spiegelberg (1984) suggests that there are six different, yet unified types of phenomenology. This unification provides us with a common purpose of ‘... giving us a fuller and deeper grasp of the phenomenon’ (Spiegelberg cited in Taylor 1993, p. 174). Taylor further defines these types of phenomenology as:

... descriptive phenomenology, which is a direct description of phenomena aimed at maximum intuitive content; essential (eidetic) phenomenology, which seeks to explain essences and their relationships; phenomenology of appearances, which attends to the ways in which phenomena appear; constitutive phenomenology, which studies the processes whereby phenomena become established in our consciousness; reductive phenomenology, which relies on suspending belief in the reality or validity of phenomena; and hermeneutic phenomenology, which is a special kind of phenomenological interpretation to unveil hidden meanings in phenomena (1993, p. 174).

In the main, this study utilises hermeneutic phenomenology—the researcher and the participants assuming a sense of mutuality and shared knowing about nursing work with dying or dead people. This common bond is clearly evident in the language of the stories of the participants and in the interaction evident in the taped conversations.

HUSSERLIAN PHENOMENOLOGY

Edmund Husserl, a student of Franz Brentano, is refuted to be the father of modern phenomenology (Parse, Coyne & Smith 1985; van Manen 1990; Gelven 1989). Husserl maintained that the whole purpose behind phenomenology was to eliminate all assumptions about the world and focus entirely on letting the facts speak for themselves. ‘The motto of such phenomenology is “To the facts [or things] themselves!” Zu den Sachen selbst!’ (Gelven 1989, p. 38). Husserl (1971) asserts that pure ‘descriptive’ phenomenology is the only true approach to
phenomenology. To this end Husserlian phenomenology is ‘transcendental’ and cannot be tainted with pre-conceptions and ‘... must describe what is given to us in immediate experience ...’ (van Manen 1990, p. 184). Thus, the concept of reduction or bracketing is central to Husserlian phenomenology and refers to ‘... the act of suspending one’s various beliefs in the reality of the natural world in order to study the essential structures of the world’ (van Manen 1990, p. 175). As Husserl was a mathematician he borrowed this concept of bracketing from his native discipline.

Bracketing has been described by van Manen (1990, p. 185) as a process involving four steps: firstly, an ‘awakening’ or ‘wonderment’ with the esoteric nature of the world; secondly, an overcoming of the subjective or private feelings that may influence the understanding of a certain phenomenon; thirdly, the removal of all theoretical or scientific assumptions which underpin the phenomenon and thus prevent the phenomenon from being viewed in a non-abstracting manner; and, finally, in the imaging of the experience it is required to focus beyond the concrete and look for the essence of the lived meaning. This approach to phenomenology is practised by many researchers and is indeed recommended by Riemen (1986), Omery (1983), Oiler (1982) and others to be an important requirement of phenomenological analysis.

Husserl (1970, cited in van Manen 1990, p. 182), in his final text before he died, composed the idea of the lifeworld, ‘Lebenswelt’, the world of everyday life. This lifeworld is the world of immediate experience and is always pragmatic. According to Husserl individual’s lifeworlds present certain pervading structures or styles which need to be studied. ‘This notion of the lifeworld has become programmatic in the development of a more existentially orientated phenomenology’ (van Manen 1990, p. 184).

HEIDEGGERIAN PHENOMENOLOGY

Heidegger was a student and colleague of Husserl and in contrast to Husserl preferred to ‘... let the things of the world speak for themselves’ (van Manen 1990, p. 184). Interpretation is the key difference between the Husserlian and Heideggerian approaches to phenomenology. Heidegger’s phenomenology is hermeneutic (1962). A closer examination of hermeneutics will be undertaken later in this chapter. Heidegger believed that there was no such thing as uninterpreted fact and that facts cannot be separated from their meanings (Gelven
1989, p. 39). Thus, Heidegger refutes the Husserlian principle of bracketing and attempts to meld the impossibility of value-free interpretation with phenomenological thought. Hermeneutic phenomenology is both descriptive and interpretive. An explanation of what may seem contradictory in this last statement is offered in subsequent paragraphs.

Gelven (1989, p. 42), in his _A commentary on Heidegger's being and time_, says:

> By "phenomenology" Heidegger means that analysis by which the meaning of the various ways in which we exist can be translated from the vague language of everyday existence into the understandable and explicit language of ontology _without destroying the way in which these meanings manifest themselves to us in our everyday lives_!

Thus, for Heidegger, phenomenology is ontology. He has been described as the most influential philosopher of the twentieth century (Gelven 1989). In his work _Being and time_ Heidegger (1962) moves the emphasis from epistemology to ontology and attempts to question what it means to be, rather than question the meaning of being (Gelven 1989, p. 5). Thus, to question what it means to be presumes that 'we are'. Heidegger believed that the fundamental question of existence cannot be asked unless 'we are', as in order to ask the question we must exist. This existence is termed 'Dasein' by Heidegger and his work _Being and time_ is largely devoted to the definition of 'Dasein'. Many researchers and writers have taken 'Dasein' to mean 'human being'. Gelven (1989, p. 28) disagrees with this translation and argues that the term '... human being refers to an actual entity or existent, with reference to its genus and species'. Gelven further argues that Heidegger defines 'Dasein' as '... that entity which is capable of inquiring into its own Being, and indeed, such an inquiry into its Being is what makes Dasein what it is' (p. 28).

Heidegger further states that to question the meaning of 'Dasein' assumes an awareness of 'Dasein'. He calls this knowledge 'a priori' knowledge of existence (Gelven 1989, p. 54). Taylor (1994, p. 22) further relates this 'a priori' 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 the world.
Being-in-the-world, the first ‘a priori’ existential to be described by Heidegger, relates to the interaction of the person and their world. Rather than viewing the world as a separate and somewhat passive entity, Heidegger, by the act of hyphenation of the phrase, unifies the concepts of self and the world. The term ‘world’ refers to ‘... a meaningful set of relationships, practices, and language that we have by virtue of being born into a culture’ (Leonard 1989, p. 48). According to Gelven (1989, p. 57), we ‘reside’ or ‘dwell’ in many worlds—the very private worlds of self and those worlds which can be shared with others such as nursing, parenting, teaching, researching. Our awareness of our presence in these worlds is hermeneutic in that we are interpreting our interpretation of being-in-the-world.

In *Being and time* Heidegger’s analysis of understanding is of significant importance. He maintains that understanding is essential to ‘Dasein' because without understanding there can be no ‘Dasein’ Heidegger (1962, p. 67) says, ‘We are ourselves the entities to be analysed.’ Thus, understanding is also ‘a priori’ to Heidegger. Gadamer (1989, cited in Guignon 1993, p. 171) said:

Heidegger’s temporal analytics of Dasein has, I think, shown convincingly that understanding is not just one of the various possible behaviours of the subject but the mode of being Dasein itself ... and hence embraces the whole of its experience of the world.

Guignon (1993, p. 172) further highlights that Heidegger’s proposal of understanding provides a distinctive hermeneutic approach to philosophy and in doing so signifies again the differences between Heideggarian and Husserlian phenomenology, the latter being ‘... a knower disengaged from the world and from practical activities in the world’. Heidegger (1962) believes that the person experiences being within the framework of time. This is referred to as being-in-time. The past and the future influence the now and are all part of being-in-time (Gelven 1989, p. 178; Leonard 1989, p. 47).

Benner and Wrubel (1989, p. 41) state that:

According to Heidegger, a person is a self interpreting being, that is, the person does not come out into the world predefined but becomes defined in the course of living life. A person also has, Heidegger proposes, an effortless and nonreflective understanding of the self in the world.

It is this involvement in the world that is central to Heidegger’s philosophy about knowing. Knowledge, according to Heidegger, is ‘embodied’ because we are
constantly involved in being-in-the-world (1962). This embodied knowledge permits us to proceed through situations and encounter situations in terms of meaning in rapid, nonreflective ways. Embodiment allows people to live in and understand the world in relationship to self.

Yet another facet of being according to Heidegger (1962, cited in Gelven 1989, p. 119) is being-involved or concern. Benner and Wrubel (1989, p. 408) view concern as the reason why people act and a necessity of life. Concern accounts for the ‘why’ of being-in-the-world, whereas understanding and meaning can account for the ‘how’ (Benner & Wrubel 1989, p. 48). Heidegger shows us that the meaning of ‘Dasein’ was to care (Gelven 1989, p. 149) and by following a similar interpretation he further shows that the meaning of death is also grounded in care.

**HEIDEGGER AND DEATH**

In his analysis of death Heidegger says, ‘I myself am in that I will die’ (1985, p. 316) and ‘Only in dying can I to some extent say absolutely, “I am”’ (1985, p. 318). Thus, for Heidegger, to question what it means to be is influenced by an awareness of what it means not to be (Gelven 1989, p. 141). To die is something we will all achieve. Many of us base our living on what we will or will not accomplish by the time we die. Gelven (1989) outlines the powerful phenomenological description of death awareness in Dostoevski’s *The idiot*. Dostoevski recounts the terror of the certainty of knowing when death would occur. For most of us, knowing when we are to die remains unknown and in the presence of that hesitancy we may successfully delude ourselves in denying death’s inevitability. Many authors have claimed that western society is a death denying society (Raphael 1984; Kellehear 1990; Kübler-Ross 1981). We may succumb to the indefiniteness of death, as Gelven (1989, p. 141) states:

> Perhaps, though, the fact is that we don’t fully realize [sic] that we are going to die. Perhaps the love of life, or the comfortable tranquillity of self-deception, keeps us from truly realizing [sic] what it means to be something that will one day cease to be.

Gelven (1989, p. 142) points out that Heidegger firmly believes that each individual will die their own death. Whilst it may be possible to live another’s life, it is impossible to die another’s death. He also contends that whilst Heidegger does not examine the phenomenon of death itself, he does purport that ‘... the most important aspect of the death phenomenon is that one’s awareness of death can focus one’s attention on the self as it belongs to the individual ‘Dasein’,—ie
the authentic self' (Gelven 1989, p. 142). Authentic existence is distinguished by a categorical awareness of what it means to be. Thus, someone who exists authentically must have ontological awareness. In inauthentic existence ontological awareness is indistinct. Gelven (1989, p. 142) argues that 'If death-awareness somehow shakes off this veil or cloud [of indistinctiveness] then there must be something in the phenomenon that focuses one's attention on the ontological question of what it means to be'. Heidegger (1962, pp. 309–310) in

*Being and time* says:

Holding death for true (death is just one's own) shows another kind of certainty, and is more primordial than any certainty which relates to entities encountered within-the-world, or to formal objects: for it is certain of Being-in-the-world. As such, holding death for true does not demand just one definite kind of behaviour in Dasein, but demands Dasein itself in the full authenticity of its existence.

Heidegger presents yet another perspective on the use of the phenomenon of death in that death may well provide us with a sense of completeness of human existence. The birth to death continuum is often viewed as the ‘... whole or totality of human existence’ (Gelven 1989, p. 143). Gelven (1989) notes that Epicurus, the Greek philosopher, argued 'If death is there, you aren't; if you are there, death isn't'. Although this argument was used to convince his followers that death was not to be feared it could also be used to argue against the presentation of the 'total perspective of existence' as described by Heidegger. However, Heidegger (1962), being a philosopher who delighted in confronting challenges and difficulties, attempts, in his work *Being and time*, to overcome this argument. For Heidegger, the important issue is not about how it feels to die, rather what death means in relation to what it means to be. He argues that it is enough to know that one can die. Gelven (1989, p. 144) attempts to relay Heidegger's opinion:

As long as Dasein *is*, it is not-yet—ie not all of its possibilities are fully realized [sic]. Yet as soon as Dasein dies, it is no more (as Dasein anyway). Hence, it seems as if a total or complete perspective of Dasein is impossible. The complete picture of what it means for a human being to exist can be comprehended only when all of the possibilities, all of the ways of existing, are tried out and realized [sic]. This can be fully accomplished, however, only when one's life is over. By that time, though, one can no longer reflect upon this complete range.

Thus for Heidegger the key lies in the understanding of the not-yet element of 'Dasein'. According to Heidegger the not-yet of 'Dasein' is contained within 'Dasein' (1962). In relation to death Heidegger (1962) argues ‘One need not be at
an end to realize [sic] that one is going to end' (cited in Gelven 1989, p. 145). However, in saying this Heidegger argues quite vehemently that to undertake a study of the meaning of others’ death cannot provide an understanding of the meaning of death. This contrast is interesting in the light of contemporary literature which is concerned with near-death experiences and the futile yet curious search to understand what it is to die.

Gelven (1989, p. 147) recounts Heidegger’s ontological meaning of death in terms of the existential ‘being-towards-death’ or, more specifically, ‘to-be-going-to-die’. In his commentary, Gelven argues that the question of what it means to be going to die falls far beyond the inquisition of Hamlet’s ‘to be or not to be?’. Heidegger advanced the view that the authentic view of death is an enticing and intrepid focus of a human being’s finitude (Gelven 1989, p. 154). Thus, Heidegger’s view of death is directed to the being question and beyond: ‘The awareness of death points out one of the most persistent doctrines of Heidegger’s philosophy; that possibility means more than merely a future actuality’ (Gelven 1989, p. 154). As human beings we live in the realms of possibilities. However, to conceptualise death only as a possibility rather than an actuality may seem absurd, yet Heidegger (1962) claims that possibility means more than the not-yet of ‘Dasein’ ‘... but is seen rather as an essential manner in which a human being exists’ (cited in Gelven 1989, p. 155), namely, freedom.

EXISTENTIALS

Given that phenomenological research explores the structures of human lifeworld through the lived experience of everyday situations, it can be argued that each of our complex lifeworlds belong to different human existences and realities (van Manen 1990, p. 101). Likewise, there are different lifeworlds in the roles that we each play in life. I have the lifeworld of a woman, a mother, a lecturer, a researcher and so on. Heidegger (1962) in his work Being and time claims that human existence may also be studied in its fundamental thematic structure and identifies themes such as ‘life’, ‘death’, ‘understanding’, and ‘everydayness’ as existential themes. Other phenomenological researchers have perceived other existentials such as ‘ordinariness’ (Taylor 1991) and ‘meaning’ (Walters 1992). Merleau-Ponty (1962) identifies the four fundamental existentials that ‘probably pervade the lifeworlds of all human beings’ (van Manen 1990, p. 101). These are spatiality or lived space, corporeality or lived body, temporality or lived time and relationality or lived human relation. Spurling (1977, p. 11) states that Merleau-
Ponty (1963) outlines behaviour within these lifeworlds is ‘... better understood as a dialogue or dialectic between organism and its environment, in which each patterns the other ...’.

**Spatiality or lived space**

The experience of lived space can be described as the space we are in at any given time. It does not refer to how far we are away from something or somebody; rather, it refers to the world in which we find ourselves as we experience our everyday lives. Merleau-Ponty (1962, p. 250) identifies lived space as ‘a certain possession of the world by my body, a certain gearing of my body to the world’. As a nurse I may find myself in the world of nursing and I experience my lived space in terms of being in a ward of beds situated close together or a unit consisting of life-saving equipment and movable trolleys. As a lecturer I may experience my lived space in my office with a comfortable chair and ergonomic equipment, my reference books and the incessant ringing of the telephone. As a mother I may experience my lived space in terms of my home and its comforting smells and quietness or when my children are around, the noise of heavy metal music and burning toast. The structure of being in different lifeworlds demands that we ask for a certain space experience. van Manen (1990, p. 103) states that ‘... lived space is a category for inquiring into ways we experience the affairs of our day to day existence; in addition it helps us uncover more fundamental meaning dimensions of lived life’.

**Corporeality or lived body**

‘Lived body refers to the phenomenological fact that we are always bodily in the world’ (van Manen 1990, p. 103). When we come into contact with others we initially meet that person through their body. Spurling (1977, p. 22) describes Merleau-Ponty’s (1962) phenomenal body as ‘... an “expressive unity” a “synergic system”, to be compared not to a physical object but to a work of art’. Sartre (1956, p. 353) describes the experience of blushing as seen through the experience of the other and that when the body is the object of someone else’s gaze it may lose its naturalness or exhibit a more positive change if the gaze is complimentary. As a nurse I may experience my lived body in the delivery of touch to a particular patient through their response of a smile or a grimace. As a lecturer I may experience my lived body by teaching a large student group in a lecture theatre and watching them yawn or, conversely, a small group of students in a tutorial situation and hearing them interact enthusiastically in response to a
question I have asked. As a mother I have certainly experienced my lived body in the action of birthing and breastfeeding my children.

**Temporality or lived time**

Lived time as described by van Manen (1990, p. 104) is ‘subjective time’ rather than ‘objective or clock time’. Lived time is not controlled by seconds, minutes or hours; it is the temporal dimensions of past, present and future. Lived time is dependent on my experience of the past but not fixed for the future. Lived time accounts for hopes or fears on our perspective of life. Merleau-Ponty (1962, p. 407) believes phenomenologically, subjectivity is temporality: ‘I am … one single temporality which is engaged, from birth, in making itself progressively explicit’. As a nurse dealing with dying patients I may experience lived time as terrifying or tranquil. As a lecturer undertaking my everyday work I may experience lived time as monotonous, or challenging and exciting. As a mother involved in parenting I may experience lived time as arduous or satisfying.

**Relationality or lived human relation or lived other**

‘Relationality is the lived relation we maintain with others in the interpersonal space that we share with them’ (van Manen 1990, p. 104). Spurling (1977, p. 41) outlines the beliefs of Merleau-Ponty (1962) regarding the lived-body: ‘My body and the bodies of other people form a system, not through any reasoning by analogy, but because our phenomenal bodies gear into each other as we perform our tasks in concert, or in competition, in the lived world’. As a nurse I may experience lived other in the practice of nursing. As a lecturer I may experience the lived other in the communication of ideas and concepts. As a mother I may experience lived other in watching the development of my children from boys to men.

Whilst I have differentiated between the four existentials of lived space, lived body, lived time and lived other, they cannot be separated. Together they form a complex synthesis of our lived experience. In research it is acceptable to ‘temporarily study the existentials in their differentiated aspects, while realising that one existential always calls forth the other aspects’ (van Manen 1990, p. 105).
HERMENEUTICS

Originating from Greek mythology and the priest Hermes, the term literally means ‘... the transmission of what is beyond human understanding into a form that human intelligence can grasp’ (Palmer 1969, cited in Walters 1992, p. 53). The method of Heideggerian hermeneutics seeks to uncover shared meanings through understanding rather than prediction and explanation. Everyday practical activities become part of our life stories and this everydayness is the focus of hermeneutics (Woolfolk, Sass & Messer 1988, p. 3). Schleiermacher (1977, cited in van Manen 1990, p. 179) ‘... opened up the idea of hermeneutics as a theory or “technology” of interpretation, especially with respect to the study of sacred (biblical) and classical texts’. Schleiermacher’s aim was to gain an understanding of the person in excess of how that person understood themselves.

Dilthey (1883, in Polkinghorne 1988, p. 38) emphasised that hermeneutics was not simply a marginal method for use in philological studies; rather, it was a general method for comprehending all human expression. Heidegger’s hermeneutics was not directed at re-experiencing another’s experience, but to come to an understanding of another’s experience as revealed by the text (van Manen 1990, p. 180). Thus, the researcher and research participant share commonalities of lived experience by virtue of language and culture. The experiences of the researcher in the interpretation process are refuted by Schleiermacher (1977) and Dilthey (1883) as interfering with the research process, yet in Heideggerian phenomenology the experience of the researcher is embraced as being integral to interpretation and understanding.

Leonard, on writing about hermeneutics (1989, p. 50), states:

... since persons are fundamentally self-interpreting beings for whom things have significance, understanding human action always involves an interpretation by the researcher of the interpretations being made by those persons being studied.

The hermeneutical approach has been used by many human science researchers and is ideal for interpretive nursing research as much of this type of nursing research concerns itself with understanding the lived experience of human beings. Benner (1984) used hermeneutics in her work with paradigm cases or exemplars of nursing practice. Nurses provided Benner with examples of everyday nursing practice experiences which other nurses could relate to and find shared meaning
and commonalities. Benner (1984, p. 8) believes that proficient and expert nurses use powerful experiences as exemplars and store them within for use in future nursing care situations. Benner likens this use of exemplars to the use of a particular paradigm by a researcher. Leonard (1989, p. 51) further states that ‘... rather than looking for deterministic or mechanistic explanations of causality, hermeneutics seeks to develop understanding that is based on concerns, commitments, practices, and meanings’.

In *Being and time*, Heidegger (1962) discloses that ‘To question what it means to be operates in the hermeneutic circle’ (cited in Gelven 1989, p. 140). 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. Gadamer (1975, in van Manen 1990) reveals that in interpreting a phenomenon we cannot separate ourselves from the meaning of that phenomenon. As researchers in hermeneutic phenomenology we have some understanding of the research, yet in engaging in a hermeneutic systematic analysis we may be able to uncover further understandings and meanings of phenomena under study. This seemingly inexhaustible process has no clear definitive ending. Termination of this process occurs when the researcher is fully satisfied with the depth of achieved understanding.

Reason and Hawkins (1988) embrace hermeneutics in relation to their analysis of ‘storytelling’. They view storytelling as a methodology of making meaning. They relate Echartberg’s suggestion that storytelling is central to hermeneutics and that ‘... to be human is to be entangled in stories’ (1981, cited in Reason & Hawkins 1988, p. 82). As has been previously stated, nurses are excellent storytellers. Thus, in a study about nurses and their lived experience it seemed natural to make use of this expression in this study.

**PHENOMENOLOGICAL RESEARCH IN NURSING**

Historically, nursing has been closely related to medicine in the cure of human beings. A review of nursing textbooks will show that their organisation, until recently, has disease processes and their effect on the patient as its focus. This cause and effect relationship of viewing science, either natural or human, has remained the dominant organiser of research and research methodologies in nursing and health care. This natural science perspective deals with the quantification of humans and their illnesses. Taylor (1993, p. 171) warns that use
of exclusive quantitative methods in nursing is problematic. Theory generated by academics using such methods may not be viewed by practitioners as addressing their concerns. The individual’s participative experience with health and illness has been largely ignored. Swanson and Cheintz (1982, cited in Taylor 1993, p. 172) say quantitative research and its linear approach fails to acknowledge the complexity of nursing work, fails to enter the real world of the patient and thus fails to provide direction for the improvement of nursing care. The real world of nursing practice enters into the realms of subjectivity which is a problematic concept for quantitative researchers.

Pirsig (1974) differentiated between observers and participators in life. When individuals observed only, they were spectators, when they observed and acted, they were participants. The real world of practice involves observation and action between humans. The contexts in which nurses and patients interrelate are value-laden and rely on people making sense of their own worlds, therefore a detached observer approach to research typified by quantitative methods, is inadequate to completely understand nursing practice (Taylor 1993, p. 172).

However, the real world of nursing may be described as two-fold, that is, concerned with service delivery and as an emerging discipline. The nursing scholar, Martha Rogers (1975), supports keeping this distinction alive and suggests that nurse researchers get on with the task of research and nurse practitioners remain primarily concerned with the delivery of nursing care, taking their lead from the nurse researchers. Taylor (1993, p. 172) agrees with Johnson (1968), that the maintenance of this theory-practice gap has socially defined nursing and thus nursing may be viewed as vocational rather than professional. Emden and Young (1987) conducted a major study of leading Australian nurse educationalists who were markedly divided on the issue of reducing or keeping the theory-practice divisions. The findings within this study heralded that a distinctive change would occur when more nurses were educated to the higher degree level. Certainly within Australia there has been a shift towards narrowing this gap, rather than widening it or maintaining the status quo. If the gap is to close, then it would seem to be appropriate that research in nursing assume a more clinical focus into the real world of nursing, thus having concern for human actions (Smith 1984, p. 43).

Carper (1978) described four ways of knowing in nursing: empirics, aesthetics, personal knowledge and ethics. Whereas the empirics of nursing lends itself to quantification, aesthetics—the art of nursing, and the components of personal
knowledge and ethics are essentially qualitative concerns. Chinn (1985, cited in Taylor 1993, p. 173) concludes that:

Qualitative methods allow exploration of humans 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, the limitations of empirical evidence in relation to studying humans, the value of ethical justification, aesthetic criticism, and personal introspection and the limitations of the meaning of statistical significance.

Questions of relevance are answered by an approach which emphasises a holistic approach to people interacting in their worlds, rather than a rigorously scientific approach. Hard science maintains the dualist notion of the mind-body split in which people are seen to be disengaged and goal oriented. Benner and Wrubel (1989, p. 23) contended that 'once the mind and body are understood as unified being, then the person can be seen as participating in a meaningful world'.

The emergent new paradigm provides a focus for human individualism, uniqueness, relativism, open system, holism and individual interpretation (Munhall 1982). According to Guba and Lincoln (1985, p. 9), new paradigm research embraces other methodologies, such as ethnography, hermeneutics and phenomenology. Oiler (1982), Omery (1983) and Knaack (1984) presented the phenomenological approach as an effective qualitative option for improving patient care through researching the practice of nursing. However, Paterson and Zderad (1976) are considered to be responsible for introducing phenomenology to nursing in their publication *Humanistic nursing*. Paterson and Zderad thought the term ‘nursology’ could be an ideal methodology to research nursing (1976). Yet, this notion was unacceptable to the profession as a whole and ‘nursology’, which combined intuition with rationality as reasoning, remains as a conceptualisation only (Taylor 1993, p. 174). Following Paterson and Zderad’s work, the interest grew in phenomenology as an appropriate methodology to research the world of nursing. Three nursing scholars, Parse (1987), Benner (1984) and Watson (1985) have used phenomenology as the philosophical base for their work (Burns & Grove 1993, p. 66). Other scholars have adopted phenomenological thought in the preparation of their work (Omery 1983; Munhall 1989; Pearson 1990).

The Heideggerian concept of embodiment, as described earlier, has aroused much interest among contemporary nursing scholars (Benner & Wrubel 1988; Parker 1988; Lawler 1992). Embodiment captures the idea of body as lived experience,
as subject rather than simply the object of another's inspection. Gadow (1980, p. 92) describes the duality of object body and lived body and maintains that, historically, health professionals have been concerned with both object body and lived body and that the differences between the two can be aligned to quantitative and qualitative approaches to nursing respectively.

Nurses by definition become involved in the everyday lives of their patients. Meleis (1986, p. 12) wrote that 'nursing phenomena are human phenomena'. The nurse-patient relationship explores these phenomena within the worlds of being the nurse and/or being a patient. Being with patients is considered by Watson (1985, cited in Burns & Grove 1993, p. 81) to be fundamental to a therapeutic relationship. At a basic practical level the concerns of nurses mirror those of phenomenological thought. The day to day concern of the nurse in seeking to understand the patient's experience of illness or wellness is well suited to exploration by way of phenomenological methodology.

Holmes (1992, p. 395) signifies a note of caution in his discussion of Heidegger's links with fascism and the implications of that linkage for nursing and nursing research. Whilst Holmes does not reject the notion of using phenomenology as a nursing research methodology, he does alert us to the pitfalls of blind faith in a particular doctrine, or in this case, 'the inseparability of Heidegger the Nazi and Heidegger the philosopher' (1992, p. 403). I acknowledge Holmes' large degree of scepticism for what it is—a plea to take care—but remind him that Heidegger himself begins his analysis of 'being' with the argument that 'being' matters. Heidegger further shows that the study of what it means to be is already 'a priori', a study of the meaningfulness of existence and '... to be at all is to be as meaningful, to matter, to care' (Gelven 1989, p. 13).

CONTRIBUTION OF PHENOMENOLOGICAL RESEARCH TO NURSING

The choice of methodology used in this study was largely influenced by my work environment where I have been increasingly exposed to the works of the contemporary nursing researchers Parse (1981), Benner (1984), Watson (1987) and Pearson (1992). Being exposed to discussion of, and involvement with, nursing research in action has broadened my horizons and stimulated my own eager search into the literature of how phenomenology has contributed to nursing. Holmes (1992) has made the observation that phenomenology has taken on the
proportions of a ‘new wave’ in nursing research and from my own experience I have met several colleagues undertaking higher degrees or involved in research who have adopted phenomenology as the methodological grounding for their work (Casey 1993; Walters 1992; Taylor 1991; Vohland 1994; Pearson, Chapman and Nay 1994 in process).

In her work *From novice to expert* (1984, Benner, 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 expand on this notion of care through examining stress and coping in nursing and highlight five areas of nursing practice, namely, health promotion, coronary care, oncology, palliative care, and neurological care for their study. Their work concludes by focusing on what it means to care as a nurse. This work, along with Benner’s previous book, have legitimised the place of caring in the nurse-patient relationship.

Watson (1979) used phenomenology to study the concept of caring. She and her colleagues classified caring behaviours and described similarities and differences between the meaning of care for nurses and the meaning of care for patients. Watson’s research emphasises the use of nursing phenomena, rather than natural sciences. Recently, Watson (1987, p. 11), through the use of transcendent phenomenology, has been researching language such as metaphor and poetry to communicate, convey and describe human caring and healing.

In his phenomenological study of the meaning of rehabilitation to the cardiac patient, Ford (1987, cited in Garratt 1990, p. 5) asked questions such as ‘what is it like to live with a history of a heart attack?’ Questioning in this manner Ford aimed, through description and interpretation, to illuminate the participants’ experiences and to reveal their meaning. The research involved the study of seven male patients two years after they had sustained a myocardial infarction and who had returned to work. The researcher attempted to identify possible shared human experiences of life after a myocardial infarction, derived from the identification of certain patterns or commonalities in the stories of the participants. It was hoped that elucidation of their experiences would open up possibilities for nurses to be
more helpful in the rehabilitation process of the post myocardial infarction patient. Using the existentials of spatiality, corporeality, temporality and relationality, Ford discovered that the participants experienced a change in the way they perceived their own bodies and the bodies of others. Ford’s research was valuable for nursing practice because it provided some useful insights for the coronary care nurse into the way in which the patient felt about their own body, in particular their heart and the possibilities for enjoying a full life in the future. The information could be invaluable in assisting the health care professional to create a sound foundation for developing a helping relationship in the care of the cardiac patient.

Lynch-Sauer (1985) describes her use of phenomenological methodology to research ‘couples having a planned first child later in life than is usual in their culture’ (p. 97). Lynch-Sauer used unstructured interviews with the participants and reflective journal entries on the interviews, and her own experience of pregnancy within the duration of the research, to inform her interpretations. Lynch-Sauer extensively used journaling to reflect her own experience of the research and shared these transcripts with the participants in order to engage them in the research process. Lynch-Sauer utilises hermeneutic phenomenology, not only to inform the research question, but also the research process. Lynch-Sauer (1985, p. 100) concludes:

The transcriptions were given very different meaning by each informant who chose to use them. In retrospect, what I really needed to give them was feedback about the analysis of these transcriptions as well, so that they could validate my interpretation of their experiences.

In discussing her ‘journey’ with a woman experiencing a life-threatening illness, Lumby (1994, p. 21) aimed to contribute to feminist nursing knowledge and praxis by engaging in a critical feminist study of one person’s experiences of illness. Although her research was located in the critical paradigm, Lumby acknowledges the importance of unselfishness in the research process. She advocates that participants should be viewed as co-researchers and that ‘... before researchers explore the deepest personal experiences of a person’s life they need to make it clear that their motives are unselfish and that they are interested not only in personal gain but also in collaborative gain’ (1994, p. 15). Throughout her work, Lumby talks of ‘our’ study rather than ‘my’ or ‘the’ study, thus alluding to the shared ownership of the meanings generated from the research process.
Some researchers move the focus of their phenomenological study from the meanings generated from patients to the meanings generated from nurses. Walters' (1992) research involved interviewing eight expert registered nurses working in the area of intensive care. The aim of the study was to elucidate the phenomenon of caring for critically ill patients in a technological environment. Using Heideggerian phenomenology and more specifically the phenomena of being-in-the-world, care, time, death, understanding, ready-at-hand and present-at-hand, Walters attempted to detect the hidden meaning of the nurse's experience (Walters 1992, p. 1). Walters uncovered the four themes of 'being busy, 'comforting', 'focusing' and 'balancing'. Walters contends that even though intensive care nursing may be viewed as technological, there is still room for caring practices to pervade this environment. 'The technology, instead of being viewed from a detached instrumental perspective, can now be considered as an integral part of the humanistic processes of caring' (Walters 1992, p. 356).

Taylor (1993) has written at length in the contemporary nursing literature on the value of interpretive nursing research. Her doctoral Thesis (1991) examined the concept of 'ordinariness' in nursing practice. Taylor (1994, p. 3) points to the central importance of context in the interpretation of the lived experience '... because people are always situated in their temporo-spatial circumstances'. Her research with six registered nurses in a nursing unit in Australia involved her taking a participant observer role as she undertook her phenomenological analysis of everyday occurrences in the lived world of the nurses practicing nursing with their patients. Taylor (1994, p. 25) saw that '... the ontological nature of ordinariness in nursing was housed within the nature of the aspects illuminating the phenomenon, that is, at the level of its actualities'. Her study focuses on the languaging of these actualities and unravels seven themes in the research, namely, 'allowingness', 'straightforwardness', 'self-likeness', 'homeliness', 'favourableness', 'lightheartedness', and 'connectedness'.

Taylor (1994, p. 26) concluded that:

... the phenomenological research exploring 'the phenomenon of ordinariness in nursing' found that nurses and patients shared a common sense of humanity. Within the context of caring, the nurses were ordinary people, perceived as being extraordinarily effective, by the very ways in which their humanness shone through their knowledge and skills, to make their whole being with patients something more than just professional helping.
Another appealing aspect of Taylor’s work is her use of poetry. Like Heidegger, Taylor agrees that artistic forms such as ‘... poetry, is not primarily a mere source of refined pleasure but a profound way in which truth happens’ (Gelven 1989, p. 223).

Pilkington (1993, p. 130) researched ‘the lived experience of loss of an important other’ by dialoguing with five women who had lost their babies at birth. She chose to use Parse’s theory of Human-Becoming (1981) and Parse’s methodology (1988) to explore this phenomenon. The choice of methodology was also influenced by the lack of knowledge about grieving available within the nursing literature. Pilkington acknowledges that knowledge about grieving is largely defined from other disciplines such as psychology and sociology and that knowledge presumes grieving can be researched by observation and quantification. She also believed that the extant literature on grieving and its emphasis on normative theories did little to inform nursing practice. Pilkington (1993, p. 130) argues ‘there is no right or best way to grieve a personal loss, from a human science perspective’. Thus, she embarked on this study which, by its methodology, allowed the uniqueness of grieving to be described. Finally, she coordinated her findings with the principles which emerge from Parse’s three major themes of meaning, rhythmicity and cotranscendence. Pilkington (1993, p. 132) used Parse’s method of data analysis, namely, ‘heuristic interpretation’ (creative logical abstraction) and extraction-synthesis to structure the lived experience. Implications for nursing practice retrieved from this research included the need for nurses to engage in the experience of being with a person in their grieving experience, continuously exploring with the person their rhythm of suffering, their paradoxes and their hopes and dreams. ‘In this way, the nurse in true presence bears witness and journeys with the person’s multidimensional experience ...’ (Pilkington 1993, p. 138).

Phenomenological methodology has not been restricted to researching the practice of nursing. Dickelmann (1992), an American nursing academic, conducted a phenomenological study on the lived experience of students and teachers. Making use of Heideggerian hermeneutical analysis, Dickelmann interviewed forty-four students and teachers from ten schools of nursing in the mid-west region of the United States. They were asked to relate significant lived experiences of being a student or a teacher in order to find meaning in what it means to be a student or a teacher in nursing. The research presented an interpretive study on the lived experience of students and teachers in testing and evaluating learning and served
to stimulate discussion and evoke thinking about the need for alternative approaches in nursing education (Diekelmann 1992, p. 72).

Whilst I acknowledge the importance of these researchers and their respective studies on my own research, perhaps the most important influence has been that of Parse. Her work and the theory of nursing which generated from that work will be examined in the following section.

PARSE’S THEORY OF HUMAN-BECOMING

Rosemary Rizzo Parse, heavily influenced by working alongside existential phenomenologists such as van Kaam and Giorgi (cited in Lee, Schumacher & Twigg 1994, p. 445) and the principles of the nursing scholar, Martha Rogers (1987), developed her conceptual model of Human-Becoming (formerly, man-living-health) which is unique to nursing (Phillips 1987; Lee et al. 1994). In developing her theoretical model, Parse challenged the totality paradigmatic stance of her contemporaries and focused on the concept of simultaneity which acknowledges the interrelatedness of the person with their environment. The simultaneity paradigm rejects the belief that the individual can be understood by reducing them to their bio-psycho-social parts. In contrast, individuals are viewed as unitary beings in mutual relationship with the universe.

Doing-with rather than doing-to is central to Parse’s belief about nursing (Phillips 1987, p. 182). Likewise, nursing practice is seen as a reflective, evolutionary process of corelating and cocreating between two people and the environment in their attempts to understand the connectedness of life itself and the meaning of the lived experience (Parse 1981, p. 11).

Many parallels may be drawn between Parse’s methodological thoughts and the existential thought of Heidegger, Sartre and Merleau-Ponty. However, it is the synthesis of these thoughts with Martha Rogers’ theory of science of unitary human beings which projects nursing towards an unfragmented view of the person (Lee et al. 1994, p. 446). Apart from the simultaneity paradigmatic concept, Parse blended the three major principles and the four concepts of Rogers’ theory into her own theory of Human-Becoming (1981). Before analysing Parse’s work it is worth first considering Rogers’ theoretical framework.
Rogers’ (1970) science of unitary human beings (formerly the science of unitary man) uses abstract elements which allow the framework to be used universally. It may be argued that some of Rogers’ work is linguistically inaccessible; however, Rogers maintains that her innovative terminology and creative use of knowledge assists the betterment of humankind and helps consumers to ‘develop patterns of living coordinate with environmental changes rather than in conflict with them’ (cited in Storch 1986, p. 20). Indeed, Rogers herself has changed much of the language within the model from the first writing of the 1970s to the second in the 1980s and judging by her recent writings is still in the process of accessing more appropriate language to adequately describe her work. Rogers (1992, cited in Daily, Maupin, Murray, Satterly, Schnell & Wallace 1994, p. 213) states ‘efforts to select words best suited to portray one’s thoughts are at best difficult because words are often inadequate to fully communicate the meaning of a particular postulate’. Rogers theorises that human beings are dynamic energy fields integral with environmental fields: ‘Both human and environmental fields are identified by pattern and characterised by a universe of open systems’ (1992, cited in Daily et al. 1994, p. 213). Developed from these concepts Rogers identifies four building blocks for her theory, namely, energy field, a universe of open systems, pattern, and paradimensionality (formerly four-dimensionality).

Energy fields are understood to compose the essential unit of the living and the nonliving. ‘Field’ is used as a unifying term and ‘energy’ is defined as dynamic. Thus, energy field is a dynamic unity (Rogers 1987, p. 142). Two fields are identified, the human field and the environmental field, and both are irreducible wholes. This irreducibility does not deny the parts of the whole but does not separate them from the whole; hence the allegiance to the simultaneity paradigm. Rogers (1987, p. 142) states, ‘What may be very valid in describing biological phenomena does not describe unitary human beings, any more than describing a molecule tells you about laughter’.

A universe of open systems ‘holds that energy fields are infinite, open and integral with one another’ (Daily et al. 1994, p. 213). Rogers refutes the idea of a steady state and reports that recent space exploration has brought the idea of open systems to everyday people (1992, cited in Daily et al. 1994, p. 214).

Pattern is the distinguishing characteristic of the energy field. ‘Manifestations of patterns have been described as unique and refer to behaviours, qualities, and characteristics of the field’ (Clarke 1986, cited in Daily et al. 1994, p. 213). The
human field is integral with the environmental field and the pattern is constantly changing and may manifest pain, illness or disease.

Paradimensionality best expresses the idea of unitary whole. It is a nonlinear domain without spatial or temporal qualities (Rogers 1987, p. 143; Daily et al. 1994, p. 213).

Three principles arise from these four building blocks: the principle of resonancy, the principle of helicy and the principle of integrality. Reed (1987, cited in Daily et al. 1994, p. 214) provides concise descriptions of these principles:

The helicy principle describes spiral development rather than a cyclical motion. This motion is continuous, nonrepeating, and always innovative patterning. According to the principle of resonancy, this patterning becomes more resonant over development, changing from lower to higher frequency. Resonancy is an enrichment process that accompanies the life span's increasing complexity ... integrality stresses the continuous mutual process of person and environment.

Parse differs from Rogers in that she does not view the person as an energy field, but rather as an open being, free to choose being in a situation (1987). She believes the person reveals and conceals values in transforming to what is not yet. The person structures meaning multi-dimensionally in cocreating rhythmic patterns while cotranscending with the possibles (Parse 1987, p. 159). Thus, Parse has woven Rogers' principles of helicy, integrality and resonancy, plus the four building blocks of energy field, pattern, openness and paradigminality with the notions of subjectivity, intentionality, coconstitution, coexistence and situated freedom from existential phenomenological thought (1987, p. 161). This intermingling has been synthesised into nine assumptions forming the foundations of her theory of man-living-health which have been further reduced to three philosophical assumptions. From these three philosophical assumptions the three major themes of meaning, rhythmicity and cotranscendence emerge (Parse 1987, p. 163). Firstly, 'Structuring meaning multidimensionally is cocreating reality through the languaging of valuing and relating' (Parse 1981, cited in Winkler 1983, p. 285). Secondly, 'Cocreating rhythmic patterns of relating is living the paradoxical unity of revealing-concealing, enabling-limiting, while connecting-separating' (Parse 1987, p. 164). Thirdly, 'Cotranscending with the possibles is powering unique ways of originating in the process of transforming' (Parse 1981, p. 51).
The first principle means that the person constructs meaning from the many different levels of their world and cocreates it through expression. There are two kinds of meaning: ultimate meaning and meaning moments in everyday life, and Parse purports that both kinds of meaning change as the result of experiencing lived-experience (1987, p. 164). The person’s worldview is influenced by what was, what is and what could be (FitzGerald 1992, p. 5). The second principle relates to the person interrelating with their environment in rhythmical interchange. Parse (1987, p. 165) states, ‘Every time one makes a choice, there are an infinite number of possibilities within that choice and also an infinite number of limitations’. In our daily lives we make the choice to connect and separate to things or people and within that reveal and conceal in our relationships with others. The very act of choosing means that we either choose to choose or choose not to choose. The third principle refers to the ‘... person’s potential to reach beyond what they are experiencing now, to be aware of more now or what is possible to choose from in the future’ (FitzGerald 1992, p. 6). This changing is motivated by the person pushing beyond what is, originating possibilities and transforming to the not yet. It is this process of transforming which signifies the constant struggles associated with change. It is the underlying principle of the phrase: to see things in a different way is more meaningful than seeing different things in the same way.

In relation to nursing research, Winkler (1983, p. 291) believes ‘This model [Parse’s model] has the potential to expand the descriptive base of nursing in regard to beliefs, behaviours, and their perceived meanings in life situations affecting health’. In this study, Parse’s views on nursing have been utilised as a framework underpinning the chapter in this Thesis which discusses the implications for nursing practice.
Chapter Three
Nursing, Death and Dying:
A Review of the Literature
This study is primarily concerned with the significant experiences of registered nurses in nursing the dying. Grounded in phenomenology, this study accepts that all nurses have varied personal experiences with death and dying prior to nursing the dying, and those experiences influence their nursing practice. Registered nurses come from a wide age group and educational background and have experienced significant differences in the way they have gained knowledge about nursing the dying or the dead.

This chapter, firstly, will briefly examine the changing focus of societal attitudes to death which may influence those engaged in nursing the dying or the dead (Aries 1978; Stannard 1978; Huntington & Metcalf 1979; Fulton, Markusen, Owen & Scheiber 1978; Kastenbaum 1988; DeSpelder & Strickland 1992). Secondly, it will examine the disparate conceptions formulated by the literature in the exploration of nursing the dying or the dead (Glaser & Strauss 1965; Kellehear 1990; Johnstone 1989; Quint 1967). Thirdly, the chapter will provide a closer examination of death education for nurses (Leviton 1977; Degner & Gow 1988; Warren 1989). Fourthly, it will undertake a brief inquiry into the work of Elizabeth Kübler-Ross and provide alternatives to her stage theory model (Kübler-Ross 1969; Kastenbaum 1988; Kellehear 1990; Raphael 1984). Finally, the chapter will consider the impact of loss and the cost of caring on those professional nurses involved with nursing the dying and the dead (Vachon 1985; Benner & Wrubel 1989; Forrest 1989; Watson 1987; Marquis 1993).

**SOCIETAL ATTITUDES TO DEATH**

Thanatologists acknowledge that there are no ‘pat’ answers when we come face to face with grief and that it is in the nature of the work (ie nursing the dying or the dead) to feel inadequate. However, western society has evolved to view death as a form of stigma and has decreased our exposure to it and subsequently our information about it (Kellehear 1990, p. 12). Aries (1978, p. 52) traces attitudes to death from the fearing seventeenth and eighteenth centuries through the romantic nineteenth century to the death denial of the current twentieth century. Aries comments on the metamorphosis which has changed death from a highly visible event of the Middle Ages to an almost invisible event in our present society (1978). Pascal (1623–1662), a French philosopher and mathematician, commented ‘man [sic] will die alone’ (cited in Aries 1978, p. 54). Pascal’s observation was quite profound at the time as the custom was to have a number of people attending the bedside of the dying person. Pascal’s meaning behind the
statement was to illuminate that, in spite of the people in attendance, the dying person was indeed alone. Aries (1978) believes Pascal’s statement has lost its impact today as many people do die alone, without the congregation of their family or loved ones.

DeSpelder and Strickland (1992) examine the factors which have altered how people in modern societies deal with death and dying. The increased longevity and decreased mortality rates have rendered experiencing death in the family at an early age to be almost an impossibility. Changes in causes of death and geographical mobility are other contributing factors to the issue of non-experience. Likewise, the displacement of death from the home to aged care institutions and hospitals in this latter half of the twentieth century has added to the social isolation of death and dying.

Stannard (1978) posits that in societies in which each individual is unique, important and irreplaceable, death is not ignored but is marked by a ‘community-wide outpouring of grief for what is a genuine social loss’ (p. 43). However, in societies in which one individual is not considered to be very different from any other ‘... little damage is done to the social fabric by the loss of an individual’ and outside personal immediate circles there is little acknowledgment of a death (Stannard 1978, p. 43), except perhaps in the case of death of world leaders.

Death at the individual level appears to be harder for individuals to accept than the death of masses of people. In the 1960s thousands filed past the coffin of Sir Winston Churchill as he lay in State at Westminster in London. Some were tearful, others reverent. Whilst Churchill’s death occurred in peace time, it is his leadership in World War II which remains significant in the minds of many people. Both World Wars and subsequent conflicts in Vietnam, Indochina and more recently the Persian Gulf, Bosnia and Rwanda, are repetitious of human beings engaging in their own destruction (Shneidman 1978, p. 372). Keen (1986) not only speaks of the horror of death in war, but exemplifies the almost opposing illumination of life experienced by many engaged in combat:

Despite the brutality of war, soldiers often report that it gave them the most vivid experiences of their lives. Never were they more filled with awe and the precious, precarious, tragic sense of life. The constant atmosphere of danger, the felt potency of killing, the comradeship of men [sic] in arms, create a psychedelic high that releases the warrior from the quiet desperation and boredom of everyday life (p. 138).
In his article ‘Megadeath. Children of the nuclear family’, Shneidman (1978) considers the effects of war, especially the threat of nuclear war on young people. Although Shneidman’s article was written during the cold war period, it reflected common thoughts among students who feared there was little prospect of long-term human survival:

For this generation there is a heightened sense of the uncertainty of the future, of the survival of the world itself. No other generation in memory has grown up with this particular global tenuousness. Young people today do not worry so much about the nature of tomorrow (as, for example, those who lived through the Depression had to do); they rather worry about whether or not there will be a tomorrow (1978, p. 376).

In spite of these fears, somehow societies world-wide have validated that mass death is acceptable and even necessary in the pursuit of peace between nations. It could be argued that this paradox is the ultimate contradiction. It is as if large scale death events ‘... support our unconscious belief in our own immortality and allow us—in the privacy and secrecy of our unconscious mind—to rejoice that it is “the next guy, not me”’ (Kübler-Ross, 1969, p. 13).

DeSpelder and Strickland (1992, p. 13) comment on the way in which people have been deprived of control over their own death. It can be argued that it was normal for people to predict their own death and to prepare for it, surrounded and supported by friends, relatives, clergy and even passers-by. Thus, in the past (and in some cultures this is the case today), dying was a shared experience and death rarely occurred in isolation. Under these circumstances death was regarded as a part of life. The lack of secrecy meant that everyone had at some time witnessed the death of another and some of the fear of the unknown was mitigated.

There is no grand theory which encompasses all sociocultural attitudes towards death (Chapman & Brown 1993b, p. 11). Because of the multicultural nature of Australian society it can be argued that we have the opportunity to observe and experience a diversity of attitudes and beliefs related to living, dying and death (Edgar, Earle & Fopp 1993). These contrasts provide a richness of experience and a chance to learn from others who have different backgrounds to our own. This very learning activity can also cause discomfort, however, when firmly held beliefs are challenged and we are forced to examine what we believe and why we believe it. There is always the temptation to engage in ethnocentrism (Joseph 1986).
However people behave in relation to dying and death, the way in which they react appears to have significance in sociological terms. Such behaviours may provide powerful insights into the underlying philosophies of individuals and groups. Huntington and Metcalf suggest that:

In all societies, regardless of whether their customs call for festive or restrained behaviour, the issue of death throws into relief the most important cultural values by which people live their lives and evaluate their experiences (1979, p. 2).

It is difficult to determine how much influence religion and religious beliefs have upon an individual’s attitude towards death. Warren (1989, p. 131) argues that ‘…except in cases of very definite and deep religious commitment, attitudes towards death seem to be relatively unaffected by religious belief’. However, when religion is an integral part of an individual’s life philosophy, it could be argued that its influence is a major contributor to the formulation and active experience of that individual. Examination of the Eastern, Western and Middle Eastern life philosophies illustrates this point. Whilst the over-riding principle behind most of these philosophies is the defeat of death, it can be shown that the manner in which this can be achieved differs according to which belief system is adopted.

Warren (1989, p. 132) takes examples from a selection of ‘holy books’ regarding the differing perspectives of death:

**The Eastern tradition:** What is soundless, touchless, formless, imperishable, tasteless, constant, odourless, without beginning, without end, higher than the great, unchanging—by discerning that, one is liberated from the mouth of death. … If one recites this supreme secret in an assembly of Brahmans, or at a time of the ceremony of the dead, devoutly—that makes for immortality (Katha Upanishad, III, 15, 17).

**The Western tradition:** Verily, verily, I say unto you, He that believeth in me hath everlasting life (John 6:47).

**The Middle Eastern tradition:** He who dispels from a believer one of the griefs of the world, Allah will dispel for him a grief on the day of resurrection; he who shields a Muslim, Allah will shield him in this world and the next (from the Forty-Two Traditions of An-Nawani).

The inevitability of death is shared by all religions; consideration of an afterlife or post-mortem existence highlights the differences between them. Markusen, quoted in Fulton et al. (1978, p. 131) describes three patterns of beliefs about life after death. Firstly, regardless of the experience of life on earth, everyone went to
'... a bleak underground place'. This view was held by the ancient Mesopotamians, the early Jews, and the Homeric Greeks. To these people, the concept of a day of judgment was irrelevant. Secondly, some religions believe their god or gods influence the ultimate fate of a person. This pattern is representative of religions of the ancient Egyptians, and later Jews, Christians, and Muslims. 'Conformity to dogma is the criterion which distinguishes the saved from the damned' (Markusen, cited in Fulton et al. 1978, p. 131). The concept of a day of judgement is integral to these religions and a belief in the hereafter serves to reconcile a person's life experiences with their hopes. The third pattern is characterised by Hinduism and Buddhism and the belief in an endless series of reincarnations. The quality of these reincarnations is dependent on a person's 'karma'. If a person experienced evil karma in a previous life, then they would be reincarnated as a lesser human or some sub-human form. Karma is not regarded as a substitute for an omniscient deity, rather an impersonal process which determines the ultimate fate of an individual. Hector and Whitfield (1982) are mindful of the meanings of religious beliefs to patients in our care and devote a chapter to these differences in their publication Nursing care for the dying patient and the family. Whilst this chapter was written for health professionals working in England, it can be adapted for the Australian scene. It details the fundamental beliefs of particular religious sects and suggests how nurses may be able to help patients with particular beliefs to fulfil their spiritual obligations.

The Cartesian influence on medicine has led to medical science's belief in the preservation of life at all costs. Capra (1982, p. 144) states, 'Disease is viewed as an enemy to be conquered, and medical scientists pursue the Utopian ideal of eliminating [it]'. It could be argued that technological advances have interfered with human spirituality and that death no longer 'fits' into the biomedical model of health. Capra (1982, p. 145) argues that modern medical practitioners are not educated towards providing the best possible comfort for their dying patients and relatives. In fact, doctors view death as a failure and a change in this attitude requires a fundamental shift in the medical view of health and illness.

It is unfortunate, but hardly surprising, that the attitudes of medicine towards death have affected the beliefs and practices of other health professionals. For example, nursing education and practice has been controlled to a large extent by the medical profession in the past, and this may explain why many nurses find it so difficult to care effectively for people approaching the end of their life. Glaser
and Strauss begin the preface to their landmark book, *Awareness of dying* (1965), with an interesting anecdote:

> Once upon a time a patient died and went to heaven, but was not certain where he was. Puzzled, he asked a nurse who was standing nearby: "Nurse, am I dead?" The answer she gave him was: "Have you asked your doctor?"

It is only recently that nurses have taken more responsibility for decision making in their practice and in the preparation of new practitioners. However, health care is witnessing an encouraging shift in emphasis away from the concept of curing at all cost. More nurses are becoming interested in providing terminal care and in being with people as they approach death. It could be anticipated that as societal demands for more caring interaction with dying people increases, nurses will be leaders in this area.

One philosophical approach which contests the traditional views of life and death is adopted by the existentialists. Their philosophy looks at death and its significance for human existence and human encounter. Existentialist philosophy views death as a vital consideration in human life. Perhaps the most prominent existentialist philosophers on the issue of death are Heidegger and Sartre. Heidegger (1962) postulates that a conscious awareness of death helps to put into perspective the triviality of everyday life; it plays a significant part in creating individuality and provides a means of achieving ‘Being-a-Whole’. In contrast, but still within existentialist thought, Sartre (1956) does not think that consciousness of personal death is possible. Rather, death, like all aspects of life, involves a strong element of choice (Warren 1989, p. 17). Death is a key concept in existentialist thought because in its essence, ‘...death condenses most of the basic characteristics of existence’ (Beckmann & Olesen 1988, p. 33). The existentialists believe that the separation from existence which death causes promotes the ultimate anxiety and it is the fear of death and death itself which creates the paradoxical focus on existence (Heidegger 1960). Beckmann and Olesen (1988, p. 37) suggest:

> The closeness of death brings me into emotional contact with what the "self" that must die, and what the life I now am anxious about, actually contains and means to me. Non-being puts being into relief and thus challenges me to see the unique and irreplaceable which is myself, and to realize this before it is too late. ... It is, therefore disastrous for life to repress death. The closeness of death is what gives life intensity and authenticity.
Rossi (1986) and Siegel (1986) speculate that an awareness of life can be utilised by those who are dying to bring extra dimensions and quality to the remaining life.

DeSpelder and Strickland (1992) trace the understanding of death throughout childhood. They suggest that early parental messages and cultural influences play major roles in shaping the child’s attitude towards death (DeSpelder & Strickland 1992, p. 114). The notion of ‘replaceability’ is one which is gleaned from parents. Death of pets is invariably met with the statement, “It’s okay dear, we’ll get you another one” (DeSpelder and Strickland 1992, p. 112). Cultural messages in childhood in the form of nursery rhymes and fairy tales are often violent in their portrayal of death. Goldreich (1977, cited in DeSpelder & Strickland 1992, pp. 113–114) remarked:

> It is inconsistent that a society which produced children’s books explaining the mysteries of molecules and atoms, of evolution and birth, should also produce works of facts and fiction which attempt to define and explain death.

This pre-occupation with understanding and explaining death is not limited to children’s literature. Several contemporary books and films have attempted to provide answers about death and near-death experiences for adults. We cannot experiment with death, despite the fanciful and rather far-fetched attempts that were portrayed in the recent film Flatliners, 1990. However, it is possible to talk with people who are dying or who have had near-death experiences. One such experience is that of Charles Lindbergh. Marilyn Ferguson, in her book The aquarian conspiracy (1980, p. 384) describes the event:

> Charles Lindbergh described in ‘The Spirit of St Louis’ (1953) an experience of disembodiment, the transcendence of space and time, loss of the fear of death, a sense of omniscience, remembrance of other lives, and a lasting shift in values. Lindbergh wrote that in the eighteenth hour of his journey, he felt himself as “an awareness spreading through space, over the earth and into the heavens, unhampered by time or substance...” The fuselage behind him filled with ghostly presences, “vaguely outlined forms, transparent, moving, riding weightless with me in the plane.” He “saw” them behind him “as though my skull was one great eye.” They conversed with him, advised him on problems of his navigation, “giving me messages of importance unattainable in ordinary life.” There was no weight to his body, no hardness to the stick. He felt more akin to the spirits, “on the borderline of life and greater realm beyond, as though caught in the field of gravitation between two planets...”. He felt as if he were acted upon by forces too weak to be measured by normal means, “yet representing power incomparably stronger than I've ever known.” The presences
seemed neither intruders nor strangers, more like a gathering of family and friends long separated, as though he had known them in some past incarnation. “Death no longer seems the final end it used to be, but rather the entrance to a new and free existence,” he wrote. Fifty years later, when Lindbergh lay dying in his cottage in Hawaii, his wife asked him to share with her the experience of confronting the end. What was it like to face death? “There isn’t anything to face,” he said.

In recent years there has been an increase in reporting of near-death and so-called ‘out-of-body’ experiences. One of the foremost researchers in this area is Raymond Moody (1975). There seems to be a fascination with the concept of ‘cheating’ death and returning to tell the tale. Psychologists and physiologists have postulated a variety of logical explanations for such accounts, and yet, of course, no definitive evidence can ever be established. There could be many reasons for the refusal to accept that when we die we are as nothing. Survival as a species as well as at an individual level could be major reasons. Warren (1989, p. 21) suggests that the realisation of ‘personal mortality’ could have catastrophic affects on our mental health and stability, and that death denial in our western society has evolved for our own good.

There seems to be little dispute among psychologists, sociologists and other writers in the area, that we live in a society which fears death and denies it. This denial is demonstrated in our society in a variety of ways, especially in language, ageism and the medical emphasis on cure.

In Evelyn Waugh’s satirical novel, The loved one (first published in 1948), Miss Thanatogenos describes her induction to employment at Whispering Glades ‘necropolis’:

Then they took me to the embalming-rooms and there was Mrs. Komstock lying on the table in her wedding dress. I shall never forget the sight of her. She was transfigured. That’s the only word for it. Since then I’ve had the pleasure of showing their Loved Ones to more people than I can count and more than half of them say: “Why, they’re quite transfigured.” Of course there was no colour in her yet and her hair was kinda wispy; she was pure white like wax, and so cool and silent. I hardly dared touch her at first. Then I gave her a shampoo and her blue rinse and a set just as she always had it, curly all over and kinda fluffed up where it was thin. Then while she was drying the cosmetician put the colour on (1951, p. 75).

Waugh’s extremely tongue in cheek send-up of American attitudes towards death could be dismissed as a work of fiction. Certainly, it appears to take an extreme
view of the American funeral industry with its elaborate use of euphemisms and its artificiality. As such, it portrays the epitome of death denial in modern western society. Before dismissing the work as a ridiculous exaggeration, it should also be noted that the research performed by Jessica Mitford (1963) actually supports many of the concepts underlying Waugh’s novel. Mitford does not dispute that funeral rituals have an important place in the way people of all cultures view death and express grief. However, she is critical of the use of guilt and death denial to establish an elaborate funeral industry which capitalises on people’s vulnerability. It is this aspect which Waugh’s novel illustrates so well.

The use of language is indicative of attitudes and beliefs. Further, language can actually mould ideas and perpetuate beliefs in society. In the case of death, it would appear that individuals seem to find it more comfortable to use euphemisms. DeSpelder and Strickland (1992, p. 22) provide an extensive list of alternative sayings for ‘death’ and ‘died’ and contend that society has been dictated to by the greeting card companies against the use of these two words. McGee (1980, p. 27), in her study of the bereavement cards, suggests that ‘Contemporary cards often include images of sunsets or fields with grain or flowers, apparently intending to convey an impression of peace, quiet, and perhaps a return to nature’. Similarly, the complexity of discomfort experienced by the western world when talking about death is concisely portrayed by the story ‘The horse on the dining-room table’ (Kalish 1985, pp. 2–4). The presence of the horse (denoting death) stunned the guests into stilted conversation about other things or absolute silence.

The meaning of death is also usually interpreted differently as a person ages. Gesser, Wong and Reker (1987, p. 113) undertook a study in which they found ‘fear of death/dying was relatively high among the young, peaked during middle age and fell to its lowest point among the elderly’. DeSpelder and Strickland (1992, p. 331) suggest that, in general, western society stereotyped the aged as silly, inconsequential, confused, dependent, ugly, weak, physically and mentally inept and useless. It could be argued that we separate them from the mainstream of society and distance ourselves. Nay (1992, p. 12) suggests that perhaps they represent an uncomfortable reminder of our own mortality. Like Dylan Thomas, we ‘Rage, rage against the dying of the light’ (1952, p. 116) and we spend an inordinate amount of money on make-up, hair dye and even reconstructive plastic surgery to assist us with our denial of ageing.
There are several films which provide an insight into these attitudes about ageing. Scenes in *Brazil*, 1984, for example, had some horrendous footage of plastic surgery and the very popular film *Cocoon*, 1985, provided some mixed messages about ageing. Of course, the stereotypes do not represent reality. Callahan (1990, cited in DeSpelder & Strickland 1992, p. 332) argues that there is a need to find:

> ... an interpretation of the social reality of old age that will provide a moral foundation for public policy ... [a policy which would do away with] ... the pretense that the elderly are just individuals who happen to be old.

In western countries the ageing population is growing rapidly. In Australia, it is estimated that by the year 2000, twelve per cent of people will be over the age of sixty-five, compared with eight per cent in 1947 (Brown 1994, p. 5). Most elderly people are healthy, active and have a great deal to contribute. However, Bennett (1983, cited in Nay 1992, p. 16) contends that:

> Although the vast majority of the aged are healthy and independent, ageing is accompanied by an increased risk of illness and disability, and the aged are the greatest users of the health care system. The over 65s in New South Wales have been estimated to occupy 30% of acute hospital beds, consume 40% of prescribed drugs, receive 70% of community health services and occupy 90% of nursing home beds.

Rowland goes further and points out that:

> The ‘old old’ (over 75) are the most vulnerable, and are expected to increase in numbers and proportion of the population at a greater risk than the young old. Between 1981–2001 the predicted increase is: over 60s — 50%; over 75s — more than 100% (1986, cited in Nay 1992, p. 16).

Historically, aged care nursing has been viewed in a negative light and it is difficult to rid the profession of this disapproving stereotype (Nay 1992; Brown 1994). Unfortunately, the stereotypes can be realised through self-fulfilling prophecy and there may be a resultant internalisation of the negative values about ageing that we expect to lose our faculties as we age. Negative attitudes towards ageing and rejection of the aged also give rise to beliefs that the death of aged people is less traumatic and more acceptable than death of children or adolescents (DeSpelder & Strickland 1992, p. 334). Christian (1994, p. 314) suggests:

> The dying aged have many needs — physical, psychological, social and spiritual. Their needs are not any less simply [sic] because they are older, perhaps less active and less involved in the wider world. Rather their needs vary, not only between people, but within the one person at different times, just as they
do with younger people. It is imperative, then, that the nurse does not stereotype what she [sic] considers to be the person’s needs. She should be prepared to ask every individual in her care, what their needs are, listen to their replies and act appropriately on them.

On the other hand, Kastenbaum (1988) supports the view that some deaths are better than others. In his article “Safe death” in the postmodern world’ he considers the modalities of dying that have dominated the western world. Kastenbaum comments on the expectation that all deaths will be pleasant and notes that ‘The relatively acceptable death is the one that nobody notices’ (1988, p. 5). In contrast but equally acceptable is the ‘good’ death which ‘… we face in an alert, composed state of mind with the opportunity to bid farewell to life and our loved ones in our own way’ (1988, p. 5). Kastenbaum indicates the two conflicting views may create a tension for either the person or the caregiver and ‘… both may fail to explicitly recognise their differences, let alone reconcile them’ (1988, p. 6). Kastenbaum relates several alternatives of a ‘good death’ and concludes that it is human nature to seek out the concept of a ‘good death’ in the face of whatever adversity society may care to nominate. In discussing death and dying in today’s society, he highlights the prospect of a living death for those people with Alzheimer’s disease or AIDS, and believes that as a ‘fantasy seeking people’ we will rise to the challenge of soliciting a ‘good death’ under the most provocative of circumstances (1988, p. 13).

**DEATH, DYING AND NURSING PRACTICE**

The publications of Glaser and Strauss (1965), *Awareness of dying*, *Time for dying* (1968) and *Anguish: A case history of a dying trajectory* (Strauss & Glaser 1970), have played a part in bringing about major changes in institutional response towards dying patients. In their early work Glaser and Strauss conducted interpretative research using the methodology of grounded theory, which emerged from the discipline of sociology (Glaser & Strauss 1965). Based on symbolic interactionism, grounded theory explores how people create their realities and subsequently builds a theory from the collected data.

In their research Glaser and Strauss (1965) studied individuals’ responses to life-threatening illnesses and isolated four modes or contexts of awareness which include the content and style of interpersonal communication about death. These contexts form the foundations of this section and will highlight the importance of Glaser and Strauss’ contribution to the literature. These contexts are the closed
awareness context, the suspected awareness context, the mutual pretence context and the open awareness context. Strauss and Glaser comment on the importance of these awarenesses on the nurse-patient interaction: 'The impact of each type of awareness context upon the interplay between patients and personnel is profound, for people guide their talk and actions according to who knows what and with what certainty' (1981, p. 128).

In the closed awareness context, there is no awareness of own death by the patient, although others may know. The debate 'to tell or not to tell' the patient about their fate is largely cultural and current beliefs are steeped in the western death denying belief system. Strauss and Glaser (1981) note that in other cultures, for instance, the Asian countries, it is customary for the extended family to be present with those about to die for at least two or three days. There is an open acknowledgment to the dying person that the family are present to assist in the rite of passage. Similarly, and closer to home, the Maori community in New Zealand exhibit a cognate ritual (Goulton, R.R. 1987, pers. comm. 9 June).

In western hospital systems, closed awareness becomes structurally simple to ensure as information is easily concealed from the patient. Progress notes are often kept away from the bedside and restricted access is implicitly assumed. Nursing personnel as well as medical personnel may collude in their attempts not to discuss a patient’s prognosis within their earshot and if they do it is often couched in such technical language that it is rendered incomprehensible by the patient. Hence, communication with the patient is very difficult because the probability of death is avoided in all interactions (Strauss & Glaser 1981; Ansell 1976).

Field and James (1993, p. 20), in their discussion related to institutionalised death, purport that in some nursing home environments, ‘... death is “marginalized” and seen primarily in terms of the practical problems which it causes for staff’. They conclude that staff tend to focus on the disposal of the body and funeral arrangements and view these procedures as an interruption to the daily routine rather than an extension of bereavement care. Field and James (1993, p. 20) further contend that:

Bereavement will only be acknowledged where death itself is significant, and in most homes the routinization [sic] and denial of death denies also the likelihood of sorrow or loss. Those most likely to suffer from this poor quality of bereavement care are not so much the relatives (if there are any), but fellow residents
who obviously need to be informed of a death with care and compassion, since it is likely to touch closely on their own situation.

Linked with, but separate from, closed awareness is supposition awareness. In this context the patient suspects that the prognosis is death, but is not told by those who know. Such patients may engage in actions such as trying to finish unfinished business or even slow down their life-work activities in an attempt to elicit information. In the contexts of closed and suspected awareness Strauss and Glaser (1981, p. 130) believe it is the nurse who is subject to strain as they spend the most time with the patient and thus becomes the target for testing the patient’s suspicions. In this situation, Strauss and Glaser feel that nurses may choose to ignore the patient for fear of disclosure (1981). Whilst Strauss and Glaser describe the North American situation, there are situations within Australia in which either health professionals and/or relatives still practise the withholding of information. I disagree with Kellehear’s (1990, p. 171) conclusion that information about dying in the western world is derived from doctors. To accept this argument negates the visibility of the nurse and implicitly agrees that the nurse’s role is subservient to the doctor’s authority. Field (1984) conducted a study with nurses which contradicted McIntosh’s (1977, cited in Field 1984, p. 63) findings of the preference for ‘closed awareness’ among nursing staff. Field (1984, p. 67) concluded that nurses preferred to nurse patients who were aware of their death rather than those who were not and that it was the nurse, through their autonomous practice and subsequent disclosure to patients, who was able to nurse dying patients in an ambience of therapeutic care.

DeSpelder and Strickland (1992, p. 317) liken the mutual pretence context to ‘... a dance in which the participants sidestep a direct confrontation about the patient’s condition’ and enter into a series of aberrant behaviours designed to sustain the illusion that the patient is recovering. In this situation Strauss and Glaser purport that ‘dangerous’ topics are avoided by all participants involved in the interaction (1981). Disease processes and even treatments may be re-named to present an illusion of returning to normality. Clearly, this behaviour cannot be sustained if the disease process worsens and Strauss and Glaser (1981, p. 131) maintain that the only direction in which the interaction can proceed is towards an open awareness.

Briefly, Strauss and Glaser (1981, p. 133) describe open awareness as the situation in which the likelihood of death is acknowledged and discussed.
Kellehear (1990, p. 72) discusses the importance of this open awareness and agrees with Lucas (1968, p. 2) that ‘If people know that death is near, the incorporation of this knowledge will be stimulus to social and role adjustments’. However, whilst open awareness offers the possibilities of sharing support in ways that would not otherwise be available, it is not without its ambiguities (Strauss & Glaser 1981; Kellehear 1990; Sheehy 1973, cited in Kellehear 1990; Marshall 1980). Open awareness does not mean acceptance, in the same way that ‘… acceptance of ideas does not necessarily mean agreement’ (Chapman 1994a, p. 41). Nevertheless, Kellehear (1990, p. 74) does contend that open awareness is an excellent starting point for discussion of what he describes as a ‘good death’. The issue of appropriate ways of dying is discussed by Strauss and Glaser (1981). They believe that ‘Once a patient has indicated his [sic] awareness of dying, he becomes responsible for his acts as a dying person’ (1981, p. 133). With this responsibility Strauss and Glaser deliberate that the patient has a two-fold obligation: firstly, an ethical one, and secondly, the manner in which they should die.

The ethical debate reflects on the care and treatment received during the period of knowing about death and the death, and involves all participants—patient, nurse and doctor. It is still considered contentious to enter into the issue of helping a patient to die in the physical meaning of the words, that is, active euthanasia (Saclier 1976). However, Butler (1985, p. 14) feels that initiation of a life review, that is, helping the patient to die in a ‘commencement of the journey’ sense, is invaluable. Crowther (1993, p. 113) contends that there is a fine line between active and passive euthanasia and that the latter has become acceptable in America and the Netherlands. He subscribes to Twycross’ (1981) argument that the withholding of ineffective treatment which may be burdensome to a dying patient ‘… could be called “mercy dying” as opposed to “mercy killing”’ (cited in Crowther 1993, p. 113).

Johnstone (1989, p. 254), in her publication *Bioethics—a nursing perspective*, discusses the arguments for and against euthanasia. The most popular arguments in support of legalising euthanasia are, firstly, respect of the individual’s autonomy and the right to die; secondly, the most dignified option in cases of chronic or painful illness is for patients to choose to die; thirdly, prevention of cruelty or mercy killing to reduce suffering; and finally, to deny the person’s right to die is to treat that person unfairly and only the person themselves can judge what is fair for them.
Johnstone (1989, p. 256) also identifies seven main arguments against the legalisation of euthanasia. Firstly, life is sacred and nothing, not even intractable suffering, can justify taking it. Secondly, there is always a possibility of misdiagnosis or recovery and once the act of euthanasia is taken it cannot be reversed. Thirdly, she suggests that relatives, significant others or friends may abuse the concept of euthanasia and gain power over another person. Fourthly, the concept of dying with dignity is a matter of prime importance within the medical and nursing profession and to legislate is not necessary. Her fifth point is that it could be argued that euthanasia is discriminatory and treats some people’s lives as less worthy than others. A sixth argument is that the patient who requests euthanasia is acting irrationally; it is in fact a cry for help rather than a death wish.

Finally there is the ‘slippery slope’ argument (Johnstone 1989, p. 258). The slippery slope debate is one of a gradual decline in society’s moral standards and once we start compromising the standards pertaining to human life, then all other standards are in danger of falling. Thus, according to this argument, euthanasia can never be justified. There are no ‘right’ answers to this debate and I contend that the pendulum will continue to swing regarding the issue of legislation for many decades to come. So often, nurses are ‘between a rock and a hard place’ on these issues. In the US, the Patient Self-Determination Act (1990) has opened the flood-gates for education in how to ‘pull the plug’ and remain sane. A little closer to home, the Euthanasia Society and, in particular, Dr. Robert Young (1988) have examined two of the ‘myths’ surrounding the ethics of euthanasia. Young’s article points to the necessity of setting up ethics committees in local hospitals. I believe this move is essential but in doing so nurses should make sure they are well represented on such committees.

Miller Mair (1989, p. 272), in his book *Between psychology and psychotherapy, a poetics of experience*, boldly states that ‘We create realities by and through the conversational practices we are involved with and undertake’. In accepting Mair’s (1989) and Butler’s (1985) arguments it can be further argued that nurses caring for the dying are placed at the nexus between the death experience for the patient and the death experience of the patient. Wesney (1985) replicated a 1982 study of nurses’ feelings about working with the dying and concurs with Stowers (1983) that not only do patients need to express their emotions about dying but also nurses require a supportive outlet for their own pathos.
Not all death is peaceful. Parkes (1985) undertook a study with first-year student nurses which revealed some nurses were left with feelings of guilt, frustration and even regret as a result of their involvement with nursing the dying patient or caring for the body after death. However, Thompson (1985) found that the work setting is a more significant force in shaping attitudes than is experience. Thompson’s study with fifty-two nurses from three settings, namely, paediatrics, palliative care and a surgical ward, found that nurses working in the curative settings could not escape the saliency of their unit’s curative focus. He concluded that ‘Palliative nurses approach their work with the dying with greater ease, may enter into more personal relationship with dying patients in that they share their feelings with the patient, and come away from their work with the feelings that work itself is rewarding and they have been useful’ (Thompson 1985, p. 240). In contrast, Thompson (1985, p. 234) purported that nursing the dying in a curative setting occurs at ‘... greater psychological cost and fewer rewards’.

Jeanne Quint (later Quint Benoliel) (1967) describes a myriad of defence mechanisms utilised by nurses to allay their anxieties produced by confrontation with dying patients. These defences have been catalogued by Quint (1967, p. 350) as:

Avoidance of the patient. Treating the patient as a thing rather than a person. Evading conversation with the patient. Wearing a bland facial expression. Avoiding emotional involvement with the patient or relatives. Intense preoccupation with life saving techniques. Avoidance of talk about the future. Maintaining a busy air which gives a message to the patient not to ask questions. Selective listening which cuts down on feedback to the patient and controls the conversation. Attending to those who will recover. Rationalisation of the patient’s death.

This formidable list provided the impetus for Quint to suggest forcefully that death education for nurses be reviewed and revamped. The following section will discuss the development of such education.

**DEATH EDUCATION FOR NURSES**

The response to Quint Benoliel’s request has been unhurried in spite of the ancillary comments of such philosophers as Illich (1976) who first alerted us to the dangers of the medicalisation of life events. As late as 1982, Quint Benoliel discovered that ‘... courses on death and dying have not become integral components of medical and nursing curricula’ (p. ix). Warren (1989) examines the concept of death education and reports that until fairly recently the philosophical
and psychological approaches to death education have remained separated. He believes that the merge of the two approaches presumes ‘... that there will be a positive outcome, that people will be better able to deal with whatever aspect of death and dying the program is aimed at illuminating, or perhaps will be generally improved as human beings’ (Warren 1989, p. 7). Warren (1989, p. 18) further addresses the importance of the philosophical outlook on death education. He contends that the traditional philosophical view of death as unimportant would not act as an incentive in the development of death education programs, whereas, in the existential philosophical opinion it is valued as a very important activity:

Somewhere between the Existentialist and traditional philosophy then, there is still a clear contrast between the view of death as significant, even vital consideration in and for human life, and the view of death as “nothing to us” (Warren 1989, p. 18).

Leviton (1977, p. 44) defines death education as ‘... a developmental process that transmits to people and society valid death-related knowledge and implications resulting from that knowledge’. In addition, Leviton points to the specific goals of promoting notions such as ‘comfortable interaction’, ‘reducing anxiety’ and ‘good or appropriate death’. In terms of the existentialist conception it would appear that comfortable death education is indeed a paradox. Warren (1989, p. 21) informs us:

Corr (1977, 1978) is one of few writers to draw attention to this contrast as well as to broader concerns of Death Education beyond a solely psychological focus. Yet between calm indifference and rage and activism, there are vastly different individual and social consequences.

Warren’s (1989, pp. 23–41) subsequent discussion concerning rights, values, morality and ethics, questions interventions with others under the umbrella of ‘education’. He asks whether educationalists have ‘... the right to intervene in another person’s life in regard to that person’s consciousness (or lack of it) of death; or of the interests behind such intervention’ (Warren 1989, p. 41). The questions of possibility and desirability of death education may well have contributed to the sluggish response to Quint Benoliel’s petition. Mauksch (1983, p. 5), in defence of nursing’s position, states:

Certainly it is crucial to understand the interface of nursing’s conditions with appropriate societal circumstances as well as their relationship to pertinent substructures within the health and illness care delivery system. Also, one must understand the historical background of these [contemporary] issues, how social change has affected them, and whether or not the profession’s attitudes towards them have changed.

Degner and Gow (1988, p. 151) respond to Quint Benoliel’s request and point out that few programs in death education have been described and further allude to the paucity of evaluation of these programs. Using quantitative evaluation Degner and Gow report that death education may reduce death anxiety and/or improve attitudes to care of the dying ‘... but the accumulated evidence is not convincing because of numerous problems with study design, instrumentation, and data analysis’ (1988, p. 151). They promulgate three approaches to teaching about death and dying:

1. integrating specific learning experiences on death and dying into a preexisting curriculum;
2. offering an elective course;
3. altering the curriculum to include a required course (Degner & Gow 1988, p. 152);

with the most frequent approach favouring integration. This approach roughly involves offering portions of education about death and dying throughout the nursing course. These portions utilise a formal approach incorporating lectures and seminars on topics such as grief and mourning (Degner & Gow 1988, p. 153). Whilst this approach is useful, it renders death and the death experience as something to be viewed, rather than a process of involvement. On the other hand, Appleyard (1982) takes a more qualitative view of what nurses should know when dealing with the dying or the dead. Appleyard (1982, p. 61) takes a two pronged approach and recognises that the nurse’s emotional needs are as important as the patient’s. However, it could be argued that Appleyard is caught up in the tendency to make death and dying a comfortable experience for all concerned.

Attig (1992) claims a person-centred approach to death education is reality based. Incorporating the use of storytelling and reflection, Attig (1992, p. 369) considers his methods respect what it is to be human from the patient’s and the nurse’s perspectives. Similarly, Chodil and Dulaney (1984, p. 5) believe that ‘... a nurse who is comfortable with her [sic] own feelings about dying and death is able to
function more effectively and humanistically ...'. They conclude that although their study was too small to draw definitive conclusions on the influence of continuing education on death anxiety in nurses, it did highlight the need to design valid methods of evaluating death education programs from a personal as well as professional orientation (Chodil & Dulaney 1984, p. 8).

Hurtig and Stewin (1990) encourage experiential learning and suggest that this method of teaching is favoured by many educators. However, a recent survey conducted by an Australian researcher revealed that information giving is still the dominant modus operandi used by educators in Australian universities today. Hurtig and Stewin (1990, p. 32) describe their teaching methods and allude to the value of published literature, music and artistic impressions of death and dying in assisting students to make their own meanings. I concur with Hurtig and Stewin but further develop their ideas and use creative writing as a strategy within the death education workshops I conduct. These sessions have already produced a publication of poetry and prose which has been widely acclaimed (Chapman 1994b).

Peace and Vincent (1988), Hopping (1977) and Murphy (1986) assert that death anxiety among nurses is reduced following death awareness workshops. However, these evaluations communicate that it is the older nurse or those who have accumulated some experience who benefit the most from such programs. In contrast, Mullins and Merriam (1983) report an increase in death anxiety in nurses undertaking a short course in death and dying. They rationalise their findings by stating:

> The fact that death anxiety was greater among those who received the training is not necessarily a negative result. If the increase in the anxiety about death stimulates nurses to spend more time considering their own demise, it may also stimulate greater empathy with those around them who are facing their own death. In realizing [sic] that their own anxiety has risen simply by hearing such information about death, nurses may also more fully understand the feelings of those persons to whom they are administering. It is hoped that the anxiety experienced can be transformed into a constructive energy outlet stimulating greater patient understanding (p. 365).

Lev (1986) designed a course for nursing students entering their final year of studies. She agreed with Peace and Vincent (1988) that the more experienced and older people appeared to gain greater insights into their work with the dying as a result of the course. Moreover, Lev (1986, p. 241) noted that courses conducted in
conjunction with clinical exposure in palliative nursing were more meaningful to the students than courses conducted in isolation from the clinical milieu.

Plato (cited in Penson 1990, p. 160) once wrote 'What matters most is not the knowledge imparted to a man [sic] but what the man himself becomes in the course of acquiring that knowledge'. Transferring this concept to death education means that those involved in this work cannot centralise their teaching on death and dying alone. The complex interrelationships which surface in the thinking and behaviour of students during the death and dying workshops I have facilitated constantly remind me that my teaching involves more than the imparting of ideas. I believe I am privileged to witness their outward and inward struggles with the phenomenon of death and consequently relish in mutual exploration and discovery.

THE CONTRIBUTIONS AND CRITIQUE OF ELIZABETH KÜBLER-ROSS’ WORK

It has been claimed that the impetus for the Death Awareness Movement in the latter half of this century may be partly attributed to the writings of Elizabeth Kübler-Ross (Aiken 1991, p. 22). Certainly, discussions surrounding death and dying were almost closeted until Kübler-Ross’ writings were publicised. Above all, Kübler-Ross postulated the stage theory of dying but it should be noted that she has been involved in other proactive events. Kübler-Ross advocated the inclusion of a ‘grief’ or ‘screaming’ room in hospitals and other settings. This special space is designed for health professionals and other caregivers to engage in open discussions with patients and family members (DeSpelder & Strickland 1992, p. 573). These rooms were set up as the result of research conducted at the Ross Centre, located in Virginia. Elizabeth Kübler-Ross is the representative of this support centre which also coordinates a variety of programs related to life-threatening illnesses, bereavement and the promotion of physical, emotional and spiritual health (DeSpelder & Strickland 1992, p. 158). Kübler-Ross’ work has not been easy to establish. In her pioneering days she was refused entry to a ward in an American suburban hospital when she was about to conduct a teaching session with young interns on the special needs of the dying. Her aim was to let the patients speak for themselves but she was told by staff members that there were no dying patients on the ward, only some patients who were critically ill (Kübler-Ross 1969, p. 219). However, this reaction did not deter Kübler-Ross and her writings remain the most read works on the subject of death and dying and are
not only useful to health professionals but to many bereaved and those about to die (Crichton 1976).

Kübler-Ross' psychodynamic theory of stages of dying has been almost universally accepted. It is interesting that Kübler-Ross herself, in her introduction to her book entitled On death and dying, states:

It is not meant to be a textbook on how to manage dying patients, nor is it intended as a complete study of the psychology of the dying. It is simply an account of a new and challenging opportunity to refocus on the patient as a human being, to include him [sic] in dialogues, to learn from him [sic] the strengths and weaknesses of our hospital management of the patient (1969, xi).

Kübler-Ross' initial study (1969) was conducted with about two hundred dying patients. Case study interviews were conducted with these patients and some of their caregivers (physicians, chaplains, relatives and nurses) and their responses were noted to form a pattern. Kellehear (1990, pp. 22–23) argues that Kübler-Ross' work lacks methodological rigour but acknowledges her work ‘… has made an important contribution to opening up communication and dialogue about the social process of dying’.

The responses elicited from Kübler-Ross' participants were grouped into five stages, namely, denial, anger, bargaining, depression and acceptance (Kübler-Ross 1969). Although these responses do not occur in a static progressive manner many health professionals have adopted them at face value and await each stage in their dying patients (Chapman & Brown 1993a, p. 22).

Denial refers to the initial response of shock or disbelief at the news of a terminal illness. A subsequent anger in the form of 'why me?' questioning in terms of a reaction may follow the initial response. Alongside the questioning period the patient may manifest envy and resentment to other less seriously ill patients or family members. ‘Bargaining is the psychodynamic description of the next stage and this refers to the active desire to postpone’ (Kellehear 1990, p. 20). Bargaining or negotiation usually happens with God or other spiritual influences. Sometimes bargaining can happen between the patient and health professionals. Some examples of bargaining could be, “I just want to see the turn of the century, then God can take me” or “If the doctor extends my life period so I can see my daughter married, I will donate a large sum of money to the hospital’s cancer
fund". Whatever the particulars of the attempt to bargain, such efforts represent a quest to alleviate suffering and postpone the dreaded outcome. Kellehear (1990, p. 20) comments that often this stage goes unnoticed by others. The depression stage may well mirror the decline of the patient's general health status and is focused on the experienced or perceived future loss. Kübler-Ross differentiates between the two as a reactive and preparatory depression (DeSpeldt & Strickland 1992, p. 171). The final stage is acceptance. Kellehear suggests that this stage is not necessarily a happy stage but the patient is able to explore more dispassionately the inherent issues and possibilities of the situation and begin to establish productive ways of dealing with the event of their death and its ramifications on others (1990, p. 22).

These stages of coping with a life-threatening illness should not be thought of as strict categories that occur in a fixed sequence. A variety of emotions may occur at any stage of the dying trajectory and patients may well disregard a stage or stages and move from anger to acceptance. Conversely, a patient may never reach the acceptance stage, although it is fashionable in terms of a 'good death' (as discussed earlier in this chapter) for health professionals to perceive their role as facilitating a patient to the stage of acceptance. The dying and those who will be bereaved by their deaths may experience a number of responses with phases of denial, anger and finally acceptance. Raphael (1984, p. 50) suggests that when informed of a fatal illness patients and their families experience initially:

... shock, numbness, disbelief and denial ... hope is a very powerful element ... That it is the source of positive feeling for the dying person and his [sic] family that may carry them through the painful process of facing his [sic] loss.

Raphael (1984, p. 33) further states:

The bereavement reaction may be described as comprising a series of phases, representing some of the processes of adaptation to loss. It must be acknowledged, however, that any such phases are not clear-cut or fixed and that bereavement may pass backward and forward among them or may indeed become locked in one or another, partially or completely.

Critics of the stage theory include Kastenbaum (1981), Charmaz (1980) and Kellehear (1990). Kastenbaum warns that labelling a patient as deviant may occur if the stages are not followed as outlined in Kübler-Ross' theory. He further contends that cultural differences are not accounted for in Kübler-Ross' work. Charmaz (1980, p. 149), on the other hand, presumes that Kübler-Ross
interviewed people who were responding to the social context of their illnesses rather than their physical dying. Kellehear (1990, p. 21) revealed three features of Kübler-Ross’ sampling. These were:

(a) Most were hospitalised;
(b) Many of the sample had not been informed of the ‘seriousness of their illness’; and
(c) Most respondents reported strained relations with medical and nursing staff in their hospital.

Kellehear further comments on the style of interviewing used by Kübler-Ross and makes the observation that no two patients were necessarily asked the same question, rather they were asked to tell their own stories. I believe Kellehear and other critics of Kübler-Ross’ methodology do not acknowledge the difficulties she experienced in undertaking the initial research. It was foremost in Kübler-Ross’ mind to ask ‘… terminally ill patients to be the teachers’ (Kübler-Ross 1969, p. 19). This thought is consistent with those of Reason and Rowan (1981), Reason and Heron (1986) and Polkinghorne (1988) in their individual approaches to storytelling as a methodology rather than a method. It could perhaps be argued that Elizabeth Kübler-Ross’ methodology was ahead of her time.

Keeping a balanced view of the criticisms posited against Kübler-Ross, a knowledge of the concepts and theories of grief will enable the nurse to plan and implement interventions for the patient and families designed to assist in helping them understand their grief and then to deal with it more effectively (Aiiken 1991). It is important to note that all those involved with the patient, including the family and other caregivers, may experience different aspects of the grieving process and bereavement at differing times (Marquis 1993).

Death has been described as the final stage of growth by Kübler-Ross. She urges people to ‘practise life with compassion, love, courage, patience, hope and faith’ and to take time every day to grow and to reach out to other human beings (1986, pp. 164–5).

**THE IMPACT OF LOSS AND COSTS OF CARING, FOR NURSES**

Nursing is taking on new profiles as we experience changes within western health care systems. Nurses have the opportunity to be involved in the decision making processes at the grass roots level as well as the policy making level. I believe that
for sound decisions to be made, nurses must be well informed. If that means becoming involved with patients' needs and their expression of these needs then, so be it. As nurses, we can no longer stand on the side-lines and watch others make the decisions which directly impact on patient care (Benner & Wrubel 1989). We should be in there with them, being proactive rather than reactive (Parker 1988). But is there a cost and can we afford it?

It has often been said that 'doctors cure and nurses care'; the debate is not an issue for this study. However, a recent booklet from the National Health and Medical Research Council (1991) which describes the role and function of the nurse, highlights that the central role of the nurse is to care. There are nursing theorists who base their writings on theories of goal attainment; symbolic interactionism; adaptation models; systems models and unitary human beings. There are other nurse theorists, such as Lydia Hall, Dorothea Orem, Madeleine Leininger, Jean Watson and Patricia Benner, who believe that caring is the central concept of their theories. Benner and Wrubel (1989, p. 1) make the following statements about caring at the beginning of their book, *The primacy of caring*:

Caring ... means that persons, events, projects, and things matter to people.

Caring is essential if the person is to live in a differentiated world where some things really matter, while others are less important or not important at all.

'Caring' as a word for being connected and having things matter works well because it fuses thought, feeling, and action—knowing and being.

Caring creates possibility.

In their article 'Comparative analysis of conceptualizations and theories of caring', Morse, Borreroff, Neander and Solberg (1991) focus on the impact of caring on nursing theories and highlight the different perceptions of caring described by these theorists. They allude to the problems of the development of a caring knowledge and confirm Laundh, Soder and Waerness' (1988, cited in Morse et al. 1991, p. 119) view that nursing caring theories are 'airy and consensus-oriented'. Morse et al. (1991, p. 119) contend that 'If caring is really the “essence of nursing” then it must be demonstrated and not simply proclaimed'. In an earlier article, Morse, Solberg, Neander, Borreroff and Johnson (1990, p. 12) contend that tensions may well arise with practitioners who value caring and administrators whose prime concerns are those of effective nursing care at a budget price:
Administrators seek to control nursing actions, to limit caring time, and to require concrete, measurable outcomes to justify their actions, whilst nurses beg for time for caring tasks (eg, listening to the patient’s concerns) that do not have solid, quantifiable outcomes other than patient satisfaction.

Perhaps Morse et al. (1990) stress the evolutionary stage which caring and nursing currently share.

Forrest (1989) describes her phenomenological study about caring, with practising bedside nurses. For these nurses ‘... caring is synonymous with nursing’ (p. 822) and arose from a deep interest in people. The participants in the study vividly recalled those educators who counselled them as students to be caring. In contrast the participants remembered also those colleagues who were deemed to be uncaring and reported their feelings of anger, frustration, hurt and disappointment with the nursing practice they gave (Forrest 1989, p. 822).

Schaefer (1990, p. 273) stated that the elements of humanistic caring were identified by the constant comparison method including (a) showing the way; (b) creating new ways; (c) working with others; and (d) taking care of the environment. This could not only be applied to the nurse-patient relationship but also the nurse-nurse relationship.

Watson (1987), in her discussion on the use of metaphor alludes to the invisibility of caring in nursing: ‘Because caring knowledge in nursing science deals with a phenomenological paradox of facts, meaning, and context, and because this knowledge is relational and expressive, it is often silent and invisible’ (p. 11). Watson discusses nurses’ silent and unheard voices and parallels Belenky, Clinch, Goldberger and Tarule’s (1986) work in Women’s ways of knowing and summons nurses to speak out loudly about the ‘primacy of caring’ before it is lost. Caring consciousness, Watson believes ‘... can transcend time and space and physicality’ (1987, p. 16).

Marquis (1993) discusses his work with nurses who care for the terminally ill and those involved in critical care. Both areas of nursing work extract different responses from nurses. Marquis (1993, p. 17) states:

... every form of dying and death places its own distinctive emotional burden on the caregiver. For example, in the wake of a swift and violent death, an emergency room nurse may believe
that he or she was not really trusted by the supervisors and not allowed to exercise his or her own professional judgment. The lack of opportunity to establish a last bond with the dying person can generate intense frustration. By contrast, the "slow death" process can result in debilitating fatigue on the caregiver's part, a fatigue whose source in the relationship with the dying person may not be recognised.

Marquis describes in detail the complexity of emotions described by his participants in experiencing the multiple deaths while working as a nurse. Marquis (1993, p. 22) believes that many of these nurses held impracticable ideas and expectations of their patients and some of their professional exhaustion could be attributed to their secret hopes and desire for a full recovery. Another ideal is that some nurses have '... the innocent wish to be endowed with mysterious virtues and powers making them modern examples of witches or almighty priests' (Marquis 1993, p. 23). The development of life-saving technology, together with exalted ego states, has assisted what Marquis calls 'the syndrome of the miracle-worker' (1993, p. 23) when nurses lose sight of realistic patient outcomes. Alongside this identified syndrome Marquis (1993, p. 24) purports that '... the nurse is continually forced to fight the idea of failing to do more to prevent the patient from dying'. The problems of a cure-all philosophy invokes this vicious circle and guilt results in a powerful attack on the nurse's self-esteem. In conjunction with aspirations of a perfect death it is easy to see how burnout can, and often does, develop.

Burnout has become a 'buzz word' in the corporate world. Along with executive stress, it has become commonplace in conversations about people who strive to achieve but for whom the energy required to reach their goals surpasses their capacity to give. Smythe (1984, p. 47) describes burnout as '... the terminal phase of failure to resolve work stress.' This state of exhaustion and helplessness can occur by working in areas which are constantly short staffed, with inadequate supplies or equipment and the feeling of trying to single-handedly manage all the patients' problems as well as coping with the deficits of the work environment. However, Smythe (1984, p. 53) provides some insight into her definition by saying:

... to become burned out, you had to have been "on fire." You would never become burned out if you weren't a caring, sensitive nurse who was once enthusiastic about your job and who once had high aspirations for your chosen profession... Nurses who are insensitive, don't care what happens to their patients, or see their job as simply a nine-to-five money-making situation don't risk becoming burned out.
In essence, what Smythe is saying is that whilst nurses are feeling burned out now, they have not been in this situation all the time. Arnold (cited in Carson 1989, p. 325) points out that ‘... most nurses enter the profession with a healthy dose of idealism and commitment’ and when their perceptions or expectations of the profession do not match the reality of the situation, there is an imbalance. The nurse’s inner spirit becomes fragmented and there is a need to reunite these shattered pieces, calm the inner turmoil and ultimately make some meaning of their life. Benner and Wrubel’s (1989, p. 373) approach to burnout in the section of their book *The primacy of caring* called ‘Coping with caregiving’, emphasises that burnout is not the result of caring too much, rather, that it is the absence of caring. Marquis (1993, p. 31) alludes to this idea but reverses it and says that nurses who indulge in self-caring habits appear to maintain high energy levels and demonstrate an inner peace which assists them to treat each new death as ‘... a means of discovery about life’.

Very often when a patient dies there seems to be a period of intensive involvement with the family and then, all of a sudden, it stops. It is as if they associate nurses with giving care only to their loved one and they do not want or feel they can continue their relationship after the death of their loved one. The important issue in a bereavement situation is the quality of the relationship. There is no need to set up situations of dependency but there is perhaps a need to acknowledge that nurses also care about the bereaved. This caring relationship may begin by the nurse involving the family in the care of the dying person. I am not advocating that the nurse should disseminate all nursing practice to the family, but merely offering the idea that families sometimes want to be actively involved in caring practices. The sharing of responsibility can be of mutual benefit to the nurse and the family member. On the other hand, failure to share may result in tensions and bitterness which are hard to resolve (Chapman & Brown 1993a, p. 16).

The involvement of relatives and friends in the care of dying patients is illuminated in a small but powerful book called *The dying* (Job 1986). It is an autobiographical account of the author’s experiences during the six months in which her husband was dying from cancer. A poignant example is given in the book when David, her husband, was immediately recovering from a lengthy anaesthetic. Jill, his wife, had been sitting with him since his return from the operating theatre and the nurse arrives to wash him and record his observations.
A nurse came, looked curiously at me. Mr. Matthew? She leaned close to his face, speaking loudly.—Mr. Matthew, we’re just going to clean you up now and take your temperature. His lids didn’t move.—Would you mind waiting outside Mrs. Matthew? We won’t be long, and you can come back afterwards. She pulled the curtains, resolving objections. My God, I hated her. Hospital habits. I wanted to say: listen; I fuck this man, I squeeze his pimples; I know his body and the sight of it does not offend me. I didn’t say it. I stood in the corridor. Maybe it was just her timing. It felt callous. Did she know? (Job 1986, pp. 45–46).

This passage provides a gentle reminder of all those occasions when nurses have asked wives, husbands and partners to leave the bedside so that they could perform all those tasks. Perhaps what I am really saying here is that there is no recipe for effective relationships and that it is part of the skill of a sensitive carer to assess each situation and provide the most appropriate support (Chapman & Brown 1993a, p. 18). In this way the nurses, doctors and other health workers can be part of a supportive team with the relatives to assist the patients and provide optimum care.

People who work with the dying sometimes come to think of themselves as special people (Vachon 1985, p. 25). This perception is often reinforced by colleagues who may say ‘I don’t know how you can work in that area,’ or ‘I suppose you get used to it, people dying all the time,’ or ‘I couldn’t do that work, it’s so depressing’. Working in palliative care units is ‘special’ nursing work but no more specialised than working in any other unit which concentrates its energy into one area (Chapman & Brown 1993a, p. 5). The missionary zeal which often accompanies an individual’s motivation to work with the dying soon becomes unrealistic and unreliable if they are unsupported (Vachon 1979, cited in Corr & Corr 1983, p. 243). I would argue that although palliative nurses are not necessarily a ‘special breed’ the need for valid support systems within this area of nursing is of the utmost importance. What kind of support systems are necessary within palliative units is largely dependent on the needs of the staff who work there. These support systems may contain resources of the human, educational, spiritual, or ritualistic kind. There may be an emphasis on one of these systems or a combination of support from all of these areas. Whatever resources are available, there is a need to ensure that the system is up-to-date with the requirements of the staff which it serves (Marquis 1993).
It has been argued that nurses often lose perspective of their own needs for caring (Benner & Wrubel 1988). Additionally, nurses have a long track record of horizontal violence between colleagues and forget that sometimes they need as much consideration as they give to their clients (Roberts 1983, p. 22). Nurses often have unrealistic expectations of themselves and imagine that they are impervious to the emotions attached to the death of a patient. Alexander and Ritchie (1990, p. 30) conducted a study of sixty-one nurses from St. Columbia’s Hospice in Canada. They identified several areas of nursing work which the nurses in the study found extremely stress-producing. These situations included relating to patients who are noisy; are depressed; are anxious; are withdrawn; are bed bound; are intractable; swear at you; are aggressive to you; develop affectionate feelings towards you; are faecally incontinent; are urinary incontinent; are young children; do not accept their illness; do not want to die; or are afraid to die. This gamut of emotions may appear rather lengthy and somewhat all encompassing of nursing work, yet Alexander and Ritchie point out that their study has major implications for research and continuing education in palliative nursing.

The tensions outlined in this section and the chapter as a whole may provide some insight into what is involved in nursing the dying. Clearly, the participants’ stories will make the picture clearer and serve to make the experience meaningful. Nevertheless, nursing the dying is not without its costs, both personal and professional, and I am hopeful that this chapter has illuminated some of those costs.
Chapter Four
Phenomenological Methods
Used in this Study
This chapter describes the methods used in this study to obtain descriptions of the participants’ experiences. These methods are congruent with the belief that nurses’ own languaging of experience best describes their being-in-the-world of nursing dying or dead people. In addition, the chapter provides a brief overview of the role of the participants in this study. Finally, the chapter will elaborate the ethical considerations undertaken by the researcher in the process of conducting this study.

**PHENOMENOLOGICAL METHODS USED IN NURSING RESEARCH**

Phenomenological research recognises the person is a self-interpreting being. ‘That is, the person does not come into the world predefined but becomes defined in the course of living a life’ (Benner & Wrubel 1989, p. 41). To uncover the meaning of lived experience, the researcher asks the person who has experienced a phenomenon to describe it. Researching human experience allows the researcher and the participant to enter into a shared relationship in order to uncover the essential meaning of that experience. Following the participant’s languaging of the experience, the researcher then interprets the description (Burns & Grove 1993, p. 66). There are a variety of phenomenological methods which explore and describe human experience. This exposé provides a concise description of the different frameworks available to nurse researchers.

Reinharz (1983, cited in Leininger 1985, p. 97) posits that phenomenologists are concerned with the process of transformation and suggests there are five steps involved in this process. Firstly, a person’s experience is transformed into actions and language which are related to the researcher. Secondly, ‘because we can never experience another person’s experience’ (Leininger 1985, p. 97), the researcher transforms whatever is seen or heard. Thirdly, the researcher transforms this understanding into essences of the original experience. Fourthly, these essences are transformed into some sort of document which can be viewed by others and, finally, ‘the audience of the researcher transforms the documentation into their understanding which can function to clarify all the preceding steps and which can also clarify new experiences that the audience has’ (Leininger 1985, p. 97).

There are three major processes which occur simultaneously in phenomenological analysis, namely, ‘intuiting, analyzing [sic] and describing’ (Parse 1988, p. 293).
She contends these processes are consistent with those described by Giorgi (1970):

The presuppositions are (1) the researcher is required to remain faithful to the phenomenon as described by the subject in the context of the situation as it emerges in everyday life; (2) description is the mode used for data collection and reporting of findings; and (3) the researcher searches for the meaning through rigorous adherence to the rules of phenomenal analysis (cited in Parse 1988, p. 293).

There are two widely accepted phenomenological methods which have been used in nursing research, namely, those designed by van Kaam (1969) and Giorgi (1970). The van Kaam method consists of (i) preliminary consideration of the actual moment of the experience; (ii) identification of the research question roused by the experience; (iii) explication of the implicit awareness of the phenomenon; (iv) listing and categorising data into groups by use of random sampling; and (v) identification and description of the data (Walters 1992, p. 155).

The second modification by Giorgi (1970) and described by Omery (1983, p. 52) is slightly different and is characterised by six stages: (i) the researcher dwells in the described experience; (ii) the researcher identifies meaningful units from the research tapes and transcripts (participant’s language); (iii) identification of preliminary themes (researcher’s language); (iv) reflection on these themes and; (v) integration and synthesis of the themes.

Parse (cited in Bunting 1993, p. 29) discusses her own research methods which she claims are unique to nursing. Parse follows Husserlian phenomenology in that she advocates bracketing in her method of analysis. The processes used by Parse are: (i) Dialogical engagement—this term refers to discussion between the participant and the researcher; (ii) Extraction synthesis—the researcher dwells in the transcribed dialogue, and is in continuous movement towards higher levels of abstraction; and (iii) Heuristic interpretation, which consists of structural and conceptual interpretation in the light of her theory of Human-Becoming (Bunting 1993, p. 30).

(1) turning to a phenomenon which seriously interests us and commits us to the world;
(2) investigating experience as we live it rather than as we conceptualize [sic] it;
(3) reflecting on the essential themes which characterize [sic] the phenomenon;
(4) describing the phenomenon through the art of writing and rewriting;
(5) maintaining a strong and oriented pedagogical relation to the phenomenon; and
(6) balancing the research context by considering parts and whole.

Benner (1984), develops the concepts of ‘exemplars’ and ‘paradigm cases’ as a result of engaging in phenomenological research in nursing. She uses these concepts as a method to communicate the richness of an experience. She defines an exemplar as ‘an example that conveys more than one intent, meaning function or outcome, and can easily be compared or translated to other clinical situations whose objective characteristics might be quite different’ (Benner 1984, p. 293). On the other hand, she states, a paradigm case is:

a clinical episode that alters one’s way of understanding and perceiving future clinical situations. These cases stand out in the clinician’s mind; they are reference points in their current clinical practice (Benner 1984, p. 296).

In her research, Benner (1984, p. 14) conducted paired interviews with beginning nurses and nurses recognised for their expertise. In the analysis, Benner used the Dreyfus (1980) model of skills acquisition as applied to nurses and described the performance characteristics at each of the five levels of development of nurses. Benner’s methods have been a motivational impetus in contemporary nursing research.

**PHENOMENOLOGICAL METHODS USED IN THIS STUDY**

Assumptions
As discussed in a previous chapter, disclosure of prior knowledge of the research area allowed the participants and I to engage in the shared meanings of nursing dying and dead people. It is precisely because of these shared understandings that I rejected the notion of bracketing and therefore chose the Heideggerian approach to phenomenology rather than the Husserlian approach. It was also assumed that the stories told by the participants and the interpretation of these stories
represented the experience of the twelve participants only. However, through the systematic analysis of the stories it may be possible to capture new insights and meanings in this area of nursing.

**Storytelling**

Reason and Hawkins (1988, p. 79) describe storytelling as being part of an emergent paradigm which provides them with ‘... an [research] approach which would express more the liveliness, the involvement, and even the passion of their experiences’. They argue that ‘meaning is part and parcel of all experience, although it may be so interwoven with that experience that it is hidden: it needs to be discovered, created, or made manifest, and communicated’ (1988, p. 80). Nurses have frequently shared their experiences with one another and in doing so invariably tell stories. Benner (1984), in asking for exemplars and paradigm cases in her research, asked the participants to tell stories. Sandelowski (1994, p. 23) states ‘whether viewed as intellectual find or fancy, telling the story of the “story-behind-the-story” has now become the province not only of literary critics but also of social scientists, ethicists, physicians, and, most significantly, of nurses’.

The use of stories rather than structured or even unstructured interviews appealed to me as a method of hearing what each participant had to say about their experiences. Storytelling could be construed as monological, with one person relating an incident to someone else. However, in this study, each story told by the participants was listened to and responded to by myself. We entered into dialogue; we entered into a relationship. The nature of this relationship was one of connectedness, equality and respect for each other rather than a hierarchical approach, which could have evolved had a more formal approach to the sessions been discharged. Stewart (1994, p. 139) posits, in this type of dialogue ‘... a person participates wholly ... with his or her eyes, lips, hands, soul, spirit, and with his or her whole body and deeds’.

After ascertaining complete agreement about their involvement in the research, I asked each participant to take themselves back to a significant experience of nursing dying or dead people and to relate that experience in their story. Following recollection and telling of this story, each participant was invited to relate further stories of significance. Sometimes the stories were difficult to relate. Either the experience had been forgotten, or the participant remembered the experience to be traumatic or too complex to express in words. An environment of constant support and understanding was provided during these difficult situations.
By allowing silences to occur and using a non-authoritarian manner, most participants were able to fully recall their experiences. One participant became very distressed when telling her story. Temporary cessation of the tape recording created a space during which time was allocated to console and comfort the participant. I gave the participant the opportunity to conclude the session. However, after regaining some composure, the participant elected to continue her story.

These sessions were conducted according to the time and place set down by the participant. Most participants invited me into their homes. One participant made contact with me at the university, another elected to tell her story after completing a shift at work and on both occasions each participant chose a suitable venue for their session. Four participants were unable to meet with me in person. Three participants chose to write their stories and one elected to exchange tape recordings. Telephone contact was made with these participants on receipt of their stories and discussions relating to clarification or expansion of particular issues were instigated.

Closure of each session was usually heralded by an extended silence after the stories were told, or by a feeling within the researcher that the session had been exhaustive. Before closing each session, careful checking was undertaken with each participant to ascertain whether they had finished describing their experiences. After transcribing the recording of the narrative, each participant was provided with a copy of the written transcript and was asked to read it and make alterations where necessary. In this process, each participant was asked not to change their story; rather, they were requested to provide details of any mistakes made in the process of transcription.

THE PARTICIPANTS

The participants in this study were registered nurses who had been working in a hospital or aged care setting for a period of time greater than two years, post registration. There was no restriction placed on age or gender, although I was cognisant of gaining representation from both male and female persons. Participants were selected primarily for their interest in being involved with the study, and for their availability and willingness to cooperate over an extended period of time.
The participants consisted of one male and eleven female registered nurses, currently employed in a health care service. Some participants were personally known to me prior to the commencement of the study. These participants were past or continuing students of the university. It was important to acknowledge that none of the participants were undertaking units of study chaired by the researcher. Undertaking research with participants who were involved in a student-academic relationship with myself could have posed some ethical problems for that relationship and the research. Participants not known to me, personally, volunteered to be part of the study as a result of hearsay and their own interest in the research.

ETHICAL CONSIDERATIONS

The research commenced following submission and review of the research proposal by the ethics committee of the University of Western Sydney, Hawkesbury. Informed written consent was obtained from all participants. This consent was in the form of a plain language statement adapted from Field and Morse (1985, p. 45). This form explained the purpose of the study and included an area for informed consent (see Appendix A).

The vulnerability of the participants in the study was acknowledged. Prior to each session, I discussed hypothetical situations which might arise as a consequence of relating stories which had the potential to be emotionally traumatic for the participant. I reinforced the position that the participants had control over the sessions and, if they so wished, they could discontinue the process at any time or withdraw from the research. We discussed the availability of resource personnel should the participant experience distress, either during or following the session. Interpersonal sensitivity and empathy as described by Kellehear formed the basis of each relationship between us (1989, p. 66).

Audio tapes, subsequent transcripts and narratives were stored in a locked filing cabinet accessible only by the researcher. Personal identification of each participant was protected by the use of pseudonyms. Pseudonyms were also used for other people identified in the stories of the participants. Biographical details at the beginning of each participant’s story were kept to a minimum to avoid recognition. This material was used solely as a means to explain the social context of each participant.
ESSENCE EXTRACTION AND ANALYSIS

The stories were transcribed and word processed by myself. During this activity I was able to listen to the tapes many times and thus become totally immersed in the stories of each participant. Repeated listening to the tapes, whilst transcribing and afterwards, provided me with a sense of being able to re-experience and reflect on the time spent with each person and re-live their stories. Whilst the following chapter presents each story in full, it lacks the emotion expressed by each participant as they related their story; it is one dimensional. Nevertheless, I wished to share the richness of the stories and felt that as part of the rigour of the study full transcripts would facilitate some consensus and credibility.

Analysis of the data was conducted using a combination of the analytical methods attributed to van Manen (1990) and Reinhart (1983, cited in Leininger 1985). The following process outlines how the researcher became immersed in the study.

Firstly, I undertook several readings of the transcript whilst listening to the tape of the story, to ascertain a sense of the whole. Secondly, I identified elements that were embedded in each story (participant’s language). Thirdly, using the highlighter approach, a search through the transcripts and tapes for the underlying meaning attached to each element identified four essences which were within and between each story (researcher’s language). Finally, again using the highlighter approach, each essence was woven into the four existentials as described by Merleau-Ponty (1962). These essences, namely, connectedness, aloneness, questioning and accepting, are discussed in detail in a later chapter.
Chapter Five

The Stories
The stories told in this chapter are depicted in their entirety. Although the written word lacks the colour and richness provided by all participants in the telling of their stories, I feel that each story, presented in full, is a vital component of phenomenological research. I have transcribed each story as told to me. I have not altered the language or grammatical construction used by each participant. I have commented where long pauses appeared in each monologue. Emotions directly related to the stories have been identified either in my supplementary comments or within the story itself. There are several stories that contain technical language commonly used by nurses and these words are usually followed by bracketed explanations to provide clarity and understanding.

Each story is prefaced by a brief biography of each participant. This introduction provides a career context and identifies the participant’s current area of nursing practice.

The use of pseudonyms is purposeful. This study has only been possible with cooperation and collaboration from twelve registered nurses from Australian backgrounds. Whilst there are no truly Australian names from which to select pseudonyms, I have chosen well known and easily recognised names. By making this choice I was aware that the work of nursing dying or dead people is also well known and easily recognisable.

Following each story a poem has been written to capture a particular essence of the narrative and the relationship formed between the participant and myself. Also, each poem has been given to each participant in honour of the time and energy they gave to the study. Merleau-Ponty (1973) believes that poetry is a language which reverberates the world.

Similarly, van Manen (1990, p. 70), writing about poetry and its contribution to phenomenological research says:

Poetry too is a literary form that transforms lived experience into poetic language of verse. Poetry allows the expression of the most intense feelings in the most intense form. ... A poet can sometimes give linguistic expression to some aspect of human experience that cannot be paraphrased without losing a sense of the vivid truthfulness that the lines of the poem are somehow able to communicate.
The majority of stories were told to me in the peace and comfort of the participants' homes. The relaxed atmosphere yielded an ease of relating the sometimes traumatic stories. I was cognisant of the possibility of the participants experiencing emotional reactions after the telling of the stories and I usually spent at least one hour with them following the taping sessions. Those participants who entered into written narrative with me were alerted to the possibility of adverse personal reaction, although none of these participants reported any occurrence of such events.

Those participants who preferred to enter into written dialogue with me have been identified in the introduction to their particular story. Their subsequent written or taped responses have been incorporated into the individual story text. Each story concludes with a brief description of the culmination of the interview process.
Jane's Story
I have known Jane for about five years. She is a good friend and colleague. Jane was a great support for me during my recent personal bereavement, the death of my mother. Jane herself has experienced family deaths—her son and her brother. Jane is a recently graduated registered nurse from a New South Wales university. She is currently undertaking distance learning studies at the undergraduate level. Jane is thirty-seven years of age, divorced with three children, aged fifteen, twelve and nine. Before commencing her education at university she worked as an enrolled nurse for a period of sixteen years, working in a variety of clinical settings. As a mother, a nurse and an independent complementary therapist, Jane has very clear ideas of how she views her future in nursing.

After Jane provided a brief biography for me I introduced the image of nursing the dying or the dead and asked her if she could describe a significant professional nursing experience with death.

Yes, I think I can. It was sort of ... (pause) ... this sounds pretty bad, it was sort of exciting 'cause I'd never seen a dead person before, but it was a bit weird too because I wasn't sure how to handle it. It was a geriatric. I was about sixteen and a half (years old)—it was an older lady and she had terminal something, I'm not quite sure now what it was. She was in a palliative ward, by herself and I don't think she had any relatives. If I remember correctly she was on her own. I had been nursing on the ward and hadn't taken much notice of her except that she was dying. I don't think she was there long so she wasn't ... (pause) ... I didn't form any real relationship like you can compared to nursing in the nursing home, for instance, where you get to know the patients and you would have a relationship with them. With her it's not such a strong remembrance of feelings, probably because I was younger, so young, I was still training, and feeling my way, and, as I said, she was the first person I had ever seen dead, which to me was ... (pause) ... I don't know whether it is strange or not.

Well, everything in nursing the first time for me was wow! Even working night duty was wow! I remember I had to prepare her, like, lay her out and she didn't have teeth, false teeth, and I didn't know that I had to put them in. So probably the biggest memory of that was that I was in a lot of trouble for not putting the teeth in. I think ... (pause) ... like, I know now, if it was now I'd have a lot more feelings because it's come up in the past or since, when somebody, a person
doesn't have somebody there, like a relative. I mean, honestly, at that time I don't really think it affected me like it does affect me now when somebody doesn't have a relative to be with sort of thing. Now, I don't really have a lot of thoughts about that first one.

Although Jane wanted to talk about a different situation, I was interested in the nursing care she gave to this patient and asked her to describe her practice at that time.

I had to do the laying out on my own and that was spooky for me. Back then, like, you had to pack all the orifices, which was the mouth, the nose, the ears, everything, and that was really more upsetting for me than anything, having to do that because ... (pause) ... it was just awful. I mean, these days they don't do that, but then they did, they stuck anything, anywhere ... (pause) ... it all looked so ugly, it just looked so horrible. They certainly didn't look like they were peaceful, jammed with all that stuff, and tied, their hands and feet and everything else. Yes, I think that was probably ... (pause) ... it wasn't sickening, it was upsetting. She didn't have, she didn't have, like some cancer patients, you know, you have, like, say, cancer of the bowel or something like that or the uterus or anything like that where they've got body fluids coming out. There was nothing like that, so that wasn't too bad.

I sensed Jane was eager to tell me of other death experiences, so I asked her if there were any other death experiences that were significant to her as a nurse.

Oh yes, I think there's been many. One that really sticks in mind was a lady in a geriatric home where I'd been working and she'd been a patient there for probably two years or more. She was an English lady, very gentle and very conservative, but always in pain. She was put down as just a whingeing old lady, but she wasn't really. She did put up with a lot of pain and never complained. She just always looked unhappy and she was always strained, you know. About three weeks before she did die they discovered she had had cancer for quite some time obviously because it was just everywhere. Anyway, I was on duty when she died and that. When she died, I mean, the whole look of her and, I mean, I'd seen enough death before that as far as in the profession goes. She was probably the first one that I'd ever seen that looked really peaceful. I mean, it oozed from her body, it was like, it was there (Jane now talks on behalf of the
dead patient) "I'm happy now and really peaceful." And she looked it, she really looked it. She just looked so much happier and peaceful and the feeling, there was an aura around her and you felt it. That one always sticks in mind. Yes, she probably affected me from then on because I looked from then on but no one's really, that I've come across since, has made me feel as though—now she's happy, she's really happy, because she's either where she wants to be or she's out of pain. No, I've not found any.

As Jane's stories appeared to me to be very lonely stories, I was interested to explore her working context a little more and asked her to describe anything significant about her colleagues who were working with her during these two experiences.

Well, the first one, I thought that they treated me fairly badly. I was a learner, an apprentice. I think they could have been a little more understanding about what I hadn't done in the laying out procedure. That didn't help me in understanding and coping with death and dying. Not that at that stage I felt that I had to cope with anything. With younger people I find I need help to cope, well, not help to cope with things, but it does affect me. I didn't talk about it with other people. Mainly because I didn't think it was right to talk about it. As far as, yes, I've come across a lot of nurses that not so much laugh and joke about it, I don't think, I think they will make comments and I feel it's their way of coping with repeated deaths and whatever, but I don't honestly feel that it's laughing at or joking at death itself.

One experience I had was, I was left in charge of the ward on the night shift. The registered nurse said to me as she left "keep an eye on Mr. Such-and-such" and I said "fine". And I did a round twenty minutes after she left, a ward round, and this guy had been coughing a lot earlier in the night, you know, cough, cough, cough and there was a patient in the ward, it was an eight bed ward and he was in traction, a young man, and he had said, I'd given him a cup of hot chocolate when I first came on duty and he had said to me and he was so fed up with this old fellow, coughing all night and keeping everybody awake and he had said, "Oh choke, you bastard!", like that, you know? And anyway, when I did the round, which was probably two o'clock in the morning, Mr Such-and-such was in his bed and he had bed rails up and one hand was up on the rail and he appeared to be sleeping. Anyway, I finished the round and walked back to the office and as I sat down, I mean, I sat down and got straight back up, it
was like an automatic ... I don’t know why I did it, and I went straight back to him, looked at him, he was still in the same position and I went over and felt his pulse and he had died and the first thing I did was I shone the torch around the room and I don’t know what I was looking for, I still don’t know what I was looking for, and I don’t know what made me go straight back because I mean half the patients on the ward were probably still in the same position two minutes later.

But then ... and that was probably one of my earlier experiences as well, and I think I was still, or just finishing, my enrolled nursing and I rang the sister who was on the next ward and I said, “Oh you’d better come back, Mr Such-and-such is dead.” And that’s how I said it. That upset me more than anything, that I had said it like that, you know, and I spoke to her about that when she came back and she said “That’s OK that you’ve reacted the way you have—quick, Mr. Such-and-such is dead. But,” she said, “it doesn’t matter that you’ve talked to me that way or told me in that way.” She was very good, this sister, and she said, “If you were telling the relatives, of course, you wouldn’t say it like that.” You know, you’re not going to rush out and tell relatives anyway. I was more upset then with the way I’d told her rather than, say, oh, you know ... I guess there was a bit of panic there and then dealing with the young man. He was feeling very guilty for weeks about it, about what he’d said and dealing with him was probably ... not hard ... we all needed ... he needed all of us, needed reinforcement all the time that he didn’t wish him dead, that he would have died anyway, no matter what he said.

But you know it was very upsetting for him for his remaining time in hospital. Yes, there are, I think, in my case anyway, there were probably far more understanding nurses that I’ve worked with than non-understanding nurses. There certainly were a few that were, I felt, cold and sort of bitter and what-have-you but I actually feel that they probably would cope worse with death themselves than people who are more understanding. I think that they’re probably more frightened of it than the others.

In light of Jane’s statement about the age factor I asked her if, because these two women were old, it made any difference to the experiences.
Yes, but not just because they were old. With the first one, as I said, I don't really think I had a lot of feelings at that time about it but the second one, yes, I did and I was happy for her. Whereas, with younger people, even though, I mean, it's different depending on why they die, how they die, my feelings are different. You know, from a stillborn right through to have different feelings and younger people, well, it depends on what they die of. If they were in a lot of pain and they were terminal, then I feel better for them when they die. I don't know whether that's right but that's the way I feel because of being in so much pain and the outcome is not going to be any more than death. But I have seen a lot of younger people that have died from cancer and I feel that they're happy too, they're more peaceful when they've died, I mean, from nursing them when they're in so much pain and they just don't want to be there.

One lady, for instance, she was the wife of my father's boss and I used to baby sit for her family. She was only forty-five or something. She had struggled with cancer after a long time of consulting doctors and treated as a neurotic. But, anyway, in her terminal stages she didn't want her family near her, she didn't want her family to see her the way she looked because she was very bloated and very yellow. She just didn't want her family to see her like that. So she chose to be on her own. They would come and they would sit outside the room and she wouldn't let them go in there, she just didn't want them in there and they would sit outside the room. They came up as much as anybody else would visit their relatives, fairly frequent, even all-night sits, but she just wouldn't let them in the room. She just chose to prefer them not to be there. It was as if she was protecting them a bit. She had a son and a daughter, and at that stage they were probably sixteen or fourteen and even though it was upsetting for them and they couldn't really understand why she wouldn't let them in there ... it was her choice, and yet she was protecting them from seeing how ugly, as she put it, cancer is.

When dealing with death I think you have to go with your feelings, like, you know, I can get really upset about a lot of deaths that I've worked with. It really is different, with every one, no two is ever the same. After dealing with death myself, it changed again and I probably get far more upset now than I did before I had to deal with death myself.

Jane used the word 'upset' throughout the conversation and I asked her what she meant by that.
I think I hurt, and I hurt for the relatives. I don’t think I express grief any more now than before, probably, yes, on the odd occasion. I mean, I’m not out of control but I’m not as controlled. Normally with death in a professional manner I try to not express too much because I like to be there for the relatives. They need somebody to be able to talk to and even though it’s very upsetting for me because I’m sort of ...(pause) ... I tend to hurt more for the relative now and I don’t think it is my right to let go as much as they would be and I feel that they would probably want someone that they can just hold or hang on to or whatever. I mean, there is nothing you can say that’s going to make things better but if you are just there and you can touch, and hold them, and let them talk, I think it’s a lot better for them.

I asked Jane what she meant by ‘I don’t think it is my right to let go’.

I don’t let go until I get home. Sometimes I go home and do lots and lots of housework. Keep myself really busy. Other times I sit down and think about it, release my emotions. Sometimes I go home and think about my own experience with death, you know, my son or my brother. I find, especially with children, I find if it’s a child that has died it does affect me quite badly, well, not badly, strongly, it brings that all back, it’s all back again and I have to sort of work at keeping it under control because ... (pause) ... I feel for the person. I understand the hurt that they are going through. Everything that they’re going through, well, I empathise with them. I don’t know exactly how they feel because I think everybody’s individual and everybody feels differently and copes differently, but the extent of the hurt, the pain and the awful ... (pause) ... everything that goes with it and its not easy to ... (pause) ... I don’t think it’s easy to cope with.

I think debriefing is important with anybody, especially with a new nurse. I guess if she’d never, I’d check if she’d ever dealt with it at all before. I’d get, no, I’d ask her if she wants to talk about it, how she’s feeling, how she’s coping with it and if she wants to talk about it. If she doesn’t want to talk about it, I’d suggest that I’m there if she changes her mind, if she wanted to talk about it later. I’d probably just ask her a few questions, you know, to try and have her realise there is nothing scary or bad or anything else about talking about how you feel—it’s quite normal to feel different emotions or whatever and, you know, she would be better if she did talk about it because it will happen again.
I invited Jane to make any other comments she felt were appropriate.

*I just think that everyone deals with it (death) different, even as professionals. You know, when I first started nursing we were told that when you walk out the front door you leave all your emotions and feelings and what-have-you in the hospital and you go home. I have never been able to do that. I don’t honestly know that there is anybody who can do that. It does affect me sometimes worse than others but I do think it is more for the relatives that I’m affected by, you know, not so much for the person that’s died but for the person that’s left behind. I’m more affected by their feelings and there’s a lot of times that I sort of want to go to them outside of nursing. Go to them and talk to them and that so they’ve got someone to talk to if they need and even ask them if they need me to talk to them. You know, working in a small country town you either always knew the family or knew the person. Maybe that had something to do with that, although I’m still much the same. Even if I don’t know them I feel as though I would still want to talk to them, I still want to be there for them if they want, as a professional sort of thing.*

Jane lapsed into a period of extended silence and I felt her story had been concluded. I gave Jane an opportunity to add additional comments and she refused. Jane, who is an independent practitioner in complementary therapies, offered to massage my back and neck and I accepted, although, in retrospect, I feel I should have made a counter offer in thanks for her contribution to the study.
For Jane

I have watched you grow in so many ways,
woman rearing
children alone,
woman creating
harmony at home,
woman devoted
to a cause,
woman in movement
to warmer shores
To realise her passion.

You have watched me grow in so many ways,
woman striving
to understand,
woman willing
to lend a hand,
woman ageing
every day,
woman searching
to find a way
to realise her passion.

We have watched each other grow in so many ways,
women
not afraid to ask,
women
shaking off the past,
women
who were born to win,
women
risking everything
to realise their passions.
Joseph's Story
My association with Joseph began almost six years ago when he was a student in the pre-registration nursing program. Joseph was always a keen and diligent student and since completing his first qualification he has proceeded to gain an honours degree. Joseph currently works in a palliative care, psychiatric nursing and medical nursing unit in a private hospital in Queensland. Joseph left school when he was fifteen and worked as an assistant-in-nursing whilst undertaking year eleven and twelve studies as an external student. Joseph was an enrolled nurse in psychiatric nursing prior to commencing his university education. Joseph is married and lives with his wife in a coastal town of Queensland. Joseph and I have maintained our friendship throughout the six years and he has also been a great comfort to me after the death of my mother.

Joseph was the only male registered nurse who agreed to assist me in this study. I felt it was very important to have a male registered nurse in the study as the percentage of males entering and completing nursing qualifications is increasing year by year. At present this percentage stands a little over eleven per cent which is almost the percentage of males to females in this study.

In his workplace, Joseph is regarded as a leader. However, he has the special ability to bring aspects of play into his leadership role. He has made significant contributions to the palliative care milieu in his research with bereaved relatives.

I asked Joseph to describe a significant experience with death as a registered nurse.

*During the early years of my nursing, for one reason or another, I never directly encountered death. Not many people died at the psychiatric hospital and I can only remember two or three incidents when I was involved, or two or three deaths. I didn’t even see the body or anything. I even worked on an old person’s ward, a psycho-geriatric ward which doubled as a general ward, within a psychiatric hospital for sick and dying people, and no one actually died during my time there that I recall, even on the shift that I was on. So people come and go. I was lucky, or unlucky, enough not to actually witness their death or be there after their death. It’s hard to recall really. It was only one of many wards we worked on. I don’t think I would have thought about it much at the time. I’d never really been actively interested in seeing someone who had died, or just*
died or was dead, so I never pursued it. Like, if someone had just died in another ward I’d never trot up there for a look or anything like that.

In the old people’s ward, it was for very old people who were psychiatrically ill for a start and then had become medically ill as well. So, basically, a lot of them were dying or so incapacitated they couldn’t function in the other wards. So, if I came on and found out that one of them had died, which did happen sometimes—it wasn’t quite a common event, like, one every six months perhaps and, like, three or four or five months might be all I ever spent there, so that didn’t worry me. I remember a fellow choked on an orange and he was a forty, forty-five year old chronic psychiatric patient. I can remember thinking that would have been awful, an awful way to die and people crowding around him and I remember they told me that they had tried to resus … (resuscitate) … but it didn’t work. But I didn’t still think, even then, much about it. I just thought that would have been a horrible way to die.

Given that Joseph had not actually experienced a death in these early years, I asked him to describe that first significant experience.

Well, my first experience with death that I recall, keeping in mind that my grandmother had died when I was young, but again, I didn’t get to see her or anything like that. Human death … (pause) … my first real experience was when I was in America at the end of my training (pre-registration university education) and a fellow had died in the accident and emergency department in which I was working, before I came on shift but he was still there and had to be transported down to the morgue which was in the bowels of the hospital, so-to-speak. So, we had to firstly transfer the man, which a wardsman helped us do onto a trolley and then a registered nurse and myself, a female nurse, put him in a lift on the trolley and then took him down to the morgue. The morgue was a big old cellar with a big thick door on it. I came in there and I can remember thinking how hard people were to move when they were dead. My main recollection of that—he was a dead weight, excuse the pun. We transferred him over onto a cold, very cold metal table. It looked like something you would dissect someone on, not that it would or, I don’t know, but it was very cold, very clinical—everything echoed around the room. You were under the hospital, there wasn’t a lot of noise either. Possibly because I wasn’t comfortable with the death, I don’t know, but the other girl was scared, she’d seen, she’d been involved with death before, she said, and she was pretty scared … (laughter) …
and I pretended that the door in the morgue had slammed shut and we couldn’t open it. I had my foot up against the wall and pretended to try to open the door and she got very worried. But that was OK; it was my little joke. But yes, mainly what I remember about that, that part of it, because I felt sorry for him having to go onto a cold table but then I realised, of course, that he wouldn’t feel that. But it didn’t seem a very fitting place to end up or start your journey into death on a cold metal table. We sort of lumped him on there too, it’s nothing you can do smoothly when there’s only two people. We were very worried about dropping him. It was a cement floor.

I talked about it to another friend on the exchange. I don’t know how much depth. I can’t really recall. It didn’t … (pause) … It wasn’t gravely significant to me as far as I know but by the same token I do recall the room fairly well, better than a lot of the other rooms in the hospital. I don’t remember anything physical about the man except he wasn’t particularly old. He wasn’t ninety, he was about sixty or something, so that’s not particularly old. I didn’t know him. I’d come on (duty) and he had already died. I think he’d had a heart attack or something like that, he wasn’t physically injured, no external injuries. It wasn’t consciously significant for me because I didn’t know him. I think that’s more important for me—I didn’t know him. He was just a body by the time I got to him.

I felt that this experience was not particularly significant for Joseph so I asked him again to describe his first significant death.

‘Um, my first significant death … (pause) … I think it must have been where I am working now, because even where I was doing my postgraduate work, someone died, again a psycho-geriatric ward where I had worked, and I left the week before he died. I thought that was sad that I didn’t get to see him or anything. Even though he wouldn’t have much quality of life as most people would want or measure, I still thought it was sad ’cause he could make us laugh. We used to have a laugh on the side. He was confined to a wheelchair. But, no, probably where I work now. It was before I even got to the palliative care ward. It was in the old, again, in, like, a ward that they’ve got for people awaiting nursing home placement and also for anyone who is demented and like that. It’s a fairly difficult ward to work on and there was a man there with chronic airways disease or limitation, what ever you like to call it and he died. He was a particularly … (pause and sigh) … challenging man to look after.
He was very agitated, as some CAL (Chronic Airways Limitation) people can be. Often than not he would take his mask off and become hypoxic and become confused. So we really had to keep the oxygen up to him, otherwise he used to wander out half naked and things like that. I was quite relieved for him and his family that he did die—more than anything because his son used to talk about what a good businessman he was and things like that and he'd lost all that. And his son used to come in at 2am in the morning and things, to help us with him if things got difficult. He was very good—difficult in that he would start screaming the place down and wouldn’t … we couldn’t get him to put his oxygen back on, didn’t want medication, he just wanted his son. So we’d get his son and that would help. But he, he died quickly. I didn’t expect him to die and he died. Primarily I thought it was good for him that he died, really. He didn’t … it certainly wasn’t reflective of the life he had led. He lost a lot of what I saw was quality of life. His independence, like, he was fully dependent on us and his son and, to me, independence is an important thing, so I measured him against what I thought was important. I think he was better … it’s hard to say … not better off but certainly I think his time on this earth had finished. And without the medications and things he was on he would have died before that.

Interested in the kind of nursing procedures Joseph had given this patient after death, I asked him if he had to care for this man’s body after death.

We don’t have to do much at that hospital, no. I was involved in laying him out. All we do is, if the relatives want to sit with them or anything, clean the people up and if they’ve got, if they’ve stained their pyjamas or anything, well we change them. In the palliative care ward we put a rose on the pillow or hibiscus flower or whatever’s available, freshen the room up and everything. Just because they like to spend time with them it’s much nicer to have a better environment for them. But down where I was working then, they didn’t do any of that. They don’t do any of that. I don’t think they still do, I wouldn’t imagine. So … (sigh) … it would have been basically just laying him down fairly flat and his son had been there with him, so no-one else was coming to see him, and just contacting the funeral people. The son asked me to ring someone. I can’t recall—I think it was his sister, the dead man’s daughter. I rang the doctor.

We don’t pack orifices and I wouldn’t like to have to do that. I would find that unpleasant, physically unpleasant. Even cleaning up bodily fluids is an
unpleasant job, there's no two ways about it. If I found it difficult with someone while they've been alive I don't have any trouble doing that, what can take up an hour, to undress someone, wash them, change their sheets, clean them, redress them, whatever. I don't have any trouble doing that. I don't see it as a waste of time or anything like that. I don't mind doing it. It's not something I guess you enjoy but it's nice to think you're doing something that I consider worthwhile, like a last token of respect I guess, if you like.

As for people to talk to, the first death that we just talked about I recall, the one in America, I did talk to another exchange student, but I've never really had much trouble about telling people how I'm feeling anyway, I don't think so. Deaths, as they've gone on, have had more impact on me. It's the latter deaths that have had more impact on me, not the early ones, mainly because where I work now I get to know people much better. Like, I might have known them for a year before they die, and their husband and wife or daughter or son or whatever. And if I'm down town shopping and if I run into them I will say 'hello' and if the person that is dying is with them, has a terminal illness, is with them, I'll be very glad to say 'hello' and everything. If they're not, I get a report on how they're going or not going. We always hear if one of our people does die. And generally, generally, it's not so much that they've died that's important, I always like to know how they've died. Generally, the people, the family, tell you about it anyway—that they went in their sleep or they were squeezing their hand or something. They always give you the final few moments, generally.

Ventilating to people in the ward, where I work now is very good. I have a good colleague that I can talk to, he'll listen, and he lost his mother. His mother died in a car accident less than two years ago, a year and a half ago, and he often talks about death and unresolved issues with her, and so we communicate a lot about death. We often relate things we talk about back to his mother I've noticed, and how she felt at the time. But generally, I don't feel it is upsetting. I feel sad sometimes when people die and I don't really know why but it is, it's still sad even when someone's at the end of their life. Somehow death's still got a sad, a sadness to it. Maybe it's because the relatives are always sad or it can also be very nasty at times. I remember helping clean someone up after they died and the relatives were outside the room and they were discussing the money, which wasn't very pleasant.
I was interested to explore Joseph’s feelings about the need to know how a person who had been in his care, had died.

I find that more important, more relevant than the fact that they had passed away, or died, whichever you prefer. I’d like to think the people that we’ve seen and have gone home have had adequate pain relief. I don’t think anyone should have to die in pain. Normally, through the Blue Nurses (home nursing service), we have a pretty good communication system with the Blue Nurses, helped a lot by the fact that one of the Blue Nurses works in our ward at the weekend. I think that’s probably a stronger communication than the other more recognised modalities. I don’t think we have to die in pain, there’s no reason for that now, particularly if you are being palliatively cared for.

My recent studies helped me a lot because it concentrated, my dissertational Thesis concentrated on the relatives primarily and it gave me a bit more of an insight into particularly what they need and there were things like information. After the person died, they (the relatives) have a great affinity with people working in the ward, because I think the death and the fact that the person dying is more readily accepted within the ward, or in our ward anyway. Perhaps in society even people that come over to see you and they’re dying, if they’re not associated with nursing and things like that, death is still quite a bit of a stigma and they will treat the person differently, I feel, when they come to visit them if they are dying.

It would depend largely—I’m generalising, of course—but their death, the fact that they’re dying is accepted by everyone on the ward and in trying to encourage an open acceptance of that. It doesn’t always occur but we try and encourage that so people can discuss how they feel about it. One of the main things to come out of my dissertation, I felt, was how much they (the relatives) need to have that involvement with people, not of their family or friends, but people that were involved with helping to care for their person that was dying after that person had died. I think they need to talk about it, they need to relive it to a degree, just to get it right in their heads maybe. I don’t know, but they’re certainly keen to talk about the experience. I don’t even think they saw it as, ‘this is where I can make a huge change’, it was mainly, ‘this is how I felt about the whole thing’ and they were eager to tell me how they felt. I think it would help if someone did go, not necessarily one select person, but perhaps the one
person that they appeared to orient towards in the ward, go and visit them after the person has died, a couple of weeks later perhaps.

I explored a little further and asked Joseph what nursing the dying and the dead means to him.

Still, despite any knowledge, it is still easier for me to look after someone who is older rather than young. The majority of people I look after are older people, not always—we have had a person in who was in their forties die, that I got quite close to. She was a nice lady. That was hard because her kids were only teenagers and things and I think that's difficult for them. So I guess a lot of the sorrow's associated with them and their sadness. I think if you are dying, naturally dying, and there's no alternative available to prolong your life and keep, whilst simultaneously maintaining, a quality of life then you should be allowed to die. You should be allowed to die, pain free. If that means we have to provide large doses of morphine or whatever to provide that pain free death, then so be it. I don't see any problem with the euthanasia debate, for instance. It would be hard, I guess, to go further and decide who should decide who lives and who dies, but if someone is suffering and will not get better despite any intervention, to what they consider is an appropriate level of functioning, then they should be allowed to die. And if giving large doses of morphine enhances their chances of dying early, then I don't see that as a problematic side effect. I would never have had such strong convictions about it until now, until working in the place where I work. Before, I more generally would think, yes, well, someone wants to die. It's very complicated too, don't underestimate how complicated it is, and I appreciate that.

Death and dealing with dying or dead patients is very subjective. We recently had a newly registered nurse on our ward who seemed quite, almost obsessed, with dying, with death. She would actually keep ringing up to find out if someone had died. It was very difficult to know how to handle her or how to help her or indeed if she even needed help or if that was just her way of coping. She got a fair bit of experience with death and that asking or ringing up did stop through not, sort of, active intervention, it did dissipate. I think, with newcomers to death you have to try and evaluate where that person is at. If they have had a fair bit of experience with death it would appear to help. I wouldn't say that's cut and dried either. It depends a lot for me, and this is a personal value, it depends how well I've got to know the person and if indeed there was a
relationship built up between us. I mean, there are people and there are people. And just like you get on with people, different people in the wider, social world, there are people that are dying that you get on better with than the next person. I encourage talking about death and if a new nurse knew that one of her patients was dying, then I would encourage her to talk. A lot of people on the ward do talk and cry when someone does die and I still cry sometimes when someone does die on the ward. I think it is important to understand that crying is not a sign of weakness or not coping or any of that other crap that people go on with, it's just a natural thing of getting attached to people and then they're gone. Plus, the relatives are all experiencing quite understandable sadness. I think with that sadness there has to be acceptance of that person is dying and will die and then they do. I think it helps.

Joseph and I continued to talk on issues related to specifics of palliative care. These issues were not directly related to this study so they are not contained in this transcript. Joseph and I ended our discussions with a walk in his garden. He appeared to be very proud of his plants and the life they gave the garden. He mentioned that several of the plants were given to him by relatives of people he had nursed. His garden was a constant reminder of the friends he had made through nursing.
For Joseph

I have journeyed with you and shared your quest for meanings.
I have journeyed with you and found the place of dreamings.
Our paths have braided lives of sames
and differences in the need for change,
Continuous with desires to know their feelings.
Teresa's Story
Teresa is an older registered nurse, having completed her initial training nearly thirty years ago. I met Teresa at a residential school at the University of New England, where she was undertaking a Bachelor of Nursing program for registered nurses. Teresa works in an aged care hostel in the country and had a beginning interest in the issues surrounding death and dying. Teresa asked if she could participate in the study as she was eager to tell her story and hear others’ stories about their first contact with death in a professional sense. Teresa wished to write her story and send it to me and for me to visit with her at a mutually convenient time to elaborate on her story if necessary. The following story is a compilation of written and spoken dialogue.

_I remember my first experience as though it were yesterday. It was October 1963 and I was six weeks into the twelve week PTS (Preliminary Training School) as a student nurse at the Base Hospital. It was a bleak, wintry day when I reported for my first day on duty to the male Medical Ward. Ward 7 was part of the old hospital buildings. It was a cold, draughty barn of a place, which, in an attempt at modernisation, had been partitioned into five smaller areas, each containing eight beds. There were two single rooms located next to the nurses’ station. The ward was painted in regulation green and cream high gloss paint and looked no different to any of the other wards in that hospital._

_Ward 7 was run by a small, rotund sister of indeterminable age, who was, I was reliably informed by a second year nurse, as having been an army nurse in the Boer War, or was it the Great War? My informant was not sure, except that Sister had been terrifying nurses, patients and doctors alike, both in and out of the Army. She ran her ward along strict lines. Nurses were scrutinised as they reported for duty. starched aprons had to be exactly four inches below the knee. Woe-betide any nurse who attempted to appear more fashionable by surreptitiously tucking her apron up an inch or two and hiding the offending bulk with her starched belt. Black lace-up shoes had to gleam with polish and elbow grease. Seams of grey lisle stockings had to run in a straight line from the Achilles tendon until they disappeared under the starched white apron. For such a small person, Sister had a formidable set of vocal chords which she used without fear or favour on all who entered her tiny kingdom. It was a fearful time for me._
I was interested in Teresa’s comment about ‘being fearful’, as most beginning nurses temper their fears with excitement, yet Teresa sounded most adamant that this period in her life was not a happy one. I asked her to elaborate on how this time was fearful for her.

I was seventeen years old. I was young, I was very young, even by the standards of thirty years ago. I think I was impressionable and immature. I had been brought up in the security and warmth of my family, in a Rectory, and this was my first time away from home. I was given into the charge of a second year nurse who, in my unworldly eyes, appeared to be very adult and knowledgeable. I think we were all told, or at least led to assume, that the older students had so much more experience than we had, which I suppose they did. But we were sort of trodden on or put down and believed we were the lowest in the pecking order. Anyway, I was doubled up with this second year nurse with the instructions to get on with the bed baths and Sister’s admonishments ringing in my ears not to touch or do anything unless expressly told to do so. I was even frightened to touch the patients unless I got the nod from my second year nurse. It was awful.

Teresa continued with her story.

It was a day that for many years afterwards I looked back on in horror. It was a day of new beginnings. It was the first time that I had to spoon feed anyone, or clean anyone’s dentures. It was the first time I had to sponge anyone, let alone a man. It was the first time I had to empty urinals and clean bedpans, to wash and tidy people who were incontinent and who were vomiting. And all the time there was Sister hurrying everyone up. “Haven’t you finished yet nurse? You’ll need to hurry up if you want to finish today.” I can still smell the smell of my own fear and illnesses that pervaded that little world. That smell was mixed with the all-pervading smell of lysol that seemed to ooze out of the pan room and permeated the beds, screens, walls and floors. I could even smell it on myself, my hands and nails, my uniform and hair. My thoughts and impressions of what I had imagined and dreamed nursing was about, had fled. The day seemed to fly in a haze of hustle and bustle, the sounds of buzzers and Sister’s voice. There seemed to be no time for anything except constant physical activity.

After early lunch with the second year nurse, we commenced a back round, when we found a patient who appeared to be dead. In those days it was not the
nurse’s right or authority, nor was it thought that nurses had the skills to say someone was dead. It was the doctor’s prerogative, and only the doctor’s, to say that. Sister was hurriedly summoned, who in turn commanded a doctor to certify death. She then informed my companion that she was to lay the gentleman out and that I was to be her assistant and to hurry up, as the end of the shift report would be in thirty-five minutes.

I hurried to fill a stainless steel bowl with water and a mixture of lysol while the other nurse collected a dirty linen trolley, clean linen and the laying out box. This box turned out to be a wooden container some 18 inches by 12 inches long and 8 inches deep which was always kept full in preparation for the next death. The box contained cotton wool swabs, a catheter, white tape, artery forceps, scissors and a safety razor. All this was arranged in what appeared to be a regulation formation around the bed. Silently the nurse handed me a white cotton gown and cap and mask and indicated that I should put them on. My own starched white cap had to be placed carefully where it would not be in the way or fall on the floor. I remember my fingers feeling numb with the cold and I had difficulty tying the tapes on the gown. It was my job to dry the body. He was a thin man with receding lank black hair. His face was covered with black stubble. He had been incontinent of urine and faeces. “We’ll have to hurry,” whispered my companion. “He is already getting stiff.” I looked at her in trepidation. Tears were rolling down her face and soaking into the mask. “I always cry,” she mumbled, “I really get upset. I’m glad you’re here because I know you won’t mind, but please don’t you cry ‘cause that makes me worse.”

I asked why the man had died and was told that he had already had one heart attack and he had probably had another. I asked where his family was. Did he have a wife and children? I was told that he lived on one of the outlying farms some 60 miles away. His wife visited him at weekends, the only time she could get in. The police or the neighbours would let her know. I remember thinking how distressing it must be to be informed by the police or someone else that someone close to you had just died. It seemed so impersonal to me. With my family upbringing still fresh in my values, I asked whether a priest or a minister should be called. I was inwardly horrified at the second year nurse’s lack of thought and her answer. She became impatient. “Sister always looks after things like that if it is appropriate.” I was cold, tired and scared and beginning to feel nauseated. All the prayers that I had learnt as a child fled from my mind. All I could think of was to ask God to take care of this man and to bless his wife.
The layout proceeded according to hospital procedure. He was shaved and washed. His finger and toenails cut and cleaned. Every orifice was packed with cotton wool, pennies were taped over his eyes. A catheter was passed and then what I felt was the final indignity, a piece of tape was tied around his penis, in case anything leaked out, I was told. I felt my knees buckle and cold sweat break out. When we turned him over, a thin trickle of green-brown fluid came out of his mouth and he made a deep gurgling sigh. I can still feel my hair at the back of my neck stand up in horror when I remember this. The nurse patted my hand and told me that it was only some residual air coming out of his lungs and that this sometimes happened.

Eventually we were finished. A white shroud was placed on the body and he was covered with a white sheet. His locker was cleaned out and his personal effects packed into bags. My companion dried her tears and we hurriedly stripped off gowns, masks and caps and, taking out bits and pieces with us, arrived in time to hear Sister give her report to the next shift. She made no comment to us. There was no acknowledgment except to inform us that we were late and that we would have to work faster in future. Half way through the report a wardsman appeared with a trolley and I was ordered to go and help him.

As I hurried down the corridor a small, vague man dressed in hospital pyjamas came shuffling up to me and said, "Nurse, there is a man in my bed and he won't get out. Perhaps he is dead." The wardsman took one look at my white face and took charge. He escorted the patient back to his room, carefully explaining to him that he was trying to get into the wrong bed. He then joined me behind the screens and we lifted the first dead person I had seen onto the trolley. The wardsman gave a grin and patted me on the shoulder. "Never mind, luv, the first one is always the worst." With these words of comfort, he headed down the corridor, pushing the white draped trolley before him, whistling cheerfully. It seemed so inappropriate at the time, him whistling and me with a pale, serious face. What a contradiction!

As soon as I could escape off duty, I stripped and stood under a steaming hot shower and tried to wash the smell of death, urine, faeces and vomitus from my skin and hair and wondered if I had made a terrible mistake in choosing nursing as my profession. My fellow students were all agog with all they had seen and done. They did not seem to be all that impressed or interested in my tale of woe.
But, with hindsight, I suspect that I was so wound up in my own misery that I was incapable of verbalising what had happened and how inadequate I felt.

Next morning, back in the class room, when we were asked in turn about our first day in the wards, I was able to speak about my anger and horror. I asked tutor sister what protocols were in place for dealing with what I assumed was a fairly commonplace happening in a busy hospital and how could the ward sister and other staff choose to ignore and appear not to care that a man had died alone in such a busy place. I remember the tutor sister looking as though I had committed the worst form of blasphemy. “Nurse,” she thundered, “you are not here to bemoan the fact that a man has died. Death is a failure. You are here to learn how to care for the living.”

After class, I made a long distance phone call to my parents and said that I was giving up nursing. After some careful questioning, I was able to tell them of my grief and, although I did not realise it then, it was also grief for my lost childhood. My childish dreams of what I had hoped nursing was all about had been stripped from me. If this was the adult world, well, I had entered it kicking and screaming, and it hurt.

My father then gave me some sound advice. “Nursing,” he said, “involved assisting people come into this world, caring for them when they became sick in mind, body or spirit, and being there for them at the end, when their souls leave their earthly bodies. By just being there and caring, perhaps nurses would be able to make this final journey a little easier.” As I progressed through nursing, I began to think that to handle and prepare a body for burial which had housed a soul, with love and respect, was one of the greatest privileges of being a nurse. As a Christian, death should not be seen as a failure or as the end. It is one of the few certainties of life. It is natural to grieve for the passing of a life. I remembered the story of Jesus who also grieved for his friend Lazarus and in his humanity he also begged not to die.

My father’s wise advice has stood me in good stead for nearly thirty years and with it the knowledge that to grieve is part of living. To help someone through these final stages of life, so that death comes with peace and dignity, is one of the greatest honours and privileges of the nursing profession.
Many things have changed over the years since I first started nursing, although there are still doctors and nurses who equate death with failure and this is seen by some as a personal failure. I have been told recently by a colleague that to grieve is a waste of time and energy. Such time and energy needs to be spent on the living. I am unsure of how to respond to that comment except to say that this attitude is not held by me and others I know who are involved in caring for the dying.

I was impressed by Teresa’s convictions to her Christian beliefs and how, throughout her years of nursing, she has been able to hold onto those beliefs in spite of the many challenges and tests the practice of nursing had evoked within her.
For Teresa

Sitting by my campsite fire
I watch the heat fade.
As the red embers turn to dust,
I am reminded of the faith
I once had but lost.
And I met you.
You whose faith was enough
for two, or more.

Sitting by my campsite fire
I feel the night pierce my bones
and I shiver, alone with my thoughts.
I am reminded of the hurt,
the cruelty of early death.
And I met you.
You whose faith
kept out the cold.

Sitting by my campsite fire
I hear the noise of the night,
haunting, trembling in my ears.
I am reminded of the noise of death
and its hostile voice.
And I met you.
You whose faith
silences the savage shout.
Ann’s Story
Ann is a registered nurse from country New South Wales. She undertook her pre-registration course in nursing as a mature age student and nursed as an assistant in nursing during this time to earn money to assist in supporting her family. Ann relates several stories in this section. Three of them refer to patients she has nursed; the last one relates to her husband. During the writing of this Thesis, Ann’s husband died. Our association made it possible for me to give some support to Ann but, most of all, Ann feels she has been able to deal with her personal loss in a more peaceful manner because of her involvement in writing her stories.

I was first seriously confronted with death and dying during my pre-registration enrolment at university as a mature age student approximately six years ago. I had managed to negotiate the first twenty-seven years of my life without ever having to confront or address this issue directly, which confirms the denying nature of our society. Working as an assistant in nursing during pre-registration, I first cared for a dying patient who died in my care. This was really the first contact I had with death and the first time I had seen a dead body. I considered myself fortunate to have cared for this lady in a small hospital utilising palliative practices. I believe this contributed to a more fulfilling experience for myself and a more dignified one for this patient.

Unfortunately, around the same time, a more distasteful experience occurred. I was confronted with a parasuicide by a person HIV positive. The treatment he received and the attitude of the staff was completely unsatisfactory to me and I knew that I had been allocated the care of this patient because no-one else wanted to care for him. I felt this patient was ostracised because of prejudice, ignorance and fear, but at the same time felt too powerless and inexperienced to confront others about his treatment. I didn’t know what to do. I sat and spent as much time as I could with him. I suppose I was trying to make up for his poor treatment. From this I gained an increasing interest and concern for HIV/AIDS patients and subsequently palliative care as a vehicle to assist patients with terminal illness achieve a better quality of life and indeed a quality of death.

My nursing education emphasised the concepts of holistic care, quality of life and patient advocacy. It is my belief that my nursing education had a substantial effect on my beliefs, attitudes and values in the cases mentioned. Throughout my nursing I have felt relatively comfortable with dying patients. I
did not avoid them and they did not distress me as they did some of my fellow colleagues. I probably felt closer to dying patients than others.

Since my graduation I have worked on an acute surgical ward where, at times, the medical intervention, patient quality of life and likelihood of cure appears paradoxical. The following incidents affected me deeply and illustrate my strong feelings about quality of life, autonomy, control and truth telling. It is my belief that my professional experiences, especially in the absence of significant previous personal experiences, have played a significant role in my attitudes and values towards death and dying.

Gelda was a small woman in her early sixties that entered hospital for amputation of a toe due to poor peripheral circulation. She also had lung cancer, although she had never smoked. Gelda’s condition deteriorated from the start. The amputation was unsuccessful and she was compelled to undergo amputation below the knee. Soon after, she developed septicaemia and she was commenced on intravenous antibiotics. Gelda was extremely ill and she refused to eat, so total parental nutrition (TPN) was commenced. Her infection resolved but clinically she did not improve. Gelda wanted to die and have the central line removed. She relayed this fact to doctors and nursing staff. However, her doctors refused to remove the line, claiming she didn’t really mean it. Her family, whilst very distressed with the situation, did not want to appear to be killing her. If she had been physically able, I am sure she would have pulled out the line herself. She died several weeks later, defeated, the TPN still running.

Thomas was in his seventies and recently diagnosed with cancer of the stomach. Treatment complications had required a second operation at a major hospital. Prior to this he had been a well man. On his return to our care, Thomas began haemorrhaging and developed severe haematemesis. Multiple blood transfusions were commenced. Thomas did not want to return to theatre and he wanted the blood transfusion stopped. The surgeon agreed and the transfusions were ceased. Thomas took many hours to die and it was unpleasant. Despite the unpleasantness, Thomas was in control of his situation and he was supported in his decision by family and staff. I felt very proud to be a nurse that day. I felt Thomas had reached the acceptance in his final hours.
Elizabeth, a woman in her seventies, recently diagnosed with cancer of the colon, was admitted to our ward for bowel surgery. Her immediate postoperative recovery was satisfactory but she did not progress. She was extremely confused, in pain, and demanded to be knocked out with drugs the whole time. Many different combinations of drug therapy did not help. The surgeon and staff continued to attempt to recover Elizabeth. Finally, palliative care was initiated after consultation with the clinical consultant for palliative care. Elizabeth died, still confused but in less pain, with questionable—or was it full?—awareness of her condition.

I believe the prospect of death provides the possibility for people to reach some type of completion to their life that is satisfactory to them and to be able to attach some stance and meaning (for them) to their lives. I feel strongly about quality of life, autonomy, control and truth telling and I believe that truth telling and control of information to dying patients plays an integral part in their autonomy and control.

My value for truth is entrenched in my upbringing, as it is most certainly an important value for my parents. I grew up in a New South Wales country town and came from a middle class background. I was not confronted by the death of people close to me. My main death related experiences during this time were with pets. My personally close death related experiences have been with my husband and it is a source of great concern to me—three life-threatening asthma attacks, two requiring ventilation, in six months have left me strongly questioning my attitude to death and dying. Medicine does not seem to be providing the answer and, while his condition is chronic, he swings between being relatively well and critically ill. I find my situation leads me to question my values with regard to palliative care and to question the impact of my personal situation on the care I provide. I suppose I feel I am not living by my convictions because in these life-threatening situations I want my husband’s physician to do everything to save his life and worry about the consequences later. It occurred to me that my upbringing and acute care working environment strongly reinforce the power of dominant life-saving ethic in critical care work. Despite these feelings, my husband and I have freely discussed our situation and I feel confident that I am aware of my husband’s wishes if quality of life or death becomes an issue he cannot control. We have put our house in order and maintain it at all times. Already we have made informed quality of life decisions with regard to
medication and treatment. At times I feel we are ostracised for it. We have also considered the benefit of a 'living will'.

The impact of my personal situation on the care I provide is a source of concern to me. At times I feel I can strongly relate to the situation that palliative patients, and especially their families, find themselves in. I can conceive that over identification might do more for my needs than those in my care. I also recognise that my Christian, though non practising, background and that of society, colours what I perceive as normal and acceptable as far as religious beliefs and behaviour are concerned, even though I consider my stance on religion and death to be non-committal and largely indifferent.

Earlier this year I was in touch with Ann and learned of her husband’s recent death. Although very sad and slightly ambivalent when viewing her life alone, Ann felt her belief system was holding true for her personal bereavement.
For Ann

In the game of life
you were dealt a cruel hand.
Yet you played it skilfully,
learning to leave
your best play
for when the game got tough.

But as with most games
the cruelest blow
is delivered when
expected least.
The ace of death
played directly into
your own house of cards.

Instead of folding,
placing down your hand
and bowing out of the round,
like a true champion
you played the hidden trump
and won the game.
Helen’s Story
Helen has been a registered nurse for the past ten years. She trained in a large city hospital in Queensland under the old hospital system of nurse education. Helen has recently started to work in a palliative care environment. I met Helen at a residential school at the University of New England and we discussed issues surrounding the establishment of palliative care units in acute care hospitals. Helen was very interested in my research and volunteered to be part of this study. I interviewed Helen at the university during a break between workshops she was attending. We sat together under the shade of a tree and she told me her story.

I guess before I begin to tell you, before describing my experiences, I should tell you what I think, what I feel about death. Death is something that will no doubt happen to all of us sooner or later. I mean, some of us will have warning of the event, others will not. I think that as I was growing up my parents shielded me, you know, protected me in many ways from being exposed to the deaths which occurred within our circle of friends and relatives. You know, I do not recall attending a funeral until I was, well, older and into adulthood. I don’t even remember being aware of the details of what happens when someone dies.

I was one of those children who used to attend Sunday School almost every week and Scripture lessons were held at school every week, so I presume those experiences provided the foundations of my religious beliefs of today. I like to think, no, I do think that I have some Christian tendencies although there are many details about the Christian faith that I am not, I do not believe in, and there are some practices that the Christian teachings advocate that I don’t use, you know, going to church regularly now. I think I can practise my faith, my beliefs, in other ways—I don’t have to go to church to tell the world what I think or feel. I believe that there is a life after death and that our presence here on earth, well, serves a kind of purpose. I don’t always know what it is but in the major plan of things, for human beings, I think our individual existence has a definite meaning. Death means to me the passing, the journey of someone from this life into another. It’s generally a sad event because of the forced separation, the wrenching from the life we know to the unknown. Despite my convictions, I am sure that I will face my own death with much trepidation, because I put a high value on living.
Death is not a subject that people like to discuss but we see it every day. I mean, every day in the papers there are reports of many deaths but it sort of passes us by. I know people who read the obituary columns every day—my parents do. I suppose they know some of the people. Well, they do know some of the people because they tell me, "Oh, So-and-so died today." It is like they are witnessing an end to their era, you know? I talk about death with my own children. Sometimes it's hard but I try to answer their questions about death honestly. I mean, I want them to be able to cope with the reality of death when and if they are confronted with it. If a relative or close friend of theirs was to die, I would encourage my children to attend the funeral as part of life, you know, their learning experience of life.

I asked Helen to focus on a significant experience of death.

Yes, I suppose I am going on. Well, I have not always thought about death in that light. I used to think that to talk about death and dying was to be morbid and depressing and my first encounter as a nurse did nothing to change that attitude. I was employed on a medical ward when a patient there, who had been diagnosed with cervical carcinoma, became unconscious. The doctor was notified and it seemed that in a very short space of time, I can't recall exactly but it seemed like only minutes, and there were people prodding and poking the poor woman, you know, people taking blood, portable x-rays and doctor's examinations. And then as quickly as all this activity had started, it stopped. The lady had died and everyone, that is, everyone except the nurses, of course, abandoned her. The lady had been left in a state of disarray, tubes everywhere, machines everywhere and she was lying naked and exposed. It was awful, it was like she was a lump of meat rather than a person, really. I wanted to cover her up but the nurses wanted to do the laying out quickly. It was like we had to clear her away as quickly as the other staff had left, you know?

I remember the relatives were sort of lingering in the hallway, looking very solemn and subdued. There were no smiles or laughter. Everyone, including myself, bustied themselves with the cleaning, packing and dressing the body, which was subsequently taken to the morgue. An older registered nurse said a few words to the relatives and they went too, without looking at the body or anything.
This whole episode seemed quite normal to the other nurses and I soon learned that I had to be like them and accept the hurried approach to dealing with dead bodies. I mean, it was common practice just to treat a dead body like a shell. There was no emotion. I learnt that to show too much emotion, you know, to cry or anything, was a sign of a weak character. It was so much easier to become detached from the whole experience than it was to be part of it.

I asked Helen whether this experience describes what could be normal procedure for her now.

No, definitely not! When I finally graduated and became a registered nurse I would often have to deal with the relatives of a dying patient. This I found more difficult than anything else as it was not so easy to ‘turn off’ from the situation. People, the relatives, would often ask questions and I think that my answers were often inadequate. I began to feel uncomfortable, dissatisfied with my nursing towards the dying, the palliative patient.

Not so long ago, a female patient died in the ward where I was working. Her physical pain had been difficult to keep under her control and she lingered on the edge of death for what seemed like eternity. The relatives were very upset, although they had been well informed and, presumably, well prepared for the death. I was frustrated that the medication she was having for pain was not effective, you know, didn’t seem to work. I blamed the patient because she should have let the medication do its work, rather than fight it as she had appeared to do. I blamed the relatives because their attitudes had obviously, to me anyway, agitated the patient and they were reluctant to leave her alone, to rest. I also felt angry towards the minister, who even though he spoke in a gentle manner, was always smiling. I thought, how dare he be happy when he should have been appropriately sympathetic and solemn.

I think he must have tuned into my thoughts somehow, or saw the disapproval on my face, because he took me aside to ask if I was alright. He told me that he believed that the patient was now wandering in a beautiful garden, feeling no pain, just a sense of peace. He explained that he felt extremely happy for this lady who had previously suffered so much and he could not help smiling about it. I suppose he must have stimulated something within me because he made me
think about my own beliefs. I was very judgmental and wasn’t looking at things from his point of view.

You know, it often takes a personal experience to put things into perspective and make us take a closer look at why we do the things the way we do. A close relative of mine was diagnosed with a terminal illness. As his condition deteriorated, he and his family turned to me, as a nurse, for not only personal care but for emotional support. I suppose because I was emotionally involved, I did not want to disappoint them by not being able to deliver what they wanted. I couldn’t pass the responsibility on to anyone else and I soon realised that this was a sort of test, that the barriers and coping mechanisms that I created for myself were not made of the right stuff and were useless in this personal confrontation. This man made me realise that he did not want someone to say ‘everything is okay’ when it was not. He did not want someone to change the subject when he had gut feelings that he wanted to talk about. He wanted someone he could talk to who would listen and understand what he was saying. The last thing he said he needed was someone busying themselves with practicalities of his care, like as if he was a machine. This experience made me question my own nursing practice when dealing with dying patients or in palliative care and I discovered that my own nursing care left a lot to be desired. I never thought that palliative nursing was any different from nursing in other areas, although I considered nursing to be a caring profession which involved sympathetic understanding of the patient’s physical needs and to a limited extent, their psychosocial requirements. There was a job to do and you did it.

There seems to be an unwritten law in the nursing world that there are no resuscitation attempts to be made when a patient known to have a terminal disease, dies. I have asked myself why I would, and indeed do, support such a principle. The answer is simply that I consider these people have a right to die naturally without intervention which could result in prolonging needless suffering. It may seem contradictory that I would not consider being involved in any euthanasia act. Because I deem life to be a gift from God, I find it inconceivable that anyone would wish to relinquish such a gift. As I see it, euthanasia is putting someone out of their misery and is in reality the committing of a grave sin very similar to murder. On the other hand, I do consider that nurses have a duty to ease the suffering, the pain, and if large doses of narcotics are ordered for a patient in distress because of their incapacitating disorder, I would not refuse to give them.
I think things are changing in nursing. I mean, very few people expect the nurse to be the sole provider of care to the terminally ill. I mean, the relatives play an important part in caring for the patients. I ask them now if they want to help. Some say yes, others just don't want to become involved and look at me strangely. But I persevere with them and some come around and it's lovely to see them doing things for the patient; it sort of feels right that they become involved too. Sometimes I feel that their eyes (the relatives) are watching me to see if I am doing things right, you know, like checking up, but I smile and ask them to help and that breaks the ice a bit. I think it helps with their (the relatives) grieving after the patient has died. If there are any rules for what one should or should not say to a dying patient, their relatives or friends, I haven't come across them yet.

Our conversation came to a silence at this point. I asked Helen if she could elaborate any further on her story. She said that she felt she had said everything she needed to say regarding these experiences.
For Helen

Can we watch them, hear them
cry out in pain?
Can we stand by and feel
their tortuous dying?

Are we their puppets?
Do we dance on command
or can we pull our own strings?
Puppets cannot answer.

A pain-free death—
it rolls off the tongue
yet haunts the mind.
It's not easy for those who care.

Twisted bodies twist your mind.
Do you have the right
to end this life,
this painful death?
Jill’s Story
Jill is a registered nurse who trained in Tasmania in a hospital based program. She came to New South Wales to work in a critical care area and has completed a critical care course through undertaking part-time study. I first met Jill several years ago when we were working at the same hospital. Jill and I have maintained contact as friends and carefully watched each other’s development in our respective careers in nursing. Jill has completed a degree in nursing and hopes to undertake a Master in Nursing degree next year. I consider Jill to be an expert nurse in her field of critical care. Jill is married and lives with her husband on their hobby farm just outside Sydney.

Jill preferred to provide a written narrative of her experience and the following story is her account of a significant experience which she identified. In addition, Jill wrote her own thoughts and philosophy on how the dying should be nursed. I have included these writings together with her story because I believe they show how Jill has been able to incorporate the negative aspects of her experience and develop a more positive attitude to nursing dying patients.

The first experience I had with death in a nursing situation occurred during the second half of my first year as a student nurse. I had very little personal experience with death prior to commencing nursing. My parents and siblings were all well and healthy. Two of my grandparents had died before I was born and a third one had died while I was still in primary school. Any recollections of his death were a very vague memory.

During our preliminary introductory course of six weeks there were no lectures delivered to us dealing with the subject of grief and death and dying. These lectures were scheduled for second year. There was no formal preparation for dealing with patients and their families in this stage of their lives. Personally, I had not been forced to deal with death and dying in a serious way.

Damien was twenty-five and married with a beautiful young wife named Angela. He was the elder child of his family and his sister was engaged to be married the next year. The family all seemed to get along well with each other although they were not openly demonstrative of their feelings for each other, possibly due to the lack of encouragement from the staff caring for Damien. The family had no previous experience with bereavement and no formal bereavement education had been organised for them.
Damien had been transferred to our hospital to be closer to his family. They had originally hoped to take Damien home with them to care for him, although this never eventuated. The idea was not discouraged by those caring for Damien but neither was it actively encouraged and arrangements were never actually made. The reasons were never really clear to me, although I believe it was because the family experienced great difficulty coming to terms with the finality of Damien’s illness and the inevitability of his death. As time elapsed they eventually realised that he was going to die but they could not come to terms with his dying at home without a doctor or a nurse being present.

Damien had previously been treated in a metropolitan hospital for acute myeloid leukaemia with several courses of chemotherapy and blood transfusions. His diagnosis had been made several months before, after investigations of the failure of a superficial wound to heal within the usual time-frame. By the time Damien was admitted to our hospital he had multiple system involvement, which included respiratory distress on mild activity, pitting oedema of his legs and scrotum, severe stomatitis, chronic diarrhoea, generalised muscle wasting and widespread purpura over most of his body.

Being the junior student on the ward, it was often my duty to care for Damien during my shifts. Soon after admission, Damien’s care was classified as ‘general nursing care’, a phrase which represented giving no further active treatment other than to attend to basic treatment including transfusion of blood and platelets, and nasogastric feeding had been withdrawn. Damien was to be kept as comfortable and pain-free as possible until he eventually died.

To care for Damien’s physical needs was relatively simple. Each morning I gave him a bed sponge. He was too weak for the ordeal of going to the shower. Then he sat out of bed in a chair for two hours. Later he returned to bed for the rest of the day and was turned every two hours to prevent the development of pressure areas. The next morning this routine would begin again. In addition to meticulous pressure area care, Damien’s mouth care was routinely performed and a ‘tick’ placed in the appropriate square on his care plan proved all his cares were attended to throughout the shift.

I may have attended particularly well to his physical needs, but emotional and psychological needs were rarely thought of. On one particular occasion, when
Damien was talking to me during his morning sponge, he expressed a desire to see his dog, a faithful golden retriever, as he described. When I asked the charge nurse about the possibility of arranging this, she simply stated it was not possible because it was against hospital policy. Accepting that this was the way things were in hospital, I should have considered his emotional needs and suggested his wife bring the dog for one last time. Instead, I merely suggested that she bring in a photograph of the dog, to be viewed from the bedside locker.

Often times when Damien spoke about the future and about his dying I would purposefully redirect the conversation to the other 'safe' subjects. I was ignoring his need to express his feelings at a very crucial time of his life. I let him down because I did not know what to say. I had no previous experience of talking to a dying patient. I also think I was scared of getting too close to my patient because of fear of being hurt and feeling lost when he finally died. This would have been an investment of emotion and feelings which would have resulted in a great emptiness when Damien finally died.

On one particularly emotional day with Damien, when he seemed to be so uncomfortable and little I did seemed to be of any relief, despite much effort, I had tried everything I could think of to make him comfortable, but to no avail. It was one of those days when very little seemed to go right. Damien was experiencing much pain and was receiving little relief from the analgesia. His wife had been unable to visit at lunchtime as usual and the cricket test had been washed out. Consequently, Damien was in a very bad mood and told me he thought I was a hopeless nurse and he did not like me caring for him. I had tried so hard to make him comfortable and he seemed so ungrateful for all of my effort. I was hiding in the pan room feeling a mixture of anger, frustration and sadness and trying very hard to suppress my tears when the charge nurse found me. Without any discussion she announced that she thought I was getting too emotionally involved and to get too close to my patient would be to my detriment and that if I did not toughen up I would be always getting hurt by my patient's death and, after all, it was not uncommon for patients to die.

I remember feeling quite angry when Damien and his doctor made the decision to withdraw all treatments and medications and to continue only with his intravenous fluids and analgesia. The doses of analgesia were increased rapidly as his pain worsened and his condition deteriorated. I found it difficult to
accept that he could just give up. After about three days Damien became unconscious and died in his sleep at about four o’clock in the morning.

One other problem I recall having to come to terms with was the refusal by the hospital hierarchy to allow those of us who requested, permission to attend the funeral. Damien died after about one month as a patient.

In caring for Damien as a dying patient, I attended very well to his physical needs but failed to help him with various feelings his terminal illness evoked within him. I failed to address the feelings of anger, sadness, regret, resentment and guilt, due to my lack of experience with death and the grieving process. I also failed to recognise my own need for education and understanding of the phases of the grief process and how best to address the problems that can be experienced by a dying patient and their family.

Clearly, learning to help dying patients and their families demands involvement, but to become involved one must first be comfortable with death. With this understanding and a concept of loss and the process of grieving, I think we all will be better able to implement creative interventions to promote optimal wellbeing and supportive care for the dying patient. When nursing a dying patient, we must possess a willingness to listen, a determination to be honest and sincere and to demonstrate real concern in order to afford our patient optimal care in the final phases of living.

With a sound knowledge of the processes of the grief reaction we will be more effective in attempting to meet the needs of the individual in our care. All interactions, including actions and conversations with the patient, must convey acceptance of all their grief reactions. This can be demonstrated through touch, attentive listening, skills and expression of concern for the feelings of the patient, all of which will assist in developing patient trust. If, however, the patient is unable to share concerns and feelings readily, we must convey to the patient a willingness to be available whenever the patient has a need to confide in someone. It is quite common for patients to feel embarrassed about expression of feelings, thus it is imperative that we are reassuring and acknowledge any feelings, beliefs and values expressed by the patient.
This fear which can be experienced by the caregivers can be reduced by our having the courage to become personally involved with the dying to enable discovery and development of our feelings regarding death and dying. To share their grief may not be easy, but the reward in personal satisfaction and inner peace will be reward for the effort that is required. This will ultimately result in being better equipped to deliver quality to the patient.

Nursing interventions for the terminally ill patient should focus on promoting the patient’s sense of identity, dignity and self esteem. This can be enhanced by listening and responding quickly to requests, ensuring privacy, and promoting comfort and optimal physical care. The dying patient will gain considerable satisfaction from being able to help themselves for as long as is physically possible. This independence will promote the patient’s sense of worth and dignity. A sense of being in control must be promoted.

Attention must also be directed towards promoting spiritual comfort and wellbeing of the patient. As death approaches and the patient accepts the inevitability, comfort may be sought through reviewing and analysing the values, beliefs and philosophies that have structured and shaped their life and are presently exerting influence on their perception of the meaning of death.

Simultaneously, support must be present for the family and loved ones of the dying patient to assist them in their grieving and to assist them in giving support to the dying person. We must recognise the family’s importance and value to the patient and encourage them to spend quality time together. It may also be of benefit to encourage the family members to assist with simple care measures, including feeding, sponging and repositioning the patient for improved comfort. As death approaches, the family should be encouraged to remain in attendance. Once the patient has died, the family should be allowed adequate time to be alone with the body and encouraged to touch the body and to talk to the deceased.

I felt it unnecessary to ask for further elaboration from Jill as her story held much meaning for us both.
For Jill

Your endless, caring arms
reach out to everyone in need.
They are your family
yet you are not related.

To you, caring is a joy.
When you are old and dying
may you have many sons and daughters
to care for you.
Sarah’s Story
Sarah is a registered nurse having graduated from university with a Diploma in Nursing in 1991. After graduating, Sarah did not undertake a recognised postgraduate program but was employed by a metropolitan Brisbane hospital in which she rotated around several different specialty areas of nursing care. Sarah found her passion in nursing patients in coronary care and after completing one year as a level one nurse in Queensland she applied and was successful in gaining a level two position in a coronary care unit in a private hospital in Queensland. Sarah commented that the hierarchy and treatment of nurses in general ward areas were very poor but when working in a unit these barriers to communication were generally less obvious and team work was more pronounced. She felt that as a university graduate she had a lot to offer the multidisciplinary team.

Since relating her story, Sarah has become involved in a cardiac catheter laboratory at her place of employment. Additionally, she relieves the in-charge position in the coronary care unit. Her quest for knowledge has led her towards gaining tertiary qualifications. Her ambition is to complete an Honours year program and study towards a PhD in the next five years. Sarah is a questioner by nature and constantly searches for the meanings of her life. As well as her excellence in nursing practice, Sarah is a very dear and trusted friend. I was holidaying with Sarah when I learned of my mother’s death. She and her husband were a great support to me in those initial hours of receiving this news.

Sarah and I held our conversation in her tranquil and peaceful home. As with the previous conversations I asked Sarah to relate the stories of her significant death experiences as a registered nurse.

The first death that I actually encountered was in the medical unit, my first ward. It was an elderly gentleman and being in a medical unit, I was ... it was actually during my preceptorship. I was still being preceptored by a nurse I admired greatly. I was about a month out (since taking up the first position of employment) and it was an elderly gentleman who was chronically ill. He was one of those patients who, when you came on each shift, you expected to hear that he had passed away. We didn’t expect him to last another day but somehow he did and it just dragged on and dragged on and the family were put through hell as well.
My preceptor and I used to have a number of patients and in this thirty bed ward there was six nurses, so we had five patients each. The back ward was always the very heavy patients, dangerously ill patients and my preceptor and I were actually there and he was one of them. I can remember, my preceptor was in caring for him and he obviously passed away, and walking in and seeing my preceptor crying. My first response was, I was really surprised that she was crying because she didn’t appear to be, she … actually, the person that she’d conveyed to me was this person who would manage it all. She had a very hard exterior—a real coping person. She was crying and was quite depressed that she was caught crying. It was almost as if I had caught her out crying. It wasn’t actually the death that was my main focus then, it was my preceptor’s reaction to it. I just went cold.

The room was dark and it was like the epitome of what death was, how I imagine it to be, do you know what I mean? Very lonely, very sad. Like, I don’t have any fear of death or believe in death to be a sad thing. I think it’s the way in which people die which is the sad thing. The lingering, the pain they experience in the preliminary towards that death and then the death is the release. So it’s almost as if … (pause) … that was actually … (pause) … and being there my immediate reaction was to reflect back on my first experience, my first ever experience of death which was a personal one. That was my grandfather. The difference in the two, my grandfather died at home, well, as far as I was concerned he died at home and it wasn’t anywhere near as bad as the dying in the hospital. Maybe the difference was that the preliminary wasn’t there. There wasn’t all that pain and suffering and labour, whereas my grandfather died suddenly. When I say suddenly, I mean he died suddenly for me, in a sense that as a young child he became quickly ill and, like, was in bed and then was taken to hospital.

Although Sarah wanted to describe the next death experience, I asked her to further explore the feelings of loneliness of this first experience.

Well, he was alone as far as his loved ones were concerned. His loved ones weren’t there. The room was like a typical hospital room. Even though we were in the newest portion of the hospital, it was still, like, very cold and it felt very cold. Whether that was, like, my projection onto the experience, I don’t know. It was very clinical. And he seemed alone. It was almost as if he needed someone to
take him on the passage—do you know what I mean, just that crossing over? I can see it very clearly but my feelings towards it are a bit hard to grab hold of.

I didn’t help lay him out. Another girl who was working, who was more, like, floating (an extra nurse) helped my preceptor. I tried to offer my support, emotional support to my preceptor, but it was almost as if she was saying “let me be, I just need to deal with this”. I think in my preceptor’s regard it was this patient was a patient who was almost, like, a regular to the ward and she’d cared for him several times over the years. And almost, I never actually really talked to her about it, but her tears may have been tears of release for her in a sense, like, ‘thank goodness it’s all over for him’.

It’s the suffering that I find the hardest thing to live with. I find it the hardest thing to cope with, with death in hospitals, because it’s always there. Whether it’s the suffering on behalf of the person physically or the suffering on the family’s behalf. But the suffering is always there. That’s the hardest thing I find because, as I said, I don’t find the actual death to be an issue for me. Sometimes it is a release.

I asked Sarah to describe what she meant by the suffering.

It’s the loss. It’s very selfish. I know myself it’s a very selfish thing, like I don’t want them to go. It’s your loss and dealing with your loss. Not so much trying to put myself in their shoes. It’s totally a selfish thing I’ve lost this person I love so dearly. They’re no longer going to be with me.

The next one was the really hard one because it was actually in the coronary care unit. And we talk about nurse’s intuition that ground nurses in their years of experience. And I’d actually come on the shift and I was working, I was on one-to-one care and this gentleman who had actually had a huge infarct and he was recovering really well and he had an uncomplicated, relatively uncomplicated, post-infarct… He was a blind gentleman and he was also very incapacitated—he had an amputated leg and he was a very sad person. I found him very sad. But, anyway, I came on, it was night duty and he was fine, the report was fine and everything, and I went up to see him and he was asleep and he seemed fine and everything. Then he started getting very restless and breathless and they had mentioned that some nights that he’d do this. I wasn’t actually concerned about
this but then his vitals (vital signs) changed and I was getting concerned that he was failing (heart failure) and I called the doctor and then I walked back to the bedside. I wasn’t like, I didn’t feel imminent death, do you know what I mean, whereas this woman who has been in practice for years and years walked up to the bedside, she was really this sturdy lady and she comes up and just takes one look, just very casually, and walks over and grabs the crash trolley (resuscitation trolley).

I can remember turning round and thinking, ‘don’t you think, that’s a bit exaggerated, aren’t you exaggerating a little bit?’ But by the time she’d got the crash trolley he was there, he had arrested (cardiac arrest). He didn’t survive. He actually died of pulmonary oedema. It was a gross death, a really gross death, the fact that he’d drowned—heaps of secretions were just coming out of his mouth and his nose. And another nurse started packing him, packing his nose, putting things in his mouth, in his bottom, things like this and I found that all very awful. I didn’t manage that well at all. I just didn’t understand. I just wondered ‘why do you want to do that?’ And I said to her, “Why are we doing this?” And she said to me, “This is the way you have to do it. This is the ritual, this is what you have to do.” “But I’ve cared for somebody, you know, I’ve prepared a body before, I’ve seen a body being prepared and they didn’t do any of this.” “Well,” she said, “they must have been doing it wrong. They weren’t doing it properly. You have to do it this way.” “And it was all very... (pause) ... do you know what I mean, at a distance. And it was all very... she had an austere face as if she was preparing a sandwich. That’s how it felt, you know.

I felt it was a real violation, ‘cause I honestly felt, ‘cause I have a great belief that they’re still there, somewhere, do you know what I mean, whether they’re sitting above the bed or standing behind me or... I don’t feel uncomfortable about it, but I feel they’re still there. It’s almost as if the disrespect... (pause). It was so quick, because of the environment of the unit, it was all open and so the patients are all very, in close proximity to each other and all very unwell. It was almost as if we had to remove the stress for them.

I asked Sarah to pick up on those thoughts of the packing being disrespectful. I asked her what she meant by that.
It just treated the body as if it was a shell and nothing else. As if it was just like a real ... reality hit for me in the sense that, you know, it’s over, forget about it, let’s get rid of it. I spoke to the registered nurse about it and I told her I can never get used to the dying, the suffering in dying. And she said, “I never have.” And I don’t think I have found anybody who I’ve spoken to similarly, they never say ‘I have’. They all say ‘I never have’, which is funny, isn’t it, because you’re working in an environment where it’s constantly there yet you never get used to it.

And there’s another one, another incident, where a woman in a coronary care unit, the same, had an horrendous history and horrendous time, like, it was June and for the previous six months she’d been fighting. She was Italian and the support of the family ... there was a member, a member of her family by the bedside twenty four hours a day and totally involved in her care and their involvement was promoted. And she was being managed by the Professor of the unit so she was getting, as far as I was concerned, she was getting the best care that she could possibly get for survival. But she had cardio-myopathy which she’d actually developed progressively because of her renal failure. She suffered acute renal failure from surgery. It was all iatrogenic and I believe the family started to feel (the same) also.

And she was going through, she was slowly dying and the family were clutching onto her life. It was almost as if she wanted to go, she was just so tired, so tired and she’d been constantly fighting for six months, and she’d been pumped full of medication that she was almost wanting her family to realise that she wanted to go but surviving for their sake. That’s how it felt for me.

She didn’t have to saying anything about it, it was almost as if it was understood. Just in my silent moments with her was like the combination of the sheer exhaustion, almost as if ‘let me be’. And that was when I became really, I wish there was a living will, or I wish people could, the legalities of the thing ... (pause). And there was a point in time where I started feeling that her care was no longer for her sake it was for medicine’s sake, do you know what I mean? It almost became ... she became a form of them studying new methods of management of cardio-myopathy.
I had great respect for the Professor, great respect, he is the most beautiful man, but I felt at that time that was the way it was becoming. The family kept on asking me, there was half of the family... When I say the family was beside her, like, there was one daughter who was with her constantly. She never left the bedside, she slept there. The only time she left the bedside was to go to, up to the Red Cross rooms to have a shower and come back. And that was, like, she was there for almost a month in our ward. People only usually stay three days in our unit and she was there for ages. She was almost, I think, being with the mother, she was of the belief, 'let her go'. It was almost as if she was fighting with the feeling that this is becoming an experiment.

I can remember her ... there was another and newer treatment that they wanted to instil her mother full of medications that would be really difficult for her to handle but could be really successful if it worked. That treatment was started and ... (pause) ... they'd given her this medication and she was on dialysis and she usually had dialysis every second day. And because this medication had a therapeutic half life, she would have to miss dialysis on the second day. So they actually let her, and the family, the girl was really uncomfortable with that, and missing the dialysis, and she actually died the following morning.

Once again I was on night duty and I can remember coming on—it was right on the change of shift and the room was just, she was actually in the back section of the ward which was the dialysis bed. But, like, the whole area was just full of her relatives and they were screaming, like, absolutely screaming and one of the nurses who, who was just lovely, the clinical specialist, an extremely feeling person a very soft person, he had worked on her trying to revive her. He was in amongst all of it, do you know what I mean, in all the family, and he couldn’t get away and he was in real need of getting away because he, he wanted, he was nearly in tears, do you know what I mean—it was almost as if he was feeling the blame, the constant 'why didn’t she have the dialysis, why, why, why?’ It was real anger, real anger was there and he was becoming the brunt of it.

And I can remember walking in and feeling in the way. And then the daughter speaking to me about the same things, you know, like, ... (pause) ... and there had been, like, actually lashing the chests of the relatives and with the male nurse. It was sheer distress. That was really, I think that was actually the hardest one I've ever had to deal with, because of the torrid emotion that was surrounding me. And they stayed with her until the body went cold, the family,
they stayed with her. That was, that was two and a half hours. I can remember
some of the nursing staff saying, "They can’t do that, they can’t stay here." And
I said, "They have every right to." She was actually in my care that night. And
then I had to prepare the body and that was the hardest one. The hardest one
because she looked so tired and she had so many holes in her, drips and, oh, it
was just awful, just awful. She just looked bashed and bruised.

I was interested in Sarah’s perception of the family and why she advocated with
the other staff for the right of the family to be in attendance for so long.

It was like they were there to assist her on her journey. It was beautiful. I
thought it was beautiful. I thought it was a beautiful tradition and I gave it
the utmost respect. I thought it was lovely and I actually thought then that I
would do the same with my loved one. I would stay with my loved one until
they went cold. And their vocalness was another thing that I found beautiful
too, in a sense that they were very immediate with their feelings, whereas
families that I’ve seen or relatives that I’ve seen previous, it’s very much ‘hold it
inside and wait ’til we get in the privacy of our own homes and then we can
express it’, do you know what I mean, which I find really difficult because it’s
so unreal.

I was interested to know what meaning Sarah found from the experience of the
deaths she described.

Consciously, I wouldn’t be aware but I do believe, sub-consciously I believe that
one death prepares you for another. My need ... I do have a great need for
assisting that passage, making that passage easy and for making that passage
comfortable. For example, I just had a death last week where the man was, like,
dead, like, he would have been brain dead but he was still gasping for breath. I
had a real need to release him and so I gave him some morphine to relax him in a
sense, like, help him. Like, I requested that he be given morphine. Yes, I have a
real need and I have a real need to convey to the family my beliefs that it is not
the end and that issue of release, that it is better and I really need to ... (pause).
The first opportunity I have in my communication with the family is to express
that and to try and express to them that the suffering has stopped and almost a
new beginning has begun again.
I wanted then to explore Sarah's philosophical difficulties with which she has to come to terms as a health care worker.

*I could be stereotypical and say that the focus of practice is always for the living, do you know what I mean, is always, the intention of care always seems to be to make them better. The unfortunate thing about that is that I have never been in a hospital, not that I've been in many, but never been in a hospital where there has been a palliative unit, where the focus has been assist the dying. So ... and once again, the unfortunate thing about it is that if you do have a critical patient in an area where, for example, in a medical ward, they can be one of a number of patients that you have, so you have a focus of care for four out of five—on the one hand, the living, and the other, the dying, do you know what I mean? The unfortunate thing about it is that the dying always seem to get second serve. The only way I could see that changing is palliative units, where the dying are taken to a place where the ambience and the care is focused on supporting their dying. Unfortunately, I just could never see it. It gets too readily missed (the need for palliative care) if it's in a busy medical ward where it commonly happens. Busy medical wards is where a lot of the dying occurs. In critical areas it's very acute, it's very sudden, except for that one case I portrayed to you and there was a great push by a lot of people to get her out of that unit and send her somewhere else because she was dying. But then there was a discussion amongst the staff, who wished her to stay. It would have been too, it was another stress she would have had to manage, that the continuity of care was of uppermost importance and we would have been breaking that.*

I pointed out to Sarah that the decision reached about the woman was in direct conflict with what she was advocating should happen with dying patients.

*Well, when I speak of people dying, and, as I said to you, the suffering that accompanies that, unfortunately a lot of that is associated with medical management, prolonging that suffering, especially in that last woman (example) I gave to you, whereas she would have been allowed to die a lot sooner had the medical management not prolonged that suffering. Now, if she had have come to us and the decision had been made that she was untreatable, then she could have been moved and had full weeks of preparation and focus of dying with her family. Similarly, in medical wards when people are admitted, and they're admitted into busy medical wards, and the management will be there for the first couple of days, and it's understood, it's almost as if it's recognised that*
there isn’t anything they can do but they’ll do it anyway, or try anyway. This acceptance of the fact that there isn’t anything they can do and let them go where they can be cared for.

I wanted Sarah to explore the duality of roles she described earlier, that is, a wellness and a dying focus which appeared to be in conflict when nursing in a busy ward.

In looking at the units I’ve worked in, the style of care which is unfortunately given, when I said to you that it becomes second best, I find that a real sadness and disappointment but it’s inevitable. And in saying that, that’s where my belief comes that they should have a specialty area.

I asked Sarah what makes the sadness inevitable.

Management, time, under staffing—all those awful, awful realities for patient care, full stop. That just made me hate medical wards from the beginning. It became a factor of time that, like, I used to feel, like, for example, people who were dying, like, I used to feel horrendously. I can remember several cases where patient would be in real need of counsel and my being unable to afford them the full amount of time that I would have wanted to, like a whole evening of just counselling and sitting and talking to them, but because of the patient load I had and no other support in order to give me that time...

I returned to Sarah’s concept of ‘second best’ nursing care and asked her what she thought contributed to that meaning for her.

Attitude towards the dying? I’d like to say ... no, when I speak to you of my ideal, a special ward, I think there is a definite concentrated focus on the living, and once a person is recognised as dying the care tends to change accordingly. The focus is removed and, unfortunately, there is not a great focus on the palliative, palliative focus. The situation is not approved. The nurse who is palliatively focused is regarded as a generalist, do you know what I mean, but then frustration is paramount and their ability to deal with it.
There's always a great push amongst nursing staff for a patient's condition to be speciality managed. Nurses will identify the patient's needs and will really push and request that the doctors relate to that. I mean, when a patient comes in with a cardiac problem and they've got diabetes as well, they are never treated in conjunction, they are always treated separately. It doesn't fit with what I've been taught, holistically, and I'm always bashing my head against a brick wall.

It would be fabulous to leave the patient in the ward or unit where they were dying. It would be fabulous if they were to receive the care. It would be fabulous and I think that would be great and I think that's why, like, I was one of the principal people saying 'leave her here'. Likewise, mainly because she was able to receive concentrated care because of the staffing ratio we had in that ward. I knew that if she got sent to a medical ward, she wouldn't get that. It's mainly my dealing with the realities of what I've seen, like the fact that they don't, they don't because the urgency and the focus aren't there, there is so much else happening, sadly, not that I believe that anybody would actually challenge you if you were to say that, 'Oh, I didn't get these patients' care done because I was counselling the dying'. I would be surprised if somebody was to challenge you, but they would most probably retort, 'Oh, but there are grieve counsellors for that'.

I asked Sarah to think about the lady's death again and asked her what she thought of the arguments put forward to transfer the lady to another ward.

The common argument in the coronary care unit is, if this person isn't for resus then what are they doing here? We are not going to actively resuscitate this person—why are they here? And it all comes down to money. It does. That's the sadness there is about it. That's where the cost sector pros pers and palliative care units are so great and if home care of the dying is able to be managed, it's lovely. The loneliness is also, when I reflect on what I was saying about loneliness, is likewise tied in to that whole thing. They are alone if they don't have that focus (palliative focus). They were allowed to just die. So they should be, but they were allowed to just die, lonely.

Given that Sarah cannot have her ideals, I then asked her what nursing the dying in a critical care unit means for her.
I am very much guided by their needs. I would talk with the patient and identify what their needs were. And when I say talk to the patient, I mean really confront the reality as it is happening, the fact that death is imminent. I think they like you to be straight out and very frank, very real. And in doing that, discussing with them the fact that there is always the potential for them to ... there's always that miracle. But, like, all the clinical indicators that we are given to date show that it is, it would be a miracle. And it's almost as if they thank you for saying that, as if, 'thank goodness someone has been truthful with me'. They're not petty footling around, they're not avoiding the issue, they're not pretending that everything's rosy when it isn't. I get really annoyed when I see nurses doing that, you know the type of thing. Speaking with them and identifying their needs and then meeting them, whether that is making sure that all their family are able to see them... We have some staff in our ward who have got this real need, I don't know, the ward I'm working in, there must be in hospitals they've worked in before there has been really strict visiting hours—nobody was allowed to see the patient during certain hours—and I really oppose that. As far as I'm concerned, immediate family can be here as long as they want, whenever they want, and really acknowledge that I resent them doing otherwise.

'There has been an instance when a patient has, the patient's immediate family have been treated like that, you know, 'No you can't visit them now 'cause it's not time.' And I have a real problem with that ... (pause). And, like, making sure they're prepared, emotionally, mentally, not emotionally, but mentally aware, that they feel as if, if there is business. For example, you know, that if it's acute, do they feel that all the financial issues are sound? Are they wanting to speak to an accountant? Are they wanting to speak to whoever?—just, like, slowly releasing all those mental stresses that are on them as it becomes acute. And talking to their family—they'll often give you sub-conscious, like, subtle indications that they want you to try to speak to the family and prepare them.

I asked Sarah whether she was any closer to finding meaning about death for herself.

'I think I've come from a focus where I never fully understand myself, in a sense that I'm always learning and always open to new experiences and new ideas and any challenges in that respect. I never would sit complacently or satisfied finding an understanding, anything to do with the human condition, 'cause I
think also I find that I tend to be a very deep thinker and the moment I really think deeply about something I realise how much I don’t know, how superficial it all is. Where will I ever get enough time to understand even a piece of reality? I believe there is a real need … it really depends on a person’s religious beliefs. I suppose it’s just my wish to project, ‘cause I have such faith in the belief that it doesn’t end. I think we are just too grand. It’s very egotistical, but I believe that we are too grand to just end. And in that respect I find that it’s almost, the death is almost, not so much exciting, but it’s a new beginning.

Our conversation came to an abrupt ending with the noise of the telephone ringing. After her telephone call I asked Sarah if she wished to add anything to her story. She declined and our conversations turned to family matters and children.
For Sarah

Speak with me of life's domains
and I speak with you of growing pains.
Speak with me of death's domains
and I speak with you of life's cruel games.
Together, we search the unexplained
for answers, which surely shall remain
within ourselves, 'til we re-claim
the question, to question yet again.
Mary’s Story
Mary is a registered nurse who trained in a small metropolitan hospital in Sydney in the mid 1960s. She continued her career until she married and became pregnant with her first child. After the birth of her first baby, Mary did not return to nursing, preferring to remain at home with her family. After her third child had started primary school, Mary decided to return to the work force and gained a part-time position in a nursing home specialising in the care of the aged. She became interested in pursuing further studies in nursing and enrolled in an undergraduate degree program. It was during this time that I first met Mary.

Mary is a lively, energetic woman who was very interested to join this study. Mary continues to work in aged care but she has taken up a full time position at the institution. I visited Mary at her home by her request and she related the following story to me.

*My nursing career began on the third of January 1964 at a private, 68 bed hospital in Sydney's inner west. I was the middle child in the family of three children.*

*Our family was a close and loving working class family living in the inner western suburbs of Sydney. My parents tended to be rather over-protective and, well, my decision to become a nurse was strongly ... (pause)... opposed by my father. My mother was not overly enthusiastic but nevertheless supported my decision. Becoming a nurse in those days meant leaving the nest, leaving home and living in the home, the hospital's nurses' home. I was enthusiastic, idealistic and determined to become a 'good' nurse.*

*Death and serious illness were not subjects which were discussed in our family. Therefore, I had no knowledge or understanding of such things. This attitude was normal for those times. Our parents sheltered us children and protected us from what they believed to be distressing and harmful influences, you know, like death.*

*My first encounter with death in a nursing situation occurred in 1964. I had been working on the wards only a few weeks. I remember feeling, well, the whole experience, really, of nursing was still new, overwhelming, exhausting and just a bit confusing. As a very junior nurse I spent much more time dusting,*
scrubbing pans and arranging flowers in vases than in caring for, looking after
the needs and comfort of my patients. There was no time for talking with
patients about anything, let alone their fears and anxieties, although I had no
real understanding of such things in any case.

The first time, the first death, I was told in hushed tones that a patient had died
by another junior nurse. I remember my first feeling was one of relief that the
patient was not one of mine. It was someone else's patient. She had been
assigned to another nurse. I didn't really know her, you know, I had not
developed any relationship with her. The lady was elderly and I can't remember
her diagnosis. I know that the death was not unexpected. I recall seeing, from
the safety of my pan room, relatives weeping in the hospital corridor. I do not
know how the sister-in-charge responded to the situation or how she cared for
the relatives. I do remember the expectation that the entire staff would maintain
professional behaviour. We had been told often during PTs that we should not
become too involved with patients.

It was not unusual for the bereaved relatives to be sent home from the hospital
with a script, prescription for sedation to help them to cope with the situation. I
don't know why 'cause it only served to delay their grieving period, but I
suppose it meant that the staff were seen to be doing something for the bereaved
person. But it lacked caring in a real sense. There was no need to become over-
involved if feelings and emotions could be patched up in this way.

When my senior nurse told me that I was to view the body of the lady who had
died I felt scared, frightened and uncertain. I was told that I must show respect
for the dead person, and maintain a quiet dignity. This I must have managed to
do because if I had not I would most certainly have been told. I had no idea
what to expect. The lady had been laid out—I was pleased, I was thankful. I
did not want to touch the body but I was told I must. I remember how cold and
unreal the body felt. I also remember how white and still the body was and that
the face was smooth, no lines. However, the body did not look to me like
someone who was just asleep. It was spooky and unnerving. In retrospect, I
probably survived the experience because it was expected that nurses should do
such things. I also did not want to admit even to myself that my father may
have been right in his objections to my chosen career.
I don't remember the ward sister saying anything to me about the death; nor do I remember her showing any concern. My senior nurse was not unkind, but she did not even seem to notice my fear or apprehension. It seemed that there was no emotion felt by anyone except me. I felt unable to express my feelings for fear of being laughed at. I don't believe that the lack of caring from my superiors was intentional but, rather, that the importance of caring, not only for patients but also for colleagues, was not generally understood in those days. Perhaps they found it difficult to offer comfort because it was showing the human side of their response. It was important to keep a stiff upper lip and to be always in control. Showing emotion was seen as being out of control and perceived as a weakness.

I remember the laughter and bravado we used to do on similar occasions, but this time laughter didn't seem appropriate. We simply talked over the events of the day in the safety of our rooms in the nurses' home. I did not want the others to think I might not have coped with the situation so there was a sense of bravado. I kept most of my uneasy feelings to myself. There was no support system available in the institution. The only support available was that given by those in our own PTS group.

Because this event occurred so long ago I cannot remember many of the details. It is clear to me though that I was not prepared for it. Death had not been discussed in my family and was a subject that had been glossed over in PTS. It was stressed that nurses must show respect for the dead and that care of the body after death was a solemn duty. There was no mention of how we, a nurse might feel or how to deal with whatever emotions might arise. The expectation was that we would deal with the situation without making anyone else feel uncomfortable.

Death was hardly ever mentioned during my training. I was never comfortable nursing dying patients in my years of nursing training. I think my fear of encountering death was probably due to ignorance. I believed in life after death but had difficulty with the dying and with the dead body. Seeing a body reminded me of my own future death and the death of those I loved. This frightened me. When I retreated to the pan room I hoped that no one would notice my absence and that I would not have anything to do with the death that had occurred. It was ignored really. I ignored it and so did everyone around me.
It's different today. Today I feel much better about death. Well, it's all around me in the nursing home. It's not, like, a daily occurrence, but it happens. It's expected and sort of respected where I am now. It's much better, I feel much better. Well, I'm a lot older now and nursing's changed. I mean, it's (death) not hidden now. We have caring nurses where I am now. We care for the relatives as much as the patient. We let them stay with their dying parents, or friends. It's like a big family. Like, the nurses feel they are family too.

But that first time, the first experience, well, it didn't teach me anything about death as I know now. It was cold, no emotion, like I couldn't have any emotion. It wasn't right to have any emotion. I prefer to work with the dying like I do now. I feel more confident I suppose.

Mary became very silent, introspective and quiet in her demeanour. I asked her if she wished to add anything to her story and she said she had no more to tell. The conversation turned to other matters unrelated to this study.
For Mary

It never ceases to amaze me
that little brown coffins
hanging from my silky oaks
hatch into butterflies
with rainbow wings.
They delicately
busy themselves
in their one-day life.

Where do they die?

And nurses, when they hatch
from years of study
and bedside practice
to be experts in their field.
They briskly
busy themselves
in their life-long world.

How do they die?
Belinda’s Story
Belinda is a registered nurse in her mid thirties, having begun her career as a cadet at the age of sixteen. Belinda’s description of her experience was tearful and I frequently asked her if she wanted to proceed with the taped conversation. Belinda’s perseverance with her storytelling is commendable.

Belinda currently works with the aged, running a church-owned hostel complex in rural New South Wales. She is married with two children aged eleven and nine. She describes herself as a Christian and tries to assist her ageing clients to achieve spiritual satisfaction before they die.

Belinda began telling her story.

My nursing career commenced when I was sixteen years of age at a small hospital in the Hunter Valley as a cadet nurse. At that time it was the done thing at this hospital to serve as a cadet nurse for twelve months prior to commencing general nursing training. I first experienced death in a nursing situation early in 1974, about four weeks after commencing nursing. The memory of this event has been suppressed for many years and has taken a lot of reflective thinking to recall the experience. I am unable to remember the patient’s name; however, I can visualise him and that moment quite clearly.

As a child, I regularly visited the cemetery with extended family members to care for the graves of deceased relatives. I grew up attending the Methodist Church, believing that when you died you went to heaven, that all the family who had died were there together. Before commencing nursing my only experience with death was when my grandfather was killed in a mine accident when I was thirteen years of age. Due to the nature of his death we didn’t view his body, but all the family attended the funeral.

I acknowledged Belinda’s difficulty in describing this experience and asked her to take time and describe significant events of a professional death.

Yes, I think I remember. I was working in a male medical ward. A doctor asked me to assist in examining a patient, so I held the man forward by both shoulders. The man died while being examined. I was unaware until the doctor told me there was no need to fix the pillows as he had just died. Immediately after, I felt
shocked, confused and disbeliefing as how could a person who I had just talked to and helped, though sick, just die? He didn't really look any different and he was still warm. The doctor left to inform the ward sister, not saying anything more to me.

I could see Belinda was visibly emotional having described this situation. I stopped the tape recorder and we sat in silence for a short period of time. Belinda was crying. After a few minutes she indicated that she wished to talk more about the situation. Belinda continued her story whilst her tears flowed freely.

After the doctor left, another nurse, one responsible for medications and treatment, came to see what I was doing. I must have looked dazed. I told this nurse what the doctor had said. The nurse put the screens around the bed. I hadn't realised this should be done. It was then organised for me to go on a break with another more experienced nurse. During this 10-15 minute break we briefly talked about the patient's death. The other nurse listening for a short while but then passing it off as 'all in a day's work' sort of manner. Then she changed the conversation.

I asked Belinda what happened when she and the other nurse returned to the ward.

When we got back, work continued as normal, you know, caring for all the other patients. The nurse who had drawn the screens around the bed took care of the dead man. I was not involved with any further care for him. You know, I don't remember anyone coming to see his body, not that ... I don't feel I expected anyone should. Family were not considered to be part of this man or what was happening at that time.

It was strange, when I finished work that day I walked home as usual and began telling my mother about the day's events in front of my two younger sisters, fourteen and ten years of age. I was hushed and the topic changed. Later when we were on our own, Mum talked briefly about death, explaining that as a nurse I would see a lot of people die.

The next day I went to work on the same ward and everything went on as usual. It was as though the dead man had not existed. No one else talked about
him so I thought I had better not. It was expected that junior nurses did as they were told, not questioned what had happened.

I asked Belinda what the non-existence of the dead man meant for her.

I suppose because the man was elderly then it was expected. I guess what I didn’t expect was not talking about it or making it as though it were nothing, a non happening. There was no follow-up counselling available—not just for nurses but for anybody. I don’t remember any kind of bereavement work. Maybe I just wasn’t aware, but I cannot remember any of the other nurses or tutors talking about it. Death and the care of the deceased person was gradually introduced over approximately the next four months until I became socially conditioned to accept death and the care involved.

I asked Belinda if there was anything else that was significant about this particular death.

I suppose I felt a good nurse should hold themself together, that if you showed emotions at work you were unable to cope. I think this behaviour was supported by my mother’s response that as a nurse I would be repeatedly exposed to death, therefore I must face and deal with death. The care I was giving was at a junior level and I felt was undervalued and invisible to the doctor, like it didn’t mean anything. I suppose I didn’t mean anything to him. Reflecting back, it was all very paternalistic. What the doctor said or did was held in high esteem, even if his actions were not very caring.

I asked Belinda if she could focus on her feelings at that time.

Shock, Confusion, Disbelief. The disbelief lasted for several minutes. I think it was a coping mechanism to protect against the reality of the event. The reality of his death was acknowledged after talking with the nurse who pulled the screens. I didn’t feel guilty as the death of this patient didn’t affect any personal relationships. I didn’t really know him. However, anger, I felt angry because of the way the doctor didn’t appear to care about this man or my being there.
After the break and returning to the ward to care for the other patients it was as if this care continued in an almost altruistic manner of concern for others at the expense of self care. The next day, work continued as though the deceased man had not existed. Nursing care took place in an immediate time frame. The bureaucratic organisation of contemporary hospitals just carried on, business as usual.

As a cadet nurse, no formal education was undertaken before commencing nursing. Orientation to nursing care by the nurse educator aimed to show how to provide personal assistance for patients and ward routines. This meagre education was supplemented by supervision and guidance by other nurses on duty.

I moved to the nurses’ quarters and lived in for a while. That was better in these situations, death situations, as I had my peers to talk to. Peer support in the nurses’ quarters was very good. We were all in the same boat. We all helped each other to distance the experiences. We were scared of getting involved, especially when it was a young person’s death. Children were the worst. I remember a child I nursed. He had been there, in the small children’s ward for ages. He had some degenerative disease and had to be nursed in a hammock and he used to spasm. And we had to hold him so he wouldn’t fall or hurt himself. I used to get so upset, thinking he would be better off, you know, if he wasn’t alive. But when he died, we all felt it. We were all very sad. We talked about him and his parents and wondered how they would be feeling, rationalising his death. But now I have children I think it would be awful to lose one of them, no matter how sick they were. It’s the young ones that make it difficult to accept—the babies, the young children especially.

I was interested in exploring Belinda’s thoughts about death in children and asked her to describe another experience of child death that was significant for her.

It was later in my career. I worked in a large hospital as a midwife. We had a woman in labour who had lost two children within weeks of their birth. Her and her husband had received lots of counselling. This was their third attempt. Labour started. It was all going well and she delivered a, what looked to be, a normal healthy baby girl. Anyway within minutes of birth the baby had difficulty with breathing and the neonatal intensive care doctor was called. The
baby was put into intensive care. It was the disappointment, the sudden change that happened in the parents—from elation to sorrow in a matter of moments. The joy at the birth and then the suddenness of possible death. The baby was transferred to another hospital but did not survive. It was so sad for those people, you know, within a whisker of happiness and then nothing. I spent time with them but there were no appropriate words, no words of comfort. The shock for all of us in the midwifery unit ... we all thought, yes, this time, yes, they would have the long awaited baby. I certainly felt sad for the baby but I think it was the parents who I felt more sad for. Being there for them was probably all I could offer. I mean, you just can’t share that kind of grief.

Belinda lapsed into silence. I asked her if there was any other death situation she wished to share.

No, I think that is all.

I thanked Belinda for telling her stories. She had shed many tears and felt comfortable about her emotions. She related to me that she had not thought about these situations very much and had not shared them with anyone else. I had a sense of gratification that Belinda had felt comfortable in sharing them with me.
For Belinda

To heal a hate takes courage.
Churning hurt, bitterness
and black despair.
    No love.
    No power to choose.

You heard a stillness.
Gentle words, kindness
and yellow warmth.
    A chance
to know what choice is.

The hurt was gone
and hurt still clinging.
The cool wind
breaks the ice
and child-like freedom sings.
Angela’s Story
Angela and I shared some affinity as we both completed our general nursing training in England. As a registered nurse, Angela now works primarily in palliative care. Angela chose to exchange audio tapes with me and her story is divided into two parts. Firstly, Angela tells her story of a significant death experience and, secondly, she provides a reflection on that experience.

Angela had a warm, generous nature and an ease with relating to me. The choice of using a tape recorder was triggered by the complications of distance from each other. Angela now lives in the north of Australia, working in an aged care environment that specialises in palliation.

Angela begins her story with a description of her first experience with death, as a student nurse.

_I trained as a registered nurse in England from September 1971 to February 1974. Compared to the hospitals in London, it was a small training school which was attached to a local district hospital. The hospital was an old Victorian building and its wards were long, with a dome ceiling that created an echo. I was on my first secondment to a ward after only six weeks in the School of Nursing. This was a female surgical ward and the lady in the first bed by the door had died and I was told to perform 'last offices'. For this procedure I was assigned to an older experienced member of the staff who was a State Enrolled Nurse (SEN). I cannot remember the circumstances that led up to the lady's death, I just remember how frightened I felt at being asked to perform this task without having gone over it in the School. There was no clinical tutor assigned to me for that day so I could not ask or expect help in dealing with this problem. I had never seen someone die, let alone dead. Touching a dead person was inconceivable to me. At eighteen years old I had not really thought of death._

_The nurses on the ward were extremely busy. There were beds up the middle of the ward and this caused problems as to gaining easy access to patients' beds. There were forty patients in the ward and only four nurses and myself on duty for the morning shift. I presume that this death was expected as the patient's bed was placed near the door, allowing easier access and to give more privacy. My first task was to prepare the trolley for the procedure. This I managed to do with the help of the procedure book. However, I was still uncertain if the trolley had been correctly prepared as the nurse assigned to me was busy and was not_
available to check the trolley. I remember I tried hard not to show my feelings of fear to the other senior nurses.

Very luckily, Joyce, the SEN to whom I was assigned to perform the last offices, was a motherly and kind lady in her late fifties. Before proceeding she explained to me what we were about to do and told me not to be frightened. When Joyce took me behind the screens and by the dead lady’s bed she did a most unusual thing. She opened the window and uttered ‘now this will let her spirit go free’. ‘Till this day I have never forgotten this and every time I have performed this task I have opened a window.

Joyce led me through the procedure, talking to me as well as the dead lady, explaining everything that we were doing and the reasons why. She performed the procedure as if the lady was still alive, showing great care and respect, and said that as nurses this is the last possible thing that we can do for our patients and that they should not be pushed around like a sack of potatoes.

Joyce told me that the other nurses thought that she was stupid for speaking to the dead person and that they had all opted out of doing this task. Joyce had overheard the other nurses tell the charge nurse to assign her, as she was older, and the first year student (me), to the task. They had also said that I should learn the hard way and not to be mothered by the clinical tutor.

That evening I talked it over with my peer group of students. They said that they were pleased that I was the one to have gone through this procedure first and that I had had such a kind and considerate nurse to show me this dreaded task. We all talked about my experience and this helped them to deal with the procedure of last offices when it came their turn. We discussed the tales that we had been told, mostly to frighten us, about how the dead sigh when they are turned and that they have been known to sit up when first moved. I had discussed this with the SEN and she had explained that air can be released from the lungs when the dead person is moved, but she had never seen a dead person sit up. The response of the clinical tutor I cannot remember but I do remember that every time my peer group of students accomplished the ‘task’ (as we now referred to it) there was a great deal of discussion as to how that student had managed.
Reflection

Looking back on my feelings at the time I can visualise how frightened I was. Eighteen, in my view, is a young age to have to face death so abruptly without prior training or counselling by my clinical tutor. My feelings of anger still persist and I would never do to another inexperienced member of staff what they did to me. On reflection though, I can now understand to a certain degree how those nurses felt. They may have even done me a favour. Obviously I still have some conflicting feelings and wonder if I’m trying to make excuses for the nurses’ behaviour. I was scared to show the other nurses how frightened I was. Was it because of the tales I had been told or being so young and inexperienced, or even both? Death seemed so final to me. The thought of death then was just inconceivable and immortality was often on my mind.

To have given the task of last offices to a very junior student nurse and a very capable older experienced nurse, now makes me wonder. Were they in a stressful environment and feeling overworked? Although this event happened in England I’m sure that the same applies to Australia. The ward was extremely busy and the nurses were having to cope with a very new student nurse who was only capable of performing simple tasks and anything else had to be explained and taught. Were they suffering from stress? Or were they not coping?

They placed me in the care of an older experienced nurse. I am grateful for this as she taught me a great deal in a matter of a short space of time. I wonder if Joyce, the SEN, had had her own personal experience with death and that is why she was able to perform last offices without any emotional problems. She was so caring, capable and kind to me.

If the death was expected and a long, drawn out event, then the nurses may have been experiencing discomfort, or perhaps they were angry about a part of the lady’s treatment. As nurses we were taught that cure is the ultimate success, then inability to cure becomes a failure. I feel that even if the nurses were unable to cope with the lady’s death, whatever the reason, they still should not have put me in that position so early in my career and that they should have shown some consideration for me. It is my belief that they were trying to hide their true feelings by engaging in other activities. I feel that the nurses, if unable to cope with death, should have faced their own fears and not have passed the task to others. They demonstrated detachment, while Joyce demonstrated involvement.
Joyce showed me how to care even in death. When she opened the window to let
the spirit go free I must admit that I thought this silly. Since then though, I
have practised the same thing, believing that maybe she was right and not
wanting to take the chance that she was not. How could Joyce be able to display
a caring attitude while the others did not? Was she able to undergo ‘debriefing’
while the other nurses were not? As nurses, we are most likely to experience
stress. Often we need to share our feelings and prevent burnout.

I believe that collectiveness would have been a better attitude for the nurses to
have adopted. Also, looking at the role of the charge nurse, she seems to have
taken the easy option. I cannot remember her ever recognising in small ways the
worth and individuality of the nurse or giving the nurses praise for their caring
attitude and thus enhancing their capacity to care. In spite of their individual
reasons, I feel that the nurses would have coped better with the death if they
had had debriefing or even a teamwork approach. At least they would have been
able to express their feelings and I would have been able to show my anger,
instead of bottling it up.

Reflecting on the situation now, I hope that someone was there with the lady
holding her hand and that she didn’t die alone, but I suspect she did. This
experience and others, I believe, have guided me towards my present employment
in palliative care. When one is older and more experienced in life, as Joyce was
and I am now, you have a different attitude to death. It’s an inevitable part of
one’s life.

Angela’s story and subsequent reflection made connections with her past and
present nursing practice. I made contact with Angela to ask her to describe a
significant story of her nursing today. However, Angela declined the offer saying
that the reflection process on her initial experience enabled her to see both sides of
the complexities of nursing the dying.
For Angela

You were lucky to find a friend,
A guide who helped you find the road
to understanding, what is death.
She opened windows in your heart.
Released the sorrow, hurt and pain
and let your spirit roam free.
Gloria’s Story
Gloria started her general nursing training in 1965 in a small Sydney hospital. Most of her training was spent in surgical wards and the operating theatre. She left nursing soon after finishing her training and had her first child. She returned to work part time in an accident and emergency department. After an initial period in the accident and emergency department, Gloria transferred to full time work in an intensive care unit on night duty. In 1975 Gloria took a five year break from nursing which culminated in a move to Queensland. She resumed working in a small private hospital and has been working at this hospital for the last ten years.

I met Gloria through one of the other participants in this study. Gloria overheard Sarah talking with me on the telephone about the study and expressed an interest in being part of the study. I visited Gloria at her place of employment and sat with her after a morning duty to listen to her story. We sat on the roof of the hospital, which was being converted into a summer garden, and enjoyed the warm afternoon sun as it sank low into the sky.

As with the other participants, I asked Gloria to describe a significant death experience.

*Well, now I am more comfortable about death. It's been very gradual. When I was first working in Queensland, I think I'd have to work from being with relatives, I think that's how I became to be comfortable with actual patients. I know how uncomfortable I was with talking to relatives. I think I... it wasn't really guilt, but there certainly was a lot I could have done to have prevented this person having this loss. Rather than face that, I wouldn't face the relatives. I'd wander off, find some excuse, pounce on the 'phone if I saw the relatives coming or move into some other room rather than face the relatives. This went on for quite a while and I had a particular patient that I was quite fond of who died. It was a reasonable time ago now. I saw her (the relative) when I was shopping in a supermarket. I sort of avoided her at first. I went into another lane and then I thought, no, I really wanted to go and ask her how she was going. So I went up to her and said, "Hello" to her and, "I'm wondering how you've been." She just broke down and cried. That was my worst fear, that that would happen. She said, "It was just such a relief for someone to stop and ask how am I because so many people have ignored me." I said, "Well, that's what I've done. I was in another alley and it really was difficult for me to come along*
and just ask you how you were.” From that experience I sort of became less frightened of relatives and from that I’ve become quite comfortable with people dying.

I then asked Gloria if there had been any other significant deaths for her.

I work in a medical ward and I have since the last ten years. Because it’s such a small area we have lots of patients who keep coming back in and a lot of the patients who have died, we’ve known for quite some time. They have all been significant in different ways.

I see death as being quite natural. I am also aware that for the people close to them it isn’t natural at all times and it’s very difficult for them, so I’d like to think that when I’m with the relatives and patients when they are dying, that some way it is conveyed to them that it is okay for this person to die, because they have such ambivalent feelings that they certainly don’t want their loved one to go away, yet they realise that it’s time.

In the past, a lot of people that were attempted resuses were successful, as far as they lived, but were not successful as far as being mentally alive. The quality of life was horrible even before the attempted resus. So, it was either prolonging what was happening for them, or in fact making it worse for them. Gradually it was an accepted thing that anyone over the age of sixty-five was … for a while there, it was almost a rule that if you were over sixty-five you didn’t attempt any resuscitation. That, too, has changed of course because of the quality of life.

I recall during the training, one of my friends was working in the male medical ward. I was in the female medical ward and we were both having similar experiences. So we went to our tutor sister who said we could always come and see her if we had any problems. So we went and spoke to her and she said, you know, about how many people had died and how this was affecting us. This tutor sister said, “Well, they’re gone and dead. You can’t do anything with them. Get on with the living.” It’s only been in the last few years I’ve really realised just what a shitty thing that was to say to anybody. It didn’t address what was happening. It helped to bury what was happening. If we were being affected by it we were inadequate was really what the message was as I received that. It wasn’t easy to go to the tutor sister and to disclose this
particular feeling. The message back was very much that it was not okay to have feelings, let alone disclose them.

I think it's changed now and if it hasn't changed and people are still of that old idea, I'm very quick to step in and talk about feelings, talk about my own feelings. I feel quite okay in doing that.

Because it's been so long since I've done my training... I haven't done my degree. I am in fact doing a post graduate diploma in palliative care but that ... (pause) ... I've sort of got special entry into that. I'm not really aware of what's actually in the curriculum for pre-registration nurses. We have at times had students who had come to the hospital and there was a particular time when one of the students was in with a patient who died. I took her aside and spoke with her and spent some time with her, not knowing how much training she'd got or what she'd been taught. Also, we spoke to the preceptor and told her about this so that she was aware for the debriefing at the end of the day. I think that the education that nurses get now there is more of an emphasis on expression of feelings, whether it be about someone dying or abuse, or whatever it is. I think that nurses these days are more apt to verbalise their feelings. I am very aware that the older nurses still don't do that. I find it very difficult. There's very much a usage of 'one's' and 'your' rather than 'I'.

I asked Gloria when she is caring for the dying, what the most significant thing is that she can do for the patient.

Just be there. Just acknowledge them and I may well acknowledge that things are not looking too good at the moment and if there is anyone they want to come in to be with them. Acknowledge that I don't know what to say. Say that I'll stay as long as they want me to, that's if they are conscious. If they are not, I frequently still speak and say the same things. I think the presence of someone is important. I like to think that there are not too many people who die alone, although I realise that there are. I think we need to consider the patient's spirituality throughout all this. I don't feel nurses have a grip on spirituality. I think they feel it's very private and something not to be discussed. It's like sex and politics.
Gloria became very silent. I sensed she may have been thinking about a particular patient so I asked her if there was another significant experience that she would like to describe.

Yes, there was one last year who was a patient who had come in with liver and renal failure. He was initially in the intensive care unit and then moved out to the medical ward. That, in itself was ... there was a lot of resistance from the medical ward staff, because sometimes the medical ward staff are up to here with people dying and why can't a patient die in intensive care, rather than be sent out to the medical ward. This particular fellow was sent out to the medical ward. I think he was out there a few days. He gradually became unconscious, and his daughter had arrived from South Australia. She was a physiotherapist and she said, "Is it okay if I massage him?" I had some massage oil out in the car so I went and got the massage oil. Both her and her mother were massaging a hand each and I had some tapes in there. We do have some quite pleasant new age tapes, not that I'm into new age, but the music is quite pleasant. The tapes were going and they were massaging his hands and he appeared to become a bit agitated. Well, they expressed it as agitation, and they pressed the buzzer.

So I went down and he was just taking his last few breaths and it was quite a meaningful death in that I was able to do something to enable the wife and the daughter to be actually physically holding him when he died. The wife spoke later on about them having some of these tapes at home and that particular music that was playing was one of his favourites. It was a very nice death. The family were very appreciative.

The next day I made a point on both shifts of talking to the staff from intensive care and letting them know how it was for them. There were lots of filled eyes and things and the staff were really pleased with the feedback and that encouraged me to do that again, whereas before I might not have thought to have talked about someone's dying experience with staff that looked after them previously.

As I was saying earlier, in the medical ward we were getting a bit fed up. I think they had possibly had two or three patients in a very short time who had come from intensive care out for terminal care on the ward. I hadn't really
looked at that incompletion for the staff in the intensive care unit. So, that was one experience.

There was another one, quite a while ago, before I became interested or realised I had a lack of interest in dying. It was a patient ... I was working night duty. This patient asked me, "What does the enemy say?" I thought, he's gone, he's confused, poor fellow. I said, "I don't understand what you are saying." He said "What does the enemy say?" I said, "I thought you said that but I've got no idea what you're talking about." He got up and leaned on his elbow and he said, "Oh, you're just a young lass, you wouldn't understand, but the enemy is time." So, what he was asking about was what time was it. So I told him the time and he asked me a few times during the night and during the time ... we spent a good deal of time together. When it became daylight he sort of laughed and said, "Oh, the enemy didn't get me last night." 'Cause his idea was time was fatal and as time went on he became closer to death. He was making that analogy. He actually died later that day. I was off after that. It was quite a significant time for me. I did some writing about that. I wrote a poem about that. He was very much a soldier in the last war and if they could get through the night without being killed they could see people in the daytime so it was safer.

I asked Gloria about her increased interest in death and dying and what that meant for her.

I haven't looked too much at my own death but I've talked with my husband and kids and we've all discussed our preferences for burial or cremation, and what songs we might like to be played at our funeral. I guess it's brought it out in the open, although I haven't looked at the actual dying as such. My parents are in their early seventies now and they won't talk about it. "Just cremate me and put me anywhere," and they don't want to know about it. They are very quick to end the conversation to do with anything like that. I guess it's quite a shift for me to be able to talk with my husband and kids about it, because it is very much history that it wasn't spoken about.

Thinking about it now, my father spoke about it. If Mum died before him and he knew that he was dying, he'd go bush. He doesn't want to be a burden for anyone. He was from the bush as a child so it's very logical. I said to him I could understand him wanting to do that but I didn't think that would be terribly fair
'cause I wouldn't know when to start grieving because I wouldn't know if he'd actually died or not. That was quite some time ago. Then, probably a few months after that, he said, "I was thinking over what you said and I won't do that now." So, I'm saying on the one hand it's not spoken about but they do allow a little bit to filter in.

Gloria's silence was broken by her beginning to talk about where people die.

I think it is important that people die where they want to die, but I think it is important to look at how it is for the other people in the family too. I don't believe it is a failure on the other members of the family not to fulfill the wishes of the person that's dying by having them in hospital. I know that a lot of the patients that have been in here, their carers have sometimes been in, stay overnight or whatever, or take shifts, and not having to be part of the actual action of caring if they don't want to. We certainly encourage it if they want to be part of the turning, and backs and things—we certainly encourage that. But if they don't want to, then they have time to rest, whereas at home they feel that they need to be doing that. It's very important to look after the carer and if those last few days are able to be made more meaningful for them while being in hospital then I would certainly discourage people from feeling guilty for their loved one's being in hospital while they are dying.

I was interested in how Gloria perceived caring for the carers in hospital, that is, as nurses.

I think ventilation of feelings is the most important way of doing it. I think what has happened to me, and I've moved away from ... and I can certainly see this happens for a lot of other people, is that I sort of have mixed feelings about this. There was a time when I would, if I knew that someone was sort of near dying, that I might even sort of feel obliged, not obliged, but wanting to come in on my days off or ring up to see how they were going. There was a very strong bond to a person who was dying. I've moved away from that now. It's okay for me to go on days off. Just recently we had a patient who said goodbye to me—he knew I was going on days off—and I said goodbye to him. It was quite okay for me to go on days off and when I came back I found out that he had died. I think there is still very much a hanging onto the person—nurses becoming attached to someone who is dying and don't realise just how much energy they
are using to be attached to a patient. Sure I think that caring is great, but that attachment, I think, is really sort of dangerous and difficult to deal with afterwards, when that person’s gone, when there isn’t a lot of debriefing after a person’s died.

That experience I was talking about earlier with the staff in intensive care: I think it’s very important to take time to explain how a patient has died. I don’t think enough is written in nursing notes about what happened towards the end. Maybe if more was, there wouldn’t be such a . . . (pause) . . . if it were out in the open when someone died and they knew when this person died they’d be informed as to what happened at the end, whether the family were there, or how it was for that person. It sort of acknowledges the attachment.

There was a very long period of silence and I asked Gloria if there was anything she would like to add to her story.

I don’t know if this is significant, but we have a particular patient up in the ward at the moment who is forty. She’s not dying, she’s coping with abdo (abdominal) pain. She’s had lots of gynae (gynaecological) surgery and as a result is self-catheterised. She’s been in for a couple of weeks. On Sunday, she was talking to me about the pain she gets and I asked her if there was anyone she could talk to about the pain she was having. She said it’s just gone on for so long that her family is tired of hearing about it. They don’t say that it’s not there but they’re tired of listening. I said, “Is there anyone you are able to talk to, someone you’ve spoken to in the past?” She said, “I could always tell Mum but she died in December.” I’ve been able to talk with her since and get the Chaplain up to talk with her about her grief and whether it’s significant or not through this extra pain that she’s getting quite a lot of. I suspect that it is. The one person that she felt she was close to and felt understood her has gone. Her mother lived in South Australia. I said, “There must have been many times you’ve gone to try to ring her.” She said, “That’s exactly how it is.” We might see a decrease in her pain as her grief is expressed.

I feel for me it’s a real honour to be allowed in to hear about where people have been on their journeys. I asked her was she able to be there when her mum died. She said that financially she wasn’t able to go to both the funeral and to be with her before she died. She spent a week with her before she died and she
stayed with her the whole time and she was actually with her when she died. In
the afternoon she said that she felt so much better for being able to talk about
how it had been for her when her mum had died. Lots of our patients have had
recent grief experiences and don't volunteer the information. It was a random
question that ... it was more of a question of how that is, not intrusive. There's
a lot of resistance if someone is asked, "How do you feel?" Asking it some other
way, often the feelings are expressed. When someone is dying I never sort of ask,"n
"Do you think you are dying?" They ask, I say, "Is that what you are thinking?"
I don't say, "Yes, you are," even though honesty is the best policy.

I asked Gloria to focus on her idea of her personal movement from one
philosophy to another.

I've been to a few different grief seminars and things over the years. Five or six
years ago I did a telephone counselling course with Lifeline which was quite an
influence. A lot of it is just straight out gutsy risk taking—seeing what works
and what doesn't work and thinking, 'Oh well, stuff up there. That didn't
work'. It's amazing the times that I thought, 'Ah, what a stuff up. That didn't
work', and something has come out of it. I don't know whether it's so much an
education process, a self education process perhaps. Whilst all this has been
happening, I've been dealing with a lot of my own stuff—I was sexually
abused as a child—and realising a lot of the grief that has come from that. So I
guess while I've been working on that, certainly not thinking that I was doing
that to help patients, I think there has been a spin off from that, looking at
awarenesses and acknowledging them. Heaps can be gained from a group
experience. I think it would be great if there was some sort of group for the
nurses, to be able to sit around and just buzz round and find out what is
happening for them. I see handover as a reasonable time for that, although there
is a task in the handing over. There have been times when I've been quite
frustrated with the waffle that goes on during the handover. I've thought about
that afterwards and I've caught myself being critical of the handover and the
time it has taken. Then I thought, hey, it's possibly the only time that's set aside
in the day that some form of nurturing expression can take place between the
staff, and for someone to say they're frustrated with a certain patient or
something, whether it be a dying experience or whatever it is, frustration with
the doctors...
Gloria’s conversation moved to another unrelated topic and soon came to a close. I thanked Gloria for her time and we moved inside to have a cup of coffee together before she left the hospital for home.
For Gloria

Wise woman, treading carefully,
choosing the right time
to be with their emotions.
How I admire the ease
with which you can decide
when to nurture,
or when to guide,
or when to stay away.
The answers are within you always,
Earth mother.
Penny’s Story
Penny started training to be a registered nurse in 1968 at the age of eighteen, in a private hospital in Queensland. After her training, Penny worked in operating theatres specialising in plastic surgery. Penny extended her training to incorporate midwifery and psychiatric nursing. She has worked for ten years in cardio-thoracic intensive care. A few years ago Penny went to America and worked as a nurse for four years. Since returning to Australia, Penny has been working in a coronary care unit in Queensland.

I met Penny at the beginning of the year whilst I was holidaying in Queensland and she expressed a wish to be part of this study. Penny told me her story one evening after we had spent some time together socially.

Penny’s story begins with her first death experience as a nurse.

Yes, I remember it—in fact I can see the room. I was trying to remember what her name was. My mother, if she was still alive, would be able to tell me because she always remembered it, because she remembered how this dear old soul complained to me about getting the dogs out from under the bed. She must have remembered how I used to come home in my first year of nursing and tell her about this. I can’t remember her name, but I can see which bed she was in, in the room. Thinking about it, how I was helping, I was probably in my first few weeks of nursing, so I was only just eighteen.

I remembered I was standing aside, we were doing this woman’s back and the other nurse, who probably was a second year nurse, was standing there and she was rubbing her back and, this sounds awful, she was doing a manual evacuation on this woman. I’m just standing there and she looked up and said, “Is that woman alright?” I didn’t have a clue if the woman was alright. I looked down and, I mean, I didn’t know and the nurse said, “Oh, my God,” and obviously she was dead, and she just left me. She didn’t say anything to me, she just went out of the room. I didn’t know what she went out of the room for, whether she went to get the sister and tell her that the old lady had died, or whether she was upset, or what she’d done.

So, here I am, standing there, holding this woman who obviously had just died. I thought, well, what do I do now? I mean, do I ... am I supposed to stay here
or...? So I can vaguely remember then I just sort of turned her back over and covered her up and I left myself. I don't remember after that what happened. I just remember I don't think I was actually upset, more confused. What are you supposed to do? I mean, PIS (Preliminary Training School) was just a week to us before we hit the wards. It wasn't months. I don't know about you, but we got a week. Obviously, we must have talked about it at some stage, but I don't remember.

After that, I remember, for the next couple of years that I was there, I never seemed to be there when anybody actually died. I always seemed to... went to tea and when I came back they said, "Oh, your patient's died," or something like that. So, it wasn't for a long time after that, that I actually experienced patients dying when I was there.

I asked Penny to describe her next experience.

My next experience, well, I guess it wasn't for a while because I was in theatres, then I did my psych (psychiatric) training and there was nothing there. So, I guess, probably my... of course, my dad died. That was a sudden death, so that was in '75. So, after that, I guess, it wouldn't have been until I was probably back doing cardio-thoracic, maybe intensive care or something like that.

It was difficult there because you had two different types of patients. You had your babies, so there was a lot of baby deaths as well as adult deaths. I think babies who die are a lot harder. You had the cardiac babies, so we had a lot of babies. It would depend on the death. I would feel for the parents, of course. I think that if you're close to the babies because you look after them a lot more than you do with the adults, and I think for the children it's always that they haven't had a chance yet. They haven't lived their life yet, whereas older people you can often say, well, they've lived a life. That's how I feel, anyway. With a baby it's more difficult, and also for the parents—having to deal with the parents on top of it, coming to terms with losing their children, especially if they've been there a long time, because you get to know them, you get to know the parents.

You know, I do remember one in particular. A child that died on Christmas Eve. A child that went into renal failure, had dialysis, and I do remember that child
because she became as hard as a board. She'd got fluid retention, and everything. She was just, just taking so long to die. It was Christmas Eve and the office ... the theatres used to have Christmas parties after the last case, and it was right next door. They were a little bit noisy. I remember how we felt because these parents were listening to—in the background—the Christmas party. It was really hard because you want to keep ... everybody still wanted to be celebrating Christmas, but you had two people in there who were losing a child. But I always remember these parents because we said something like, we apologised to these people. This woman said, "No, don't apologise, because it's Christmas Eve, just because we're going through this, doesn't mean to say the world stops," which I thought was very fair.

I asked Penny what that death meant to her.

I think I'm fairly realistic, in that, you know, if people are ... say, that baby who was dying, there was absolutely nothing you could do for that child. It was in pain, blown up like a balloon. It was probably even brain dead. I mean, it's very sad but I wouldn't want it back again in that position. And I feel like that even with my own family. I don't know how to explain it to you. I even felt like that when I lost my mum, even though there's pain and you're very sad. I don't sort of say I want them back. I mean, I've had people, I've had relatives who've stood at beds and said I want them back; it doesn't matter even if they're going to be like this. For me, that's not an option.

I asked Penny to tell me what death was like for her in her training.

For me... Okay, let me say that, I think, for me, having death in my family affected me more as it affected me in clinical practice more. I tend to, and I know even after my dad died it was different, especially after my mum died, I'm different again. So I tend to, like, to look after people, and relatives, and I tend to look after them the way I wanted to be looked after, and I remembered what helped to me or if I saw the nurses doing something to my mother, that's the way I would like to do it. And again, the opposite.

I asked Penny what some of those things were that she would like to do, and things she would never do.
Some of things that I would do and which I do now is, I think, is things that I think are important, are time: making sure there is plenty of time for relatives and patients—not having to rush in and rush out again; that you allow relatives to be there twenty-six hours a day, all the time, and to do within reason, when I say within reason, whatever, they want to do. If they want to sit up on the bed, if they want to get into the bed, whatever they want to do. So that, to me, is all important. And I think having patients look and smell nice and clean and looked after and men shaved and ladies’ hair … nice nighties, not hospital gowns, their own clothes. I noticed a patient today which I thought was really nice … no, it wasn’t today, it was yesterday, when he was sitting up dying—he was blue black as you could get, hardly breathing at all, I mean, looked like he’d last another half an hour and it was really lovely because his wife was there just holding his hand, and he had his glasses on and his hair combed. I think that’s really important. They’re not just looking like … things like oxygen masks, like, he had an oxygen mask over his face and I asked her, because I wasn’t looking after him, being in the role of the supervisor, but seeing her, I asked her if she would like the mask off and perhaps some nasal prongs put on so that the mask wasn’t sitting there looking at her. She surprised me, she said, no, because he normally has a mask at home. He never liked nasal prongs at all—she would prefer the mask. So I think it is important to ask the relatives what they want rather than just presume, which I was presuming in one way, ‘let’s get this mask off so she could look at him’. But for her it was important that he had it on.

Today I went up to a ward to inquire how a patient was who’s terminal. His family was there and one of the older nurses had just come out from washing the patient and she looked a little hassled and I asked her what the problem was. She said, “I’ve just finished washing, tidying up the room, and got rid of all the clinical stuff,” which I thought was very nice. So I think those things are important. What I’m saying is, I’m sure that I don’t think I was prepared for all those sorts of things from my nursing practice, but it was a personal experience. May be they do now, it’s a while ago. I mean, what we were told was a lot of respect. You never laid out people like … laying out you got the giggles, like, you giggled because you were scared. But you even felt guilty doing that. I think it’s a nicety to keep a little more subdued. Like, you don’t strip patients off completely when they were dead—if you were sponging them that you ensure some modesty—and talking to them, I would say things like, ‘you’re out of pain now, you’re okay now’, talk about their family.
I think it's also important to talk to them before they are dead. I think to encourage family to say all the things they would like to say, things that haven't been said to resolve things perhaps, to say that you love them. I mean, a lot of people don't. And I think what I see is important is that there is a time, when the time is right, and I saw it with the babies, that you often wondered why these little babies kicked on for days and days. I mean, God, they should have died ages ago. Mum and Dad probably weren't quite ready. Mum and Dad were probably thinking, 'can we still take him home?' or 'there might be another operation.' Then you would notice that Mum and Dad would start to change and start to accept, and the baby would die. I think that's even true now.

I had a patient recently, forty-four year old, with cancer, lovely married couple, very nice, I mean just hung on and hung on. I was talking to the minister later who visited with her. She had spent a lot of time with her the day before. And she said to the lady, 'Are you ready to die?" and the lady said, "Yes I am ready." So she said, "Well, tell your husband that you're ready because he is waiting." And she did, and it was great, and he... The day before he was terrible and all of a sudden... when I went up to see her, "Everything's okay," he said, "we're both ready and we're right." It was great.

You remember how COAD (chronic obstructive airways disease) patients get a reputation? You know they get anxiety and they can't breathe? I remember when my mum was in our hospital as a patient, I was doing a couple of night shifts, supervising, she was downstairs and I was called by this nurse, "Get down to your mother, I can't control her." She was hypoxic. I walked in—screens were pulled round her, no oxygen, blue in the face, gasping for breath. I pulled the screens back, turned the fan on, gave her a bit of oxygen and she started breathing and within five minutes she was sweet. And where's the nurse when I arrive? Sitting at the desk. To this day I would hate nurses who would say things like, "COAD patients, oh, they are cracked," because they are not.

I like to visit patients, especially terminal patients, because I like to see that they are getting the care I would like to give them.

I asked Penny whether there were any other significant death experiences she would like to describe.
I've had one suicide—a young guy, twenty-five, twenty-seven. He was also in my first ward and his name was Mr. Steel. The guy in the next bed came from New Guinea. He was an island guy, who was dying of cancer and he died on Good Friday. I was the nurse who carbolised the bed and I'm cleaning the bed and Mr. Steel, twenty-seven, married, said to me, "Oh, lucky." I said, "Yes, I guess you know he hasn't got any more pain." Seventeen years old, you haven't got any idea, he was in this depression. Now, the bells would be clanging. Then, they weren't, I was just carbolising the bed. So you can imagine what he did in the night—he overdosed. Now, if someone said that, you would immediately start to talk a bit more about why he is saying that.

Penny talked about how ill prepared nurses are to deal with death and went on to talk about how she thought they could be better prepared.

I think we have to make sure that nurses understand that it's part of nursing, it's not a failure if you lose a patient, through whatever reason. It might be a chronic disease or somebody stroke out after something minor and you didn't think it was going to happen—all those things. And I think that you have to realise that it's not part of... I think doctors have a problem with death and patients for that reason. But I think in nursing, that's part of it, to take it to the end and even later, with relatives.

It's a part of life—I know it sounds funny but that's it, it's part of life. And some of that nursing towards the end is helping patients prepare. I mean, we talk about preparing patients for discharge through other parts of their illness. We should be preparing them, helping them prepare for death as well. A lot of it is time. They come to that in their own time anyway. It's definitely spending time, not formal time, I mean sitting. It's spending the time. That's why I get very annoyed when people say that nurses shouldn't be doing hygiene and washes, let's leave it to the assistants or whatever. I mean, that's the time when you're doing other things and you're washing patients and doing fairly personal things for people, backs and massages and all that sort of stuff, and finding out a lot more than if you're going to come and pull up a chair or sit on the bed with a pad and pencil. I think that's a really bad thing about people in the United States in that they don't do a lot of hands on. They used to laugh at me because I used to rub backs. "Why do you rub backs?" they said. "People don't get bed sores." Well it's not actually back rubbing, as such, it's more a touch and it's more a time thing.
You have to be aware of what they (the patients) want. Then it all gets back to being a time thing, creating, getting to know them. But in nursing, the way it is now, that's not always ... there is not always enough time. And it's just going to get worse. I think it's all to do with money, that's what it boils down to. I mean, I heard a nurse, today at tea, say that she could just get her work done. She said, "I can just get in there and do the washes and the pills and the obs (observations). I can't do any more." And yet, they were adequately staffed according to the so called dependencies and man hours. I don't know how they do it.

I don't think we put a value on social interaction. I don't think they are included when you look at things like dependencies. I mean, they have a tick for admission and a tick for this and a tick for that. But, no, I don't think it (communication) comes into it.

A long silence followed and I asked Penny if she felt she had anything else to say.

I would hope we are going to somehow see a change towards people dying at home, more than dying in hospitals and that it's acceptable to die at home. And that we have ... and if they have to be in hospital, even in a place like our hospital, that we have some areas that are less clinical. Where I was previously, we, on the oncology ward, we had a room that was set up. It had a hospital bed in it, but it had cane furniture, it had a sofa which pulled out to a double bed. It had nice curtains and nice paintings so it wasn't felt to be a very clinical room. I'd like to see more things like that, I think.

I think ... I guess I look at more terminal, chronic things rather than sudden. There's a difference when we get into things like intensive care and people on ventilators and turning people off, and I dealt with babies and we were turning off ventilators. What we used to do is, even before they were actually turned off, babies would die, or getting to that stage, we did a lot of getting them out of the cots to be held—sitting mother in a chair—and they had numerous lines, drips and tubes and ventilators and all that. We got to the stage where you even had to hand ventilate, even for a while that was fine, so you do a lot of that. If a mother ... we were going to turn off the child, we gave them that option of perhaps taking the tube out and popping them straight in Mum's arms, that sort of thing, turning the machinery off so that people aren't looking at straight lines
and preventing people going absolutely mental rushing around and sticking stethoscopes on. I think that's important.

There are so many aspects. You get people talking about maternity, stillborns. There was one, but I wasn't about. A baby that was born anencephalic or something like that. (pause). My mother told me that her second... she lost a baby at seven or eight months, and... taken away, never to be seen again—never looked at it, wouldn't even know where it was buried. Isn't that terrible? Really, who had the right to say 'you're not going to see that child'? Interesting, in that book 'April Fool's Day', his first bleed was a cranial bleed, like superficial, but he ended up with a head out to here and he was only a baby of, say, about nine months. And the doctor said to the husband and wife, "You're not to see this child. I won't allow you to." She wasn't allowed to visit—it was ten days before that child was allowed to go home, until the swelling let down, the bruising, the bleeding and Bryce Courtney himself was allowed in to see it. And he remembers just going in and the child would just blow bubbles and he talks about a big purple melon, just blowing bubbles at him. And there's a chapter in it that she wrote, and how angry she was at how dare he tell her, not even to tell her but tell her husband, that she couldn't go in and see him.

I think that (the issues surrounding parents seeing stillbirths and children who are grossly deformed) has changed, it has changed incredibly. I have friends, friends who live in Singapore. Their second child was a Fallows syndrome. She was probably my closest friend and the first child was born perfectly fine, and three years later another baby, and she had a girl and she called me from the hospital and said, "Where are you? You haven't come to visit me yet." I said, "I'm coming tonight. I've been at work, you know that, and I've talked to you." I couldn't understand why she was so angry until I got up there to find out she had just been told the baby had a murmur and that they thought she had a Fallows, which it turned out to be. And the child had cardiac catheters done, it was okay, sent home to come back in a year's time to have a total repair.

She was a lovely child, but looking back, more a strangeness about her, an aloofness. She never walked or crawled and she would just sit there. She liked you or she didn't and she liked me because I smoked in those days and she used to like my lighter. Anyway, she went in for her surgery and she had her catheters done—she stroke out, never to wake again. The mother told me she lived that day and she was taken to the nursery, she was ventilated and the mother said
something to the nurse like ... I've forgotten what she said but the doctors had told them everything that had happened etc. She was telling me about this nurse, and I know this particular nurse, she was an older woman who was a fantastic nurse and she looked at the mother and she said, "Did you know your baby's dying?" And she said, "Penny, it just hit me. I was so glad she told me 'cause, you know, we were just sitting there for this child thinking, 'what's happening?' Finally somebody was able to tell us, to say that." Sometimes that's what people want. That was really good.

In my own experience, I can remember a nurse who used to look after my mum, who actually used to live down the road from us, so she knew us as being a neighbour as well. And she was going off duty, whichever day it must have been, 'cause my mum died on the Saturday so I think she might have been going off duty on the ... might have been the Saturday morning, maybe it was, I can't recollect exactly, and she popped her head in to say goodbye. And she said, "I just want to say goodbye because I don't think she'll be here next time I come back." And she wasn't. But I remember that as... I mean, it was the way she said it. You need, sometimes, those things. She needed to come in and say goodbye for her own self, which was important for her. But that was an oncology ward and the girls were generally very good.

Penny asked me some questions about nurses who choose certain areas of work. We talked about our own personal choices of work and how they have changed over the years we have been nursing. We compared our lives and lived experiences and how that may have contributed to our choices in work areas. I thanked Penny for her assistance and how she brought a different aspect of working with the dying with her experience of nursing children.
For Penny

I will sing you a lullaby
not for sleeping,
but for dreaming
of fearless fantasies
and fairy tales,
and phantom's wails,
drifting souls
from life's space
to another.

I will sing you a lullaby
to ease your pain
as you explain
their passing.
Children sleeping,
mothers weeping,
silently, your soul
is screaming—
smooth the passage
from life's space
to the other.
Chapter Six
Weaving the Essences into the Existentials
This chapter presents the essential meanings of the experience of nursing the dying or the dead person through extracting the essences of each participant’s experience and weaving them into the four existentials as described by Merleau-Ponty (1962): lived space or spatiality; lived body or corporeality; lived time or temporality; and lived human relation or relationality.

Prior to specific discussion of each essence an explanation is given of Merleau-Ponty’s (1962) concept of the lived-body. Merleau-Ponty (1962) argues that the lived-body is pivotal to the other existentials. Following this exegetic process the three remaining existentials are discussed in relation to the concept of lived-body. The chapter then elaborates the four essences of aloneness, connectedness, questioning and accepting which arose from this study. The interrelatedness and interconnectedness of each essence with each existential can be likened to the weft and the warp of a tapestry, interlocking to form a total picture. In this study, this image is a representation of the lived experience of nursing the dying or the dead person.

Essences are not merely those themes which are apparent in the statements made by each participant; they are the coalescence of the streams of consciousness of each participant and the researcher represented here in order to convey the lived experience of nursing the dying or the dead person. Merleau-Ponty’s impression of phenomenology ‘... undertakes to reunite the subjective and the objective in the primary phenomenon of the world, as given in our lived experience’ (Spiegelberg 1984, p. 541). Macann (1993, p. 202) describes Merleau-Ponty’s phenomenological perspective as the bridge between the two schools of thought of Husserl and Heidegger. Lived experience, or the expression of lived experience through language, Merleau-Ponty believes ‘... first makes it possible to separate essences from the experiences in which they are originally situated’ (Macann 1993, p. 163). The action of extraction of essences by reflection frees the essences from their fixed context and makes it possible for them to be relocated in the original experience. Macann (1993, p. 164) argues that Merleau-Ponty’s phenomenology clarified that ‘... the most difficult thing to understand is what is most obvious’.

This chapter does not assert that experiences of all nurses nursing the dying and the dead concur with those of the participants in this study. Rather, the intention is to reproduce the stories of twelve registered nurses who share a common interest
in searching for meaning in their work of nursing the dying or the dead person. Within each section extracts from the participants’ narratives are recorded in order to allow the study to ‘come alive’ and permit their subjective truths to be disclosed. At the conclusion of each section a short summary provides an overriding thematic statement that is reflective of the lived experience of these twelve registered nurses and is encapsulated by the four existentials.

**THE CENTRALITY OF THE BODY**

Before interlacing the lived experience of the participants within the four existentials, it would be useful to enter into some discussion about the importance of the centrality of the lived-body relative to the other identified existentials. Lived-body, or embodiment as it is sometimes termed in contemporary nursing literature (Benner & Wrubel 1989; Oiler 1982; Omery 1983), takes as a basic premise a belief in the unification of mind and body and a refutation of the Cartesian dualism which has in many respects overshadowed the world of nursing in recent times. Benner and Wrubel (1989, p. 23) assert that this unification of mind and body enables the person to share perceptions which are founded in commonalities of participating in a meaningful world. Benner and Wrubel (1989) base their assumptions on the work of Merleau-Ponty’s concept of embodiment, which ‘... is the grounding of the being of human being in its being a body’ (Macann 1993, p. 200).

Spurling (1977) highlights Merleau-Ponty’s rejection of the notion of ‘object body’, where the person is a pure spectator of their own consciousness, and embraces the idea of embodied consciousness or a study of the body as experienced:

> It is by means of my body that I can observe objects and situate myself in relation to them. But I cannot observe my body in the same way, there is no perspective I can gain on the whole of my body, since it is my body which enables me to have a perspective, as it is my body that enables me to move (p. 21).

However, Merleau-Ponty does address the ambiguity between ‘being a body’ and ‘having a body’. There are times when there will be a clear distinction between consciousness and body. For instance, when a person is ill or hungry, Spurling (1977, p. 23) states ‘... I do not experience my body as the spontaneous expression of my intentions, but as a barrier or mask separating “myself” from the world’. Similarly, Spurling (1977, p. 24) argues that there will be times when the
consciousness and the body are totally integrated and we experience our bodies as opening into our world. Merleau-Ponty (1962) claims that the apparent dualism here is partial and provisional yet still grounded in our whole mode of being-in-the-world. ‘The body is a centre, a point of view on which I cannot take up a point of view; the body yields double sensations, that is, sensations which are supposed to inform me about my actions’ (Macann 1993, p. 173).

The relation of the body to the world can only be understood in terms of co-existence; ‘the synthesis of one’s own body is ... a synthesis of the world and a synthesis of the body in the world’ (Macann 1993, p. 176). Merleau-Ponty (1962) locates the body in time, space and relationality and considers the body integral to human existence. ‘The body is the vehicle of being in the world, and having a body is for a living creature, to be involved in a definite environment, to identify oneself with certain projects and to be continually committed to them’ (Merleau-Ponty 1962, p. 82).

EMBODIMENT AND MEANING

Benner and Wrubel (1989, p. 47) assert that ‘embodiment allows people to live in the world and understand it in relation to themselves’. They further contend that the content of what is understood is provided by background meaning. Background meaning is not an entity in itself; rather it is a way of understanding the world. Benner and Wrubel (1989, p. 114) when discussing background meaning state:

It is temporal in nature because it is the result of a person being reared in a particular culture, subculture, and family at a particular time. Background meaning is a part of context in that it permits perception of the factual world. Background meaning is not itself a thing. It is not propositional knowledge. It is, as Merleau-Ponty (1968) has analogized [sic], like a light. One does not see the light but what it illuminates. Without the light, one can see nothing because there is no basic, “objective” world, only the interpreted one. Thus, background meaning enables one to live in a context.

In this study, background meaning can include all the social and cultural meanings attributed to death awareness in our Western society and the resultant individual, familial and commonly held attitudes of nurses who provide care for dying people.
Benner and Wrubel (1989, p. 70) state that ‘the body has the capacity to dwell in meanings …’ In addition, they suggest that the bodily responses to meaningful situations are more pronounced when that situation is deemed to be one of conflict. It is interesting to note that the essences differentiated in this study, that is, aloneness and connectedness, questioning and accepting, are paired opposites and could be interpreted as conflicting abstractions.
The Existentials
LIVED BODY OR CORPOREALITY

Macann (1993, p. 174) argues that ‘... being-in-the-world cannot itself be understood as a certain relation which obtains between a central body and a surrounding world but has to be understood in terms of tasks, actions to be accomplished, a free space which outlines in advance the possibilities available to the body at any time’. Merleau-Ponty (1962) believed the lived body to be the foundation of intentionality:

It has always been observed that speech or gesture transfigure the body... The fact was overlooked that, in order to express it, the body must in the last analysis become the thought or intention that it signifies for us (p. 197).

Nursing is concerned with the care of the body and nurses also assist people with the experience of illness, recovery and dying (Lawler 1992, p. 29). Lawler and Benner and Wrubel (1989) contend that nurses are concerned with the integrated body not the object body and in being so embody their nursing experience as an integration of the physical and metaphysical aspects of the patient’s experience of being unwell (Walters 1992, p. 151). However, Benner and Wrubel (1989), Lawler (1992) and Walters (1992) agree that true integration does not occur until the nurse is deemed to be an ‘expert’. The participants in this study describe death events from the view of both student nurses and experienced registered nurses. Whilst there is no intention in this study to compare initial experiences with subsequent experiences, clearly there are notable differences across time within each lived experience.

In their stories, the participants elucidated the many tasks and actions involved in the lived body experience of nursing the dying person. These included alleviation of suffering; comforting the person; presencing or being with the person; undertaking the ritualistic practices associated with care of the dead person; attending to the relatives; and attending to self.

LIVED SPACE OR SPATIALITY

Macann begins his explanation of lived space using Merleau-Ponty’s (1962) discussion of what it is not:

For the empiricist, space is a physical setting which is passively registered by an embodied subject which has its place in such a
space, just like any other thing. For the intellectualist, space is a geometrical construction put together by a disembodied subject who, as such, has no specific location in the spatial construction for which he [sic] is responsible (1993, p. 184).

Both the empiricist and the intellectualist ignore our actual experience of being orientated in the world and situated in relation to objects, that is, lived space. Merleau-Ponty (1962, p. 250) states ‘it [spatiality] is a certain possession of the world by my body, a certain gearing of my body to the world’. Spurling (1977, p. 36) contends that ‘my body unfolds spatial relations so that it can inhabit or be at home in its environment’. Spurling (1977) further discusses the four different kinds of existential space in relation to being-in-the-world: the space of night-time; the space of dreams or myths; the space of dancing; and hallucinatory space. He suggests that our meaning of being-in-the-world changes and is dependent upon our particular spatial hold on the world. ‘Spatiality, in so far as it makes possible and expresses our implantation in the world, is co-extensive with existence’ (Spurling 1977, p. 37).

The space in which we find ourselves alters the way we feel (van Manen 1990, p. 102). Walking in the park may make us feel free or possibly vulnerable. Conversely, walking in a crowded street may make us feel confined or sometimes secure. In a strange country we may feel bewildered or excited or even challenged, yet in our own homes we could possibly feel safe or protected. van Manen (1990, p. 102) suggests that ‘... we become the space we are in’.

Within this existential Merleau-Ponty (1962) discusses the relationship of movement and distance to lived space. He distinguishes between felt distance and objective distance and concludes that although travelling from one place to another may be a relatively short distance, the felt distance may have a larger qualitative dimension. Bollnow (1960) explains this phenomena in his example of the action of visiting a neighbour. He traces the actions of leaving one house and walking to the front door of the neighbour’s house and contends that the various actions undertaken to achieve this movement change the perception of the distance travelled (cited in van Manen 1990, p. 103).

Nurses often need to know about the world of the patient and we ask about their particular space when we want to understand their world. We seek knowledge of their birth date, their address, their profession. Likewise, movement and distance is of importance to nurses in the consideration of the location of the patient who is
dying. The place of death, perhaps a hospital or hospice, may be situated nearby a patient's home but in their mind this environment may be a significant distance from the place in which they feel most comfortable. Naturally, the converse of this argument may be true for the patient. However, it is part of nurses' work to assist the patient to identify which is the most opportune space.

The nurses in this study refer to personal knowledge of the patient and the impact that lack of this knowledge had on their experience of nursing these people. The participants also discussed how they felt in situations of being in a particular space with the patient. They spoke also about the importance of creating a harmonious environment for the person who was close to death. By fashioning such an ambience, the participants were then able to feel more comfortable with implementing their nursing practice with the dying or the dead.

**LIVED TIME OR TEMPORALITY**

Lived time is not the linear progression of moments, nor is it clock or calendar time. Macann (1993, p. 196) argues that existential time as outlined by Merleau-Ponty (1962) is ‘...effectively nothing more than a reflective recuperation of time as originally lived out by an embodied consciousness situated in the world’. Merleau-Ponty (1962, p. 90) further contends that temporality and spatiality are inseparable, that one implicates the other: ‘Things co-exist in space because they are present to the same perceiving subject and enveloped in one and the same temporal wave’. Spurling (1977, p. 39) states:

Time is, metaphorically, not a line, moving in one direction through only one real point, the present. Neither is it a stream or river, making us believe that the past pushes the present into view, which in turn pushes the future—the problem with all the spatial metaphors is that they are based on motion, which itself presupposes time. Time is rather to be understood as a flux, a pattern of intentionalities.

van Manen (1990, p. 104) notes that 'lived time is also our temporal way of being in the world'. He gives the examples of a young person looking towards the future and an elderly person reminiscing the past.

In addition, van Manen (1990, p. 104) discusses a person's 'temporal landscape horizon' which is built up from past experiences which leave their impact on the person. He believes that lived time enables the person to constantly re-evaluate who they are from reinterpreting the past and expectations of the future, and
concurs with Merleau-Ponty’s idea that lived time is ‘the perpetual reiteration of the sequence of past, present and future’ (1962, p. 453).

Lived time is an important issue for nurses as they elicit information of a person’s past health history and facilitate the person to set realistic health goals for the future. Likewise, lived time is of significant concern to the dying as their hopes and expectations towards a viable future may be somewhat diminished.

Benner and Wrubel (1989, p. 64) state that ‘time creates a story’. Through their narrative some participants in this study noted their experience of lived time in relation to the differences in their experiences of death as students and as registered nurses. Additionally, the influence of personal death experience, death education programs, changes in hospital procedures and changes in their personal growth affected their own outlook on death and dying. These participants were cognisant of the influence of lived time on the various attitudes of their patients as they approach death. Merleau-Ponty (1962, p. 83) discusses the relationship of lived time to traumatic life events: ‘time in its passage does not carry away with it these impossible projects; it does not close up on traumatic experience; the subject remains open to the same impossible future, if not in his [sic] explicit thought, at any rate in his actual being’.

**LIVED HUMAN RELATION OR RELATIONALITY**

Spurling (1977, p. 41) argues that the concept of lived other ‘... is precisely where existential phenomenology starts, from how, existentially, we concretely experience other people, or, more accurately, experience takes on an intersubjective significance’. He agrees with Merleau-Ponty (1962) that the abstraction of lived other grows from an appreciation of ‘living solipsism’ (1977, p. 41). Spurling continues his discussion of lived other by arguing that the blending of experiences of self and others creates ‘intersubjective meanings’:

> We share perceptions of the same objects, we share a generalized [sic] time and space, and the same natural and human worlds as the backdrops to our lives... Other people are a permanent horizon to my own existence, like a constant double at my side (1977, p. 41).

Our experience of lived other has the potential to be ‘... highly personal and charged with interpersonal significance’ (van Manen 1990, p. 106). In addition, van Manen suggests that even indirect knowledge of another person leads us to
form a physical impression of that person which, on meeting them, will either be confirmed or re-evaluated. ‘As we meet the other we are able to develop a conversational relation which allows us to transcend our selves’ (van Manen 1990, p.105).

The nurse-patient relation is experienced as a special lived relation to the other in that this relation is usually one of mutual trust, support and security. The participants in this study spoke of developing a privileged relationship or a unique relationship with the patient as they approached death. Several participants described how this special relationship enabled them to constantly reassess and re-evaluate themselves in terms of their own self-esteem, sense of purpose and mortality.
The Essences
van Manen (1990, p. 177) defines the term essence as ‘...that which makes a thing what it is’. Phenomenology is ‘a systematic attempt to uncover and describe the structures, the internal meaning of structures, of lived experience’ (van Manen 1990, p. 10). This study does not attempt to question how nurses care for people who are dying or who are dead. It asks: what is the nature or essence of the experience of nursing dying or dead people? van Manen (1990, p. 10) states ‘the essence or nature of an experience has been adequately described in language if the description reawakens or shows us the lived quality and significance of the experience in a fuller or deeper manner’. The metaphor of peeling an onion aptly describes the process of the search for essences within the transcripts and the recorded stories of the participants in this study. Unravelling the multiple layers of the participants’ experiences has revealed four essences: namely, connectedness, aloneness, questioning and accepting. The remaining sections of this chapter will systematically select anecdotes from the participants’ stories and weave them into the four interpreted essences using the structure of the four identified lifeworlds or existentials.
Connectedness
Belenky, Clinchay, Goldberger and Tarule (1986), in their discussions of knowing, maintain that connected ‘knowers’ have a fundamental capacity for empathy in order to access other people’s knowledge. They argue that being connected, in their case to others, enables the knower to experience not only their own truths but the ability to see other’s truths through an empathetic understanding which is usually grounded in first hand experience. Similarly, Stein-Parbury (1993) and Morse (1991) describe a connected relationship as being one of complete trust and a deep commitment for those involved in the interaction. Benner (1984) and Stein-Parbury (1993) agree that in connected relationships most nurses experience the feeling of making a significant difference to the outcome of nursing care for their patient. The participants in this study revealed that not only did they experience connecting to and with the dying or dead person, but also connections with the process of dying, the environment of dying, the dying trajectory, and other people relevant to their experiences of nursing dying or dead people.

LIVED BODY

In the domain of understanding the meaning of the world of the dying person, the nurse embodies the experience of being-in-the-world of the dying. Many participants commented upon their own awareness or consciousness of the dying person’s body. There was a strong identification with the dying person’s body, resulting in a myriad of emotions which facilitated an awareness of the nurses’ own suffering as they considered the death experience for themselves. Many of the participants described unpleasant scenes of dying and Joseph described a particular death experience which was traumatic and undignified.

*I remember a fellow choked on an orange and he was a forty, forty-five year old chronic psychiatric patient. I can remember thinking that would have been awful, an awful way to die and people crowding around him and I remember they told me that they had tried to resus (resuscitate) . . . but it didn’t work. But I didn’t still think, even then, much about it. I just thought that would have been a horrible way to die.*

Not all participants described the dying process as uncomfortable. In contrast, Jane related the serenity of one experience for her which has not been replicated in other death situations:
When she died, I mean, the whole look of her and, I mean, I'd seen enough death before that as far as in the profession goes. She was probably the first one that I'd ever seen that looked really peaceful. I mean, it oozed from her body, it was like, it was there. (Jane now talks on behalf of the dead patient) "I'm happy now and really peaceful." And she looked it, she really looked it. She just looked so much happier and peaceful and the feeling, there was an aura around her and you felt it. That one always sticks in mind.

An important issue for all participants was how connecting with the death experience could be transformed into skillful nursing practices. To establish this consciousness it was necessary for these nurses to try to connect themselves with the dying person and their situation; in other words, to try to imagine themselves in the dying person’s experience. All participants described how being involved with the dying situation enabled them to fully utilise personal and professional resources to enhance their carative practices.

So I tend to like to look after people, and relatives, and I tend to look after them the way I wanted to be looked after. And I remembered what helped me or if I saw the nurses doing something to my mother, that’s the way I would like to do it. And again, the opposite. (Penny)

Connecting self as a nurse to the preparation of the body after death generated personal perspectives within each participant. Many of the participants noted the differences in the laying out procedures as students and as more experienced registered nurses. Overall, these initial experiences were construed as an invasion of the dead person’s body which was distressing for the nurse. Some participants described that, as newly registered nurses, this procedure was carried out with a sense of urgency or indifference. This situation left them feeling that they had broken their connection with the dead person.

I felt it was a real violation, ‘cause I honestly felt, ‘cause I have a great belief that they’re still there, somewhere, do you know what I mean, whether they’re sitting above the bed or standing behind me or... I don’t feel uncomfortable about it, but I feel they’re still there. (Sarah)

In the lifeworld of the lived body, the phenomenon of connecting with the body after death is best described by Sarah:
And then I had to prepare the body and that was the hardest one. The hardest one because she looked so tired and she had so many holes in her, drips and, oh, it was just awful, just awful. She just looked bashed and bruised.

LIVED TIME

In the lifeworld of lived time, the phenomenon of connectedness is unveiled in the participants’ responses to the person’s time to die; the death event related to the participants’ personal life history; the death event related to the participants’ professional experience; and the mutual recognition of impending death in the process of nursing the dying person.

All in all, the participants recognised that the death event coincided with the patient wanting to die. Most participants agreed that it was easier for them to accept the death of an older person than a younger one. Several of the participants talked of the quality of life as opposed to the quantity of life of the dying person and how they connected with the patient’s wishes to die.

Primarily, I thought it was good for him that he died really. He didn’t … it certainly wasn’t reflective of the life he had led. He lost a lot of what I saw was quality of life. His independence, like, he was fully independent on us and his son and, to me, independence is an important thing, so I measured him against what I thought was important. I think he was better … it’s hard to say … not better off but certainly I think his time on this earth had finished. And without the medications and things he was on he would have died before that. (Joseph)

Several participants described the importance of conveying their knowledge of the nearness of the death event to the dying person. They spoke of their need to connect with the patient and in doing so create an awareness of the approaching death event. This open awareness as postulated by Glaser and Strauss (1965) is encapsulated by Sarah and Ann.

I am very much guided by their needs. I would talk with the patient and identify what their needs were, and when I say talk to the patient I mean really confront the reality as it is happening, the fact that death is imminent. I think they like you to be straight out and very frank, very real. (Sarah)
I believe the prospect of death provides the possibility for people to reach some type of completion to their life that is satisfactory to them and to be able to attach some stance and meaning (for them) to their lives. I feel strongly about quality of life, autonomy, control and truth telling and I believe that truth telling and control of information to dying patients plays an integral part in their autonomy and control. (Ann)

Penny extended this open awareness to include acknowledgment of the connection with relatives and friends of the dying person. She endorsed that spending quality time with the relatives gave them a sense of belonging in the caring processes directed towards the dying person: Making sure there is plenty of time for relatives and patients; not having to rush in and rush out again; that you allow relatives to be there twenty six hours a day, all the time, and to do, within reason, when I say within reason, whatever they want to do.

The majority of the participants described the significance of spending quality time with the dying person. During this time they were able to get to know the patient on a personal as well as professional level. These nurses spoke of how time spent with the patient allowed the nurse to discover and build a patient profile regarding coping mechanisms and individual needs. Thus, in entering a connected relationship the nurse created a knowledge base which was unique for the dying person and in turn extended the nurse’s own awareness of the dying process.

A lot of it is time. They come to that in their own time anyway. It’s definitely spending time, not formal time—I mean sitting. It’s spending the time. That’s why I get very annoyed when people say that nurses shouldn’t be doing hygiene and washes, let’s leave it to the assistants or whatever. I mean that’s the time when you’re doing other things and you’re washing patients and doing fairly personal things for people, backs and massages and all that sort of stuff, and finding out a lot more than if you’re going to come and pull up a chair or sit on the bed with a pad and pencil. (Penny)

Holistic nursing care often requires extending nursing care to the relatives of the dying person. Two of the participants commented on the importance of spending quality time with the relatives. During such times, discussions about the impending death facilitated all those involved in the interaction to connect with
the death event and ultimately connect with the patient’s sense of reality of the situation.

*I see death as being quite natural. I am also aware that for the people close to them it isn’t natural at all times and it’s very difficult for them, so I’d like to think that when I’m with the relatives, and patients when they are dying, that some way it is conveyed to them that it is okay for this person to die, because they have such ambivalent feelings that they certainly don’t want their loved one to go away, yet they realise that it’s time.* (Gloria)

*She was telling me about this nurse, and I know this particular nurse. She was an older woman who was a fantastic nurse, and she looked at the mother and she said, “Did you know your baby’s dying?” And she said, “Penny, it just hit me. I was so glad she told me ‘cause, you know, we were just sitting there for this child thinking, ‘what’s happening?’ Finally somebody was able to tell us, to say that.” Sometimes that’s what people want. That was really good.* (Penny)

Several of the participants confirmed that as they progressed through their nursing careers, their own attitudes to death changed. Instead of feeling apart from the death experience they had learned to accept death as a part of life and thus connect in a more meaningful manner to the death event.

*It’s different today. Today I feel much better about death. Well, it’s all around me in the nursing home. It’s not like a daily occurrence, but it happens. It’s expected and sort of respected where I am now. It’s much better, I feel much better. Well, I’m a lot older now and nursing’s changed. I mean, it’s (death) not hidden now.* (Mary)

*As I progressed through nursing I began to think that to handle and prepare a body for burial which had housed a soul, with love and respect, was one of the greatest privileges of being a nurse.* (Teresa)

In reaching professional maturity, these nurses expressed concern for those less experienced in caring for the dying. They commented upon the necessity to be aware of the emotional reactions of less experienced staff and the need to connect with these staff during and after the death event. They realised their role as
registered nurses included making quality time available for these less experienced nurses and assisting them to ventilate their feelings about death.

I think debriefing is important with anybody, especially with a new nurse. I guess if she'd never ... I'd check if she'd ever dealt with it at all before. I'd get, no, I'd ask her if she wants to talk about it, how she's feeling, how she's coping with it and if she wants to talk about it. If she doesn't want to talk about it, I'd suggest that I'm there if she changes her mind, if she wanted to talk about it later. I'd probably just ask her a few questions, you know, to try and have her realise there is nothing scary or bad or anything else about talking about how you feel. It's quite normal to feel different emotions or whatever and, you know, she would be better if she did talk about it because it will happen again. (Jane)

LIVED SPACE

The death environment was often described by the participants as impersonal or clinical. Some participants spoke with resentment about their inability to fashion the environment to suit the dying or dead person.

We transferred him over onto a cold, very cold metal table. It looked like something you would dissect someone on, not that it would or, I don't know, but it was very cold, very clinical, everything echoed around the room. ... But it didn't seem a very fitting place to end up or start your journey into death, on a cold metal table. We sort of lumped him on there too, it's nothing you can do smoothly when there's only two people. We were very worried about dropping him. It was a cement floor. (Joseph)

It would be fabulous to leave the patient in the ward or unit where they were dying. It would be fabulous if they were to receive the care. (Sarah)

Many participants spoke of their need to change the dying environment from one of a seemingly clinical appearance to that of creating an ambience of peacefulness. Changing the environment was advantageous to both the patient and the relatives and succeeded in helping them to constitute an acceptable dying environment.
In the palliative care ward we put a rose on the pillow or hibiscus flower or whatever’s available, freshen the room up and everything. Just because they like to spend time with them it’s much nicer to have a better environment for them. (Joseph)

If they want to sit up on the bed, if they want to get into the bed, whatever they want to do. So, that to me is all important. And I think having patients look and smell nice and clean and looked after and men shaved and ladies’ hair … nice nighties, not hospital gowns, their own clothes. (Penny)

I think it is important that people die where they want to die. But I think it is important to look at how it is for the other people in the family too. I don’t believe it is a failure on the other members of the family not to fulfill the wishes of the person that’s dying by having them in hospital. … It’s very important to look after the carer and if those last few days are able to be made more meaningful for them while being in hospital then I would certainly discourage people from feeling guilty for their loved one’s being in hospital while they are dying. (Gloria)

Penny described several instances in her experience where she directly or indirectly interfered with the normal environment of the acute ward setting, making the landscape conducive to the death event:

Today I went up to a ward to inquire how a patient was who’s terminal. His family was there and one of the older nurses had just come out of washing the patient and she looked a little hassled and I asked her what the problem was. She said, “I’ve just finished washing, tidying up the room, and got rid of all the clinical stuff,” which I thought was very nice.

I would hope we are going to somehow see a change towards people dying at home, more than dying in hospitals and that it’s acceptable to die at home. And that we have, and if they have to be in hospital, even in a place like our hospital, that we have some areas that are less clinical. Where I was previously, we, on the oncology ward, we had a room that was set up. It had a hospital bed in it, but it had cane furniture, it had a sofa which pulled out to a double bed. It had nice curtains and nice paintings so it wasn’t felt to be a very clinical room. I’d like to see more things like that, I think.
Sitting mother in a chair and they had numerous lines, drips and tubes and ventilators—all that. We got to the stage where you even had to hand ventilate, even for a while that was fine, so you do a lot of that. If a mother, we were going to turn off the child, we gave them that option of perhaps taking the tube out and popping them straight in Mum's arms, that sort of thing, turning the machinery off so that people aren't looking at straight lines and preventing people going absolutely mental rushing around and sticking stethoscopes on. I think that's important.

I noticed a patient today which I thought was really nice, no, it wasn't today, it was yesterday, when he was sitting up dying, he was blue black as you could get, hardly breathing at all. I mean, looked like he'd last another half an hour and it was really lovely because his wife was there just holding his hand, and he had his glasses on and his hair combed. I think that's really important. They're not just looking like ... things like oxygen masks, like, he had an oxygen mask over his face and I asked her, because I wasn't looking after him, being in the role of the supervisor, but seeing her, I asked her if she would like the mask off and perhaps some nasal prongs put on so that the mask wasn't sitting there looking at her. She surprised me, she said, no, because he normally has a mask at home. He never liked nasal prongs at all—she would prefer the mask. So I think it is important to ask the relatives what they want rather than just presume, which I was presuming in one way, 'let's get this mask off so she could look at him'. But for her it was important that he had it on.

Creating an ambience for connecting with the patient and the death event is equally important as creating an acceptable milieu for the dying person. Stein-Parbury (1983, p. 124) states:

> Connecting thoughts and feelings adds depth to the nurse's understanding and moves the interaction in a forward direction. Through this response a nurse is moving into the area of fully understanding a patient's experience.

Joseph commented on how he entered into creating this ambience with dying patients in his care: *It depends a lot for me, and this is a personal value, it depends how well I've got to know the person and if indeed there was a relationship built up between us. I mean, there are people and there are people. And just like you get on with people, different people in the wider, social world, there are people that are dying that you get on better with than the next person.*
Additionally, Jill observed that nurses used all their communication skills to make connections with dying patients: *When nursing a dying patient, we must possess a willingness to listen, a determination to be honest and sincere and to demonstrate real concern in order to afford her patient optimal care in the final phases of living.*

Gloria disclosed that her willingness to create an ambience of connectedness with the dying person and the relatives enabled her to facilitate a ‘good death’ for her patient:

*Just be there. Just acknowledge them and I may well acknowledge that things are not looking too good at the moment and if there is anyone they wanted to come in to be with them. Acknowledge that I don’t know what to say. Say that I’ll stay as long as they want me to, that’s if they are conscious. If they are not, I frequently still speak and say the same things. I think the presence of someone is important. I like to think that there are not too many people who die alone, although I realise that there are. I think we need to consider the patient’s spirituality throughout all this.*

Most of the participants spoke of the fulfilling emotions associated with presencing or ‘being with’ the person as they were dying. However, two of the nurses purported that this connectedness could also be maintained if they happened to be off-duty or somewhere else when the person died. It is interesting to note that both of these participants were speaking of the nurse’s role in a palliative care or oncology setting where death appears to be an acceptable part of the ward pattern.

*There was a time when I would, if I knew that someone was sort of near dying, that I might even sort of feel obliged, not obliged, but wanting to come in on my days off or ring up to see how they were going. There was a very strong bond to a person who was dying. I’ve moved away from that now. It’s okay for me to go on days off. Just recently we had a patient who said goodbye to me—he knew I was going on days off—and I said goodbye to him. It was quite okay for me to go on days off and when I came back I found out that he had died. (Gloria)*

*... and she was going off duty, whichever day it must have been, 'cause my mum died on the Saturday so I think she might have been going off duty on the ...*
might have been the Saturday morning, maybe it was, I can’t recollect exactly, and she popped her head in to say goodbye. And she said “I just want to say goodbye because I don’t think she’ll be here next time I come back,” And she wasn’t. But I remember that as... I mean, it was the way she said it. You need, sometimes, those things. She needed to come in and say goodbye for her own self, which was important for her. But that was an oncology ward and the girls were generally very good. (Penny)

LIVED HUMAN RELATION

Stein-Parbury (1993, p. 220) states that ‘in connected relationships, nurses attend and listen to the entirety of the patient’s story, and are able to perceive themes, by relating content to underlying feelings’. Sarah captured this essence in the following description:

She didn’t have to saying anything about it, it was almost as if it was understood. Just in my silent moments with her was like the combination of the sheer exhaustion, almost as if ‘let me be’.

In developing connectedness, many participants spoke of being able to be aware of the deeply personal and subjective nature of the dying experience of the person. They described the therapeutic intimacy shared with their patients as they connected with the feelings of power and control which the dying person emanated in their final hours of living.

Thomas took many hours to die and it was unpleasant. Despite the unpleasantness, Thomas was in control of his situation and he was supported in his decision by family and staff. I felt very proud to be a nurse that day. I felt Thomas had reached the acceptance in his final hours. (Ann)

I had a patient recently, forty-four year old with cancer, lovely married couple, very nice, I mean, just hung on and hung on. I was talking to the minister later who visited with her. She had spent a lot of time with her the day before. And she said to the lady, “Are you ready to die?” And the lady said, “Yes, I am ready.” So she said, “Well, tell your husband that you’re ready because he is waiting.” And she did, and it was great, and he... The day before he was
terrible and all of a sudden ... when I went up to see her, “Everything’s okay,” he said, “we’re both ready and we’re right.” It was great. (Penny)

A close relative of mine was diagnosed with a terminal illness. As his condition deteriorated, he and his family turned to me, as a nurse, for not only personal care but for emotional support. I suppose because I was emotionally involved, I did not want to disappoint them by not being able to deliver what they wanted. ... This man made me realise that he did not want someone to say ‘everything is okay’ when it was not. He did not want someone to change the subject when he had gut feelings that he wanted to talk about. He wanted someone he could talk to who would listen and understand what he was saying. The last thing he said he needed was someone busying themselves with practicalities of his care, like as if he was a machine. (Helen)

In developing a connected relationship with a dying person, many participants spoke of their need to be educated in the multi-faceted concepts of therapeutic communication and the grief response.

With a sound knowledge of the processes of the grief reaction we will be more effective in attempting to meet the needs of the individual in their care. All interactions including actions and conversations with the patient must convey acceptance of all their grief reactions. This can be demonstrated through touch, attentive listening skills and expression of concern for the feelings of the patient, all of which will assist in developing patient trust. If, however, the patient is unable to share concerns and feelings readily, we must convey to the patient a willingness to be available whenever the patient has a need to confide in someone. It is quite common for patients to feel embarrassed about expression of feelings, thus it is imperative that we are reassuring and acknowledge any feelings, beliefs and values expressed by the patient. (Jill)

All of the participants recognised the value of exploration of the dying process with the relatives of the dying or dead person. Several participants noted that active involvement of the relatives in the caring process often soothed a somewhat uneasy alliance which may have been evident in the patient-relative relationship.
The first opportunity I have in my communication with the family is to express that and to try and express to them that the suffering has stopped and almost a new beginning has begun again. (Sarah)

We have caring nurses where I am now. We care for the relatives as much as the patient. We let them stay with their dying parents, or friends. It’s like a big family. Like the nurses feel they are family too. (Mary)

I mean, the relatives play an important part in caring for the patients. I ask them now if they want to help. Some say yes, others just don’t want to become involved and look at me strangely. But I persevere with them and some come around and it’s lovely to see them doing things for the patient, it sort of feels right that they become involved too. (Helen)

However, it may be argued that connecting with the relatives could be a painful experience for the nurse. Jane noted that ‘being there’ for the relatives invoked many memories of her own losses through death.

I think I hurt and I hurt for the relatives. I don’t think I express grief any more now than before, probably yes, on the odd occasion. I mean I’m not out of control but I’m not as controlled. Normally with death in a professional manner I try to not express too much because I like to be there for the relatives. They need somebody to be able to talk to, and even though it’s very upsetting for me because I’m sort of... (pause)... I tend to hurt more for the relative now and I don’t think it is my right to let go as much as they would be and I feel that they would probably want someone that they can just hold or hang on to or whatever. I mean, there is nothing you can say that’s going to make things better but if you are just there and you can touch, and hold them, and let them talk, I think it’s a lot better for them.

Belinda described that this connectedness with the relatives could be easily terminated when the outcome of events for the patient changed suddenly:

It was the disappointment, the sudden change that happened in the parents. From elation to sorrow in a matter of moments. The joy at the birth and then the suddenness of possible death... It was so sad for those people, you know—
within a whisker of happiness and then nothing. I spent time with them but there were no appropriate words, no words of comfort.

Two participants commented on the closeness of connected relationships with relatives of the dying person. They advocated that this attachment was more pronounced when working in a small community.

*You know, working in a small country town you either always knew the family or knew the person. Maybe that had something to do with that, although I’m still much the same, even if I don’t know them I feel as though I would still want to talk to them, I still want to be there for them if they want, as a professional sort of thing.* (Jane)

*Like, I might have known them for a year before they die, and their husband and wife or daughter or son or whatever. And if I’m down town shopping and if I run into them I will say ‘hello’ and if the person that is dying is with them, has a terminal illness, is with them, I’ll be very glad to say ‘hello’ and everything. If they’re not, I get a report on how they’re going or not going. We always hear if one of our people does die. And generally, generally it’s not so much that they’ve died that’s important—I always like to know how they’ve died. Generally, the people, the family tell you about it anyway: that they went in their sleep or they were squeezing their hand or something. They always give you the final few moments generally.* (Joseph)

Three participants placed emphasis on the need to remain connected to the relatives immediately after the death event and over a period of subsequent weeks during their grieving process.

*As death approaches, the family should be encouraged to remain in attendance. Once the patient has died, the family should be allowed adequate time to be alone with the body and encouraged to touch the body and to talk to the deceased.* (Jill)

*It was like they were there to assist her on her journey. It was beautiful. I thought it was beautiful. I thought it was a beautiful tradition and I gave it the utmost respect. I thought it was lovely and I actually thought then that I*
would do the same with my loved one. I would stay with my loved one until they went cold. (Sarah)

... I felt was how much they (the relatives) need to have that involvement with people, not of their family or friends, people that were involved with helping to care for their person that was dying after that person had died. I think they need to talk about it, they need to relieve it to a degree, just to get it right in their heads maybe, I don’t know. But they’re certainly keen to talk about the experience. (Joseph)

Whilst most of the participants felt the need to share their immediate reactions about the death experience with other nurses, only a few of them commented on experiencing a positive reaction when connecting with their peers.

Ventilating to people in the ward where I work now is very good. I have a good colleague that I can talk to, he’ll listen, and he lost his mother. His mother died in a car accident less than two years ago, a year and a half ago, and he often talks about death and unresolved issues with her and so we communicate a lot about death. We often relate things we talk about back to his mother, I’ve noticed, and how he felt at the time. (Joseph)

That evening I talked it over with my peer group of students. ... We all talked about my experience and this helped them to deal with the procedure of last offices when it came their turn. (Angela)

One participant described her first experience with death and how she connected with a senior nurse who guided her through the procedure of laying out the body after death. She viewed this experience as a role model for herself should she encounter another death event. Overall, it was disappointing that most of the participants in the study did not appear to feel safe in sharing the death event with other nurses.

When Joyce took me behind the screens and by the dead lady’s bed she did a most unusual thing. She opened the window and uttered, “Now this will let her spirit go free.” ’Til this day I have never forgotten this and every time I have performed this task, I have opened a window. Joyce led me through the procedure, talking to me as well as the dead lady, explaining everything that we
were doing and the reasons why. She performed the procedure as if the lady was still alive, showing great care and respect and said that as nurses this is the last possible thing that we can do for our patients and that they should not be pushed around like a sack of potatoes. (Angela)

Jane described how, as a very junior nurse, she looked for confirmation from a senior nurse about the correct manner in which to relate a death event. There was a sense of connectedness in this relationship but it was tenuous and only appeared to be based on Jane’s apparent vulnerability in the situation she describes:

‘But then … and that was probably one of my earlier experiences as well, and I think I was still, or just finishing, my enrolled nursing and I rang the sister who was on the next ward and I said, “Oh, you’d better come back. Mr Such-and-such is dead,” and that’s how I said it. That upset me more than anything, that I had said it like that, you know, and I spoke to her about that when she came back and she said, “That’s OK, that you’ve reacted the way you have, “quick Mr. Such-and-such is dead”, but,” she said, “it doesn’t matter that you’ve talked to me that way or told me in that way.” She was very good, this sister, and she said, “If you were telling the relatives, of course, you wouldn’t say it like that.” You know, you’re not going to rush out and tell relatives anyway.

Gloria made the point of outlining her personal need to connect with staff who had previously nursed a patient in another setting. She felt that when patients are transferred from one ward to another, it is important to remember that staff members previously involved in their care may be interested to hear about the manner, the time and the place of death.

‘The next day I made a point on both shifts of talking to the staff from intensive care and letting them know how it was for them. There were lots of filled eyes and things and the staff were really pleased with the feedback, and that encouraged me to do that again, whereas before I might not have thought to have talked about someone’s dying experience with staff that looked after them previously.

Finally, I would like to conclude this section with a plea for the concept of connectedness which was apparent from one of the participants. Jill provided a
succinct summation of the value of being involved or connecting with dying patients.

*This fear which can be experienced by the caregivers can be reduced by our having the courage to become personally involved with the dying to enable discovery and development of our feelings regarding death and dying. To share their grief may not be easy, but the reward in personal satisfaction and inner peace will be reward for the effort that is required. This will ultimately result in being better equipped to deliver quality to the patient.*

**SUMMARY**

The phenomenon of connectedness in nursing dying or dead people can be defined as a willingness by the nurse to be actively involved with the dying milieu: the dying patient, the relatives of the dying patient, and their working colleagues. Connectedness also implies a two-way conversational existence between the nurse and the dying person in which each person has the potential to grow and change.
Aloneness
Backer, Hannon and Russell (1994, p. 49) discuss the challenges involved in nursing dying and dead people. They state: ‘The work will never be easy. In some ways, a part of the caregiver dies with each dying patient.’

Nurses face their own fears and anxieties about death with each death event and face these concerns alone. In Western society, death has been relegated to a position of invisibility. Thus, sometimes the burdens nurses carry regarding their internal conflict with the dying event are hidden from those persons closest to them. The literature speaks of the advantage of self-awareness in coming to terms with these struggles (Penson 1990; Backer et al. 1994; Benner & Wrubel 1989). However, to reach the stage of acknowledging the importance of self-awareness, I would argue that the nurse may spend a great deal of time alone in a self reflective state. Certainly, I would agree that reflective practices are sometimes more enlightening if entered into in solitude. However, the participants in this study have described their experiences of nursing dying or dead people as an imposed aloneness and one which cannot be prevented. Whether this phenomenon is partly related to societal attitudes and values about death or partly attributable to the view that in the ‘medical model’ death is a failure (Holman 1990) does not fully explain how these nurses experienced their aloneness. The participants revealed that the experience of aloneness was evidenced in their embodiment of the dying process; the timing of the experience related to personal and professional development; their abilities to recognise their own emotionality; and in conflicting relationships surrounding the death event.

**LIVED BODY**

In the lifeworld of lived body, the phenomenon of aloneness is laid open in the participants’ recollections of their experience of nursing dying or dead people. These responses comprised: excluding death from their own reality; embodiment of negative emotions; feeling disconnected in performing ritualistic practices; and physically attempting to rid the death event from their own bodies.

Sontegard, Hansen, Zillman and Johnson (1976, p. 1490) suggest that nurses identify with the patient’s fears of isolation and loneliness of death and wonder whether their own feelings of isolation will be perceived when a patient dies. As discussed in the previous section, several of the participants related connecting with the death event. However, for some participants, death, whilst recognised,
was not acknowledged. Thus, deeming death invisible helped these nurses
distance the experience from their reality.

*Seeing a body reminded me of my own future death and the death of those I
loved. This frightened me. When I retreated to the pan room I hoped that no one
would notice my absence and that I would not have anything to do with the
death that had occurred. It was ignored really. I ignored it and so did everyone
around me.* (Mary)

Parallel with the invisibility of death many participants described their initial
experience with death as disturbing. Their inexperience in the profession of
nursing and lack of personal death situations compounded their feelings of
inadequacy in the death event leading to feelings of illusiveness and isolation.

*I can still smell the smell of my own fear and illnesses that pervaded that little
world. That smell was mixed with the all-pervading smell of lysol that seemed to
ooze out of the pan room and permeated the beds, screens, walls and floors. I
could even smell it on myself, my hands and nails, my uniform and hair. My
thoughts and impressions of what I had imagined and dreamed nursing was
about, had fled.* (Teresa)

*I had no idea what to expect. The lady had been laid out, I was pleased, I was
thankful. I did not want to touch the body but I was told I must. I remember
how cold and unreal the body felt. I also remember how white and still the body
was and that the face was smooth, no lines. However, the body did not look to
me like someone who was just asleep. It was spooky and unnerving.* (Mary)

In discussing their early experiences of nursing dying or dead people, almost all
of the experienced registered nurses described how it felt to be alone with their
negative emotions when nursing dying or dead people. In conjunction with the
invisibility of the death event, these nurses recalled how it was expected that these
powerful emotions somehow dissipated as they finished their shift in the
institution. Like Jane, most of the participants who spoke of similar experiences
felt there was an unrealistic expectation placed upon them which served to
exacerbate the feelings of aloneness in the death event.
I just think that everyone deals with it (death) different, even as professionals. You know, when I first started nursing we were told that when you walk out the front door you leave all your emotions and feelings and what-have-you in the hospital and you go home. I have never been able to do that. I don’t honestly know that there is anybody who can do that. (Jane)

I suppose I felt a good nurse should hold themself together, that if you showed emotions at work you were unable to cope. I think this behaviour was supported by my mother’s response that as a nurse I would be repeatedly exposed to death, therefore, I must face and deal with death. (Belinda)

I remember the laughter and bravado we used to do on similar occasions, but this time laughter didn’t seem appropriate. We simply talked over the events of the day in the safety of our rooms in the nurses’ home. I did not want the others to think I might not have coped with the situation, so there was a sense of bravado. I kept most of my uneasy feelings to myself. (Mary)

In performing the rituals after death, many of the participants spoke of their own distancing from the procedure. Most of these nurses reported in graphic detail the archaic practices of early experiences. Instead of connecting with the apparent disrespect for the dead body, several participants described their experience as ghoulish, ‘not real’ or distressing, resulting in a non-involvement reaction within themselves.

He was shaved and washed. His finger and toe nails cut and cleaned. Every orifice was packed with cotton wool, pennies were taped over his eyes. A catheter was passed and then, what I felt was the final indignity, a piece of tape was tied around his penis, in case anything leaked out, I was told. I felt my knees buckle and a cold sweat break out. When we turned him over a thin trickle of green-brown fluid came out of his mouth and he made a deep gurgling sigh. I can still feel my hair at the back of my neck stand up in horror when I remember this. (Teresa)

It just treated the body as if it was a shell and nothing else, as if it was just like a real, reality hit for me in the sense that, you know, it’s over, forget about it, let’s get rid of it. (Sarah)
I mean, it was common practice just to treat a dead body like a shell. There was no emotion. I learnt that to show too much emotion, you know, to cry or anything, was a sign of a weak character. It was so much easier to become detached from the whole experience than it was to be part of it. (Helen)

I had to do the laying out on my own and that was spooky for me. Back then, like, you had to pack all the orifices, which was the mouth, the nose, the ears, everything, and that was really more upsetting for me than anything, having to do that because ... (pause) ... it was just awful. I mean, these days they don't do that, but then they did, they stuck anything, anywhere ... (pause) ... it all looked so ugly, it just looked so horrible. They certainly didn't look like they were peaceful, jammed with all that stuff, and tied, their hands and feet and everything else. Yes, I think that was probably ... (pause) ... it wasn't sickening, it was upsetting. (Jane)

One participant acknowledged that her experience with these seemingly barbaric practices resulted in her need to remove the sense of death from her own body and she engaged in a self cleansing ritual. Some similarity can be drawn with cleansing rituals after body violations, like rape.

As soon as I could escape off duty, I stripped and stood under a steaming hot shower and tried to wash the smell of death, urine, faeces and vomitus from my skin and hair and wondered if I had made a terrible mistake in choosing nursing as my profession. (Teresa)

LIVED TIME

In the lifeworld of lived time the phenomenon of aloneness was exposed by the participants in their recollections of earlier death experiences, their immaturity, both personally and professionally, the social context of nursing during their initial education period, and the recognition that sadness is incidental to the death event.

The stories from the older, more experienced registered nurses were conspicuous with the identification that their individual upbringing and socialisation in the world played an influential part in the experience of nursing dying or dead people. Many participants spoke freely about their childhood and how death did not
feature as a high priority in their early lives. Consequently, when they faced death in their earlier years of nursing, either as a student or as a registered nurse, they were reminded of their lack of knowing how to respond and subsequent feelings of abandonment.

_I was seventeen years old. I was young, I was very young, even by the standards of thirty years ago. I think I was impressionable and immature. I had been brought up in the security and warmth of my family, in a Rectory and this was my first time away from home._ (Teresa)

_I think that as I was growing up my parents shielded me, you know, protected me in many ways from being exposed to the deaths which occurred within our circle of friends and relatives. You know, I do not recall attending a funeral until I was, well, older and into adulthood. I don’t even remember being aware of the details of what happens when someone dies._ (Helen)

As students, some of the participants described their perceptions of being in a subordinate position. The hierarchy in nursing was well identified and students were made to feel they had to obey the rules without questioning. This position of inferiority contributed to their observation that it was expected that junior staff did not have input into the care of the patient. It was conventional for students or junior registered nurses to remain on the fringe of decision making. Teresa best described this situation:

_I think we were all told or at least led to assume that the older students had so much more experience than we had, which I suppose they did. But we were sort of trodden on or put down and believed we were the lowest in the pecking order. … In those days it was not the nurse’s right or authority, nor was it thought that nurses had the skills to say someone was dead. It was the doctor’s prerogative, and only the doctor’s, to say that._

Consistent with the social context of being a student and having little or no influence in situations of death or with senior members of staff, several participants expressed their feelings of aloneness in the death situation:

_I was confronted with a parasuicide by a person HIV positive. The treatment he received and the attitude of the staff was completely unsatisfactory to me and I_
knew that I had been allocated the care of this patient because no one else wanted to care for him. I felt this patient was ostracised because of prejudice, ignorance and fear but at the same time felt too powerless and inexperienced to confront others about his treatment. (Ann)

It seemed that there was no emotion felt by anyone except me. I felt unable to express my feelings for fear of being laughed at. ... It was important to keep a stiff upper lip and to be always in control. Showing emotion was seen as being out of control and perceived as a weakness. (Mary)

I cannot remember the circumstances that led up to the lady’s death, I just remember how frightened I felt at being asked to perform this task without having gone over it in the School. There was no clinical tutor assigned to me for that day so I could not ask or expect help in dealing with this problem. I had never seen someone die, let alone dead. Touching a dead person was inconceivable to me. At eighteen years old I had not really thought of death. (Angela)

Backer et al. (1994, p. 55) reaffirm Quint Benoliel’s (1988) findings in her research on nurses’ responses to dying patients. They state:

... there is some evidence that avoidance is a preferred coping strategy among nurses relating to dying patients. Behaviours that nurses may use to avoid interacting with patients may include evading conversation ...

Jill remembered an experience when she ignored a patient because she was fearful of not responding to the person in an appropriate manner and concerned about her own feelings of aloneness if the patient died:

I was ignoring his needs to express his feelings at a very crucial time of his life. I let him down because I did not know what to say. I had no previous experience of talking to a dying patient. I also think I was scared of getting too close to my patient because of fear of being hurt and feeling lost when he finally died. This would have been an investment of emotion and feelings which would have resulted in a great emptiness when Damien finally died.

Without doubt, all participants mentioned the death event was a sad occasion for all people involved with the dying or dead person. This sadness invariably
resulted in a sense of loss as the emotional bonds between the patient and the nurse were severed.

*I feel sad sometimes when people die and I don’t really know why, but it is. It’s still sad even when someone’s at the end of their life. Somehow death’s still got a sad, a sadness to it. Maybe it’s because the relatives are always sad or it can also be very nasty at times.* (Joseph)

*It’s the loss. It’s very selfish, I know myself, it’s a very selfish thing, like, I don’t want them to go. It’s your loss and dealing with your loss, not so much trying to put myself in their shoes. It’s totally a selfish thing—I’ve lost this person I love so dearly, they’re no longer going to be with me.* (Sarah)

One participant remarked on the emotional impact of being apprised of the death event by someone outside the family or carer’s situation. She identified with the detached and isolated feelings of that particular situation:

*I remember thinking how distressing it must be to be informed by the police or someone else that someone close to you had just died. It seemed so impersonal to me.* (Teresa)

It was recognised by all participants that dealing with death and dying was a significant experience of nursing. A few participants remarked about the uniqueness of each death event. Jane commented on the intertwining of personal and professional death experiences within herself and, whilst experience may be a good teacher, for Jane, the loneliness of the death situation still prevails:

*When dealing with death I think you have to go with your feelings, like, you know, I can get really upset about a lot of deaths that I’ve worked with. It really is different with every one, no two is ever the same. After dealing with death myself, it changed again and I probably get far more upset now than I did before I had to deal with death myself.*

**LIVED SPACE**

In the lifeworld of lived space the phenomenon of aloneness was revealed by the participants in a variety of behaviours, such as ignoring or distancing the event;
being unable to manipulate a ‘hostile’ environment; feeling desolate in the presence of death; and grieving in solitude. Several participants described that either they themselves were initially uncomfortable with the death experience, or the organisation appeared to disregard that a patient had died in their care.

After the break and returning to the ward to care for the other patients it was as if this care continued in an almost altruistic manner of concern for others at the expense of self care. The next day, work continued as though the deceased man had not existed. Nursing care took place in an immediate time frame. The bureaucratic organisation of contemporary hospitals just carried on, business as usual. (Belinda)

The next day I went to work on the same ward and everything went on as usual. It was as though the dead man had not existed. No one else talked about him, so I thought I had better not. It was expected that junior nurses did as they were told, not questioned what had happened. . . . I guess what I didn’t expect was not talking about it or making it as though it were nothing, a non happening. (Belinda)

I think that I wasn’t at all comfortable with people dying so I was very quick to move it from memory. (Gloria)

The participants gave graphic descriptions of the setting of the death event. Many of them commented on their own identification with the loneliness of dying in an unfamiliar environment.

The room was dark and it was like the epitome of what death was, how I imagine it to be, do you know what I mean, very lonely, very sad. Like, I don’t have any fear of death or believe in death to be a sad thing. I think it’s the way in which people die which is the sad thing—the lingering, the pain they experience in the preliminary towards that death and then the death is the release. (Sarah)

His loved ones weren’t there. The room was like a typical hospital room. Even though we were in the newest portion of the hospital, it was still, like, very cold and it felt very cold. It was very clinical. And he seemed alone. It was almost as
if he needed someone to take him on the passage, do you know what I mean, just that crossing over. (Sarah)

Death means to me the passing, the journey of someone from this life into another. It's generally a sad event because of the forced separation, the wrenching from the life we know, to the unknown. (Helen)

Professional failure was seen by some participants to contribute to their feelings of desolation in the death event. This ambience of inadequacy was often perpetuated by the dying patient or nursing colleagues.

I'm just standing there and she looked up and said, "Is that woman alright?" I didn't have a clue if the woman was alright. I looked down and, I mean, I didn't know and the nurse said, "Oh, my God!" and obviously she was dead, and she just left me. She didn't say anything to me, she just went out of the room. (Gloria)

... Damien was in a very bad mood and told me he thought I was a hopeless nurse and he did not like me caring for him. I had tried so hard to make him comfortable and he seemed so ungrateful for all of my effort. I was hiding in the pan room, feeling a mixture of anger, frustration and sadness and trying very hard to suppress my tears when the Charge Nurse found me. (Jill)

When a patient dies, nurses need to come to terms with their own feelings of loss and grief. Several participants spoke of the lack of space and time within the working environment to undertake such a function. Jane poignantly remembers her behaviours which were usually undertaken in solitude:

I don't let go until I get home. Sometimes I go home and do lots and lots of housework, keep myself really busy. Other times I sit down and think about it, release my emotions. Sometimes I go home and think about my own experience with death, you know, my son or my brother.

One participant spoke of her belief system about death and dying. In the environment in which she was working, whilst she felt alone in purporting this
belief system, she was adamant that she would continue to fashion her nursing care towards the dying according to these beliefs:

Consciously, I wouldn't be aware but I do believe, sub-consciously, I believe that one death prepares you for another. My need ... I do have a great need for assisting that passage, making that passage easy and for making that passage comfortable. (Sarah)

LIVED HUMAN RELATION

In the lifeworld of lived human relation the phenomenon of aloneness was acknowledged by the participants in their perception that the dying person is alone in their dying; their identification of being deserted by colleagues in the death event; and a recognition that some people have accepted that death is a lonely experience.

We are born alone, and we die alone. The well known cliche is of little consolation for nurses who feel inadequate with their skills in caring for the dying or dead person. Helen described the sense of abandonment for the patient and herself in one of her death experiences:

The lady had died and everyone, that is, everyone except the nurses, of course, abandoned her. The lady had been left in a state of disarray, tubes everywhere, machines everywhere and she was lying naked and exposed. It was awful, it was like she was a lump of meat rather than a person really. I wanted to cover her up but the nurses wanted to do the laying out quickly. It was like we had to clear her away as quickly as the other staff had left, you know?

Similarly, Sarah and Ann aptly summarised their experiences of nursing dying patients in the acute care setting. They were intensely aware of the need to be able to assist the dying person in their dying rather than allowing death to occur in an impassionate manner.

The loneliness is also, when I reflect on what I was saying about loneliness, is likewise tied in to that whole thing. They are alone if they don’t have that focus (palliative focus), they were allowed to just die. So they should be but they were allowed to just die, lonely. (Sarah)
Her family, whilst very distressed with the situation, did not want to appear to be killing her. If she had have been physically able I am sure she would have pulled out the line herself. She died several weeks later, defeated, the TPN still running. (Ann)

The literature reflects nurses’ needs for support in caring for dying or dead people. Parkes (1985, p. 6) states ‘no seriously ill person should be cared for in circumstances that do not allow the patient and the family to share their feelings with staff and staff to share their feelings with each other’. Three participants commented on the minimal communication from colleagues during and after the patient’s dying process. This lack of interaction contributed to their feelings of ineptitude and aloneness in the death event.

Silently the nurse handed me a white cotton gown and cap and mask and indicated that I should put them on. My own starched white cap had to be placed carefully where it would not be in the way or fall on the floor. I remember my fingers feeling numb with the cold and I had difficulty tying the tapes on the gown. It was my job to dry the body. (Teresa)

My companion dried her tears and we hurriedly stripped off gowns, masks and caps and, taking out bits and pieces with us, arrived in time to hear Sister give her report to the next shift. She made no comment to us. There was no acknowledgment except to inform us that we were late and that we would have to work faster in future. (Teresa)

So we went to our tutor sister, who said we could always come and see her if we had any problems. So we went and spoke to her and she said, you know, about how many people had died and how this was affecting us. This tutor sister said, “Well, they're gone and dead. You can't do anything with them. Get on with the living.” It's only been in the last few years I've really realised just what a shitty thing that was to say to anybody. It didn't address what was happening for us. It helped to bury what was happening. If we were being affected by it we were inadequate, was really what the message was as I received that. (Gloria)

My fellow students were all agog with all they had seen and done. They did not seem to be all that impressed or interested in my tale of woe. But, with
hindsight, I suspect that I was so wound up in my own misery that I was incapable of verbalising what had happened and how inadequate I felt. (Teresa)

We were all in the same boat. We all helped each other to distance the experiences. We were scared of getting involved. (Belinda)

Finally, Gloria spoke about her parents’ attitudes to death and dying. Whilst these beliefs do not concur with her own, she is cognisant of the need for nurses to recognise that other generations may have different ideas about dying and the communication of the dying process with health care professionals.

My parents are in their early seventies now and they won’t talk about it. “Just cremate me and put me anywhere,” and they don’t want to know about it. They are very quick to end the conversation to do with anything like that.

SUMMARY

The phenomenon of aloneness in nursing dying or dead people is in direct conflict with that of connectedness. Aloneness is congruent with the nurse’s feelings of retreating from involvement in the dying process, either from inexperience or as a result of pressure from others to remain detached.
Questioning
Backer et al. (1994, p. 49) suggest ‘the struggle to find a balance and harmony in the continuation of one’s own personal and professional life while being involved with another person’s exiting life can be difficult’. In this endeavour nurses consistently question the meaning of life and death, as well as their approaches to, and delivery of, nursing to dying or dead people. Questioning arises from our experiences and ‘we make our experience a problem to be solved as we demand an explanation for our experience’ (Maturana 1992, p. 2). By constantly asking questions such as ‘what is it that we do?’, ‘why do we do it?’ and ‘can we do it better?’, nurses are re-searching their experience for explanations which inform the art and science of nursing. These explanations formulate the foundations for nursing practice and theoretical constructions are built. Theory building in nursing is generated from praxis, a dialectical relationship between theory and practice (Benner 1984).

Rowan (1981, cited in Reason 1988, p. 8) proposes that inquiry is ‘an alive process of engaging in the world’. In this study, the participants illustrated questioning by referring to persistent self exploration, and investigation of their own practice and the practice of others, as they described how they busied themselves in the world of nursing dying or dead people.

**LIVED BODY**

In the lifeworld of lived body, the participants posed questions to find explanations about their own and others’ responses to particular aspects of care of the dying as an attempt to find meaning in death and dying that provided a degree of comfort within themselves, and as a vehicle which could inform and improve their practice as nurses.

In their early years of nursing, some participants described their naivety in the death situation. Additionally, some newly registered nurses were clearly in the midst of questioning their own attitudes and values about nursing dying or dead people. However, common to both groups was the idea of questioning their embodied responses to being exposed to dying or dead people as a nurse and whether these responses assisted them to be better practitioners.
It was sort of ... (pause) ... this sounds pretty bad, it was sort of exciting 'cause I'd never seen a dead person before but it was a bit weird too because I wasn't sure how to handle it. (Jane)

I find my situation leads me to question my values with regard to palliative care and to question the impact of my personal situation on the care I provide. (Ann)

I have been told recently by a colleague that to grieve is a waste of time and energy. Such time and energy needs to be spent on the living. I am unsure of how to respond to that comment except to say that this attitude is not held by me and others I know who are involved in caring for the dying. (Teresa)

I think he'd had a heart attack or something like that. He wasn't physically injured—no external injuries. It wasn't consciously significant for me because I didn't know him. I think that's more important for me—I didn't know him. He was just a body by the time I got to him. (Joseph)

Several participants described how their experiences of nursing the dying person brought into question their personal meanings of death. They discussed their difficulties in coming to grips with the reality of death and the personal qualities they wished to develop to equip them to relate to a patient whose death was imminent.

I suppose he must have stimulated something within me because he made me think about my own beliefs. I was very judgmental and wasn't looking at things from his point of view. You know, it often takes a personal experience to put things into perspective and make us take a closer look at why we do the things the way we do. ... I couldn't pass the responsibility on to anyone else and I soon realised that this was a sort of test, that the barriers and coping mechanisms that I created for myself were not made of the right stuff and were useless in this personal confrontation. (Helen)

Death was hardly ever mentioned during my training. I was never comfortable nursing dying patients in my years of nursing training. I think my fear of encountering death was probably due to ignorance. I believed in life after death but had difficulty with the dying and with the dead body. Seeing a body
reminded me of my own future death and the death of those I loved. This frightened me. (Mary)

One participant commented that her continual search for meaning arose with each death situation she encountered. She was mindful that whilst she may find some degree of comfort as her experiences increased, she would find it difficult to accept that she would ever fully understand the meaning of death:

I think I've come from a focus where I never fully understand myself, in a sense that I'm always learning and always open to new experiences and new ideas and any challenges in that respect. I never would sit complacently or satisfied finding an understanding, anything to do with the human condition. 'Cause I think, also, I find that I tend to be a very deep thinker and the moment I really think deeply about something I realise how much I don't know, how superficial it all is. Where will I ever get enough time to understand even a piece of reality? I believe there is a real need, it really depends on a person's religious beliefs. I suppose it's just my wish to project, 'cause I have such faith in the belief that it doesn't end. I think we are just too grand. It's very egotistical, but I believe that we are too grand to just end. And in that respect I find that it's almost, the death is almost, not so much exciting, but it's a new beginning. (Sarah)

Benner and Wrubel (1989, p. 22) state 'suffering is part of the illness experience, a part of the human world of meaning'. In her story, Sarah discussed her thoughts on suffering and continually questioned its relationship to the death experience and in turn its impact on her quest to find meaning in death and dying:

It's the suffering that I find the hardest thing to live with. I find it the hardest thing to cope with, with death in hospitals, because it's always there, whether it's the suffering on behalf of the person physically or the suffering on the family's behalf. But the suffering is always there. That's the hardest thing I find because, as I said, I don't find the actual death to be an issue for me. Sometimes it is a release.

LIVED TIME

In the lifeworld of lived time the phenomenon of questioning was exposed by the participants trying to seek explanations about their practice as student nurses and
as registered nurses; reflecting on the health care system and its apparent failure to meet the needs of dying patients; and their changing perceptions on controversial issues such as euthanasia.

Benner (1984, p. 32) says that intuition plays a major role in defining the ‘expert’ practitioner. In developing intuition, many nurses review their own performances over time and record them in their memory as valuable exemplars for future, similar encounters. As a student nurse, one participant recalled how she questioned her own intuitive responses in the death situation:

*I don’t know why I did it and I went straight back to him, looked at him—he was still in the same position and I went over and felt his pulse and he had died and the first thing I did was I shone the torch around the room and I don’t know what I was looking for. I still don’t know what I was looking for, and I don’t know what made me go straight back because, I mean, half the patients on the ward were probably still in the same position two minutes later. (Jane)*

Several participants remarked how their practice was informed by both personal and professional experiences:

*What I’m saying is, I’m sure that I don’t think I was prepared for all those sorts of things from my nursing practice, but it was a personal experience. Maybe they do now—it’s a while ago. I mean, what we were told was a lot of respect. (Penny)*

Many participants noted how, as they gained more experience in nursing the dying, the level of involvement with each case increased. Helen describes how she began to question her practice in greater detail after having to deal with the relatives of a dying patient:

*When I finally graduated and became a registered nurse I would often have to deal with the relatives of a dying patient. This I found more difficult than anything else as it was not so easy to ‘turn off’ from the situation. People, the relatives, would often ask questions and I think that my answers were often inadequate. I began to feel uncomfortable, dissatisfied with my nursing towards the dying, the palliative patient.*
Several participants spoke about their perceived inadequacies of the health care system. From early experiences as students through to the more experienced registered nurse, most participants continually questioned the ability of the health care system to answer their own personal and philosophical questions about death and dying, and questions referring to issues of care of the dying patient.

Next morning, back in the classroom, when we were asked in turn about our first day in the wards I was able to speak about my anger and horror. I asked Tutor Sister what protocols were in place for dealing with what I assumed was a fairly commonplace happening in a busy hospital and how could the ward sister and other staff choose to ignore and appear not to care that a man had died alone in such a busy place. (Teresa)

Well, when I speak of people dying and, as I said to you, the suffering that accompanies that, unfortunately a lot of that is associated with medical management, prolonging that suffering, especially in that last woman (example) I gave to you, whereas she would have been allowed to die a lot sooner had the medical management not prolonged that suffering. Now if she had have come to us and the decision had been made that she was untreatable, then she could have been moved and had full weeks of preparation and focus of dying with her family. Similarly, in medical wards when people are admitted and they’re admitted into busy medical wards and the management will be there for the first couple of days, and it’s understood, it’s almost as if it’s recognised that there isn’t anything they can do but they’ll do it anyway, or try anyway—this acceptance of the fact that there isn’t anything they can do and let them go where they can be cared for. (Sarah)

I mean, when a patient comes in with a cardiac problem and they’ve got diabetes as well, they are never treated in conjunction—they are always treated separately. It doesn’t fit with what I’ve been taught, holistically, and I’m always bashing my head against a brick wall. (Sarah)

Only two participants spoke freely about their own practice and the contentious issue of euthanasia. Both of them appeared slightly uncomfortable in their descriptions, yet both were committed to the view that nurses do not question the impact of euthanasia. They advised that it would be useful for all nurses to be fully aware of the socio-political and legal issues surrounding the current debate.
I think if you are dying, naturally dying, and there’s no alternative available to prolong your life and keep, whilst simultaneously maintaining, a quality of life, then you should be allowed to die. You should be allowed to die, pain free. If that means we have to provide large doses of morphine or whatever to provide that pain-free death, then so be it. I don’t see any problem with the euthanasia debate, for instance. It would be hard, I guess, to go further and decide who should decide who lives and who dies. But if someone is suffering and will not get better, despite any intervention, to what they consider is an appropriate level of functioning then they should be allowed to die. And if giving large doses of morphine enhances their chances of dying early then I don’t see that as a problematic side effect. (Joseph)

There seems to be an unwritten law in the nursing world that there are no resuscitation attempts to be made when a patient known to have a terminal disease, dies. I have asked myself why I would, and indeed do, support such a principle. The answer is simply that I consider these people have a right to die naturally without intervention which could result in prolonging needless suffering. It may seem contradictory that I would not consider being involved in any euthanasia act. Because I deem life to be a gift from God, I find it inconceivable that anyone would wish to relinquish such a gift. As I see it, euthanasia is putting someone out of their misery and is in reality the committing of a grave sin very similar to murder. On the other hand, I do consider that nurses have a duty to ease the suffering, the pain, and if large doses of narcotics are ordered for a patient in distress because of their incapacitating disorder, I would not refuse to give them. (Jill)

LIVED SPACE

In the lifeworld of lived space, questioning enabled many participants to identify areas where they perceived deficiencies in their practice; to question the influence of their belief systems on their practice; and to question the practice of others within their life-work experiences.

Benner and Wrubel (1989, p. 20) contend:

... it is important to study the practice ... to determine new areas of knowledge, new lines of inquiry, and new puzzles or confusion which may exist in advanced levels of practice. The nurse is a knowledge worker and a developer of clinical knowledge.
Several participants shared their sense of incompetence within their own areas of practice. Identification of these deficiencies caused them to question how they could find answers to overcome these difficulties and thus extend their knowledge base about nursing the dead or the dying person.

*With younger people I find I need help to cope, well, not help to cope with things, but it does affect me.* (Jane)

*I didn’t know what to do. I sat and spent as much time as I could with him. I suppose I was trying to make up for his poor treatment. From this I gained an increasing interest and concern for HIV/AIDS patients and subsequently palliative care as a vehicle to assist patients with terminal illness achieve a better quality of life and indeed a quality of death.* (Ann)

*This experience made me question my own nursing practice when dealing with dying patients or in palliative care and I discovered that my own nursing care left a lot to be desired. I never thought that palliative nursing was any different from nursing in other areas, although I considered nursing to be a caring profession which involved sympathetic understanding of the patient’s physical needs and, to a limited extent, their psychosocial requirements. There was a job to do and you did it.* (Helen)

*On one particularly emotional day with Damien, when he seemed to be so uncomfortable and little I did seemed to be of any relief, despite much effort, I had tried everything I could think of to make him comfortable, but to no avail. It was one of those days when very little seemed to go right.* (Jill)

*It occurred to me that my upbringing and acute care working environment strongly reinforce the power of a dominant life-saving ethic in critical care work.* (Ann)

Two participants spoke about their religious upbringing and the consequential impact on their belief system about death and dying. Helen questioned her personal philosophy as she described her childhood experiences and the influence they played shaping her professional responses to the dying:
I was one of those children who used to attend Sunday School almost every week and Scripture lessons were held at school every week, so I presume those experiences provided the foundations of my religious beliefs of today. I like to think, no, I do think, that I have some Christian tendencies although there are many details about the Christian faith that I am not, I do not believe in, and there are some practices that the Christian teachings advocate that I don't use, you know, like going to church regularly now. I think I can practise my faith, my beliefs, in other ways—I don't have to go to church to tell the world what I think or feel. I believe that there is a life after death and that our presence here on earth, well, serves a kind of purpose. I don't always know what it is but in the major plan of things, for human beings, I think our individual existence has a definite meaning. ... Despite my convictions, I am sure that I will face my own death with much trepidation, because I put a high value on living.

Benner and Wrubel (1989, p. 21) contend 'by articulating them [examples of practice] and holding them up ... we can extend them, confirm them, and use them as the basis for new visions of practice'. Thus, in this study, the participants, in questioning the practice of others, have been able to uncover new knowledge in the area of caring for the dying.

I remember feeling quite angry when Damien and his doctor made the decision to withdraw all treatments and medications and to continue only with his intravenous fluids and analgesia. The doses of analgesia were increased rapidly as his pain worsened and his condition deteriorated. I found it difficult to accept that he could just give up. (Jill)

Elizabeth, a woman in her seventies, recently diagnosed with cancer of the colon, was admitted to our ward for bowel surgery. Her immediate postoperative recovery was satisfactory but she did not progress. She was extremely confused, in pain, and demanded to be knocked out with drugs the whole time. Many different combinations of drug therapy did not help. The surgeon and staff continued to attempt to recover Elizabeth. Finally, palliative care was initiated after consultation with the clinical consultant for palliative care. Elizabeth died, still confused but in less pain, with questionable, or was it full, awareness of her condition. (Ann)
I can remember turning round and thinking, don't you think that's a bit exaggerated, aren't you exaggerating a little bit? But by the time she'd got the crash trolley he was there, he had arrested (cardiac arrest). He didn't survive, he actually died of pulmonary oedema. It was a gross death, a really gross death. The fact that he'd drowned, heaps of secretions were just coming out of his mouth and his nose. And another nurse started packing him, packing his nose, putting things in his mouth, in his bottom, things like this, and I found that all very awful. I didn't manage that well at all. I just didn't understand. I just wondered, why do you want to do that? And I said to her, "Why are we doing this?" and she said to me, "This is the way you have to do it. This is the ritual, this is what you have to do." "But I've cared for somebody, you know, I've prepared a body before. I've seen a body being prepared and they didn't do any of this." "Well," she said, "they must have been doing it wrong. They weren't doing it properly. You have to do it this way." And it was all very ... (pause) ... do you know what I mean, at a distance, and it was all very ... she had an austere face, as if she was preparing a sandwich—that's how it felt, you know. (Sarah)

I don't feel nurses have a grip on spirituality. I think they feel it's very private and something not to be discussed. It's like sex and politics. (Gloria)

LIVED HUMAN RELATION

In the lifeworld of lived human relation, the phenomenon of questioning was revealed in the participants' conflict with others regarding their questionable coping mechanisms with death and dying; their approach to care of the dying; and in the participants' own concerns about the degree of involvement with the dying person and their relatives.

As students, some participants described how they looked towards other, more senior registered nurses to act as role models for themselves. Some participants questioned the idea that some senior staff may not have been able to provide them with adequate explanations of how to respond to, or cope with, death.

Yes, there are, I think. In my case, anyway, there were probably far more understanding nurses that I've worked with than non-understanding nurses. There certainly were a few that were, I felt, cold and sort of bitter and what-have-you but I actually feel that they probably would cope worse with death.
themselves than people who are more understanding. I think that they’re probably more frightened of it than the others. (Jane)

My first response was, I was really surprised that she was crying because she didn’t appear to be, she actually, the person that she’d conveyed to me was this person who would manage it all. She had a very hard exterior—a real coping person. She was crying and was quite depressed that she was caught crying. It was almost as if I had caught her out crying. It wasn’t actually the death that was my main focus then, it was my preceptor’s reaction to it. I just went cold. (Sarah)

To have given the task of last offices to a very junior student nurse and a very capable older experienced nurse, now makes me wonder. Were they in a stressful environment and feeling overworked? … Were they suffering from stress or were they not coping? … I feel that even if the nurses were unable to cope with the lady’s death, whatever the reason, they still should not have put me in that position so early in my career and that they should have shown some consideration for me. It is my belief that they were trying to hide their true feelings by engaging in other activities. I feel that the nurses, if unable to cope with death, should have faced their own fears and not have passed the task to others. (Angela)

A few participants spoke about their relationships with colleagues and new staff whilst nursing the dying person. They questioned themselves about the qualities they would need to possess in order to facilitate a caring environment for these staff members.

We recently had a newly registered nurse on our ward who seemed quite, almost obsessed, with dying, with death. She would actually keep ringing up to find out if someone had died. It was very difficult to know how to handle her or how to help her. Or, indeed, if she even needed help or if that was just her way of coping. She got a fair bit of experience with death and that asking or ringing up did stop through, not sort of active intervention, it did dissipate. I think with newcomers to death you have to try and evaluate where that person is at. (Joseph)
The advantages of questioning others’ practices has already been discussed. However, in the lifeworld of lived human relationships the questioning of colleagues’ nursing practices encompassed the nurses’ relationships with the family of the dying person.

_We have some staff in our ward who have got this real need, I don’t know ... the ward I’m working in, they must be in hospitals they’ve worked in before there has been really strict visiting hours—nobody was allowed to see the patient during certain hours and I really oppose that. As far as I’m concerned, immediate family can be here as long as they want, whenever they want, and really acknowledge that I resent them doing otherwise._ (Sarah)

_The thing it’s also important to talk to them before they are dead, I think, to encourage family to say all the things they would like to say—things that haven’t been said to resolve things, perhaps, to say that you love them. I mean, a lot of people don’t._ (Penny)

Finally, several participants discussed their professional interactions with the dying patient and the personal costs which may arise as a consequence of involvement with that person or their family. Stein-Parbury (1993, p. 297) states, ‘the most significant aspect of interpersonally relating to patients who are living with dying is that of simply being there, unafraid and unencumbered by fears about death’. However, Gloria questioned the level of involvement necessary to give good nursing care and pointed to some potential difficulties associated with over involvement:

_I think there is still very much a hanging onto the person—nurses becoming attached to someone who is dying and don’t realise just how much energy they are using to be attached to a patient. Sure, I think that caring is great but that attachment, I think, is really sort of dangerous and difficult to deal with afterwards, when that person’s gone, when there isn’t a lot of debriefing after a person’s died._
SUMMARY

Questioning self and others’ personal and professional philosophies and practices of nursing dying or dead people is essential to the development of new knowledge and improvement in nursing care.
Accepting
The essence of accepting can be construed as being in direct contrast to the essence of questioning. That is, the nurse may choose, for a variety of reasons, not to question a particular issue in the practice of nursing the dying or the dead. However, accepting can also be defined as an appreciation of the limitations that nurses have set on themselves in feeling comfortable with nursing dying or dead people. I am not postulating that accepting in this sense is in any way a negative issue, rather, these limitations may well have arisen from constant questioning and evaluation of self in the domain of this particular nursing work.

Our culture, primarily guided by the positivistic paradigm, purports that there are certain universal truths which are independent of ourselves. An authority or an academic may have led us to believe, through sound philosophical principles, that there is an objective reality which has provided us with a reference point outside ourselves (Fell & Russell 1994, p. 26). This particular stance has proved to be very comfortable and convenient for most people in our society. In the world of nursing, accepting an objective reality in many domains of understanding has been somewhat traditional. The profession’s link to the mechanistic medical model has contributed to individuals within nursing to adopt this viewpoint.

Accepting has also been part of the nurse’s role in the nurse-patient interaction. As communicators, nurses have learned to accept the patient’s point of view without necessarily agreeing with it. This type of acceptance does not preclude the nurse engaging in their own internal questioning. On the contrary, in achieving an acceptance of self, the patient, and others, the nurse may have engaged in a process of understanding based on sound holistic principles.

The participants in this study have described accepting in their discussions about understanding their own belief systems; the nurse-patient interaction; their interactions with others; their unique understanding of issues surrounding death and dying; and their own understanding of the social context of nursing dying or dead people.

**LIVED BODY**

Making choices and decisions about the way we are in the process of living and working arise from our understanding of self. Sometimes this understanding is promoted by reflection on our attitudes and values which contribute to our
personal belief systems. 'These values and personal beliefs are not static: they are altered, revised and adapted through life experiences' (Stein-Parbury 1993, p. 33). Nurses, through their experiences of nursing and life itself, may change their personal and professional philosophies through a process of self awareness. In some cases this process involves consistent reflection and a willingness to learn and un-learn through these experiences. For others, understanding of self may be triggered by traumatic events in their life-work situation. Stein-Parbury (1993, p. 44) contends, 'self-awareness leads to self-understanding, self-challenge, and eventual acceptance of aspects which characterize [sic] each nurse'.

In the lifeworld of lived body, the phenomenon of accepting was described by the emotioning of individual death experiences of the participants. Some of these experiences were described as traumatic or distressful, others enlightening.

Nursing dying or dead people encompasses certain ritualistic practices which could be perceived as an assault of a person's body. Prior to very recent changes in these practices, nurses were asked to pack every orifice of the dead body. In addition, it is customary to cleanse the body and remove any evidence of leakage of body fluids as nurses prepare the body for transportation to the mortuary or the funeral agency. Several participants described the embodiment of these processes. Some nurses felt distressed or disturbed as they connected with this procedure.

In his reflections, Joseph described his feelings about laying out a dead person's body and how he has become accepting of his own limitations with undertaking this procedure:

*We don’t pack orifices and I wouldn’t like to have to do that. I would find that unpleasant, physically unpleasant. Even cleaning up bodily fluids is an unpleasant job, there’s no two ways about it. If I found it difficult with someone while they’ve been alive, I don’t have any trouble doing the … what can take up an hour, to undress someone, wash them, change their sheets, clean them, redress them, whatever. I don’t have any trouble doing that. I don’t see it as a waste of time or anything like that— I don’t mind doing it.*

The death of an older person has been identified by society as less stressful for carers than the death of a younger person. The very nature that this idea has been adopted by society means that most people within society have accepted this
premise. Similarly, Joseph described his preference for dealing with older dying people rather than younger people who are dying. This partiality was shared by several participants in this study.

Still, despite any knowledge, it is still easier for me to look after someone who is older rather than young. (Joseph)

Death awareness for some of these registered nurses was underpinned by the influence of the moral and ethical considerations they had developed as a result of being exposed to certain religious teachings. Several participants talked about their religious convictions and accepted that their beliefs about death and dying were firmly linked to their faith.

As a Christian, death should not be seen as a failure or as the end. It is one of the few certainties of life. It is natural to grieve for the passing of a life. (Teresa)

The impact of my personal situation on the care I provide is a source of concern to me. At times I feel I can strongly relate to the situation that palliative patients and especially their families find themselves. I can conceive that over identification (with religious principles) might do more for my needs than those in my care. I also recognise that my Christian, though non-practising, background and that of society, colours what I perceive as normal and acceptable as far as religious beliefs and behaviour are concerned, even though I consider my stance on religion and death to be non-committal and largely indifferent. (Ann)

Backer et al. (1994, p. 53) suggest, ‘in caring for dying patients, nurses need to assess their own feelings and responses about death as well as those of their patients’. All participants described aspects of feeling comfortable with death. In our conversations, most participants were enthusiastic to share their processes of becoming accepting about death.

My nursing education emphasised the concepts of holistic care, quality of life and patient advocacy. It is my belief that my nursing education had a substantial effect on my beliefs, attitudes and values in the cases mentioned. Throughout my nursing I have felt relatively comfortable with dying patients. I
did not avoid them and they did not distress me as they did some of my fellow colleagues. I probably felt closer to dying patients than others. (Ann)

Well, now I am more comfortable about death. It's been very gradual. ... I think I'd have to work from being with relatives, I think that's how I became to be comfortable with actual patients. (Gloria)

I think I'm fairly realistic, in that, you know, if people are ... say, that baby who was dying, there was absolutely nothing you could do for that child. It was in pain, blown up like a balloon. It was probably even brain dead. I mean, it's very sad but I wouldn't want it back again in that position. And I feel like that even with my own family, I don't know how to explain it to you, I even felt like that when I lost my mum, even though there's pain and you're very sad. I don't, sort of, say I want them back, I mean, I've had people, I've had relatives who've stood at beds and said I want them back, it doesn't matter even if they're going to be like this. For me, that's not an option. (Penny)

One participant noted that her acceptance of death was triggered by the realisation that involvement with dying people and their relatives necessitated an understanding of all the issues surrounding death and dying. She advocated this awareness was best achieved through experience.

Clearly, learning to help dying patients and their families demands involvement, but to become involved one must first be comfortable with death. With this understanding and a concept of loss and the process of grieving, I think we all will be better able to implement creative interventions to promote optimal wellbeing and supportive care for the dying patient. (Jill)

Continuing education in nursing dying or dead people is proposed in much of the reviewed literature in this study. However, many traditional death education programs which were reviewed posed little discussion of self awareness and resultant self acceptance. Gloria described how her life problems enabled her to find educational programs which helped her confront her own awareness and ultimately allowed her to accept death.

I've been to a few different grief seminars and things over the years. Five or six years ago I did a telephone counselling course with Lifeline which was quite an
influence. A lot of it is just straight out gutsy risk taking, seeing what works and what doesn’t work and thinking, ‘Oh well, stuff up there. That didn’t work’. It’s amazing the times that I thought, ‘Ah, what a stuff up. That didn’t work’, and something has come out of it. I don’t know whether it’s so much an education process—a self education process perhaps. Whilst all this has been happening I’ve been dealing with a lot of my own stuff—I was sexually abused as a child—and realising a lot of the grief that has come from that. So, I guess, while I’ve been working on that, certainly not thinking that I was doing that to help patients, I think there has been a spin-off from that, looking at awarenesses and acknowledging them. Heaps can be gained from a group experience. I think it would be great if there was some sort of group for the nurses to be able to sit around and just buzz round and find out what is happening for them.

LIVED TIME

The ‘Deserata’ prayer suggests we need the courage to do what we have to do, the serenity to accept what we cannot change and the wisdom to know the difference. In the lifeworld of lived time, the participants described their experiences as students and accepted that, at the time of their training, there were many of their own nursing practices that they were unable to change. Similarly, as more experienced registered nurses they understood, albeit transitionally, that the health care system steered them into accepting some degree of compromise in their nursing actions with dying and dead people.

As students, many participants described that their own inexperience placed them in a position of accepting certain truths about death and dying and the delivery of care at that time.

_I didn’t talk about it with other people, mainly because I didn’t think it was right to talk about it (death). (Jane)_

_I was given into the charge of a second year nurse who, in my unworlbidly eyes, appeared to be very adult and knowledgeable. … Anyway, I was doubled up with this second year nurse with the instructions to get on with the bed baths and Sister’s admonishments ringing in my ears not to touch or do anything unless expressly told to do so. I was even frightened to touch the patients unless I got the nod from my second year nurse. It was awful. (Teresa)_
On reflection though, I can now understand to a certain degree how those nurses felt. They may have even done me a favour. Obviously I still have some conflicting feelings and wonder if I'm trying to make excuses for the nurses' behaviour. I was scared to show the other nurses how frightened I was. Was it because of the tales I had been told or being so young and inexperienced, or even both? Death seemed so final to me. The thought of death then, was just inconceivable and immortality was often on my mind. (Angela)

This whole episode seemed quite normal to the other nurses and I soon learned that I had to be like them and accept the hurried approach to dealing with dead bodies. (Helen)

My first encounter with death in a nursing situation occurred in 1964. I had been working on the wards only a few weeks. I remember feeling, well, the whole experience, really, of nursing was still new, overwhelming, exhausting and just a bit confusing. As a very junior nurse I spent much more time dusting, scrubbing pans and arranging flowers in vases than in caring for, looking after the needs and comfort of my patients. There was no time for talking with patients about anything, let alone their fears and anxieties, although I had no real understanding of such things in any case. (Mary)

Nurses often place themselves in a position of conflict. Choosing to work within a particular hospital could mean an acceptance of policies which may contradict their own belief system. Sometimes the energies required to institute changes to accommodate these beliefs may not be available to the individual, and compromise may be the only mechanism at hand. Sarah discloses how, over time, she has come to accept the discrepancies within the health care system in which she is currently employed:

In looking at the units I've worked in, the style of care which is unfortunately given, when I said to you that it becomes second best, I find that a real sadness and disappointment but it's inevitable. And in saying that, that's where my belief comes that they should have a specialty area. Management. Time. Under staffing. All those awful, awful realities for patient care, full stop. That just made me hate medical wards from the beginning. It became a factor of time that, like, I used to feel, like, for example, people who were dying, like, I used to feel horrendously… I can remember several cases where a patient would be in real
need of counsel and my being unable to afford them the full amount of time that I would have wanted to, like, a whole evening of just counselling and sitting and talking to them but because of the patient load I had and no other support in order to give me that time...

Backer et al. (1994, p. 49) believe ‘caring for dying people can promote learning for caregivers that goes beyond simple intellectual development; it can offer them new perspectives that may allow for exploration of their own lives and what it means to be human’. Helen noted how nursing dying people has enabled her to accept different reactions to the dying process and in turn has assisted her to discuss her beliefs with her own family:

Death is not a subject that people like to discuss but we see it everyday. I mean, everyday in the papers there are reports of many deaths but it sort of passes us by. I know people who read the obituary columns every day—my parents do. I suppose they know some of the people. Well, they do know some of the people because they tell me, "Oh, So-and-so died today." It is like they are witnessing an end to their era, you know. I talk about death with my own children. Sometimes it’s hard but I try to answer their questions about death honestly. I mean, I want them to be able to cope with the reality of death when and if they are confronted with it. If a relative or close friend of theirs was to die, I would encourage my children to attend the funeral as part of life, you know, their learning experience of life.

LIVED SPACE

In the literature review, it was discussed how death awareness has changed over time and space. The death environment has altered from one of visibility to invisibility. In the lifeworld of lived space, the participants revealed that accepting is a process of continual development as they continue to experience and reflect upon nursing dead and dying people in the past and present.

When my senior nurse told me that I was to view the body of the lady who had died, I felt scared, frightened and uncertain. I was told that I must show respect for the dead person, and maintain a quiet dignity. This I must have managed to do because if I had not I would most certainly have been told. ... In retrospect, I probably survived the experience because it was expected that nurses should do such things. ... I don’t believe that the lack of caring from my superiors was
intentional but rather that the importance of caring, not only for patients but also for colleagues, was not generally understood in those days. Perhaps they found it difficult to offer comfort because it was showing the human side of their response. (Mary)

I think we have to make sure that nurses understand that it's part of nursing, it's not a failure, if you lose a patient through whatever reason. It might be a chronic disease or somebody stroked out after something minor and you didn't think it was going to happen, all those things, and I think that you have to realise that it's not part of... I think doctors have a problem with death and patients for that reason. But I think, in nursing, that's part of it—to take it to the end and even later, with relatives. ... It's a part of life. I know it sounds funny but that's it, it's part of life. And some of that nursing towards the end is helping patients prepare. I mean, we talk about preparing patients for discharge through other parts of their illness. We should be preparing them, helping them prepare for death as well. (Penny)

As some of the participants became more experienced registered nurses, they chose to work in areas of nursing which gave them increased opportunities to work with dying people. Two participants spoke about their individual changes and in that process of change they have become more accepting of their nursing actions towards the dying.

I think its changed now and if it hasn't changed and people are still of that old idea, I'm very quick to step in and talk about feelings, talk about my own feelings. I feel quite okay in doing that. (Gloria)

Nursing interventions for the terminally ill patient should focus on promoting the patient's sense of identity, dignity and self esteem. This can be enhanced by listening and responding quickly to requests, ensuring privacy, and promoting comfort and optimal physical care. The dying patient will gain considerable satisfaction from being able to help themself for as long as is physically possible. This independence will promote the patient's sense of worth and dignity. A sense of being in control must be promoted. ... Attention must also be directed towards promoting spiritual comfort and well-being of the patient. As death approaches and the patient accepts the inevitability, comfort may be sought through reviewing and analysing the values, beliefs and philosophies that have
structured and shaped their life and are presently exerting influence on their perception of the meaning of death. (Jill)

LIVED HUMAN RELATION

Backer et al. (1994, p. 60) state, ‘... nurses who may be trying to come to a realistic acceptance of their own mortality may also need to talk about death and dying, especially if, for example, they are seeing themselves in each dying patient’. In the lifeworld of lived other, the participants unveiled accepting in their recollections of discussions about death, with relatives, with other patients, and in their interactions with colleagues.

When a patient dies in an open ward setting, it is unrealistic to expect that the death will proceed unnoticed by other patients. Yet some nurses engage in the common, rather ritualistic, practice of talking in hushed tones behind closed screens as they prepare the dead body for transfer to the mortuary. Very few nurses engage in open discussion with other patients about the dead person. Jane related a story of how another patient feared himself responsible for another’s death and her intervention made it possible for all concerned to accept the death without feeling guilty.

One experience I had was, I was left in charge of the ward on the night shift. The registered nurse said to me as she left, “Keep an eye on Mr Such-and-such,” and I said, “Fine.” And I did a round twenty minutes after she left, a ward round, and this guy had been coughing a lot earlier in the night, you know, cough, cough, cough, and there was a patient in the ward, it was an eight bed ward and he was in traction, a young man, and he had said—I’d given him a cup of hot chocolate when I first came on duty—and he had said to me, and he was so fed up with this old fellow, coughing all night and keeping everybody awake, and he had said, “Oh, choke, you bastard!”—like that, you know? ... I guess there was a bit of panic there and then dealing with the young man. He was feeling very guilty for weeks about it, about what he’d said and dealing with him was probably ... not hard ... we all needed ... he needed all of us, needed reinforcement all the time that he didn’t wish him dead, that he would have died anyway, no matter what he said. But you know it was very upsetting for him for his remaining time in hospital.
Finally, as nurses become more accepting of sharing their feelings of grief, they in turn may become more comfortable with helping patients, their families, and colleagues experience their losses. The following participants spoke about their role in helping others to discharge their anxieties in the grief response.

*I mean, the relatives play an important part in caring for the patients. I ask them now if they want to help. Some say yes, others just don’t want to become involved and look at me strangely. But I persevere with them and some come around and it’s lovely to see them doing things for the patient, it sort of feels right that they become involved too. Sometimes I feel that their eyes (the relatives) are watching me to see if I am doing things right, you know, like checking up. But I smile and ask them to help and that breaks the ice a bit. I think it helps with their (the relatives) grieving after the patient has died. If there are any rules for what one should or should not say to a dying patient, their relatives or friends, I haven’t come across them yet. (Helen)*

*And then the daughter speaking to me about the same things, you know, like … (pause) … and there had been, like, actually lashing the chests of the relatives and with the male nurse. It was sheer distress. That was really, I think that was actually the hardest one I’ve ever had to deal with because of the torrid emotion that was surrounding me. And they stayed with her until the body went cold, the family, they stayed with her. That was, that was two and a half hours. I can remember some of the nursing staff saying, “They can’t do that, they can’t stay here,” and I said, “They have every right to.” (Sarah)*

**SUMMARY**

Accepting in nursing dying or dead people is established through an evolutionary process of self understanding and reflection on each experience. Accepting is also indicative of nurses’ non judgmental interaction with those people actively involved with the dying process.
Chapter Seven
Being-in-the-world of Nursing
Dying or Dead People:
Insights for Nursing
This chapter will review the essences extracted from the study and apply them to Parse's (1981) theory of Human-Becoming. Secondly, it will suggest some insights and possibilities for approaches to clinical practice. Finally, some suggestions for further research in this area will be presented.

This study began with the formal statement that the methodology used was grounded in Heideggerian phenomenological hermeneutics. Studies of this nature seek to describe events or experiences as they are lived-in-the-world by people, in this case, twelve registered nurses. The philosophy of Merleau-Ponty (1962), in particular the existentials of lived body, lived space, lived time, and lived human relation, provided a theoretical framework which was used to guide the analysis of the experiences of the participating nurses. Phenomenological inquiry seeks to describe the essence of the thing itself which can lead to an understanding of the underlying meaning of the phenomenon, in this instance the experience of nursing dying or dead people.

The experience of twelve registered nurses, as they live in their world of nursing dying or dead people, was analysed to gain an understanding of how these nurses practise caring for dying and dead people in a variety of environments. The participants: Jane, Joseph, Teresa, Ann, Helen, Jill, Sarah, Mary, Belinda, Angela, Gloria and Penny are registered nurses who are current practising nurses and are recognised as senior staff in their respective places of employment. The following four essences emerged from their stories.

**THE FOUR ESSENCES**

Being-in-the-world of nursing dying or dead people is partially understood by the revealing of these four essences. This study recognises that the meaning that comes to the individual is personalised and is based on a multi-dimensional structure of meaning—past, present and future. Interpretation of life experience is ongoing as we constantly and simultaneously interact with the environment and those people within it. No two life experiences will ever be exactly the same, nor is another study expected to duplicate the interpretations of this research. Each experience is unique and private as 'the way a person is in a situation is cocreated by a personal view and the context of the situation' (Parse, Coyne & Smith 1985, p. 10).
This study focuses on being-in-the-world of dying or dead people as shared by the twelve registered nurses and through essence extraction, brings together the commonalities of their experiences. These four essences, of the lived experience of nursing dying or dead people, will be discussed in relation to Parse’s (1981) theory of health as Human-Becoming. Using Parse’s theory, Bunting defines nursing as a ‘discipline focusing on the study of health of persons in interrelationship with their environment’ (1993, p. 23).

**Connectedness and Parse**

Bunting states Parse’s theory is ‘... based on a belief that events and people mutually shape and influence one another’ (1993, p. 9). Parse (1987, p. 164) also contends that nurses, in interrelating with people and with nursing, are constantly transforming their world through languaging and in doing so move through a sequence of connecting and separating as they find meaning in what they do.

These twelve registered nurses describe connectedness as an ability for them to move towards a greater understanding of what death means for their patient and themselves. Being connected to the dying person also allows these nurses to move the focus of their practice from one which is essentially medically driven to one which demands a humanistic nursing orientation. Connectedness permits the nurse to practise holistic nursing principles towards the dying person, their relatives and others involved in the delivery of care. ‘Being-with’ each other as nurses and with the health care team in a supportive and caring environment is seen to enhance practice and thus impact on the quality of care given to the dying person.

Learning to connect is seen as an important issue for these twelve registered nurses. In Parse’s terms it is a process of ‘becoming’ skilled in the care of dying people (1981). Connectedness can occur if the environment is fashioned to value this process. Relating to the patient and to each other in an environment which values connectedness also fosters each person’s individuality and allows people to choose their own way rather than imposing the ideals of another on the situation at hand.

Connecting with people during their own dying process and in the hour of their death provides a unique opportunity for nurses. The way we act and respond is under constant observation, not only from our own perspective but also by the
patient, their relatives and other health professionals (Vohland 1994, p. 152). When the nurse respects the person’s right to die and validates the feelings of others concerned with their dying, the situation can be transformed from one of hopelessness and sadness to that of peacefulness and comfort. Whilst dying in hospital may not be desirable, the nurse, through connecting with all the existentials of the dying milieu, has the possibility to make the situation legitimate for the dying person and their relatives and friends. Dying in hospital may be the only viable alternative for some people. In this situation the attending nurse can be seen as a source of strength, validation and support.

**Aloneness and Parse**

One of Parse’s theoretical principles acknowledges that nurses are constantly ‘cocreating rhythmical patterns of relating’ (1987, p. 164). For these twelve registered nurses, aloneness forms an important dimension of their understanding of nursing dying or dead people. Aloneness involves being able to confront their personal feelings about death and ultimately find individual meaning. Consistent with Parse’s theory of Human-Becoming, situated aloneness permits the nurse to appreciate the nature of isolation in which many dying people are placed. The meaning of aloneness, being in direct contrast to that of connectedness, allows nurses to move through the myriad of emotions associated with nursing dying and dead people and to personalise the experience. Being able to identify with the dying patient and their aloneness in the dying trajectory enables the nurse to understand what is happening and to coordinate the personalised care required.

The art of providing care for the dying and the dead is not easy for most nurses. The twelve registered nurses describe that learning to care for these people in a skilled way evolves out of feeling completely lost and abandoned in their early experiences. These feelings of discomfort could well be as a result of personal identification with the dying trajectory, or inexperience of work and life situations dealing with dying people. Aloneness is viewed as a necessary transitional state for all nurses to move through so that they may ultimately engage in self-reflective processes which inform their practice.

Aloneness was not always viewed as a positive state by the participants in this study. Aloneness described many of these nurses’ fears of abandonment, in the death situation, by their peers. Some nurses felt devalued and overwhelmed by their understanding that nursing dying or dead people was expected to be an
impassioned event. Many of these nurses perceived their role in nursing dying or dead people to be invisible. As society tends to deny the existence of death, so too did these nurses feel that some health care institutions, and workers therein, tend to ignore that some people do die in their care. The marginalisation of death only serves to exacerbate these negative feelings of aloneness, preventing aloneness acting as a catalyst for change.

**Questioning and Parse**

According to Parse (1987, p. 162) nursing practice is being in relationship, in true loving presence, with people while they describe the meaning of their lifeworld, and as they struggle with the paradoxes intrinsic in health experiences and discover and fulfil hopes and dreams. This third principle of Parse’s theory is termed ‘mobilizing [sic] transcendence’, as the nurse, dwelling in true presence with the person as they struggle with everchanging situations, moves beyond the present meaning of events towards ‘what is not yet’ (1987, p. 169). In this study, the participants described how questioning leads to an exploration of self and others involved in the care of the dying person. Questioning also involves inquiry into their own practice and the practice of others with a view to ultimately improving the quality of care delivered to dying people and their families.

Questioning enables some of these registered nurses to confront current, controversial issues such as pain management and euthanasia, and institutional issues such as the placement of dying patients in the acute care environment. The participants related passionately to the dying person and personal needs were transiently negated in favour of delivering skilled and excellent care. Personal perspectives on issues such as highly emotional grieving of relatives, professional sadness, the meaning of life and death, are concurrently questioned as these participants nurse dying people. The struggle emanating from questioning internal beliefs and external systems of control places value on these nurses’ abilities to make their own choices about the best ways in which to care for dying people. In turn, validation of the questioning process is a reference to nurses’ potential to reach beyond what they are experiencing now, to be aware of what may become. Humans are always in the process of changing and transforming in moving toward unfolding possibilities (FitzGerald 1992, p. 6; Vohland 1994, p. 132).

Moving towards improving aspects of care occurs through questioning the resistance of the status quo. This movement has been described by Parse as
‘powering’ (1987, p. 193). Powering or empowerment is neither something which can be given from one person to another, nor is it something we own or exert over others. Used in the context of a verb, ‘power’ is a process we participate in. ‘The challenge for us in developing our personal power is our willingness to recognise that power is within us and in our courageous choice to forgive and release anything that prevents this power from fully manifesting’ (Mariechild cited in Wheeler & Chinn 1989, p. 5). Powering in this context has led to a continuous pushing-resisting force which has propelled these twelve registered nurses towards changing their personal attitudes and professional actions in nursing dying or dead people.

**Accepting and Parse**

The first principle of Parse’s theory is ‘illuminating meaning’ (1987, p. 163). This principle connects the concepts of imaging, valuing and languaging and structures multi-dimensional meaning of situations. ‘Individuals, by the choices they make between meanings, are active in cocreating their personal reality’ (Bunting 1993, p. 17). The essence of accepting in this study involves these nurses becoming aware of the multi-faceted nature of the influences on their personal meanings in constructing death and dying. During the telling of their stories, these nurses envisioned the past and present of their lives as nurses in the situation of nursing dying and dead people and realised how these different constructs lead to the formulation of belief systems which guide their practice.

Accepting feeling of comfort with death could be viewed as illusionary rather than realistic. Death in many circumstances is not a comforting event, yet as nurses we strive to make it so, for ourselves and others. In the various nursing contexts of these participants, accepting death and dying for what it is, be that comfortable or otherwise, is largely dependent upon the embodiment of these nurses’ own limitations. Paradoxically, individuals seek to be like others and also be uniquely themselves (Parse 1987, p. 170). Living out this paradox of certainty and uncertainty illuminates the different meanings nurses and other health care professionals can have about the same situation. Accepting of self and others can create the possibilities of viewing a familiar situation in a new way. This sharing of ideas and knowledge about nursing dying people assists in transforming, changing and increasing the diversity of nursing practice with dying people.
POSSIBILITIES FOR NURSING PRACTICE

The findings of this research do not claim to generalise the experience of nursing dying or dead people; however, there are some nurses who may benefit personally and professionally from reading the description of these twelve registered nurses’ experiences and the subsequent interpretation. Following the discussion of the findings and their link to Parse’s (1987) theory, it is worth considering these findings as applied to the everyday event of nursing dying and dead people. It is important to recognise the high profile of nurses in the role of caring for the dying person in the hospital setting, and how their exhibited behaviours can potentially influence the outcomes of care.

Connectedness and nursing practice

The multi-faceted phenomenon of connectedness was regularly mentioned by the participants in relation to forming relationships with the dying person, their relatives and with other health care professionals. ‘Being with’ these people necessitates that the nurse is able to be flexible in approaches to different people involved in the same situation. Being-in-the-world-of-the-patient assists the nurse to identify and experience, through their own existence, shared understanding of the patient’s experience of dying. Similarly, holistic nursing practice permits this shared understanding to encompass the dying person’s relatives and/or friends.

These participants mentioned the difficulties of providing a palliative focus in a technological environment such as intensive or coronary care. Walters (1992, p. 351) claims that the nursing knowledge needed to function well in the technical environments is reductionist in nature and usually highly valued, whereas the skills and knowledge of a humanistic nature, necessary for the care of dying patients, are not always given the same degree of credibility. Moving beyond the obvious of nursing in a technical setting is difficult for some nurses to achieve. When a patient is told, in a technical environment, that ‘nothing more can be done for them’ and palliation is the best care that can be offered, the transition from one type of care to another has its impact on the nursing staff as well as the patient. Being in a connected relationship with the patient and the family can provide a supportive environment whereby each person can assist others in reframing towards a different outcome. ‘By reframing the situation, the person may open up new alternatives’ (Benner & Wrubel 1989, p. 168).
Benner (1984) implies that if we make conceptual distinctions between caring into ‘expressive’ or ‘instrumental’ roles rather than keeping them united, we run the risk of perpetuating the care versus cure dichotomy. Benner further suggests that ‘caring cannot be controlled or coerced … caring is embedded in personal and cultural meanings’ (1984, p. 170). The participants in this study were mindful that their own personal and cultural meanings of death could not be easily put aside when caring for dying people. Their personal qualities equip them to relate effectively to a person whose death is imminent. Although Arblaster, Brooks, Hudson and Petty (1990, p. 41) suggest, from their study, that dying patients express a need for normalcy rather than actively discussing their death, it is clear from the participants’ stories in this study, that many dying patients appreciate the open awareness approach which arises from the establishment of a connected relationship.

Presencing or ‘being there’ for patients is articulated in studies by Rieman (1986), Watson (1985), Benner and Wrubel (1989) and Vohland (1994) as central to caring for patients who may be facing death. Presencing in this sense means more than the physical closeness of the nurse. It is the nature of the time spent with the dying person which is important. Stein-Parbury (1993, p. 305) reminds us of some nurses’ attitudes: ‘spending time talking with patients is still viewed by some nurses as “wasting time” or that which is done after the “real” work is completed’. I would argue that spending time in meaningful dialogue with the patient and their family is ‘real’ work and sometimes less stressful than pretending to be busy to appease others. The rather out-dated perception as described by Stein-Parbury can be rectified by increasing studies which value the nurse-patient interaction. Phenomenology being an ideal methodology as human experience is not excluded from the research process.

Aloneness and nursing practice

The participants in this study allude to their perceptions of imposed aloneness in the experience of nursing dying or dead people. In the situation of imposed aloneness many of the registered nurses discuss the lack of a supportive environment in the work situation. It is unfortunate that in some health care agencies a climate of horizontal violence is perpetuated within nursing and the formation of a workplace which values each other’s feelings is not considered to be legitimate. For a profession which claims to be part of a health care team, it is rather ironic that the conflict between individuals within that team leads to
factionalism and formation of cliques (Stein-Parbury 1993, p. 303). White (1989, p. 13), when discussing the palliative care team, states ‘teams are not born, they are made’ and comments upon the need for all team members to work hard at maintaining trust and harmony.

In a health care environment where the emphasis is on caring for patients, it is easy to become so involved in the nurse-patient relationship, that we neglect to care for our colleagues. Yet studies by Gray-Toft and Anderson (1985), Norbeck (1985) and MacNeil and Weisz (1987) have demonstrated that supportive working environments for nurses can directly reduce or prevent stress itself, buffer the negative effects of stress and function as a resource for coping. Stein-Parbury (1993, p. 309) states:

The sad irony is that work-related stress on nurses is exacerbated when colleague support is absent, and colleague support is lacking when it is needed most—during times of increased stress. What is most disturbing is that colleague relationships add to stress, not necessarily by creating overt conflict, but by failing to provide needed support.

Kavanagh (1989) notes that lack of time is the most frequent excuse given by nurses when challenged about a non-supportive environment. However, it could be argued that time spent in complaining about a situation could be put to better use; for example, planning an environment of trust and support. Active listening is a valuable tool in the nurse-patient interaction and could be easily transferred to the nurse-nurse relationship. Larson (1987) points out that nurses often have difficulty disclosing their feelings to other colleagues, especially when these feelings are negative about a patient or another staff member. Concealment of these feelings is supported by the view that nurses are unprofessional if they admit to feeling inadequate (Stein-Parbury 1993, p. 312). Nevertheless, the participants in this study who took the risk of exposing their feelings to other staff members in a supportive environment found they were able to address, through informal sharing, their perceived lack of knowledge or fears of incompetence. Margretta Styles (1982, p. 143) sums up the type of culture needed in nursing so that the intense aloneness experienced through lack of support can be avoided: ‘Collegiality is as sacred as a vow; it is a solemn promise whereby we bind ourselves to those who share our cause, our convictions, our identity, our destiny.’

It is the practice in many specialised palliative care units to include a debriefing session as part of the normal routine of the working day. Some units conduct these
sessions using the available nursing staff, others employ non-nurses, such as social workers or ministers, as leaders or group facilitators. Debriefing sessions can be both emotionally healing and educative. Again, the financial constraints of providing this type of care for health care workers may be perceived as over indulgent. However, I would argue that the health dollar is better spent in fashioning this type of supportive environment, rather than dealing with the cost of replacing staff at short notice.

Allied to providing a supportive environment for staff is the issue of emotional detachment. The participants spoke of the sense of loss and aloneness experienced as a result of the death of a patient. However, many nurses avoid these feelings by choosing not to be personally involved with their patients. This type of aloneness could be construed as imposed as the bureaucratic organisation of a hospital may demand that nurses work understaffed. One participant clearly stated that dying in the critical care area was not beneficial to the patient as the staff-patient ratio did not allow for the increase in nursing time necessitated by such situations. This unresponsive environment fosters detachment, which in turn poses little threat to the issues of professional competency (Stein-Parbury 1993, p. 304).

Several participants spoke of their identification with the aloneness of the dying experience for the patient. Whilst encouraging family members or friends to stay with the dying person sometimes assists in making this experience peaceful, it does not alter that many patients die in unfamiliar surroundings, away from their treasured possessions or pets. Dying in hospital may be the preferred option for many people. However, hospitalisation does not imply depersonalisation. Loew and Rapin (1994), in a discussion on what constitutes quality of life for dying patients within the hospital setting, highlight measures they have taken to individualise care. In the cases they describe, breaking the rules not only gives solace to the patient but also reminds nursing staff that simple measures can be taken to provide meaningful quality of care for the dying person. By attending to the perceived aloneness of the patients, many nurses would vicariously gain:

Jean was an engineer who had helped administer a large railway construction site in the Middle East. From that time on he loved walking. Back in Switzerland he married and had two children, one of whom became a doctor. At the age of 74 he was diagnosed with bladder cancer. He underwent 10 operations and suffered numerous complications. He spent four months in a private room without being able to leave it. During his terminal phase he was transferred to our department where an early discussion revealed he had not been able to see his dog for four months. He was torn between his desire for a walk with his dog
and his respect for hospital rules so as not to bother his son. In this context we wrote a “prescription for a walk with his dog” in the hospital park. A few days later Jean died with his dog by his side (Loew & Rapin 1994, p. 38).

This poignant account reveals how nurses can be active in creating an environment of caring by serious consideration of obvious solutions in the light of the patient’s wishes, rather than submitting to rule-driven, outdated practices which do not ‘rock the boat’ but remain within bureaucratic boundaries.

Finally, aloneness is not always a negative issue. As stated in a previous chapter, many participants valued periods of aloneness in which they could undertake some self reflection. However, if reflective practices are to be of any value, there is a need to educate nurses in these skills. Duke and Copp (1994) concede that awareness of the personal-professional interface can be seen as the key to working effectively with dying patients and their families:

It is for this reason that we see reflection as a crucial tool in enabling students to explore this aspect of themselves in order to begin to address some of the demands that caring for dying patients inevitably brings. While there are potential benefits in this approach to learning, it is nevertheless an approach that is very personal and can be difficult, and sometimes, painful (p. 101).

The negative aspects of the phenomenon of aloneness in nursing dying and dead people is largely the responsibility of all nurses engaged in this type of care. It can be overcome by the development of collegiate assistance and the establishment of a supportive environment for both patients and staff.

**Questioning and nursing practice**

Palmer (1994, p. 1) states: ‘Today’s nurses, more than at any other time, are faced with an increasing obligation to evaluate and improve their practice.’ In accepting this assumption, it could be argued that the participants in this study found questioning all aspects of their approaches to caring for dying and dead people valuable in assessing their own practice and the practice of others. Freire (1972) coined the term ‘praxis’ and defines it as acting on one’s world in order to change it. Furthermore, Freire argues that the two main components of praxis are action and reflection (1972, p. 96). Boyd and Fales (cited in Murphy & Atkins 1994, p. 13) suggest that reflection is ‘the process of internally examining and exploring an
issue of concern, triggered by an experience, which creates and clarifies meaning in terms of self, and which results in a changed conceptual perspective'.

It is clear from these stories that the participants engaged in the two types of reflection as described by Schon (1991), namely, reflection-in-action and reflection-on-action. Murphy and Atkins (1994, p. 13) state that:

Reflection-in-action occurs while practising, and influences the decisions made and the care given, whereas reflection-on-action occurs after the event and contributes to the development of practice skills. Practitioners learn from both types of reflection and these need to be facilitated within a practice-led curriculum.

From listening to the stories of the participants, I would argue that there is another component worth mentioning in the process of actioning reflection: that of questioning. Again, questioning-in-action and questioning-on-action can occur. Both contribute to informing practice and ultimately the discipline of nursing. Questioning-in-action could involve all members of the health care team in the situation of nursing a dying or dead person. Questioning-on-action can be either a team approach or more often occur individually, for example, whilst journalling the experience.

Street (1991) believes that in the busy world of contemporary nursing there is a strong tendency for nurses to switch to ‘autopilot just to complete the myriad tasks which are part of professional practice’ (cited in Palmer 1994, p. 1). Palmer further argues:

There are, however, real problems associated with switching to autopilot, the most important being that when a practitioner fails to consider his or her practice in a thoughtful and critical way, the individual needs of the client may not be met. This may lead to professionals who will increasingly alienate themselves from their clients and their colleagues in order to survive the trials of practice (p. 1).

The search for the absolute truth within the positivist paradigm may prompt only superficial questioning. As nursing turns towards engaging in new paradigm research, the quest for ultimate truths fades and context driven answers become more meaningful. Questioning and reflecting using an interpretive or critical perspective ‘... is revelationary because these perspectives show how knowledge is sought, developed, appreciated and indeed why it may deviate from another view’ (FitzGerald 1994, p. 65).
Accepting and nursing practice

The phenomenon of accepting can be viewed as antithetical to that of questioning. However, in the context of the participants’ stories, accepting could be linked to creating a climate of being non-judgmental in caring for dying or dead people. Being non-judgmental does not imply that challenges to problematic issues in caring for the dying are unacceptable. On the contrary, Stein-Parbury (1993, p. 190) believes that challenges are best presented in a positive manner; one which will not ‘give the impression that patients “should not” think or feel the way they do’. In challenging, it is important to avoid being judgmental in a negative manner as it may be seen by the patient as coercive, victim blaming and punitive.

The nature of being non-judgmental implies that a judgment has already occurred within the challenger; there is a choice. By choosing the non-judgmental approach, accepting others’ choices creates an environment of mutuality and trust. In this milieu, knowledge about a particular issue or event can be respected, shared and discussed and new knowledge potentially generated.

Working in a team necessitates accepting the limitations of individuals within that team as well as the limitations of the team as a whole. Many of the participants in this study alluded to an awareness of their own limitations and those of the institutions in which they work. I am not arguing for complacency, rather the need to develop an awareness of when our personal and professional boundaries have reached their limits, coupled with some undertaking to share this knowledge with others.

Finally, it is worth considering the issue of acceptance of change for nurses and nursing practice when caring for dying and dead people. The registered nurses in this study related the changes in practice which span their individual careers and resultant personal and professional learning achievements. Lumby (1994, p. 6) speaks in favour of nurses being the agents of change when she discusses nurses’ involvement in research into the experience of illness. She further contends that nurses are well placed to undertake such research as they are with the patient for the greatest amount of time and are privy to their perceptions of inadequacies in the health care system. It is obvious the way forward for nursing involves reflecting on our experience, sharing our knowledge, and accepting new challenges. Nursing dying or dead people may appear to be a daunting task; however, Penson’s (1990, p. 164) summation captures the ultimate goal:
The pain of bereavement is the price we have to pay for loving; so that, though it is costly, it is not too dear, since the experience of losing what you have loved and grieving over it, is a challenge, to learn more about yourself.

Whilst Penson had bereaved relatives in mind when she wrote these words, I find them equally applicable to nurses as they struggle to achieve excellence in care of the dying.

**SOME INSIGHTS FOR FUTURE NURSING RESEARCH**

As nursing dying or dead people becomes a priority on the health care agenda as the incidence of people suffering from terminal illness increases, death can no longer reside in the confines of invisibility. Death awareness may well be elevated to a position of priority in the carative practices of nurses. This situation would necessitate further studies with nurses. Further exploration to uncover the meaning of the nexus between personal and professional grieving when nursing dying or dead people may assist nurses to develop better coping mechanisms, reduce stress and lessen burnout. Given the personable nature of nurses' responses to caring for dying or dead people, research methodologies which reflect this experience are of most value. Qualitative research using the interpretive or critical paradigms lend themselves to describing, interpreting or challenging changes to the nature of this work.

Additionally, future research is necessary with people who are receiving palliative care. People with a terminal illness who are facing death are increasingly electing to receive this care at home (Clark 1993). The present paucity of palliative care services in the home, and the debate as to whom, in health dollar terms, should be providing this care, has led to a degree of mediocrity in service provision (Clark 1993). Expansion of hospice services into the community is largely a metropolitan advance. Rural or remote palliative care practices are presently not well represented in outlying communities. Allied to rural practices, there is little research on the care of the indigenous Australian who lives in remote areas and suffers from a terminal illness and elects to die at home.

Finally, the literature on death awareness is largely American or European in its origin. The Australian way of death could be viewed as an amalgamation of these stereotypes. Research into how Australians construct death and dying would be a
useful adjunct for planners to provide visionary health care which is representative of the diversity of the current Australian culture.
Epilogue
This epilogue is an accumulation of the researcher's reflective processes undertaken during and on completion of this study. Firstly, I will reflect on my experiences as a researcher immersed in the research process and highlight some issues for change in future, similar research. Secondly, I will discuss some of the personal and professional changes experienced by the participants following their involvement in the study. Finally, I will conclude with a description of my perceived changes, both personally and professionally, and look towards the future.

In the Prologue of this Thesis I outlined how I came to be interested in the phenomenon of nursing dying or dead people. My passion for understanding this area of nursing practice has increased as I have journeyed through this research process. In turn, my interaction and personal reflections with the research have informed my own practice of teaching nurses about nursing dying and dead people.

If I was asked to provide a brief description of my journey through this research process I would have to say that I found it exciting, liberating, challenging and incredibly frustrating. Balancing my life-work program with study is not a new concept for me, nor is it for many nurses in similar circumstances. The opportunity for full-time study in nursing and in the academy is contingent on the interrelationship of many issues, including: personal finances, the availability of time release from the work situation, professional support, family support, supervisory support, resource materials and, in this study, the cooperation and collaboration of twelve working registered nurses. In my case, full-time study was not available and lengthy periods of application to the research were made possible by short periods of study time; accumulation of holiday leave; supportive persons in the work place, such as the Head of School; my immediate family and friends, the accommodating manner of the twelve registered nurses; and two supervisors who constantly challenged me as I worked through the research process.

The pathways towards this research were marred by many obstacles. The focus of my initial research concentrated on educative issues surrounding dying, death and nursing. Approximately one year into the research my home was burgled and several computer discs and hard copies of the initial research were stolen. The work was lost and to replace it proved to be a formidable task. I spent many
months grieving over the loss of this rich data and after speaking with my on-site supervisor I formulated the present research initiative. Researching lived experience allowed me to travel the pathways of the interpretive paradigm and become familiar with the works of Heidegger, who was known to me only through the works of contemporary nursing scholars.

Understanding Heidegger (1962) led me to read the works of Husserl (1970) and other phenomenologists. Whilst undertaking research for a work project, I was introduced to van Manen’s (1990) account of researching lived experience. Reading van Manen’s book Researching lived experience (1990) and talking with other nursing researchers led me to become familiar with Merleau-Ponty’s (1962) phenomenology and its focus on the body. I had a feeling that the work of these philosophers was assisting me to shape this study. After securing the collaboration of the twelve registered nurses and beginning the process of gathering their stories, I was excited by the prospect of using an amalgamation of the methods outlined in the various methodologies I had been uncovering in my search through phenomenology.

Transcribing tapes and working with narratives of the participants was a lengthy process. The electronic media used in this study was rather outdated by today’s standards, yet this crude adaptation of technology enabled me to become fully conversant with the participants’ stories. Listening to the taped recordings necessitated a very quiet and private room and unfailing patience as some of the recordings were difficult to hear because of excessive background noise. On reflection, if I were to undertake a similar study I would invest in ‘state of the art’ equipment and ensure that the interviews were conducted away from distracting noises, such as traffic, small children, telephones and busy work places. Similarly, the use of suitable foot operated electronic play back devices in a sound proof room would be preferred. Nevertheless, the equipment used in this study did permit me to be fully immersed in the stories.

I was overwhelmed by the cooperation and collaboration from the twelve participants who agreed to be involved with me in this study. Each person had their own individual qualities and each told their story in a unique style; however, a common bond was formed between them and myself as the stories unfolded. Each story brought another dimension of understanding nursing in the context of care for the dying. Each story was a personal journey in itself for the participants, and mirrored the professional journey of nursing through the dimensions of time.
On the whole, I felt the participants needed to tell these stories as some personal release. Subsequent feedback from several participants has confirmed that changes have occurred in the way they relate to dying people. The action of telling their stories has been liberating for these nurses and will be useful to others involved in similar caring situations. The stories provide excellent examples of the myriad of emotions usually expressed by nurses when caring for dying and dead people and will be most useful for beginning students and registered nurses as they move into the clinical arena.

Throughout writing this Thesis I have maintained contact with the participants. Without doubt, all of these registered nurses continue to be supportive and encouraging and keen to see the work to its finality. This study has been conducted over a period of two years and many changes have occurred in the lives of some of the registered nurses, which they generously attribute to being involved in the study. Prior to moving to another state, Jane’s grandmother died. I felt privileged when Jane invited me to share in conversation during her grieving process. Joseph is proceeding with higher degree studies in the area of palliation and nursing. Ann has started a new life following the death of her husband. She is emphatic that her involvement in this study helped her through her grieving and made her aware of her own strengths. Whilst Gloria is continuing in her role as a registered nurse, she is pursuing an interest in grief counselling and hopes to be able to use these skills with nursing staff in the workplace. Sarah’s interest in critical care has taken on a new dimension. She is actively working towards the inclusion of a palliative care in-service education program for the staff working in critical care. Following on from her interest in death and children, Penny has become an active member of her local Stillborn And Neonatal Death (SAND) group. Whether these changes have occurred as a direct result of being involved with the study or not, I feel part of the empowerment processes which have motivated these people to widen their awareness of the issues surrounding death and dying.

Experiencing this study has been a catalyst for change within my own personal and professional life. As I began writing this Thesis, my mother died. She had been living with me for eighteen months prior to her death. Although her health was continually failing and her death expected, the finality of the death event was painful, sad and distressing. However, before her death I had shared the experience of the twelve registered nurses telling their stories. The collective nature of their approaches to personal death experiences, coupled with the
knowledge gained from my own experiences, provided stalwart support during my grieving. There is no doubt that I miss my mother and her unsolicited counsel. Nevertheless, the lived experience of being-in-this-study has allowed me to look at death from twelve differing perspectives and find some solace and comfort when the pain of grieving visits my door.

As a lecturer involved in teaching aspects of care for dying patients, my experience in this study has informed my practice. Prior to the study, I would approach tentative or grieving students with the feeling that I had the answers to help them in their distress. Since listening to the participants’ stories I am aware that I do not have all the answers and my interaction with grieving students now focuses on listening and being-with them in their distress. It is a softer approach and one which permits the student to journey through their grief experience at their own pace.

As a researcher, phenomenological methodology re-awakened my questioning nature to look beyond the obvious to reveal the essence of experience. I have used the metaphor of peeling an onion to equate with analysing data in this research. As each layer of the onion is peeled away, another layer is confronted. Subsequent layers are tighter and sometimes difficult to peel away. At the centre of the onion is a perfect bulb formation which reveals how the previous layers have been established. Transferring the metaphor back to the research, the bulb represents the essence of the experience. As an aside, peeling an onion usually brings tears if the person doing the peeling does not have the skills which help avoid such a dilemma. At the commencement of the analysis stage of this study, I shed many tears grappling with my search for meaning. I am grateful for all the assistance given to me by my on-site supervisor and research students of the academy for their patience and guidance during this phase. The temptation to go with the obvious, rather than continuing to search for the underlying meanings, was compelling. Nevertheless, with the help of my colleagues, my determination was enhanced and I resisted what could be seen as the easy way out. Using the interpretive approach in this research has confirmed my belief that the discipline of nursing can benefit from developing and undertaking research projects which focus on meaning making.

Death and dying remains a passionate research topic within my being. I feel very strongly that my future research will involve questioning nursing care from the dying person’s perspective. The specific focus for a future topic, or the
methodology I will use, is not yet clear. However, I feel confident that when I have finished grieving the loss of involvement in this Thesis, a new, exciting and challenging research project will be revealed.
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Appendix
APPENDIX A

PLAIN LANGUAGE STATEMENT FOR PARTICIPANTS

The Lived Experience of Nursing Dying or Dead People
Investigator: Ysanne B. Chapman RN

The purpose of this study is to increase nurses' understanding of the experience of nursing dying or dead people. 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 your feelings about nursing dying or dead people. These tapes will not be shared with anyone else and when I have transcribed them I will send you a copy for your own interest and validation.

The topic of each story 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 sessions together, I will undertake to cease recording and 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.

Any questions concerning the research entitled "The lived experience of nursing dying or dead people" can be directed to Ysanne B. Chapman of 124 Mann Street, Armidale, NSW 2350 on (067) 725849.

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 abovenamed 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