

**BODY BOUNDARIES AND DISCURSIVE
PRACTICES IN LIFE THREATENING ILLNESS: NARRATIVES OF THE
SELF**

by

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**A THESIS SUBMITTED TO THE VICTORIA UNIVERSITY OF
WELLINGTON**

in fulfilment of the

requirements for the degree of

Master of Arts

in

Nursing

Victoria University of Wellington

2000

Abstract

This thesis tells a story from within and between the boundaries of my professional work as a nurse and my private life as the wife of a patient with life threatening illness. The events related in the thesis are told using a technique I have called writing back to myself, where my own journals and stories of the experience of living with life threatening illness provide data for analysis. The reader is invited to participate in these representations and to consider the potential for the skilful practice of nursing which may be read in the stories, and the analysis I have developed from them. I have developed the theoretical and methodological positionings for the thesis from the work of Foucault (1975,1979,1982,1988), Deleuze (1988), Ellis (1995), Richardson (1998) and other writers who utilise genealogical or narrative approaches.

The analysis of my own stories in the thesis explores the philosophical and contextual positionings of the nurse as a knowledge worker through genealogies of practice and the specific intellectual work of the nurse. Local and contextual epistemologies are considered as ways of theorising nursing practice through personal knowledge, which is surfaced through the critical analysis of contextual positionings and the process of writing as inquiry. The idea of harmonising nursing practice in the patient's local world through contingent and thinking responses, and the recognition of one's own agency as the nurse, are considered in terms of what might constitute ethical practice. The thinking nurse is a specific intellectual, who critically engages with the context of her/his own practice to form new discourses derived from local and contextual 'truths' about illness, suffering and dying. The capacities for vision that are developed through the stories in the thesis, are explored as having the potential to present new possibilities for the practice of professional nursing.

Notions of what constitutes ethical practice are negotiated and contested through local conversations, which privilege the capacities of the patient and the nurse in taking up new discursive positionings as alternatives to those prescribed through the sovereignty of expert power. In the local and contextual world of the patient, visions for practice may be negotiated moment by moment through careful exploration of discursive tensions and the critical appraisal of the utility of alternative possibilities. This

development of local knowledge relies on the ability of the nurse to explore and trust her/his own judgement and nursing responses in situations where visions for practice may not be clear. The ‘un-picking’ and ‘re-sewing’ of stories related in the analysis of the discursive production of the cancer patient and the ‘private nurse’ present new possibilities for the ethical substance of nursing. This ethical substance creates the potential for new conceptualisations of practice, where nurses and other health professionals take responsibility for the effects of their activities with patients. In this ‘un-picking’ of the stories in the thesis, I am concerned with the discursive positionings that are taken up by the patient and the health professional in the story. I identify the means through which subjects become visible in discursive statements and the effects of these subject positionings on specific moments of practice with the patient. The ‘re-sewing’ of events involves the telling of alternative stories, negotiated between the actors in the events, to produce a more ethically desirable outcome in the specific contexts of nursing practice.

Acknowledgements

This thesis is derived from my personal experience of caring for my husband during his illness and subsequent death. The stories of events, which we shared together, provide the data for the analysis. While I commenced this thesis during the year following Kevin's death, I am profoundly grateful for the years of support he gave me in undertaking my studies before his illness. I continue to live with the technological gadgets he invented to assist me, such as the purpose built computer designed especially for my studies. I am also grateful to our son for teaching me how to use these gadgets, and for upgrading my computer when Kevin was no longer here to assist me.

The memory of the support given to us by Kevin's parents and sisters through the difficult times during Kevin's illness and following his death will remain with me always. My parents, and brothers and sisters also surrounded me with their incredible care and support, and remind me that I am well loved. They have given me continuing support and encouragement in undertaking this study. My colleagues at The Waikato Polytechnic have been unconditionally supportive throughout my husband's illness and the writing of this thesis. In particular, Rose McEldowney, Trish Wright, Brenda Paton, Lyn Dalton, Bet Ineke, Judi Honeyfield, Peggy Nawalaniec, and Dawn Walsh. I am particularly grateful to Swarna Lecamwasam for her critique of my writing.

My supervisors, Pamela Wood and Elaine Papps, were truly inspirational. I thank them for believing in my project and me and will treasure the hours we spent together in supervision sessions, where they pulled and pushed my ideas and shared their own favourite references with me. The staff in the Nursing and Midwifery Department at Victoria University of Wellington is also exceptional. Alison Dixon, Margie Martin, Cheryle Moss, and Margaret Southwick, along with visiting scholars Penny Cash and Jackie Crisp, have created a unique and inspirational learning environment with their students. I could not have hoped to work with a more caring and professional group of nurse scholars. I would also like to thank my student colleagues who offered stimulating discussion, unstinting support, and great fun. You taught me to appreciate

your different points of view and research approaches, and you actually believed I could do this study.

Finally, I am indebted to the support given to me from the Department of Nursing and Health Studies at The Waikato Polytechnic. This support has included partial payment of my fees while I have been enrolled in the thesis programme at Victoria University of Wellington. As well, the Department has fostered a spirit of learning in ensuring that I was able to take leave owing to me, to complete the thesis.

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CHAPTER ONE

HISTORICAL POSITIONINGS FOR THE STUDY

Introduction

This chapter sets out the background and location of the thesis and introduces the reader to the ideas that I have developed through my reading and reflection on the research topic. I have developed the theoretical and methodological positionings for the thesis from the work of Foucault (1975,1979,1982,1988), Deleuze (1988), Ellis (1995), Richardson (1998) and other writers who utilise genealogical or narrative approaches. I show how the development of this thesis represents a journey through the experience of life threatening illness. The thesis is informed by my personal experience of caring for my husband (Kevin) as well as references to literature, which support the analysis and interpretation of the situations that will be presented. Some of the ideas presented in this chapter will be further developed in terms of description and analysis in the following chapters.

Telling the story in writing back to (my) self

The romantics would call this a love story; the cynics would call it a tragedy. In my mind it's a little bit of both, and no matter how you choose to view it in the end, it does not change the fact that it involves a great deal of my life and the path I've chosen to follow (Sparks, 1996 p.2).

These well-crafted words by Nicholas Sparks are useful in considering my journey through the writing of this thesis, which tells a story from within and between the boundaries of my personal and professional life. My own narratives and journals provide the data for this scholarly work. The reader is invited to participate in the representations I have constructed around this experience of life threatening illness, and to consider the potential for the skilful practice of nursing that may be read in these representations. Some people might read this text as a love story, though my feminist values rebel against such romantic notions. But as I think about this, the story

does involve the lives of two people who met as teenagers and stayed together for half a lifetime, and perhaps Kevin's illness and dying gave our relationship an intensity that others might not experience. I think there was something very special in living this experience together and some people might call this love.

Other people might read this as the story of a professional nurse caring for her patient. I think this is also true for it is the path I have chosen to follow in my life, and I could never absolutely delineate between my professional knowledge and experience and my personal positioning as the "patient's" wife. And yes, it was a tragedy that someone only half way through his life had to die when he had so much to live for. But most of all, I think this is a story about life and its fragility; its joys and sorrows and the fact that some things are inevitable. In coming to understand that Kevin's dying was inevitable, I found my own agency in being with him through this. This sense of my own agency, in choosing to act in certain ways and to understand events as having particular meanings, gave me a strength that was profound. The telling of this story, and the analysis of it in both personal and professional terms, is derived from this strength.

The text in this thesis is multi-voiced (Lincoln, 1997) rather than presenting a linear autobiographical accounting of events. My multiple, and sometimes contradictory, positionings in different discourses are represented as different voices which shift and change with time. The text becomes circular as I talk back to myself in the recalling of particular events and my reading of them in relation to ideas drawn from the theoretical writing of other authors. The italicised text of personal narratives blends with the academic writing of the professional nurse and the references to literature. This blending is in turn disrupted, as one text interrupts the other, and where the personal intrudes into the professional and vice versa. The authority of my own analyses and those of other writers are held up for scrutiny through my writing as a method of inquiry. In undertaking this inquiry, I have become the archaeologist who excavates the sites and sources of knowledge and the archivist who deals with

statements and hidden discourses (Deleuze,1988). As the genealogical inquirer I have become the cartographer who maps the topography (Deleuze,1988) of knowledge construction and the ways in which such constructions are maintained. In working as the genealogical ethicist I am created as the specific intellectual (Blacker,1998) who is concerned with issues of representation and the effects of my practice in the local world of other people.

The view from within/between the boundaries

My interest in body boundaries and technologies of health care has developed over the years through my academic work in poststructuralism and reflection on practice experiences with patients and students. This reflection challenged my previously taken for granted assumptions about the ways patients' bodies, and health care needs, have been constructed and represented in discourses of medicine and nursing. Recognition of other possibilities for understanding the positioning of patients as people, albeit as recipients of health care inside these discourses, influenced my practice with patients and students in the institutions of health care and education. As a nurse educator, I began to teach students how to work within the discursive practices of pathological-technological health care and at the same time to look for, and work with, the ways in which their patients took up alternative discursive positionings. I had come to understand that intersections of, and tensions between, the discursive practices of health care and social constructions of the patient's body, produced sites of contestation and accommodation.

This concern with the discursive practices of health care was to move beyond a merely professional interest in the situations that arose in my practice as a nurse educator. In 1993, my husband developed a primary melanoma, which rapidly progressed through secondary and tertiary stage diagnoses. Over four years I watched him move from a reasonably willing submission to the discursive practices of health care technologies, to a very clear understanding of his own agency. In closing off the

boundaries of his body to the medical gaze, Kevin repositioned himself as a healthy person. He reformed himself as a person with a life threatening illness who was capable of living his life on his own terms and with a sense of wellbeing and peace.

As his illness progressed, and he was required to seek interventions to manage complications arising from the pathology, he did this on his own terms. He resisted the lure of biomedical discourses and their ability to cross body boundaries and track the minute progression of the disease. My work in grappling with the potential of poststructuralism for nursing knowledge helped me to understand and support the choices he made about managing his health and using health care services. Given that melanoma, once it has developed to the tertiary stage is incurable, Kevin chose not to use medical diagnostic and therapeutic approaches until these were essential for comfort measures in the palliative care stage. I think this denial of access to his body was associated with containing a sense of self, in what otherwise could have been an overwhelming image of himself as a diseased being, privileged only in his relationship with medicine as a subject of pathology.

During the time we were coming to terms with the diagnosis of melanoma secondaries, I read a narrative written by a surgeon who had diagnosed his own brain tumour. This narrative focussed my attention on the terrifying realities for a person experiencing life-threatening illness.

And I was terrified. I did not know how to do this. I have seen patients die. I have been there when the life went out. But me! I do not know how to do this! I'm not ready. Who will help me understand what is happening? Who will be with me along the way? Where am I going? I looked for hope, and I looked for help..... (Visnick in Peterson,1994 p.81).

Visnick's narrative brought home to me the fact that there is no "safe conduct", no cure inside scientific medicine, for the person who knows they are dying. Thus to be loved, cared for and connected with people who are supportive and healing become centrally important aspects of this person's life. As Liaschenko (1998) puts it, nurses understand that the promised cure of medical discourse is sometimes an illusion.

People live their lives within their own everyday existence, centred in their own community, while medical discourse and scientific technologies speak a different language; one that has the power to reconstruct this everyday existence. For Kevin and me, living our lives inside this diagnosis of melanoma made us rethink our priorities and values and the ways in which we understood we could respond to this situation. We sought a path through this journey to Kevin's dying and to understand the enormity of it. As health professionals this experience of life threatening illness was both foreign and familiar, and as a personal experience, incredibly frightening. This was a journey into the unknown as we had real understanding of how the pathology of the disease would manifest and what impact it would have on his functional ability and emotional and cognitive states. In a personal and professional sense, the presence of nursing became a critical reference point. It was a means of gaining direction "in the dark".

In the final weeks of Kevin's life we prepared ourselves to work together in a supportive and peaceful way. In an effort to understand how other people had endured such experiences, I began reading stories that illustrated the hardship others had experienced in life threatening situation and their courage in facing what they knew would be the likely outcome.

Had we lived, I should have had a tale to tell of the hardihood, endurance and courage of my companions which would have stirred the heart of every Englishman. These rough notes and our dead bodies must tell the tale (Robert Scott, Antarctic Expedition 1913, in Bowles, 1995 p.365).

Scott's narrative spoke to me of hardship and endurance, loneliness and fear, isolation and connection, and courage in the face of an ultimate struggle. It reminded me that while connectedness and caring was central to our existence, the capacity to endure was also important. This endurance meant getting through each day, hour by hour, in Morse's (1996) terms, focussed intensely on the present. We were unable to look into the future because the future was to bring an outcome we both dreaded.

I also drew on my practice background, in particular the experience of nursing people who were dying. The following exemplar from my nursing practice journal was written over ten years ago. I remember reading this exemplar at the time Kevin became ill. It made me think about the ways in which I might work to support him and manage the practicalities of his dying along side family and our community of friends who were so concerned for him.

...I had been asked to care for a man who was dying at home. When I arrived at the farm homestead, all of his family was there, his wife, his sons and daughters and their partners. I was struck by how well organised this family was. The husband/father was in a bedroom off the large living area, where family members were sitting around talking. He was unconscious and unresponsive, but looked comfortable and well cared for and there were several family members sitting with him. At first I couldn't work out why they needed a nurse as they were managing his physical care very well, and had been for some time.

And then I understood that this family wanted support through the final stage of this man's illness and dying. They could manage his physical care but they did not know what death looked like or what to do when the time finally came. It was the presence of nursing that they wanted to guide and support them, to pull the threads of the final stage together. I also understood that my presence here should not disrupt the patterns of care that the family had developed, so I worked with the women of the family in the giving the physical care and medications.

At first I felt a little disoriented by the degree of family involvement in his physical care, but working with hospitalised children had taught me to take a step back and coach the parents in giving care. I had come to understand that many children preferred the comforting and familiar touch of a parent.

And so, as the night wore on, I came to know this family through my presence in this man's circle of care. As they sat around the living area, they started telling stories about their father, going back over the years recalling the times on the farm that had been significant for them. This large and very expressive family included me in their caring, offering food and drink and expressed their concerns about my comfort. They asked questions about the process of dying, what they could expect to see and probable time frames.... they wanted to know, understand and be involved in this process.

For some time during the night I became the person the family told their stories of their history to, perhaps a kind of family friend. I was touched by this family's ability to live the pain and grief of losing their father and at the same time to celebrate his life. In this sense they taught me about respecting unique the ways that people negotiate such life experiences. At other times I was the professional nurse who could tell them what was happening in this process of dying by drawing on scientific knowledge about changes in breathing and circulation. I could comfort them by assuring them that their father did not appear to be in pain, and by coaching and supporting them to touch and be with him.

Somehow I knew when he was going to die, so I called the family together, and they stood around his bed holding each other and farewelled their father/husband. Then we talked about preparing him for the next stage of his journey. They had said that they wanted to keep him at home for a few hours, until they were ready to part with him... so I arranged this with the undertaker. I explained to them that I had been taught to wash and change the clothes on the body after someone had died, as a sort of final caring act, and they thought this something they would like to do.....and it was the sons who wanted to do this.

So we organised them with a bowl of water, towels and clean pyjamas, and they washed him and changed the clothes on their father's body..... talking to him about how he had undressed them and put them to bed when they came home exhausted or drunk....and I think they expressed feelings and touched him in a way that they might not have been able to when he was alive. This was a unique moment of caring, a way of being that touched me deeply.

This narrative represents the ambivalence, uncertainty and confusion present in entering a new field of practice where I experienced tensions between the sense of needing to do something and the recognition that the usual doing was not sufficient. The family wanted my presence as the professional nurse but also related to me as a person, a sort of new-found family friend. For me this illuminates the central importance of understanding the gaps or moments where a nurse may intercede peacefully, preserving a sense of agency in the recipients of nursing care; working with them moment by moment and respecting their unique ways of managing such life events.

This journey through my husband's illness and dying surfaced some critical issues for me in relation to the practice of nursing with patients who are experiencing life threatening illness. Some health professionals had advised me to remember that I was Kevin's wife and not his nurse. I had difficulty imagining where I might begin to draw lines between the multiple and contradictory positionings of wife and nurse as I was always/already situated in the discourse of nursing. In reality I had to be whatever it was that Kevin wished me to be. This experience involved the crossing of personal and professional boundaries in ways that made me realise that our reality, rather than considering these two positions as binary opposites, concerned negotiating the intersections and managing the tensions between them. As a professional nurse and wife/partner I was uniquely positioned in a way that moved the (my) nurse's gaze from "the body as an object of medical intervention to the body of someone who is living a life" (Liaschenko,1998 p.16). I began to think there were other ways nurses could support this negotiation between the roles of partner and professional nurse; in particular approaches that did not involve the exclusion of prior professional knowledge and experience for either the patient or family members.

I was always/already positioned in the discourse of nursing. I could not deny my recognition of liver failure as I read the clinical signs of the pathology visible in my husband's body. The evidence of the pathology was not unexpected and yet I clearly understood the implications for his life and mine; for the loss of our relationship in his dying as well as the ethical issues involved in supporting his desire not to be told such things about pathology. This 'inside-out' positioning as a nurse highlighted the ways in which we as nurses manage the 'abject' (Kristeva,1982 ; Wiltshire & Parker,1996) in our practice. It may be that nurses manage the uncanny and horrifying aspects of their work through an understanding of their own agency with the patient. This notion of containing the abject may give rise to a potential for understanding how nurses may construct compassionate and caring practice within the lived reality of the patient's situation.

I also gained new insight into the ways in which powerful health care technologies, such as diagnostic imaging, surgery and highly technical pharmacological approaches, may work to alienate a patient from their own body and own experience of life. In particular I was interested in how the self "... constituted and reconstituted relationally, its boundaries repeatedly recomposed and renegotiated" (Scott,1987 p.17; Dawson,1998 p.169) risked being engulfed by these health care technologies that penetrated body boundaries and exposed the pathology with representations outside the body. Through this visual imaging, and the interpretations of it within scientific knowledge, the body was seemingly turned inside out, privileging the disease process and its association with mortality.

For my husband, who refused to look at such representations and to speak about them in relation to his own dying, this refusal could have been constructed as denial. Thinking about this idea of denial made me question the association we as nurses make between the pathology people have and the imperative to accept the fact they are dying. In this sense we construct the notion of a rational death. At this point, concepts such as denial, acceptance and non-compliance became problematic for me in what I understood as a situation that a person is likely to negotiate on their own terms and in their own unique way. As nurses we risk colonising the patient's 'self' through our own 'institutional authority' in ways that may produce anguish for the patient as a person who is dying, but still living a life. Furthermore, I came to understand the extreme vulnerability that patients and their family's experience in such situations and this understanding went beyond what is usually possible in terms of the professional empathy we offer our patients. As a professional nurse and wife/partner I was uniquely positioned in a way that highlighted enormous potential for the compassionate and caring practice of nursing.

This thesis tells the story of my husband's journey through life threatening illness and my experience of caring for him. I use Liaschencko's (1998 p.12) notion of testimony; or "bearing witness to the event about which one then speaks" in an effort to bring the

personal experience of illness, and its intersections with the discursive practices of health care, out from under cover as a private experience. In this way, I illuminate the 'attentive gaze' (Murdoch,1985; Liaschenko,1998) of nursing to reveal the personal experience of illness and suffering in a life threatening situation and my personal/professional work as the wife/nurse. As an autobiographical account this study creates a narrative of the self, and as such represents another way of understanding an experience of life threatening illness. It potentially unsettles the truths (Kosta,1994) that define our identity when we are subjected to the discursive practices of health care.

My philosophy of nursing as a journey through time

I was never going to be a nurse. People said I wasn't the right sort of person, I was too outspoken, and according to one teacher, too "headstrong". I also didn't like the idea of having to wear a uniform and take orders. The idea of working in an institution certainly did not appeal to me, a convent boarding school had been an experience I did not wish to repeat. I have vivid memories of the anti-Vietnam and other "demos" of the early nineteen seventies.... of seeing Tim Shadbolt in a demo at the Auckland Town Hall. I imagined myself destined for something academic and activist. I had always thought I would be a teacher, but the idea of re-entering the education system when I had just escaped it was more than I could tolerate. University held a strong appeal for me, but I couldn't imagine what I would do at the end of three years of study. In the end, I sort of fell into nursing because there didn't seem to be any other viable option that would give me a career and financial independence.

And so I became a nurse. In retrospect, I cannot imagine having done anything else because nursing has given me opportunities that another career may have limited. I have become a nurse, a teacher, in some ways an academic and perhaps an activist as well. Becoming a nurse was not an easy process for me perhaps because of the tensions I experienced between my early life and the demands of institutional nursing. It is likely that my father's stories about being nursed after he was wounded during the war formed my early understandings of what nursing was about. As well, my mother had wanted to train as a nurse at the beginning of World War Two and always regretted that she had allowed her parents to influence her against it.

.....I guess that when I think about my mother coming from her very religious but also liberal kind of feminist background, she instilled an education value in me, and also the need to have a career. My father was fairly socialist in a political sense, a soldier in World War Two, a prisoner of war, and avid reader and story teller, and he taught me a lot about personal reflection..... about finding meaning in experiences. Here was this man who had been a soldier, who had experienced extremes of deprivation..... My parents taught me that to have respect for people was one of the most important things I could ever learn. They believed in children learning through experience, through interpretation.... through stories if you like.... and they instilled in me an understanding of my own capacity to act.

My first year as a student was particularly problematic as I struggled to come to terms with new experiences that were to be formative in teaching me about what nursing was not. In thinking about this first year, my experiences on a geriatric ward were significant because I experienced an enormous gulf between the caring I had learned within the context of my family and the institutionalised caring of a health care setting.

I was working on this geriatric ward..... and this was my first ward, straight out of prelim.... I guess that my family background was significant in coming into a practice situation in nursing where I felt that the patients were treated less well than animals, where I felt so overwhelmed by having to work with these patients, and so unsupported that I bathed them and fed them and didn't even have the capacity to talk with them..... So here I am on this geriatric ward, caring for people.... who I really feel I'm unable to care for.... here we were doing activities and I couldn't find any meaning in it. I think this first year of my nursing training taught me about what nursing is not. It taught me that nursing is not about doing activities that do not take account of other people's humanity, that humanity and recognising the humanness of other people has to be critical in nursing practice.....I don't believe nursing is about appropriating people's dignity and integrity or putting them at risk through our own ignorance or prejudice or lack of judgement or understanding.

This early experience of becoming a nurse was an enormously stressful time for me. I remember being constantly on sick leave with illnesses that I had never had before. I also have a recollection of visiting a friend's mother who had been admitted to a

surgical ward, where I had to leave because I experienced a panic attack on seeing her in a bed with the same hospital linen that was used in my geriatric ward. The really sad thing was that we had no where to take these feelings and fears. The only formal support offered to students was from one of the hospital psychiatrists, and I could not see this as an option. The relationships between student and registered nurses were intensely hierarchical (even between intakes in the same year) and therefore did not offer much possibility of support. In those days we really were afraid of the ward sisters and even of the senior student nurses.

These hierarchical and sometimes abusive relationships seemed to promote an agonistic passage into nursing (Bradby,1990) where we had to prove ourselves in order to earn status in the hierarchy, overcoming obstacles in the same painful ways as other nurses before us. The structural dominance of this institution was such that many ward sisters really did “eat their young” (Bent,1993 p.298). In a sense I found myself caught between my personal values and my practice that I perceived as full of meaningless ministrations under the surveillance of my superiors. My hands were nursing people, but there was no healing connection in this practice - to my heart or my mind, and this feeling of being incapacitated was painful. And yet, if I was to become a nurse, I had to work through this. Somehow, nursing had become important to me and it was not something I could walk away from.

So I guess that over the period of a year or so I managed to come to some kind of understanding with myself, where I believed if I did my very best as a nurse....then that was all that I could do..... So I learned that my capacity to act was to be a really excellent nurse and this was a matter of survival.

I don't remember actually coming to a decision about how I would go about this business of surviving, as this transformation into a reasonably competent nurse was only something I could see in retrospect.

..... it must have been a process that I worked through over a period of time, and then maybe tried out a few tactics and found that they worked. I also needed a period of time to gain some experience and a

little bit of expertise... and a little bit of courage, to be able to experiment a bit.....about..... finally getting the courage together to say, okay, how am I going to deal with these ward sisters, and actually going and fronting them and saying, “OK, I’m new on your ward. How do you like things done?”, like I don’t want to be taken unaware here.... and so it was about survival.

Gradually, over a period of a year or so, I started putting aspects of practice and knowledge together, and started to make sense of things. By my second year as a student, I was starting to gain some satisfaction from my practice and was able to make connections between the work of my hands, the feelings in my heart, and my knowledge about what I thought nursing should be.

On from there over the years, I’ve developed some very personal values about what nursing is.... and I guess this is baggage that I carry into my role as an educator.... I’m sure my students could stand up and tell you what is important to me. So I believe in nursing being nurturing in terms of fostering growth, fostering development, movement towards wellbeing.....I see nurturing as also mediating the environment, creating the conditions for growth and healing..... I see caring as involving compassion and compassionate acts, recognising people as unique human beings.... connecting with them and working with them, and offering comfort. I imagine nursing as a lifetime human journey where, as one travels through the world of nursing, we become connected to accumulation of knowledge, wisdom, and creativity; connections that travel from the past and into the future.

For me, the central concerns of nursing are compassion, concern, and care for people where the healing power of nursing is embodied in “personal contact, attentive listening, skilful responding, careful touch and the creation with the patient of new hope” (Basford & Slevin,1995 p.50); or a dignified death surrounded by love and care. These values and concerns extend beyond the professional boundaries of nursing and into the blurred lines between my private and professional lives.

A few years ago my elderly aunt was admitted to hospital with a severe stroke. The family was told that she was dying, so I took my parents to see her. As a nurse, I had become accustomed to caring for dying people, where the ministrations of nursing can help to make this passage a peaceful and inclusive experience, but I was unprepared for my intensely personal response to this situation. This aunt had been

particularly significant to me... and I am not sure I can explain the reasons why. I remember her lying on the bed in her hospital room, facing the window. In the view from the window the mountain was clearly visible, and I could imagine the homestead farm high up near the bush line, where she had spent most of her life. As I looked at her lying in this bed, I had a sudden vision of her.... when I was a child.... and she was working in the kitchen, setting the table for dinner.....

.... and it had been a wonderful day.... and our cousin had led all the children on an adventure to climb the mountain. It was Winter, and our bare feet were stung with cold as we climbed and climbed, up through the bush to get to the top of the mountain... and the big kids helped the little ones... piggy-backing us some of the way. And when we got to the top, our feet numb and our breathing ragged, we marvelled at the view... you could just about see the whole world from up there.... and there was snow..... and then the race to get home before dark, arriving at the homestead when dinner was almost ready..... and our aunt telling us in her sternest voice to get washed before dinner.

Returning to the homestead for dinner was a homecoming, to the warmth and security of well-known and well-loved things after the risks and adventures of the day. In my aunt's hospital room, this experience reminded me of my sense of connectedness with people and the world, and also, that this connectedness has its joys and its sorrows. I had an overwhelming sense of impending loss and a feeling of time, having moved on. The healing power was being there with the family and working through this experience of loss. Within the circle of my family I was both the nurse and the niece/cousin. My expertise was called upon to assist in her care and to offer support, but there was a difference here in that I was not primarily acting as the professional nurse. That role was fulfilled by a third year nursing student.

When Luana (fictitious name) first came into the room, I couldn't work out why she was there..... and then I understood that she was my aunt's nurse... and she was a nurse who confidently centred her whole attention on my aunt's care. There was something in the way she spoke to my aunt, the way she touched her, that said she was there with my aunt..... in a way that reflected her capacity to think, feel and do, this practice of nursing.

I believe nursing is about reaching out to others and welcoming them into a circle of care. As my positionings in these events moved across personal, family and professional boundaries I had a feeling of being part of interconnected elements, where I understood that everything I do as a nurse is in relation to, and influences others (Basford & Slevin,1995). Luana's presence was a comforting reminder of my nursing practice as an educator, and her gift to me was her skilled response to my aunt's needs. As the place where my parents grew up, this mountain framed in the window remains an anchor point in my life. It was a central theme in my parents' stories of their childhood, and a place of fun and adventure for my generation. Today, as I look at this mountain to the west of where I live, I think of it as a magic place, full of stories and mythology; a symbol of the things that are important to me. This mountain reminds me of the vision needed for artful practice. This vision is not always clear and sometimes it is a struggle to catch glimpses of where I need to go in my practice. Sometimes I find my way by intuition, trusting that my experience and connectedness with other people within the terrain of my practice will show me the way. The clarity of vision often becomes apparent in retrospect.

The significance and purpose of laying open the experience

Where I trained we have the image of the lamp on our hospital medal.... we have these symbols that represent certain ideas from the past... so the image of the lamp is about the nurse being constant and attentive.....and present..... in Nightingale's terms the lamp was also about knowledge and enlightenment..... I am coming to see this as the conversation place... the place that Katherine Maeve talks about as a campfire..... where the lamp is the place to gather and talk and develop meaning and understanding... like around the nurses station.

Talking about our practice while sitting around the nurse's station is probably as Maeve (1994 p.15) suggests, a time honoured nursing practice where we are

.... telling the story of who we are, what our fears are, what our successes and failures are like, what we wish for, how we resolve conflicts, how we care, and how we create practice knowledge.

For me, this in-between space among nursing colleagues is embodied in the metaphor of the lamp, the place where nurses have the potential to create visions of possibility; where we can work to extend the boundaries of what it means to be a nurse (Schoenhofer,1994). This is a transformative space where nurses make connections back through time and into the future, and in circles with one another, weaving together voice and understanding (Baker & Diekelmann,1994). It is the place where we bring moments of practice into the light to make them visible and to consider their soundness, quality and usefulness to us. This thesis represents such a conversation, where I lay open this experience in the light of our collective nursing wisdom, in order to foster further conversations in the border (line) territory between our professional and private lives. In doing this work I believe I may create new possibilities for understanding the ways in which our professional work as nurses and our own life experiences are inextricably intertwined.

One of the most difficult elements in this thesis, and arguably one of the most important, is the consideration of professional ethics. The stories underlying this thesis bind elements of my professional and personal lives together in a way that produces tensions between these positionings. In a sense, the stories are about my professional chickens coming home to roost in my personal hen house.

I remember as a child my mother would sometimes ask me to let the hens out of the hen house in the afternoon. On opening the door to the hen house there would be a great flapping of wings and squawking, and feathers everywhere, floating through the air in the musty darkness. Then gradually the hens would settle down and each go off to some location, in the paddock or under the hedge, making the noises that hens do, and begin to scratch about. They would pay minute attention to a particular piece of ground, pecking and scratching and uncovering whatever was to be found.

This thesis is about scratching and pecking and turning over the ground of this experience, paying attention to particular locations and moments, to uncover what might be found. In terms of professional ethics, this thesis involves opening a door

and stepping into uncharted territory where the ground is less than firm. In telling these stories I take up discursive positionings with a self-conscious awareness about what is going on in a particular narrative location and how I am implicated in it. As Blacker (1998) puts it, in paying meticulous attention to the detail of knowledge construction, there is a losing/finding of self, and the potential for the writer to become a politically strategic and intensely local knowledge worker; a channel through which power passes in the construction of knowledge. Opening the door to this hen house of experience has indeed created a flurry of feathers, in other words, a very real need to consider my own and others' safety in relating such intensely private stories. The vulnerability of people involved in the stories is a centrally important ethic in the thesis.

In a theoretical sense, this study may be significant in re-presenting knowledge about patient's responses to the experience of life threatening illness. It may help to reconstruct the 'theorising' on the patient's experience of life threatening illness as socially produced representations of the structure and form that the patient's experience and the nurse's practice with the patient could take. In this way, this exploration of the experience of life threatening illness seeks to contextualise knowledge about health care practices within particular discursive positionings. It will document the ways in which theories about, and practices with, patients experiencing life threatening illness are bounded by particular ways of knowing that are connected to the values and practices of particular times, places and disciplines. This study may be significant in making the journey through life threatening illness visible, and offering nurses some alternative readings of their practice and the opportunity to contest commonly held assumptions and beliefs about patients.

In terms of the methodological approach, any claim to objectivity would be unsustainable in this thesis. The stories that are presented should be understood as subjective recollections; texts, which could be subject to multiple interpretations rather than having one "true" or confirmed understanding of events. The narratives

should not to be considered as a means to factually represent particular situations (Crowe,1998) or to hold out particular ways of acting as more moral than others in a prescriptive sense. Rather than create a comprehensive theory on the experience of life threatening illness, the aim of this thesis is to show how particular discursive statements and institutional practices may constrain the nurse's interpretations of patients' experiences and thus nursing relationships with the patient as the recipient of health care.

The structure of the thesis

The boundaries between the chapters in the thesis are in some ways arbitrary demarcations. The review of the literature seeps into the theoretical and methodological positionings of the study, and elements of autobiography, inquiry and analysis are spattered through my writing on these foundational chapters of the thesis. The resulting dampness from this seepage creates a fertile landscape for my imagination where there is a crossing over between these boundaries into spaces where I am able to tend and coach the growth of new ideas. This chapter sets out the background and location of the research and introduced the reader to the ideas that I have developed through my reading and reflection. The theoretical positioning for the research has been developed from the work of Foucault (1988) and other writers whose work can be understood as utilising poststructuralist approaches. The thesis is a representation of a journey through the experience of life threatening illness. It is informed by my personal experience of caring for my husband (Kevin) as well as references to literature, which will support the analysis and interpretation of the situations that will be presented.

The discussion in Chapter Two sets the contextual positioning for the thesis. The literature is reviewed in relation to the discursive positionings of patients experiencing life threatening illness, and the nurses who care for them. It maps some of the tensions that may be experienced by the patient and the nurse who live this experience of life threatening illness inside the culture of health care institutions

where ways of understanding are mainly informed by technical rational knowledge. The use of high-powered technology in health care has reconstituted the boundaries of patient's body to produce an openness where visions of the body interior are reconstructed and projected in spaces outside the body. As the patient's body boundaries become increasingly permeable, both the patient and nurse are called into being in new ways, which are profoundly significant for the relationships these people may construct with themselves and each other.

Chapter Three explores the theoretical considerations for the thesis. I describe poststructuralism as supporting new ways of understanding the world and consider its significance as a method of inquiry. I consider how in poststructuralist terms, the 'self' is understood as socially constructed through discursive positionings and productive of identities, which are based upon constantly shifting ground. Notions of what is right and wrong in terms of moral conduct with the recipients of health care become understood as constituted through local conversations and the subject's capacity for choice rather than given by some authority. Body boundaries or borders are recognised as socially constructed demarcations, which signify difference, and as such may be reconstituted in more or less permeable terms. For my husband, as a person diagnosed with a life threatening illness, and myself as the nurse/wife caring for him, notions of containment, permeability and transgression of body boundaries become centrally important themes as this experience unfolds.

Chapter Four explains the methodological considerations for the study. I discuss how I have drawn on ideas from Foucaultian genealogical analysis, autobiography and writing as inquiry in developing a methodological path for this thesis. I consider the ways in which the ontology and epistemology of these approaches relate to my practice as a nurse and the personal beliefs and values informing how I live my life. The scope and boundaries of the study are laid out and central questions, which guide the analysis of this patient's experiences of life threatening illness, and my work as the nurse/wife in caring for him, are identified. The means used to work through the

development of the methodology are explained as a circular process of reading, writing and a type of critical reflection, which I have named “talking back to myself”. Specific ethical problems arising from the methodology and the context of the study are considered, and my paths through particular difficulties to finding safe ethical ground are tracked and explained. My visions for enacting the methodology, and the techniques I have utilised in making sense of the stories in relation to it, are also presented.

The analysis in Chapter Five explores the tensions arising from contradictory discursive positionings for the patient and the nurse in entering discursive fields where the patient is diagnosed with primary cancer. I explore the experience of being always/already the nurse as Kevin became the patient, and how living with the probability of a future diagnosis of cancer marked his ‘patient’s body’ in ways that included him as well as excluded him from certain discursive practices. Finding the secondary melanoma two years later raises the stakes in living with life threatening illness. The discussion highlights the tensions between the discourses of the closed and open body following the diagnosis of metastatic melanoma and the ways in which Kevin and I, as the patient and the nurse, negotiated paths through these contradictory discursive positionings.

The analysis in Chapter Six considers the discourses surrounding our movement through the experience of surgical intervention and subsequent health care events. The discursive production of the subjectivities of the nurse and patient are explored in relation to this where I become the private nurse, and Kevin is the cancer patient. I explore the development of a new relationship with him as the patient through my discursive positioning as the ‘private nurse’. The fragile identity of the ‘private nurse’ encompasses a borderline professional capacity across the boundaries of insider and outsider, and allows my entry to privileged spaces. I consider the ways my presence as the ‘private nurse’ mediates the entry of this patient’s body into the discursive practices of healthcare. As well, I discuss the implications of working between

personal and professional boundaries in relation to discourses of pollution and bodily control. Finally, I explore discourses of care and abjection and the potential for nursing in understanding and negotiating such intense and intimate relationships with the patient.

The analysis in Chapter Seven uncovers the discursive production of life threatening illness and the work of the private nurse where the patient is dying. Running in the dark becomes a metaphor for the mediation of body boundaries as we both recognise the limits of medicine in treating this disease. The stories show how discourses that produce self forming activities related to health and fitness become privileged as Kevin attempts to live his life in the shadow of life threatening illness. An intimate relationship with the technology of radiotherapy extends the discourse of the open body across the personal and professional boundaries of Kevin's life. The rituals of monitoring and surveillance serve to maintain the privileged vision of the pathology until the point when a tertiary diagnosis is confirmed with the discovery of the tertiary stage lesion. The experience of living with life threatening illness finds expression in my teaching as I struggle to manage the boundaries between private experience and professional practice. Finally, I consider the discourses present in the care of the patient with tertiary stage melanoma as Kevin and I struggle to find a path through the inevitability of his dying. Discourses of hope, denial, acceptance, and suffering are considered in relation to the pathological body and the self's relation to the self.

Chapter Eight considers genealogies of practice and forms the conclusion of the thesis. The genealogies of the thesis, and my relationship with it, are discussed as paths that have been negotiated through the telling of the stories, where the whisper of other voices appear at the margins and through the gaps in the text. The philosophical and contextual positionings of the nurse as a border traveller are explored in relation to the idea of the nurse as the specific intellectual. This is the 'thinking nurse', who critically engages with her/his own practice, and the stories of the patient, to form new discourses as local and contextual 'truths' about illness, suffering and dying. Finally, I

explore the agency of the nurse, and professional nursing, in creating harmony with the discursive productions in the patient's local world, and in doing so, construct ethically sound practice for both the patient and the nurse.

CHAPTER TWO

CONTEXTUAL POSITIONINGS FOR THE STUDY

Introduction

The discussion in this chapter creates the contextual positionings for the study through critical analysis of the discourses present in health care practices with people who are experiencing life threatening illness. I draw attention to the ways metaphors based in the language of health care technologies cover over other ways of knowing about the body in health and illness, and call people into being in particular ways as patients within the discursive practices of health care. I deconstruct the tensions arising between the discursive positionings of patients as recipients of health care inside the culture of health care institutions where ways of understanding the world are mainly informed by technical-rational knowledge.

I consider how technologies of observation and visualisation are likely to be used in situations of life threatening illness, where invasive approaches may be used the fullest extent in order to effect a cure or at the very least to keep the patient alive. The tensions experienced between the patient's socially constructed body and health care technologies are considered in relation to the capacity for such technologies to cross body boundaries and lay open the interior of the body to outside view. The analysis shows how this viewing of the body interior, and the changed functions within it, has the potential to call the discursive subject into being through the interpretations of health professionals, where the body 'becomes' its pathology. Finally, I explore how nurses are implicated in such readings of the body and consider the potential for nurses to find themselves positioned in liminal spaces with patients who are experiencing life threatening illness.

The body in discourses of health and illness

As people we create ourselves in our worlds in unique, similar and different ways. Our realities are socially constructed in response to our interactions with our social world through our family, community, culture and society. We choose to take up, or not, particular ways of being as social actors. In discourses of health and illness the body can be understood as an important medium the social construction of the self, or as a mediator between the person's sense of self, and the society, history and culture in which they are embedded. The person's body becomes inscribed with the knowledge, values and beliefs of their culture.

In western societies the body has been socially constructed primarily through discourses of science and medicine. Our understanding and experience of the body is influenced by these social constructions. We tend to take our bodies for granted in everyday life until the sense of something wrong with the body intrudes into our consciousness and requires us to seek help to manage this change. The experience of illness and subsequent opening of the body to the gaze of medicine and science may result in the body taking over our sense of self, almost as something that is external to our being (Lupton,1994). The body can be understood as the constantly changing product of certain kinds of knowledge, a blend of social discourses and biological matter; in Haraway's (1989) terms something that is made rather than born. The body is shaped by its entry social relationships. Its construction is both limited and facilitated by historical, political and cultural knowledge and practices (Lupton,1994).

Bodies are subject to monitoring, surveillance, regulation and discipline by external discourses and institutions (Frank,1991). People learn to discipline their own bodies by taking up particular discursive positionings in relation to societal, cultural and political knowledge and understandings of the body. Foucault (1979), in his work on the historical genealogy of the body, considers the body to be a site of political and

ideological struggle, a point of focus for state apparatuses such as medicine, education, law, and the military. Bodies are thus contained within certain normative, and seemingly naturally given, boundaries and are punished for transgressing beyond what is considered to be economically and politically productive to a society (Lupton,1994). Foucault (1975) saw the institution of medicine as a major influence in defining these normative standards through the development of increasingly sophisticated scientific examination and monitoring techniques and the organisation of sites of medical surveillance in particular locations such as hospitals, schools, psychiatric institutions, prisons and the military (Lupton,1994). The patient, or inhabitant of the body under examination, was constructed as unknowing in these medical encounters in opposition to the secret, scientific knowing of the examiner.

The body, as an entity subject to examination, was understood as having economically and politically productive potential, which could be developed through discipline and control of its boundaries. Discourses of public health arose out of understandings of body as always potentially dangerous, subject to disease and in need of control for the public good given the potential of the deviant (ill) body to contaminate the healthy (economically and politically productive) population. Some individuals were marked as potentially contaminating, in particular strangers such as immigrants (Lupton,1994). The containment of dirt can thus be understood as a social practice where systems of (disease) classification attempt to bring order to the malfunctioning and socially dangerous body (Wood,1997). Such classifications are central to the development of public control measures, which are justified in utilitarian terms, for the collective social good.

Scientific classification involves the generation and institutionalisation of knowledge that legitimises these dividing practices (Rafael,1996) in ways that they are seen to be natural or for the common-sense (Crowe,1998) good of people. Thus the classification and signification of patients is associated with the “normalising” discursive practices that seek to identify what is normal and mark that which deviates

from normal. Subjectification involves the active participation of the person, as subject, taking up or constituting themselves from within particular discursive positionings that have always/already existed prior to the formation of the subject. As Crowe states, “the subject is an effect of meaning constituted by discursive practices” (1998 p.341), where cultural constructions of what is normal and natural are taken up where the subject denies a consciousness of alternatives. Where subjectivities are experienced as contradictory the person may choose to resist the ‘obvious’ and take up alternative discursive positionings. In this way the social order of health care is constantly reproduced, where the professional person is understood as the expert knower, or the bearer of reason, and the patient risks becoming that which is known.

In becoming a patient, the person gives the doctor licence to work on the body and in doing so, consents to becoming scientifically classified and reconstructed within the practices of medical science (Brown & Sneddon,1996). Challenging the classifications of disease and illness (and therefore the validity of the classifications themselves) according to the lived experience of the body is politically dangerous as it subverts the relations of social (re) production. Medicalization of the body has resulted in scientifically and socially constructed normative understandings about how people should inhabit their bodies. While people live their bodies experientially as well as actively engaging in discursive practices (Groz,1989), in a society where everyone is seen as the potential victim of disease, people submit to the public gaze of medicine and actively encourage others to do the same. Lupton (1994) believes the relations of power are not always visible in these social transactions as the prescribed behaviours are seen as being normal and common sense. As Williams (1997 p.14) notes, “bodies become public property for medicine to work on without interruption”. The body, colonised as an object, becomes a territory to be explored and conquered (Parker,1997) in the battle against disease.

Liaschenko (1998) suggests that in Foucault’s (1975) terms, the gaze of medicine historically reconstructed the view of the patient’s body by reducing the perception of

the patient to the disease, as a location in the body. Through the medical gaze, the patient is represented as the disease, and the lived experience of the person becomes invisible. Recognising the lived experience of illness constructs the person as a central actor his/her encounter with the provider of health care, as a person who retains some agency and authority in naming the problem with their body. Shifting the focus to the point of location where the disease is manifest in the body does not, as Liaschenko (1998 p.19) puts it, 'solicit a story of a life lived'.

Imagery and symbolism in discourses of health and illness

The use of metaphor is significant in shaping our understandings of the body and the meaning of illness. As Malone (1999 p.16) suggests, metaphors

.... structure understanding and experience by bringing forth certain aspects of that experience and hiding or silencing others and they do this so seamlessly and constitutively that we are often hard put to identify them as metaphors, much less to identify alternative metaphorical conceptions.

The metaphors present in health care discourses shape how we think about our bodies. They bring forth certain realities and capacities for action in terms of how a situation is read and understood. Similarly, Lupton (1994) sees imagery and symbolism as important the way people experience and live with their social bodies. Much of this symbolism is focused on policing body boundaries in terms of what enters and leaves the body. The symbolic concepts of dirt and hygiene are constructed as binary opposites. Dirt offends the social order of the body and is associated with disease in relation to the internal and external organisation of the body and its environment (Douglas,1980/1966). Hygiene, and the health it produces, have become commodified (Lupton,1994); able to be purchased as marketed products to be used in the environment, as well as on or in the body. The body itself also has capital value and has become a medium for exchange, while the ill body becomes invalidated, losing its capital value. The person with cancer discovers he/she has become an outsider, a

stranger with only partial citizenship, when excluded from health or life insurance policies or mortgages. The person with cancer is no longer a good economic risk.

The symbolism produced by the metaphor of the body as a machine is important in understanding the ways in which the body is reduced to parts inside the discourses of medicine and science. The body has been conceptualised as a machine since the time of the industrial revolution (Lupton,1994). Karl Marx believed Capitalist technology and work practices (such as production lines) were a means of subordinating working class bodies to machinery (Shilling,1993). In this sense, the body is seen as subject to social order, an object that provides commercial advantage to those who colonise it (Parker,1997). Stauning (1993) also links the machine metaphor with industry. She believes there is a relationship between medical knowledge and the drugs and devices used in health care and the interests of industry in the development and use of health care technology. The use of such technology quickly becomes common practice in health care settings and if the technology is available, it is likely to be used. Stauning (1993 p.361) suggests this is because the “strategies of industry walk hand in hand with the mechanistic view of science”.

The body may be understood as both a machine and as an object that is subject to machinery. Medical technology such as pacemakers, implants, lasers and microscopes construct the body as a machine with interchangeable parts that can be repaired if they break down (Martin,1994), just like any other machine. A machine is thus used to fix a machine (Lupton,1994), imposing the discipline and rationality of medical science on the malfunctioning body and its parts (Martin,1994; Gatens,1996). Computer technology extends this symbolism of the body as machine. For example, with the capacity to map human genetic structure, the body can be understood as having minute interchangeable parts or files, which can be altered to erase malfunctions. Haraway (1989) uses the term ‘cyborg’ to describe this blending of biology and technology, where the human body is part human and part machine. Technological advances have resulted in the body being rediscovered as uncharted territory awaiting

exploration and medical intervention (Lupton,1994) where the boundaries between what is human, and what is not, become blurred.

The military metaphor, which portrays the body as a battleground is another common theme in the discourses of medicine and public health. The body is seen as fighting, attacking and killing invaders when it is under attack from disease (Martin,1994). Medical access to the body is legitimated on the grounds that disease is an evil atrocity committed on the body. Doctors work on the “front line” using aggressive pharmacological treatments such as “shotgun therapy” and “magic bullets” in the war against death (Lupton,1994 p.62) fighting the enemy until it is destroyed (Castledine,1999). This military imagery constructs the body as a nation-state with vulnerable borders which must be policed and legitimates violent responses to body boundary transgression as a “natural” response (Lupton,1994 p.66). Castledine (1999) suggests that medicine does have a warlike approach to illness and that aggression may be an appropriate response to a crisis. The problem is that within medical discourse, all illnesses are likely to be treated as a crisis, and such an aggressive approach serves to overshadow other representations of the illness experience.

Cancer metaphors are closely associated with military symbolism and are represented by statements such as ‘losing the battle with cancer’. Cancer is understood as a disease that comes from the outside, cutting the person down in their prime. It is part of the filth of nature that illicitly transgresses body boundaries, a disease that requires the intervention of professional experts (Tester,1993). This symbolism constructs the human body as a host for a hostile life form that has invaded the body, something that is ‘other’ than the person themselves. Cancer becomes the ‘intimate enemy’, a disorderly and out of control entity that challenges the order of the body and threatens to engulf the rational self. Discourses on cancer include notions of hope, courage, and strength and will to overcome the disease or to die bravely (Lupton,1994).

The metaphor of body as a frontier existing solely to be transgressed by the modern scientist, draws on the imagery of colonialism and the daring exploration of the “dark continent” or that which is unknown (Bauman,1995 p.164). This crossing of the border into the interior territory (of the body) constructs the patient as the colonised through co-optation of his/her body. A cultural understanding of the coloniser’s ability to transgress the statutory border (of the body) comes into being with the person’s consent to be induced with some reward or deprivation, and his/her identification with the coloniser (Nandy,1983). The skin, as a border, creates the categories of interior/exterior, familiar/alien and self/other as well as the simultaneous opposition and co-dependence between the coloniser and colonised.

Health Care Technologies

The term health care technologies may be interpreted to mean the effects of the culture of health care institutions; the techniques of monitoring, surveillance and governance, that classify and signify patients as the bearers of particular diseases. Foucault understood power in terms of unequal relationships between people; “an intricate web of power technologies operating throughout society” (Foucault,1982 cited in Rafael,1996 p.4), where the term technologies refers to an understanding of power and knowledge as inseparable. The knowledge that health professionals possess thus affords them a privileged status in relation to that of the patient. Within the knowledge/power web operating in health care institutions, patients are objectified, or called into being as subjects with particular status; through dividing practices, scientific classification and subjectification (Foucault,1982 cited in Rafael,1996). Dividing practices arise out of the construction of hierarchical difference where one person or group is excluded from holding power on the basis of what they lack in relation to those understood as the bearers of power. This means the patient and the health professional are constructed as identifiable categories and the status accorded to them within the web of power connections reflects the value of their categorisation.

Health care technology may be understood as any means employed to meet diagnostic or therapeutic goals, such as diagnostic and therapeutic machinery, surgical procedures and high power medicines. This description relates to the means to greatly extend human action beyond the skills and knowledge of the particular user of the technology (Cassell,1996), in the same way that driving a motor vehicle extends a person's ability to travel over distances with minimum physical effort. In a cultural sense this ability to utilise technologically produced machinery has moved contemporary society to a commuter culture, where goods and services are constantly moved to supply and consumer demand. For some people the motor vehicle has become the source of a subculture where their identity is linked to the particular ways in which this machine invests them with power and status. This metaphor may be extended to the utilisation of technology in health care where health professionals have been able to extend their practice.

Technology has come to be seen as a common sense part of every day life in the culture of the late twentieth century. The use of technology is closely linked with the modernist desire to make things different and was both produced by, and productive of, the ability to transcend nature. In this sense, technology has created a culture of transcendence. As Bauman (1995) suggests, the easier it is to transcend something, the more likely human beings are to do so. Thus the need to intervene and the ability to intervene define one another. Technology has been transformed from a means of societal independence into something that is seemingly independent of, and profoundly shapes human action. It defines our environment rather than allowing human activities to be defining of it. The ability to intervene defines and changes the user of technology in terms of the specialised knowledge required to use it as well as extending the user's capabilities. As well human beings have become something which technology acts upon and are redefined through this relationship (Tester,1993).

Inside the culture of health care, the use of technology has enormous potential to change human lives and reduce human suffering (Chandler & Smith,1998), however, as Bauman (1995 p.170) suggests, the

..... freedom to control one's own body and manipulate its actions came hand in hand with the growing dependence on technology and its offers; individual power was closely intertwined with submission to expert guidance and the necessity to consume technology products. More and more the owner of the body came to think and live as a foreman appointed by medical authorities to invigilate and supervise the machinery assigned to his or her care.

While people may see themselves as emancipated by technology, and in certain ways this is probably true, science tends to construct human beings as relatively passive objects upon which it acts. Technology has imposed new boundaries on human existence substantially altering the way we locate ourselves in the world. It has developed its own legitimation, "constructing a circular and self referential discourse" (Tester,1993 p.100) that is difficult to challenge. Like the "Sorcerer's Broom" (Cassell,1996 p.178), technology has taken on a life of its own allowing the user (health professional) to substantially define and change outcomes for the patient without entering the world of the patient. The seductive, alluring power that technology confers on the user is associated with the opportunity for immediate and unambiguous results as well as the constructing both the desire and ability to intervene. In this sense, health care technologies and health care technology produce and sustain one another.

Historical developments and cultural tensions

During the late nineteenth century, the development and use of imaging devices in health care was to produce cultural shifts in health care practices and the way people understood the human body. Cultural tensions are apparent in historical writing on health care technologies particularly concerning the invention of Xrays. In late 19th century Europe, the invention of Xrays was strongly connected with invasion of the privacy of people's bodies in terms of being able to cross body boundaries and make

visible what had before been invisible. The people of the time responded to this new technology with both awe and ambivalence (Kelves,1997) as it threatened to overturn the accepted conventions of their time concerning what was held to be public and private.

Xray was to open the living body to external view and make the previously invisible and mystical elements of the body visible. Emily Culverhouse summed up the ambivalence of Victorian Society in her 1897 poem (Kelves,1997) where she depicted Xray as invading the privacy of the body and exposing the person's inner most thoughts to the outside world. The human body had become a new territory able to be conquered with Xray technology, allowing the interpretation of a person's inner most being by an external source. Personal space, until this time been defined by clothing, was redefined. Skin was no longer a border defining the limits of the human body, as it had become transparent in the living body Xrays revealed "the naked truth" of the body (Kelves,1997 p.118). Personhood risked becoming subordinate to the importance of this scientific representation.

This crossing of body boundaries to open up the body for external scrutiny was to create a new medium for art and literature. Xray provided a new medium for the ideological critique of socio-political relations of the time. The words 'truth', 'superficial' and 'exposure' took on new meanings within the discourse of Xray transparency. In 1933, Rivera used an Xray style image of a woman's body in a painting called "*Mechanised Maternity*" (Kelves,1974 pp. 124, 134) to display the pregnant woman's abdomen as if she were a machine, as an attempt to depict the depersonalising or alienating effects of machines in Capitalist society. As well, some doctors of the time were concerned that Xrays could be used in a mechanistic approach to medicine. Instead of the "healing touch" of the physician, the doctor would become distanced from the patient by visually penetrating the patient's "machine like" body, using another machine (Kelves,1997 p.134).

Technologically produced vision

In the culture of health care technology has created a compulsion to visualise the interior of the human body in order to seek the pathology that medicine aims to cure. The phenomenon of viewing the body inside its internal boundaries can be understood as the “scopic drive” (Braidotti, cited in Grace,1997 p.85) which refers to an impulse to open something up to look inside. In this process of visualisation the disease, as an imaged representation, takes centre stage erasing the person-as-subject in the “process of reifying the significance of the observation of the tissues of the bodily interior” (Grace,1997 p.89). The patient’s body becomes depersonalised and objectified as the clinical focus on the diseased part is privileged; inscribed and marked with signifiers as a text to be interpreted as pathology (Parker,1997) alienating the patient from the subjective experience of his/her body.

These ideas of distance and difference are strong themes in the literature on health care technology. We live in a society that is primarily concerned with the technologically produced vision (Brooker & Brooker,1997) where signifiers exist separated from their context and reference (Baudrillard,1992). Cassell (1997) argues that with the utilisation of technology, knowledge of the patient is acquired at a distance and in a representative rather than real form. This kind of objective, scientific knowledge risks being understood as something that is separate from its human context where technology produces new representations of the patient’s reality that are understood as a reality in themselves. Scientific knowledge may be seen as more accurate or real than the patient’s subjective experience of their body if the health professional’s interest is focused on the technological representation of the disease or body part and divorced from the lived experience of the patient (Cassell,1996). It is in these moments that the “master” discourse of science serves to suppress the local narratives of the patient (Brooker & Brooker,1997 p.53).

Computer reconstructed images have “enlarged the window into the body that Xray opened” (Kelves, 1997 p. 261) and this reinforces the notion of the machine metaphor as patient’s body is broken up into disconnected parts in the form of transitory images on a screen. Boundaries or borders that define and differentiate the margins of the body become blurred (Brooker & Brooker,1997) creating a new intimacy between the person and the machine where surfaces cease to exist (Kelves,1997). Technology thus invades personal space, transforming and augmenting the body in a cultural sense, potentially violating the body as it turns the inside outside.

Liaschenko (1998) echoes this sentiment suggesting that visual imaging devices have turned the body ‘inside out’, taking the viewer’s gaze beyond the surface of the lived body. In her terms this moves the gaze of the practitioner from the patient’s face as the signifier of the person’s identity, towards externally constructed realities of the open body that are held to signify the problem with the patient. She argues that the closed body constructs a different relationship because the practitioner (nurse) sees the other (patient) as him/herself, and in this recognition of the patient as a person, bears witness to the other’s suffering (Liaschenko,1998).

The “inside out” body in life threatening illness

The idea of alienation from one’s own body through the diagnostic imaging of technological devices is an important theme in contemporary writing. Patients speak of developing an image of themselves as a diseased being, privileged only in their relationship to medicine as a subject of pathology (Grace,1997; Parker,1997; Cassell,1997). People experiencing life threatening illness may tolerate the crossing of body boundaries by technology in the hope of cure, or at least some mediation of the disease. Life threatening illness is an extreme situation, in terms of the threat to the patient’s life and the vulnerability experienced in relation to this. For the patient, medical intervention utilising technological approaches may be compelling as a life saving or life prolonging measure.

For people who know there is no cure to be offered by health care technology, continued surveillance of the developing pathology may become problematic. Technological approaches allow the production of unambiguous results, which clearly detail the progression of a disease such as cancer inside the patient's living body (Cassell,1996). While there may be no hope of a cure in this circumstance, it becomes very difficult to disengage from the use of these technologies. They become self-perpetuating in terms of their "vision" and invite intervention because the pathology can be seen. The patient may become caught in the medically constructed death preventing and death postponing practices which technology generates; where "survival and self preservation become the meaning of life" (Bauman,1995 p.68) and life is colonised by death. In this sense, technology moves from offering comforting and life saving possibilities to an invasive transgression of bodily boundaries that heightens the dying person's sense of vulnerability.

In conceptualising the body as a socio-political entity, the tensions become visible between an individual's need to contain themselves within their body boundaries and the ways the presence of disease legitimises medical access to the body. The body may be understood as a mediator between the person's sense of self and the society, history and culture in which they are embedded. According to Boughton (1997) selfness is created through making sense of the abundant data that is presented to a person. In other words, people are called into being as unique subject/selves through their simultaneous and contradictory positionings within multiple discourses, and position themselves according to the potential offered by certain discourses (Rudge,1997). The person's sense of self is constructed in terms of how they manage data presented to them.

Grace (1997) relates the loss of a sense of self among women when their subjective reality of pelvic pain was dismissed or misunderstood by doctors. As Grace (1997 p.92) suggests, the patient's experience of illness and their "construction of a sense of

self as a speaking subject are interconnected". When the patient's representation of their experience is silenced or marginalised, s/he risks a disengagement of this sense of self where the objectified body is made meaningful only in terms of its threat to their wellbeing. Rudge (1997) sees the skin as an emotional, symbolic, socio-cultural and physical boundary where the body is understood as a metaphor for interpreting social relations. She suggests that our skin "represents the social and cultural experience of being a self contained individual" (Rudge,1997 p.79) and that the closure of body boundaries decreases vulnerability.

For the terminally ill person, the view of pathology seen in representations of the open body may construct the body as hostile and oppressive (Boughton,1997) in terms of the threat it represents to their mortality. Shilling (1993) describes this experience as a marginal situation where a glimpse of one's own mortality takes us to the edge or border of our existence with the recognition that the world is unstable and discontinuous. He suggests that the body represents the last bastion of a solid and reliable sense of self in an ever-changing world (Shilling,1993). This is the moment of dread when the fiction of the symbolic world becomes visible and the person comes to 'see through' him/herself (Becker,1996) and the certainty and inevitability of death. The fear of erasure or annihilation is one of the most central anxieties that inform human existence (Wright,1992).

In Kristeva's (1982) terms, the glimpse of one's own mortality can be understood as encompassing the notion of the abject. The abject represents the subject's failure to suppress the recognition of his/her own corporeality and fragile body boundaries. The delineation of such boundaries, in terms of the inside and outside of the body and spaces between self and other, are conditions of the subject's construction as a speaking subject (Groz,1989). It is the unthinkable, the other; something that exists outside borders, positions or rules and which disturbs identity, systems and order (Kristeva,1982). The abject attempts to conceptualise something that is unimaginable, outside the limits of the clean, bounded body and the unified self and yet always

threatens the unity of the subject, hovering at the margins of our existence (Groz,1989). The abject is

... what the symbolic must reject, cover over or contain. The abject is what beckons the subject closer to its edge. It insists on the subject's necessary relation to death, corporeality, animality, materiality - those relations which consciousness and reason find intolerable. The abject attests to the impossibility of clear borders, lines of demarcation or divisions between the proper and the improper, the clean and the unclean, order and disorder, as required by the symbolic. Symbolic relations separate the subject from the abyss that haunts and terrifies it (Groz,1989 p.73).

In feminist terms the abject describes the position of the feminine and maternal in opposition to the paternal and symbolic. The female body is portrayed as that which is unknown, monstrous, and terrifying (Creed,1987), threatening the male figure/subject with castration, and consequently the stability of the symbolic order of culture and language. In horror movies the abject is represented by the maternal body and the masculine as the rational, coherent and unified subject (Thornham,1997). For the patient whose body is turned inside out through diagnostic imaging, the abject takes on the form of pathology that signifies a threat to their mortality. Death, in opposition to life, exists outside the rational order of the symbolic and the coherent, unified subject.

The closed body and the attentive gaze of the nurse

As nurses, much of our work with patients involves care of their bodies. So common and every day is our contact with patients' bodies that we seldom consider how we view, perceive, experience and relate to them (Madjar,1997). As Madjar suggests, we often experience our own bodies in an unselfconscious way; that is we are often not aware of the body itself until it fails to do something we require of it. When we become ill there is a conscious awareness of "the effort involved in usually taken-for-granted bodily activities" (Madjar,1997 p.54). In this sense, we take our own bodies and those of our patients for granted, perhaps overlooking the realities of the illness experience and the significance of our transgressions into the patient's body space.

Even when we acknowledge the subjective reality of the body, we may subjugate this understanding to the expertise and dominance of medical knowledge (Williams,1997).

Parker (1997) sees the body as a central concern to nursing in terms of being able to understand the ways in which subjectivity is constituted through the discursive practices of health care, technology and science. In a culture of health care where the body is a highly contested site of commodification and colonisation, nurses are situated in the space between the patient's body and the discursive practices of medicine; between the professional and private roles of 'doing to' and 'being with' the patient (Parker,1997). Gaddow (1995 p.212) constructs a metaphor of the patient's body as a colonised land where nurses assist patients in negotiating a "safe and honourable passage" through the experience of illness. The (medical) colonist sees the land (the patient's body) as a space that is empty of meaning until it is mapped by external techniques of surveillance that give referent points for understanding. Nurses on the other hand, are explorers who spend time living in the land and come to know the topography and environment through their own experience. The patient's body, like the land, is a place that needs to be understood in terms of the local, that is, what it is like to live there (Gaddow,1995).

Liaschenko (1998) understands nursing as constituting relational practices where the attentive gaze of the nurse is concerned with the patient's closed body. She sees the nurse as less concerned with the actual pathology inscribed on the patient's body, and more concerned about the implications of an illness for the patient as someone who is living a life. Knowledge of the patient's experience of illness involves the notion of testimony; bearing witness to the patient's experience of suffering and coming to know, and testify to, the meaning of a life disrupted by illness (Liaschenko,1998). Wiltshire (1998) sees nursing as a practice of the body where nurses work in a transitional space between one place and another, attentive to the shared humanity of the patient and themselves. The patient's body is understood as having corporeality in

common with the nurse, which constitutes the relationship between two subjects. Inside this transitional space nurses use their own bodies as a means to support the ill or disabled bodies of others.

The experience of life threatening illness

Nurses are involved in some of the most significant moments of people's lives, in particular times of illness, trauma and vulnerability. We often take our participation in the lives of others for granted, making extreme and life threatening situations into everyday work (Parker & Gardener, 1992); situations that have profound implications for the patient. Morse (1996) uses the concept of 'enduring' to illustrate the containment and control which patients develop to get through the suffering associated with illness and trauma. She believes nurses need to understand the ways in which patients may exist intensely in the present, focusing all their energy on getting through the present situation. To look into the future moves the patient, and/or their family, beyond what is manageable in the present moment. This notion of enduring suggests to me that the patient and family become uniquely positioned inside such events and interpret them according to their own historically constructed values and beliefs.

Notions of containment and control are important in understanding how the ill person may perceive his/her malfunctioning body. When the ill and malfunctioning body makes demands on the person and reinterprets that person's life, the body may be seen as an enemy which is separate or 'other' than the person (Cassell, 1991). Lumby's (1997) research provides some valuable insights into what it was like for the women in her study to experience life threatening illness. The themes developed in this study are concerned with experiencing the ill body, where the women related a sense of control as the most important theme in relation to the body. This was illustrated in the setting of boundaries around the 'disintegrating' body. Boundary setting was represented as maintaining the capacity to work and fulfil family and

relationship roles for as long as possible, and adapting to functional losses by finding new capacities inside relationships and roles. Containing the body was further understood as maintaining a semblance of normality. Control seemed to be related to a sense of agency or capacity to act inside their situation, in terms of getting access to information regarding their health; being a part of the decision making process; and setting goals and prioritising family needs.

Lumby (1997) relates how the women in her study worked to protect family and friends (and themselves) by keeping things normal and balanced and hiding physical deterioration and functional loss and their illness progressed. They also wanted to continue working as long as possible. Relationships were important in sustaining the women through the experience. They actively sought out other women who were well known to them and trusted, and who would support them through conversations that would allow articulation of fears and concerns without silencing. The idea of safe conversational spaces alludes to the experience of people with life threatening illness actually finding a place to speak (the unspeakable) about their deteriorating body. They might want to speak about their own concerns without the need to deal with distraught responses or the other person's obvious need to change the subject.

Generalising ideas from women's experience of life threatening illness in a study that is centered around the experience of a man presents some problematic issues in terms of the situatedness of local knowledge within particular knowledge/power structures. However, the social construction of women's bodies cannot be generalised to something that is experienced by all women. As Allen and Whatley (1986) suggest, the women's health movement has challenged health systems in ways that benefit both women and men. Men and women have had similar and different experiences in health and health care. One could argue that men have benefited from traditional patriarchal health care systems and health care technologies, but we cannot assume that all men are articulated to patriarchy all of the time. Nurses cannot assume that they work in a value free health system or society. Social and political issues are

central to the social constructions of both men's and women's bodies, and impact on the experience of life threatening illness, albeit in similar and different ways.

Nursing practice in the patient's local world

As Liaschenko (1998) reminds us, nurses do not control the technologies of the open body. While nurses may become highly skilled in utilising technology and interpreting results they do not control the development or use of it. However, nurses remain implicated in the use of health care technologies, particularly in terms of the choices patients are required to make with knowledge derived from surveillance of the open body. Chandler and Smith (1998) use the metaphor of 'Sophie's Choice' to illustrate the agonising decisions that women have to make following prenatal screening that identifies foetal abnormalities. For the patient experiencing life threatening illness, and in particular the person who is dying, the decisions to be made may be no less agonising. As Liaschenko (1998) suggests, we need to be clear about what knowledge is for, who controls it, and what it means in terms of the patient's local world. The ethical issues in these circumstances concern managing the patient's vulnerability.

As nurses we are often tempted to colonise the patient's self through our own morality and institutional authority. The modernist construction of the autonomous individual is predicated upon future oriented thinking. This becomes problematic in the local world of the dying patient. The theories on death and dying, which are embedded in professional and lay discourses of health and illness tend to normalise the patient's progression towards an acceptance of death. The stages of denial, anger, bargaining, depression and acceptance (Kubler-Ross, 1969) produce a modernist notion of a rational death which assumes that the patient can come to some logical and rational understanding of their own erasure. Such a normalising approach fails to recognise the multiple and contradictory subject positionings, which people may take up in the face of death. In this respect, encouraging dying patients come to terms with such abject subject positionings, when patient autonomy could be understood as

supporting a person to engage in the world on their own terms (Hess,1996), does not seem entirely ethical practice.

The discursive positionings of family members and patients across the personal and professional boundaries of health care are poorly represented in the literature. Savage (1997) considers the discursive positioning of nurses in public and private spaces in health care. She suggests that an opposition between public and private life is an important structuring principle in western societies where clear distinctions are made between what is considered to be public and private work. However, closeness is considered to be an element of professional nursing where there is a sense of shared domestic space between nurses and patients; a space Savage (1997) conceptualises as a contested and ambiguous site of resistance. Other writers (Rose,1995; Burr,1996) have researched the meaning of critical illness for family members but consider the experience of life threatening illness from within clearly demarcated boundaries of professional nursing.

The positioning of the nurse in relation to the closed body of the patient constructs nursing as a borderline or boundary profession which will sometimes place the nurse in conflict with the scientific medical understandings of what is best for the patient (Liaschenko,1998). Nursing can be understood as marginalised in the order of governance (health care technologies) and positioned inside competing discourses in disoriented and disturbed space (Parker,1997). Van Gennep's (1960) work on rites of passage is helpful in understanding the liminal space, which the patient occupies in the journey through healthcare with a diagnosed life threatening illness. The diagnosis represents a territorial passage where the person moves through, or becomes implicated in the discursive practices of healthcare. Within this passage, there are rites of separation from the old, pre-diagnosis, sense of self where the power relations of healthcare reconstruct the person's relationship with themselves in taking up the identity of the patient. The identity of the patient occupies a liminal space in the discursive practices of healthcare where the patient is unsure, feels out of place, and

experiences anxiety in not knowing what to expect. This sense of liminality is increased by the threat to self that the diagnosis signifies.

Nurses might articulate themselves those who are the bearers of power in order to distance and protect themselves from the seeming paradox in this liminal, turbulent and sometimes dangerous space between the patient and healthcare technologies. But in a sense this idea of safety is a fiction because the nurse is always/already “other” and cannot claim equality with medicine in the technologies of the open body. On the other hand, there is no real agency in standing with the patient in this liminal space, while practising a politics of ‘ressentiment’ as an ‘emancipatory’ subject turned victim (Gunew & Yeatman,1993). A more inclusive politics would seem to involve bringing together the anatomical body and the speaking subject in a way that confronts the paradox between the dichotomous split (Grace,1997) in the patient’s subjectivity and which recognises the positioning of the nurse across and between body boundaries and discursive margins.

This argument proposes an approach to working with patients experiencing life threatening illness that does not rely totally upon knowledge fixed within an objectified fiction of science (Grace,1997). The agency of nursing may lie within conceptualisations of nursing practice as contingent and responsive in the location of the patient’s life and the implications of the disease. In this location, the nurse and the patient are understood as constructed in/through their critical engagement and interactions with each other. Grace (1997 p.96) uses the term ‘open materiality’ to conceptualise bodies as “discursive fields that are simultaneously surfaces inscribed with meaning”. Through the negotiation of these bodily inscriptions, the subjectivities of the nurse and patient understood as performed, with the capacity for action and choice.

Summary of contextual positionings

The discussion in this chapter sets the contextual positioning for the thesis. The literature is reviewed in relation to the discursive positionings of patients experiencing life threatening illness, and the nurses who care for them. It maps some of the tensions that may be experienced by the patient and the nurse inside the culture of healthcare institutions, where ways of knowing are mainly informed by technical rational knowledge. The use of high-powered technology in health care has reconstituted the boundaries of patient's body to produce an openness, where visions of the body interior are reconstructed and projected into spaces outside the body. As the patient's body boundaries become increasingly permeable, both the patient and nurse are called into being in new ways, which are profoundly significant for the relationships these people may construct with themselves and each other.

The following chapter explores the theoretical considerations for the thesis. I describe poststructuralism as supporting new ways of understanding the world and consider its significance as a method of inquiry. I consider how in poststructuralist terms, the 'self' is understood as socially constructed through discursive positionings and productive of identities, which are based upon constantly shifting ground. Notions of what is right and wrong in terms of moral conduct with the recipients of health care become understood as constituted through local conversations and the subject's capacity for choice rather than given by some authority. Body boundaries or borders are recognised as socially constructed demarcations, which signify difference, and as such may be reconstituted in more or less permeable terms. For my husband, as a person diagnosed with life threatening illness and myself as the nurse/wife caring for him, notions of containment, permeability and transgression of body boundaries become centrally important themes as this experience unfolds.

CHAPTER THREE

THEORETICAL CONSIDERATIONS

Introduction

This chapter explores the theoretical considerations for the thesis. I describe poststructuralism as supporting new ways of understanding the world and consider its significance as a method of inquiry. I consider how in poststructuralist terms, the 'self' is understood as socially constructed through discursive positionings and productive of identities, which are based upon constantly shifting ground. Ethical conduct with the recipients of health care become understood as constituted through local conversations and the subject's capacity for choice rather than given by some authority. Body boundaries or borders are recognised as socially constructed demarcations, which signify difference, and as such may be reconstituted in more or less permeable terms. For my husband, as a person diagnosed with a life threatening illness and myself as the nurse/wife caring for him, notions of containment, permeability and transgression of body boundaries become centrally important themes as this experience unfolds.

New ways of understanding the world

Poststructuralism can be broadly understood as a group of theoretical approaches, including deconstruction, psychoanalysis, and postmodernism, situate the speaking subject within specific localities (Haraway,1991; Gunew & Yeatman,1993). Poststructuralist approaches have gained increasing attention in the worlds of academia, art and architecture in the latter part of the twentieth century. This movement towards poststructuralism as a new cultural vision (Tarnas,1991) is sometimes described as an epochal shift, heralding the beginning of a new era which

has yet to be named, hence the use of the term 'post'. Tarnas (1991) credits the German philosopher, Nietzsche with being the prophet of poststructuralism, in his work on nihilism which challenged the taken for granted order of reality in Western culture. Kvale (1996) echoes this point about Nietzsche, and further identifies postmodern themes as present in the (now historical) fictional writing of authors such as Blixen and Borges. He suggests that the difference in our time is the explosion of postmodern/poststructuralist approaches in contemporary culture.

Poststructuralism challenges the Western modernist notions of the certainty of knowledge claims, mastery over nature, and the idea of progressive movement toward a utopian freedom (Tarnas,1991). Modernism understands human history in a progressive and linear way, forever moving toward greater understanding through the discovery of new knowledge. The Enlightenment/scientific project relies upon universal or generalisable knowledge that claims essential 'truths' about phenomena; and rationality which embodies the notion of reasoned decisions taken on the basis of objectively derived information (Parton,1994; Cheek,1998). For Lyotard (1992 p.15), the postmodern invokes "the unrepresentable in the presentation itself", where the writer or artist draws attention to what is not present, thus investigating and challenging the rules and categories of such presentations. The postmodern 'author' becomes a medium of culture, utilising rules and categories that have yet to be made, in order to allude to what might be possible.

An inside out and upside down world

Anderson (1996) tells the following story as a postmodern news item.

An American anthropologist visited Japan during the Christmas season and noticed that the retail merchants there had begun to take a great interest in the symbolism of Christmas. When he wandered into a large department store in Tokyo, he saw a striking example of this: a Christmas display that prominently featured Santa Claus nailed to a cross (Shweder,1993 cited in Anderson,1996 p.1).

This representation of Santa nailed to a cross is likely to create feelings of ambivalence in a person who was, for example, raised in a western country as a Roman Catholic. My immediate response to this image is that it represents sacrilege in terms of making something that is understood as sacred (the image of Christ on the cross), profane. The image is powerful in illustrating what is absent and what is present, and my eye would always be drawn towards trying to complete this image according to my knowledge of these separate stories. As Anderson (1996) suggests, this image represents elements of poststructuralism in terms of a time in history that shifts our understanding of the world, where the boundaries between cultures have become permeable, resulting in new and multiple constructions of reality. What is missing from the image of Santa on the cross is of course the image of Christ. For me, this absence makes visible the discourse of Christianity and the sacrifice of Christ on the cross as a symbol of the salvation of humankind. The presence of Santa, in crossing cultural boundaries, however, allows a new reading of both the discourse of Christianity and the discourse of St Nicholas or Santa. I could construct a new narrative by reading this image of Santa as a sacrifice in the midst of the consumerism in contemporary representations of Christmas.

I understand poststructuralist approaches as constructing local narratives that go beyond the singular, totalising and purist interpretations of modernist metanarratives and challenge taken for granted or naturally given truths they present to us (Bertens,1995; Cheek,1998). Cheek sees postmodernism as challenging the idea that it is possible to construct universal and essentialist representations of knowledge or to claim to speak on behalf of others. She argues instead that postmodernism supports a multiplicity of voices and worldviews where the reader interrogates the text to identify what is present and what is absent from representations. The modernist construction of the individual as a rational, self contained and unified subject becomes a discursively constituted, decentred and fragmented subject (Cheek,1998).

Poststructuralism and the cracked mirror

Poststructuralism aims to analyse social organisation, meanings, power and individual consciousness through language (Weedon,1987). I see this approach concerned with the ways in which language works with discourse to construct the various subject positions we inhabit in our everyday lives. Foucault defines the term discourse as ways of

.... constituting knowledge, together with social practices, forms of subjectivity and power relations which, inhere in such knowledge and relations between them. Discourses are more than ways of thinking and producing meaning. They constitute the 'nature' of the body, unconscious and conscious mind and emotional life of the subjects they seek to govern (Weedon,1987 p.108).

A discourse can be understood as a domain of knowledge and social practices that hold certain assumptions, for example, societal knowledge about what it is that a nurse does, or how a patient should act. Within this unified domain, which represents a readymade way of knowing, other ways of knowing are closed off, meaning that some things cannot be thought or spoken (Abercrombie, Hill & Turner,1988). It is this ability to close off other possibilities that allows the preservation of power relations within a particular discursive field. This term discursive field was used by Foucault to understand the relationship between language, social institutions, and subjectivity and power (Weedon,1987). Discourses represent particular hegemonic/political interests that attempt to privilege themselves in relation to others. The subjectivity of the individual becomes the site of power struggles as the various political interests compete for representation within the individual's consciousness (Weedon,1987).

Poststructuralism challenges the humanist view of the subject as a rational autonomous individual who possesses a static and unitary sense of self (Lather,1991). This idea of the subject is decentred to a notion of subjectivity as constituted through the various discourses in which a person is positioned at a particular point in time, and through which they are speaking. One's subjectivity thus becomes contradictory because one discourse that contradicts another does not necessarily change that

person's constitution within the original discourse. One cannot stand outside discourse because we are always engaged with/in it, transforming and being transformed by it. The subject is seen as embodied in the world, unable to be disconnected from it, and understood, as always/already constituted through knowledge (Tarnas, 1991).

From my perspective as the nurse/wife engaged in caring for my husband/patient who was experiencing life threatening illness, I was already engaged in the multiple discursive positionings of the wife and nurse; constantly shifting and challenging the constructions of self that these positionings called into being. My history of engagement in poststructural methodologies supported my capacity to challenge cultural representations of the ways in which I 'ought' to act these roles. For example, I understood the ways in which knowledge arises from particular historical and cultural locations which are value laden or informed by particular interests (Tarnas,1991). This represented an epistemological shift in my thinking, a movement from being concerned with absolute/certain truth to an understanding of the construction of knowledge as relative and contingent. For me, a fractured and fragmented epistemology replaced the modernist conception of a unified and singular over-arching reality (Reed,1995) that attempts to represent an ultimate and incontestable truth. I also understand that there cannot be a poststructuralist worldview because this approach subverts all paradigms by constructing reality as relative, multiple, local and without essential foundation (Tarnas,1991).

Poststructuralism works to destabilise the authority of the 'god's eye view' in constructions of the 'truth' in favour of locally constructed and situated knowledge. Where modern Western epistemology seeks to present an accurate view of the world, using the metaphor of the mind as a mirror, the poststructuralist mirror does not provide a clear view. Rather it is cracked and distorted, and there is a fragmented and partial understanding rather than a clear image of the world (Nash,1994). As a methodological approach, poststructuralism fragments or dissolves unities and refutes

the possibility of an autonomous subject to study (Reed,1995). The stories in this thesis reflect my multiple and contradictory subject positionings in a variety of discourses. The text of these stories should be viewed as the carriers of societal discursive knowledge and practices rather than sources of individual discourse (Dickson,1990).

Furthermore, in Foucault's approach to the analysis of discourse and culture, this inscription of subjectivity should not be understood as constructing an oppressed or passive subject who is incapable of action. Yeatman's (1994) writing on feminism and power has drawn my attention to the potential for understanding the subject's power in performing a gendered identity.

When a conception of power as action is operative, we come to understand Foucault's point that a discursive formation interpellates us not as passive subjects of power but as specific kinds of agency or capacity (Yeatman,1994 p.94).

In Yeatman's terms, gender may be conceptualised as something that we perform rather than a clearly bounded and static discursive inscription. Discursive formations work to call us into being with particular capacities for action as women or men, rather than as passive recipients of discourse. The patient and the nurse may then be understood as performing discursively produced subjectivities, which they take up in acting as the patient or nurse. Our agency lies in this ability to perform particular subjectivities and, in this choosing, to participate in an interlocutory and performative micropolitics of power where conversation, negotiation, confrontation or accommodation are possible (Yeatman,1994). The analysis in this thesis is concerned with what the particular culture has inscribed on the subjectivity(s) of the individual and the ways in which the performance of these discursive subject positionings transforms selfhood, identity and action.

Power, discourse and the body

According to Davidson (1986) Foucault's work is centred on three domains of analysis: archaeology, genealogy and ethics. In this thesis, I will use the notion of archaeology to uncover the historical construction of systems of knowledge production, dissemination, regulation and control of what is understood as the 'truth' in a given situation. Discursive practices will be identified and analysed through identification of culturally constructed norms which set boundaries and prescriptions for behaviour and thus limit the patient's potential for choice in making decisions about health care (Davidson,1986). Archaeological analysis is concerned with a re-reading of history where this reading makes the means of knowledge production problematic. The construction of a particular effect can no longer be understood as the seemingly natural consequence of an identified cause. In terms of the social construction of illness, the diagnosis can no longer be seen as having the 'natural' consequence of a particular intervention, where a series of diagnostic events results in generally accepted prescriptions for treatment. The analysis of stories in this thesis aims to deconstruct the continuity of the 'clean bounded' narratives of the patient's body which have been produced through the subject's engagement with the discursive practices of health care technologies. New continuities may be produced through this discursive analysis as well as the potential for understanding the 'un-naturalness' of seemingly natural connections between particular kinds of knowledge (Davidson, 1986).

Foucault's work on genealogy, developed in his text *Discipline and Punish*, is concerned with the political strategies, which produce knowledge, or the relationships between systems of knowledge and regimes of power (Davidson, 1986). Weedon (1987 p.113) describes Foucault's notion of power as

... a dynamic of control and lack of control between discourses and the subjects constituted by discourses, who are their agents. Power is exercised within discourses in the ways in which they constitute and govern individual subjects.

Foucault was interested in the productive aspects of power, particularly this way in which power works to construct new ways of seeing the world (Gilbert, 1995). The genealogical approach holds that there is no unified essence or naturally given truth to be discovered about people or events. It is concerned with the accidents of history that support the development of particular knowledge regimes, which are universalised from local and seemingly insignificant beginnings. Power is understood as positively constituted between acting local agents rather than enshrined in the universalisms of, for example, the law, education or religion. Power does not necessarily move from the universal to the particular. Foucault constructs a microphysics of power, arguing that power circulates through a weblike network of social and institutional relations (Davidson, 1986). In this thesis, genealogical analysis is concerned with the techniques of power, which are embedded in the discursive practices of health care technologies. The ways in which these techniques of power construct the patient's subjection through local operations such as examination, documentation and discipline of the body will be identified through this analysis. As Davidson (1986) puts it, the analysis is concerned with the forces and relations of power and their connections to discursive practices.

The genealogical approach supports an analysis of the relations of domination that establish themselves in different circumstances, according to the particular institutional frameworks in which the power relations are constituted. Foucault contends that power and knowledge cannot be separated because they are inter-related and constitutive of each other. He disagrees that reflection and rational argument enable resistance to power (Street, 1992). For Foucault, emancipatory action must always be located within the power/knowledge relationship, which he sees as acting upon the existing or future actions of others, rather than immediately or directly on another person (Street, 1992). Foucault sees power as structuring the actions of others in ways that make individuals subjects. That is, subject to others through control, violence, seduction, dependence or acceptance, and self policing in his/her behaviour through the 'self knowledge' produced within these relations of power (Street, 1992).

Power, in this sense, is both enabling and constraining. With knowledge, the patient or nurse can be understood having agency or the capacity to act or intervene according to his/her positionings as the discursive subject. At the same time it is constraining because this inter-relationship between power and knowledge constructs a discourse as a unified domain, closing of possibilities or limiting what can be said or thought within that discourse. Foucault's notion of disciplinary power and the ways in which knowledge/power is connected with the desire for control lets us understand the notion of the 'gaze'. The 'gaze' is a metaphor for the techniques of monitoring and surveillance, which are the means through which institutions such as medicine and education produce knowledge. Individuals are constituted through the institutional power/knowledge of disciplinary processes such as normalising judgement, where they are required to conform to the practices of the institution (Henderson, 1994).

The third domain of genealogical analysis is concerned with ethics or the self's relationship with the self. Foucault developed his work on ethics in the second and third volumes of *The History of Sexuality* and *On the Genealogy of Ethics* in Rabinow's (1984) text *The Foucault Reader* (Davidson, 1986). Foucault saw ethics as one part of the study of morals. He was concerned with the morally relevant actions of people's behaviour and the moral codes that attribute negative or positive value to certain actions. While not denying the social value of moral codes, he was interested in how a person might constitute him/herself as the "moral subject of their own actions" (Rabinow, 1984 p.19). That is, the self's relationship with the self as an acting moral subject (Davidson, 1986).

According to Foucault (cited in Dreyfus & Rabinow, 1982) the self's relation to the self has four elements including ethical substance, the mode of subjection, self-forming activities, and telos. Ethical substance is the aspect of ourselves, or our behaviour, such as feelings, intentions or desires, which is taken to be the ground or domain of ethical consideration. The domain of ethical consideration is strongly

linked to cultural and societal beliefs at given points in history (Davidson, 1986). Foucault suggests “for the Christians it was desire, for Kant it was intentions, for us now it’s feelings” (cited in Dreyfus & Rabinow, 1982 p.238). The second element is the mode of subjection or the ways in which people come to recognise their moral obligations, to others, and to themselves. These moral obligations may be derived from religious doctrine such as the Ten Commandments, natural law, universal Kantian rationality, or from cultural customs or conventions. The mode of subjection provides the link between moral codes and the self as the way outside authority is taken up by people as their own concern at particular points in time (Foucault cited in Dreyfus & Rabinow, 1982; Davidson, 1986; Hacking, 1986).

Foucaultian ethics are concerned with the means by which we work on ourselves to become ethical subjects, or the self forming techniques and practices we apply to ourselves in order to behave ethically (Foucault cited in Dreyfus & Rabinow, 1982; Davidson, 1986). As Davidson (1986) suggests, this could be understood as the self-examination techniques that we undertake to change us into the kind of people we wish to be. Such techniques help to eradicate certain desires or to moderate our behaviour towards that which is considered to be more ethically acceptable. Techniques for self-improvement could be a way of working on ourselves that involves setting ideals such as weight loss. Cutting off or moderating certain behaviours (such as overeating), or carrying out certain desirable behaviours (exercise), and the creation of guilt when these ideals (actually losing the weight) are not met (Hacking, 1986) would be other examples. The final element of the genealogy of ethics is telos, or the kind of moral beings we aspire to be when we act in certain ways. This can be understood as the goal towards which our self-forming activities are directed such as freedom, immortality or self mastery (Foucault cited in Dreyfus & Rabinow, 1982; Davidson, 1986).

The self’s relation to the self and the body

Shilling (1993) sees Foucault's historical explorations as concerned with the discursive construction of the body and the social institutions and practices which work to govern the body. These explorations set out the relationships between the body and the effects of power on it, linking individual daily life practices with the 'panopticon' gaze of institutions (Dreyfus & Rabinow, 1982). In the historical sense, the rise of modernity was to produce a shift in the way the body was represented in, and worked on, through discourse. The ethical substance of moral practices moved from a concern with actual behaviours and activities performed by bodies. Instead this ethical substance became centred on the intentions of the mind, which were reflected in bodily actions or structured in consciousness through language (Shilling, 1993).

In traditional societies preceding the rise of modernity, sovereign power was concerned with the repression, punishment and annihilation of the bodies of deviant individuals. The modernist approach utilised power as a means to govern the activities of the individual through the control of populations. The focus on the body as flesh, the actions of the body, and the individual as the site of repression, moved to a concern with the mindful body and the management of population groups through surveillance and techniques of the self (Shilling, 1993). This control of populations was concerned with the management of people's minds in terms of their intentions. Particular populations were examined, classified, and were selected out to be worked on through self-forming activities. Foucault's notion of the prison as the 'panopticon', where inmates were subject to the constant surveillance or gaze of the prison management is an example of the way in which individuals become subject to the discursive practices of governing authorities. The relationship between the governing authority of the prison and the mind of the subject of surveillance, encouraged self forming and regulating activities as a means of control. This relationship moved the prisoner's intentions towards a more useful and productive life (Shilling, 1993).

The control of populations is concerned with disciplining the body in ways that construct a legitimate body. In other words, the body that will be of most value to a society (Shilling, 1993). As Walzer (1986 p.59) suggests

.... the function of discipline is to create useful subjects, men and women who conform to the standard, who are certifiably sane or healthy or docile or competent, not free agents who invent their own standards, who in the language of rights, give law to themselves.

This disciplining of the body may be understood in terms of codes of behaviour that are illustrated in the following examples. Labour produces the capacity for economically productive work. Sexuality supports the possibility of reproduction. Engagement in education results in the acquisition of knowledge. Subjection to the law creates the moderation of desires. The confession of sins produces the declaration of good intentions within religious doctrine (or psychiatric discourse). The regulation of the body and subjection to physical examination to is undertaken in order to promote health. Self-awareness and communication techniques are developed to manage relationships. Aesthetic taste works on the surface of the body to produce representations of beauty. A whole variety of specialists, such as priests, doctors, nurses, educators, counsellors, lawyers, beauty therapists and fashion designers, are concerned with developing knowledge and techniques of the self to support self improvement, that is, the development of the legitimate body. A key issue here is the construction of desire as Foucault's mode of subjection, or the internalisation of the desire to possess or act as the legitimate body (Hacking, 1986). This in turn creates the body as docile, productive and useful.

The politics of Foucault as a 'tool kit' for local resistance

Foucault's notion of power acting through local networks is useful in understanding the potential for local resistance. Foucault challenged the idea of a revolutionary group who speaks for and acts on behalf of oppressed others. His work represents

.... a sharp break with state centred conceptions of power and by extension, with revolutionary or radical politics which defined itself by opposition to, or overthrow of the state (Wolin, 1988, cited in Blacker, 1998 p.356).

Instead the genealogical approach is minutely concerned with the network of disciplines that administer power and the specific locations where this power is endured or resisted (Walzer, 1986). Yeatman (1994) draws on Foucault's work to develop a conception of power as action and capacity. She focuses on the performative aspects of gender, for example, as something we do rather than something we are. I understand this as meaning that even when we appear to be acting as passive recipients of institutional discipline, we are acting subjects even though we might deny this capacity. A discursive formation or field calls us into being with particular kinds of agency or capacity rather than constructing us as passive subjects/recipients of power.

This moves my understanding from a politics of identity to a politics of action; that is, transformation of the self as a capacity for action, or performance of subjectivity, rather than preservation of a static identity, as a diseased patient. Nurses and patients may be understood as called into being as particular kinds of agents, with the capacity for local resistance, within the discursive practices of health care. The challenge for me will be to see the emancipatory subject as someone who is in between legitimate participation in self governance and exclusion from governance, not as a marginalised subject who is excluded from participation and incapable of action (Yeatman, 1994). The patient's 'otherness' within the discursive practices of the institution may be understood as constructed and performed and, therefore, open to contestation and negotiation. Resistance or accommodation may be understood as a freely chosen mode of acting.

In this thesis, the analysis is concerned with the techniques of monitoring and surveillance and the locations where the exercise of power exceeds what could be held as legitimate in the particular context. In this space, I am likely to find the processes of ongoing subjection and exclusion. Individuals will be seen as the bearers

of power, and understood as simultaneously undergoing and exercising power. Social practices may be identified as self-maintaining and links may be seen to wider social strategies of power outside the institution or particular context of this study. The techniques through which knowledge is generated will be analysed in terms of links between knowledge and power, the status of particular knowledge, and the means by which knowledge is disseminated, suppressed (Gilbert, 1995), accommodated or resisted.

Surfacing the local as the ‘worm’s eye view’

As a methodological approach, genealogy is concerned with the study of the specific and local rather than the universal. It unsettles the consensus about taken for granted truths using an approach Blacker (1998 p.351) calls “high stakes storytelling”. Genealogy is undertaken by the specific intellectual as ‘eventualisation’, or the study of single events in such a way as to make visible the tendency towards explaining events in terms of what is already known, or ‘self evident’. Eventualisation involves “multiplying causality and identifying the multiple processes that were required to constitute an event; the connections, strategies, supports, forces and blockages that came into play at a particular moment in time” (Foucault, cited in Baynes, Bohman & McCarthy, 1987 p.104). That is how the reading of a particular event became privileged over other possibilities and generalised to act as the measure for the perception and evaluation of events in other situations. Genealogy examines what knowledge has been produced, under what circumstances whose values supported the development of this truth, and whose knowledge is held to constitute the truth.

This study of the microphysics of power may be understood as analysing the relations of power in specific localities or at its local extremities. It is the “worm’s eye view”

(Blacker, 1998 p.356) as opposed to the 'god's eye view' that is constructed in metanarratives. This 'worm's eye view' moves me from the modernist notion of the metanarrative that legitimates an absolute and sovereign truth, towards an understanding of the significance of local stories. From this perspective, the telling of people's experience of the world can be seen as weaving "the fabric of everyday life" (Lyotard,1992 p.19). In writing from the specific localities of everyday life, I am unable to sustain an authoritative subject position or call upon established regimes of thought to support a claim to 'truth' (Blacker,1998). The universal intellectual, who, in modernist terms, claimed the theoretical expertise to speak the truth for others, has become the specific intellectual. This new breed of intellectual has a 'self conscious' modesty (Foucault,1986 cited in Blacker, 1998). S/he is concerned with the breadth of the knowledge claims being made, the consequences of what is being said, and the interests of the constituencies for whom s/he is speaking (Blacker, 1998).

My project as the inquirer is concerned with the ethics of genealogy, or the self's relation to the self, in the telling of a story and in the analysis of knowledge claims. I am called into being, or I take up particular discursive positionings, through the telling of the story. As Blacker (1998 p.357) puts it, "one becomes as one struggles". For the specific intellectual, the ethical substance (Foucault, 1983) moves from the modernist concern with intentions, desire or feelings, to a self consciousness awareness about what is going on in the location of the story and how, as the author/inquirer, I am implicated in it (Blacker, 1998). The mode of subjection, or the basis from which self relation is produced, becomes harmonisation. Harmonisation involves bringing one's own work into harmony with location in which one is working (Blacker, 1998) to avoid what Deleuze and Foucault (1977 p.209) call "the indignity of speaking for others". The critical issue here involves the representation of particular interests and my own awareness of how I participate in the manufacture of knowledge concerning those interests.

The self forming activities of the specific intellectual involves the rigorous practice of honesty where there is an attentiveness to the results derived from inquiry and a wariness about how these results may be used (Blacker,1998). The telos, or ultimate goal of the author/inquirer, is concerned with being self overcoming; that is, striving for self mastery as a knowledge worker and having control over the actions taken in the research and the outcomes of it. In this thesis, I may be understood as a channel through which power passes in the construction of knowledge. In paying meticulous attention to the detail of knowledge construction in a particular location, there is a losing/finding of the self (Blacker,1998). I see this new construction of (my) self as a politically strategic, and intensely local, knowledge worker as central to my capacity for resistance and accommodation within nursing practice.

Autobiography and the author (re) positioned in the text

Poststructural approaches radically reconstruct the positioning of the author in telling a story (Lyotard,1992). The absent author of the modernist text is required to present himself or herself in person; not with the unitary selfness of the Author but rather with situatedness that uncovers the contradictory positionings of the author as a discursive medium. While the poststructuralist author lacks the clean bounded and absent coherence of the modernist author, s/he may instead possess a contextual richness and diversity, which is capable of producing multiple expressions of self (Lincoln, 1997).

Kosta's (1994) writing on autobiography illustrates the tensions between autobiographical writing for women as a means of assigning meaning to events in their lives, and the subject positions they inhabit, and the epistemological shift to the textual practices of poststructuralism. It seems that just as women have some authority as presence in literature in telling the stories of their lives, the notion of the author has moved to become fragmented and partial. Kosta (1994) argues for a new

understanding of the function of the author, using Foucault's idea of the 'author function'. Using this approach, the author becomes 'sites' which fluctuate, creating an "infinite number of presences or traces in the text" (Walker, 1990, cited in Kosta, 1997 p.5). The author becomes one possible site of meaning in the text, a point of departure, which presents multiple possibilities for representation through the reader's engagement with the text.

Autobiographical writing may be understood as creating narratives of the self (Kosta, 1994) where women constitute themselves through engagement within the text of their own writing. This is what Eakin (1985 cited in Kosta, 1994 p.17) calls "a ceaseless process of identity formation in which new versions of the past evolve to meet constantly changing requirements of the self in each successive present". In the spaces between my past and present, in between the spoken and the written texts, I recreate and reassemble critical events in my life as personal histories, which explore my own sense of self, and positioning as other. The dissolution of the boundaries between my public and private worlds makes the interdependence between them visible. It brings out new narratives of self where I am positioned as the subject of my own stories. In these stories the self is always/already the 'other', enmeshed in the tensions between the multiple discursive positionings of the nurse and wife.

I do not have one authentic self to share with others. However, as Lincoln (1997) suggests, I have a range of voices and choices that create the potential for new ways of understanding the world, both for myself and for others who read and interpret my work. Speaking in a range of voices reflecting multiple discursive positionings of self offers multiple points of connection and engagement, where writing becomes a way of knowing. Writing is a method of inquiry for self and others (Richardson, 1998) where evocative representations of experience invite the reader to relive the events with the author and to participate in their own constructions of self. But this telling is sometimes painful. The telling illuminates the struggle; the agonising ethical decisions that arise from the tensions between the multiple discursive positionings we

are called to take up as researchers, authors, and nurses and as our private selves. It illuminates the need to find ways to tell these private stories of our own and others' experiences in a way that communicates their meaning and at the same time respects the professional and academic rules of knowledge construction.

Speaking in a range of voices creates the potential for a new permeability in the boundaries between academia, practice, and ourselves. There is a bringing out of the interior into the public realm of the texts we create; a space where we are minutely concerned with the interests of the people we write for and whose needs we seek to represent. But this is also a space where we need to journey carefully, mindful of the turbulence and danger in the shifting of boundaries where things are no longer contained. Lincoln (1997 p.51) reminds me there may be "beasties and monsters" in the uncharted territories I am exploring.

Summary of the theoretical considerations

Poststructuralist methods of inquiry support new ways of understanding our social and material worlds. The modernist construction of a singular and overarching metanarrative is replaced with a fractured and fragmented epistemology where a multiplicity of voices and ways of knowing about the world are brought into view. As a theoretical approach, Foucaultian genealogy supports the cultural and discursive analysis of the relations of power, which become established in particular circumstances. The stories in the text of this thesis can be understood as the carriers of societal knowledge. In using this theoretical approach I uncover the performance of the discursively produced subjectivities which the patient and nurse may actively take up or not, in acting these social roles. The notion of agency is critical in the performance of these subjectivities in a micropolitics of power where conversation, negotiation, confrontation and accommodation become possible as freely chosen modes of acting. The analysis in this thesis is concerned with what the particular

culture has inscribed on the subjectivities of the patient and the nurse and the ways in which the performance of these discursive subject positionings transforms selfhood, identity and action.

The following chapter explains the methodological considerations for the thesis. I relate how I have drawn on ideas from genealogical analysis, autobiography and writing as inquiry to develop methodological paths. I consider how the ontology and epistemology of these approaches relate to my practice as a nurse and the personal beliefs and values informing how I live my life. The scope and boundaries of the study are set out and central questions, which guide the analysis of this patient's experiences of life threatening illness, and my work as the nurse/wife in caring for him, are identified. The means used to work through the development of the methodology are explained as a circular process of reading, writing and a type of critical reflection, which I have named "talking back to myself". I consider the ethical problems arising from the methodology and the context of the study and explain my paths through particular difficulties to find safe ethical ground. I also present my visions for enacting the methodology and the techniques that I have utilised in making sense of the stories in relation to it.

CHAPTER FOUR

METHODOLOGICAL CONSIDERATIONS

Introduction

This chapter explains how the methodological considerations for the thesis are derived from Foucault's original writing on genealogical analysis, as well as interpretations of his ideas by other authors such as Deleuze (1988), Blacker (1998), and Kendall and Wickham (1999). I have also drawn ideas from Kosta's (1994) discussion of autobiography, and Richardson's (1998) 'writing as inquiry'. I consider how the ontology and epistemology of these approaches relate to my practice as a nurse and the personal beliefs and values informing how I live my life. The scope and boundaries of the study are laid out and central questions, which guide the analysis of this patient's experiences of life threatening illness, and my work as the nurse/wife in caring for him, are identified. The means used to work through the development of the methodology are explained as a circular process of reading, writing and a type of critical reflection, which I have named "talking back to myself". Specific ethical problems arising from the methodology and the context of the study are considered and my paths through particular difficulties to finding safe ethical ground are explained. My visions for enacting the methodology, and the techniques I have utilised in making sense of the stories in relation to it, are also presented.

Fine stitchwork and straight seams

For me, creating this thesis is like making a garment with a tailored fit that supports the freedom to move and blends colour, texture and shape. I begin with an idea that is a sense of form and shape and then think about the construction of it, each stitch, each seam. And then, as I work with it, the fabric undergoes a transformation and becomes something; not a mirror reflection of my vision, because the vision was

not crystal clear in the first place, but it comes together as I knew it would. Somehow, as I work with it, the garment grows into a form that works for me and reflects something about me, my way of being. Often as I work with fabric, I remember sitting with my old Austrian grandmother, Nanie, as she supervised my stitching. “Now that’s not quite good enough, unpick it and do it again”, she would say, as a veteran of handcraft techniques. So Nanie taught me about excellence and attention to detail, and she grounded these techniques in my relationship with her.

This thesis blends the fine stitchwork of my own professional and personal experience with the straight seams and formal techniques of academic writing. It weaves together my nursing practice with values and elements of my personal life along with my experience of working with ideas from poststructuralism. However, the boundaries between these three elements seem much more permeable than I would have imagined before beginning this study. I did not intend that working with my recollections of this experience would be therapeutic, but I had a strong desire to speak about my journey through Kevin’s illness and dying and my work with him as the nurse/wife. I think this desire to speak arose from the extremity of this experience where I called on all the knowledge, skills and experience that I have gained through my life to manage it. Through this extremity, and my work in poststructuralism which preceded it, I developed new understandings about the ways culture and discourse attempts to call us into being as social actors, and the choices we make in performing these discursive positionings.

Theoretical work with one particular lecturer in my undergraduate degree was significant in learning to trust my own thinking, and myself. This lecturer she taught me not to be afraid to challenge my own ideas and those of other people and she fostered my capacity to imagine new possibilities.

I remember sitting in her class as she talked about the ideas in Foucault’s writing she didn’t only challenge my thinking, she moved all the academic ground I was used to. I had thought I was pretty good at this academic university work but I didn’t know what she was talking about and my lack of understanding made me frustrated and angry with her. But as I slogged through the course

readings and listened to her speak, I began to engage with her, I felt her pull me beyond my own understanding. She forced me out to the boundaries of my understanding and beyond, to places where I could only exist in my own imagination, to places where the view was entirely different. In those classes, she changed my ways of understanding the world. My engagement with her ideas made me realise that the neat theoretical frameworks I was so used to calling on did not necessarily have anymore authority than being simply the imaginings of another person.

Inside the seemingly ‘knife edge’ existence of caring for a person with life threatening illness, I was forced to trust my own judgement. I knew I would have to live with the decisions that I made in certain moments. I learned to believe in myself and my own judgement, particularly in feeling the moments of tension at discursive intersections, where I knew there were choices to be made. Recognising this feeling of tension would make me think carefully about what was happening in a given moment, and lead me to consider the alternative possibilities for ethical practice in our specific, local context. In surfacing “subjugated knowledges” (Lupton,1997 p.103) disguised beneath the dominant discourses about how I ought to respond in specific situations, I held my own visions of how to behave while keeping my thinking open to challenge. I did a great deal of thinking even during the most extreme times of this experience and this thinking lead me to understand myself and my nursing practice in new ways.

The methodological approach in this thesis reflects the values and knowledges, which underpin my nursing practice. My philosophy of practice supports my own and others multiple ways of acting in complex social worlds, where in each contact with the nurse, the person is respected for the uniqueness of their responses to life events. I believe the nurse, the patient, and their families are people who bring multiple, complex and changing values and beliefs into the experience of life threatening illness. The practice of nursing involves managing the physical, emotional, social, cultural and spiritual boundaries between the nurse and the patient. The people moving within the patient’s circle of care may be profoundly affected by the connections and encounters in this circle. I believe the intention of nursing is to

support people to live their lives with the capacity for action and choice, with each person's wellbeing as the central concern of the nurse.

The theoretical ground of my practice arises from ways of knowing about nursing where knowledge is understood as partial, relative, and contextually derived from historical events, present interactions and future possibilities. Theoretical knowledge is understood as presenting possibilities for action within the realities of nursing practice situations rather than as prescriptions for how the patient and the nurse ought to act. Nursing knowledge grows out of the ground of my practice where there is an intertwining of self with self and others among the tensions, contradictions and unpredictability of practice situations. The social realities of the nurse and patient are understood as contestable, negotiated, and changing in response to new possibilities, as life events unfold. Each person is understood as having stories to tell which uncover their own contradictions, vulnerabilities, aspirations and beliefs about life and themselves. I understand institutional knowledge and protocols of practice as having particular histories of knowledge production that are contingent upon the specific relations of power existing between the individuals who practice within health care institutions. In acting as the professional nurse, I constitute myself as "the moral subject of my own actions" (Rabinow, 1984 p.19) where I become a politically strategic and intensely local knowledge worker (Blacker, 1998) who is concerned with local events and how I am implicated in them.

Marking out the territory and boundaries for the study

As an exploration of the discursive practices in life threatening illness, this study critically examines the relationships between technologically oriented health care, nursing practice and the patient's socially inscribed body. My use of the genealogical approach to inform the analysis allows consideration of the meanings, assumptions, power relations, and subject positions that are embedded in discursive practices of healthcare and life threatening illness. As unified domains, these discourses represent

a ready-made way of knowing that works to preserve particular power relations within nursing practice and nursing relationships. Genealogical analysis supports the 'unpicking' of discursive practices, where "the focus of inquiry is the problematics of representation through which social experience is shaped and re-presented as knowledge" (Jaques,1992 p.84). In this thesis the analysis seeks to uncover multiple possibilities for the ways in which nurses may understand the experience of life threatening illness, illuminating the discursive intersections or gaps where nursing may recognise the "disqualification of local.....knowledge" (Papps & Olssen,1997 p.39) and imagine capacities for action and choice arising from the surfacing and valuing of local knowledge. My use of autobiography in creating narratives of the self brings together landscapes of experience and local knowledge. In this process of writing as 'engaged' inquiry, I make visible my own subjectivities in performing as the nurse/wife available to the analysis as sites of discursive practice.

The questions, which guide this inquiry, are framed as

What are the technologies of health care which are apparent in situations where a patient is experiencing life threatening illness? How might the patient and the nurse take up and perform subject positionings within the discursive practices of health care? What are the strategies the patient and the nurse employ to mediate body boundaries and the self's relation to the self? What were the genealogies of my practice as the nurse/wife in this unique context of life threatening illness?

My specific aim in working with narratives of self in life threatening illness is to explore the political context of health care practices to "detach the power of truth from its forms of hegemony..... social, economic and cultural in which it operates" (Smart,1985 p.68); to offer representations of the ways a patient and/or a nurse might mediate body boundaries and take up alternative discursive positionings to construct

new narratives of self; and to consider the ways in which nurses might intercede to work with patients peacefully, bringing one's own nursing practice into harmony with location in which one is working.

Working through the methodological considerations

I developed the methodological considerations for the thesis from Foucault's original writing as well as the interpretations of other writers who have used his ideas of genealogy and techniques of the self. From these authors, I have drawn together a purposeful group of interpretations of Foucault's writing to construct the methodological approach for the thesis. These interpretations, and my own reading of them, may contradict ideas in Foucault's original work. Developing an understanding some elements of Foucault's writing has been a journey in itself as I could not find discernible patterns, or identify how to use his ideas as techniques for the analysis of data. In thinking about this, it was probably more out of a sense of frustration that I moved to reading about his work in secondary sources, which were written in the 1980's. This included the writings of Davidson (1986), Dreyfus and Rabinow (1982), Smart (1985), Hacking (1986), Rabinow (1984), Walzer (1986), Wolin (1988), and Weedon (1987).

Having gained some way of framing Foucault's ideas as a methodological approach, I then re-read some of his original writing. These texts included *The birth of the clinic* (1975), *The history of sexuality* (1979), Deleuze and Foucault (1977), *On the genealogy of ethics* in Dreyfus and Rabinow (1982), and *Technologies of the self*, Foucault in Martin, Gutman and Hutton (1988). This began to make a little more sense. I then moved to more recent writing to see how contemporary writers were using his notions of archaeology, genealogy and ethics. I read Kendall and Wickham (1999) on using Foucault's methods, Blacker (1998), Yeatman (1994), Lupton (1997), and finally Kosta (1994) on autobiography and the 'author function'. I have also

drawn ideas from the work of film theory writers such as Brooker and Brooker (1997), Creed (1997), and Thornham (1997) as well as reading the work of nurse writers who have used Foucault.

Of these, I have found Jaques' (1992) thesis on *Representing the knowledge worker* useful as an example of how Foucault's writing was used in a nursing research study. This study demonstrates how the theoretical tools of the genealogical approach were developed as a method for the analysis. In drawing theoretical tools from the genealogical approach for this study, I consider how it is possible to re-present events within a system of knowledge, and how a particular ways of knowing come to be held as 'common sense' beliefs. This approach subverts dominant modes of knowledge construction because the inquirer is concerned with the means of the production of knowledge, what holds particular knowledge in place, and how particular statements in the discourse are allowed or disallowed (Kendall & Wickham,1999). In destabilising the notion that any one approach is natural, inevitable or inherently superior, it is possible to consider other possible representations of events.

The analysis in this study focuses on the relationship between power, knowledge, the body and space. For example, the ways in which technologies of power have produced the patient and the nurse as objects within the discursive spaces of health care technologies and academic theories about nursing and health care. The term discursive space describes the networks of knowledge and practices which act upon the body in social relationships (Jaques,1992). Jaques (1992 p.96) describes a discursive space as, "the site of force and resistance between bodies and power/knowledge". It is a social space that shapes and is shaped by the bodies that enter it, such as the body of the patient or the nurse. This discursive space becomes the site of objectification, subjectification and resistance.

The analysis of the stories related in the study identifies the discourses populating the text and mapping the ways in which particular discourses become privileged over

others. That is, what is present and what is absent from the text of the story. The analysis of each discourse present in the story concerns identifying regularities in the appearance of the discursive statements. Discursive statements are made up of the words, or what is sayable within the discourse, and the things which are present, or visible, in the practice of the discourse. What is sayable could be understood as the theories underpinning certain practices, which are consistent with the discourse. The visible alludes to the things that are used in these discursive practices, such as buildings and instruments (Kendall & Wickham,1999). The analysis explores how mutually sustaining power relations that exist between the sayable and the visible works as a mechanism or a strategy “which keeps things going” (Kendall & Wickham,1999 p.49) through sites of discursive practice.

The identification of rules of the production of statements uncovers the genealogy of the discourse in an historical sense. In undertaking an analysis of the ‘history of the present’, I identify the ways in which the discourse emerged or was produced a given points in time. In uncovering the shifts in thinking that may have occurred at a particular point in time, the conditions of emergence for this discourse may be identified; that is, the ways in which particular statements became operational as a public apparatus with particular rules for the production and repeatability of statements as the discourse (Kendall & Wickham,1999). The identification of rules that delimit the sayable help me to chart the boundaries of the discourse in terms of what may be said within it and what is likely to be excluded from it.

The identification of rules that create spaces in which new statements can be made, refers to the capacity for discursive practices to create new forms of subjectivity (such as the patient in medical discourse), and new categories for understanding human behaviour (for example the diseased person). This creativity demonstrates the inventiveness of discursive statements in producing subject positions through the mechanisms of operation of public apparatuses (such as the hospital or clinic) (Kendall & Wickham,1999). Through these mechanisms of operation, ways of

thinking and practising within the discourse tend to call the person into being as a patient who, as the patient, may choose to act in certain ways. Public apparatuses are the 'surfaces of emergence' or the places where objects (such as the body) are acted upon in certain ways according to the how they have become classified through discursive practices. Institutions, such as the hospital, have acquired the authority to operate in ways, which set limits and prescribe certain activities for (patients as) discursive objects. In this way, 'forms of specification' develop as ways of knowing, which set boundaries within which the discursive object (or patient) should perform (Kendall & Wickham,1999).

Identification of rules that ensure a practice is material and discursive at the same time refers to the inseparability of materiality and thought. This means that discursive practices always concern knowledge, or theory, as well as the materiality of practice in specific locations. Events or actions should be understood as the complex, inseparable and ongoing interaction of discourse and materiality where the nondiscursive is always/already under the sovereignty of discourse (Kendall & Wickham,1999). The relations of power are the mechanisms or strategies which hold these two conflicting poles of knowledge, the discursive and nondiscursive, together. Power can be thought of as an ongoing process of production; it is the mechanism or energy which drives the operation of these discursive relations, but always in an imperfect sense as resistance ensures that the operation of discourse is never carried out in exactly the same way (Kendall & Wickham,1999). As Deleuze (1988 pp.70-71) suggests

..... power is a relation between forces, or rather every relation between forces is a "power relation"..... We can therefore conceive of a necessarily open list of variables expressing a relation between forces or power relation, constituting actions upon actions: to incite, to induce, to seduce, to make easy or difficult, to enlarge or limit, to make more or less probable..... power is not essentially repressive ... it is practiced before it is possessed it passes through the hands of the mastered no less than through the hands of the masters

The analysis maps the techniques of power that are practised at specific points in the relations between the sayable and the visible and the way power is implicated in the constitution of the subject through discourse. Kendall and Wickham (1999 p.53) explain how the subject is produced through discursive positionings.

Subject's actions take place in discourse, and subjects themselves are produced through discourse. Subjects are the punctuation of discourse, and provide the bodies on and through which discourse may act.... the subject is produced out of the doubling of force upon itself, the attention to self. This production of subjectivity always occurs as a doubling of self upon self in every realm - in the realm of the body, the realm of force and the realm of knowledge. Human action within discourse is always positional, that is, it always occurs through a subject position inhabiting a space between the two poles of knowledge, the discursive and the non-discursive.

Moral duties toward oneself form a central theme in Foucault's writing on ethics. Deleuze (1988) describes how the relation to oneself is created through a doubling of the relations of the outside. A new inside is created as self mastery where the power which is exercised over the self is a doubling or folding inward of the power that is exercised over others. The self's relation to the self is constructed within these relations of power and knowledge in a way that is constantly reforming through the discursive positionings taken up by the subject.

The individual is coded or recoded within a 'moral' knowledge The fold therefore seems unfolded, and the subjectivation of the free man is transformed into subjection: on the one hand it involves being 'subject to someone else by control and dependence', with all the processes of individuation and modulation which power installs, acting on the daily life and the interiority of these it calls its subjects; on the other hand it makes the subject 'tied to his own identity by a conscience of self knowledge', through all the techniques of moral and human sciences that go to make up the knowledge of the subject (Deleuze, 1988 p.103).

The subject forms his/her interiority as part of, and yet separate from, the power relations of the outside. Hacking (1986) stresses the capacity of the subject in undertaking these self improving and self forming activities where we constitute ourselves as subjects through the particular truths we take up and act upon. He

suggests it is the subject's conscience rather than the force of any outside authority, which informs the way we produce ourselves as subjects (Hacking,1986).

In specific moments we create self knowledge to guide our choices and actions, producing our own ethics and our own forms of truth. The mode of subjection reflects what we internalise from outside authorities, that is, what we take on as being the truth and the recognition of an obligation to oneself put this truth into practice. The body thus becomes a local site of political and ideological struggle. It is the point of focus for the practice of medicine and provides the discursive surface where the subject freely chooses to transform him/herself in taking up the identity of the patient. The self forming activities, or self practice on the body by the patient, provides the link between ethics and self mastery (Hacking,1986). Self mastery, or power over one's actions and their results, is the goal of Foucault's notion of freedom (Blacker,1998). The subject's agency lies in this choosing to become absorbed into another world, to create oneself as the patient. In charting the ways 'microphysical' networks of power relations produce discursive positionings, I localise the points where the non-discursive (the body) becomes subject to the discursive (knowledge and practice). In analysing the means through which the social body becomes the target of these power relations, I identify how subjectivity, and the governance of individual subjects, is produced through these articulations of power (Walzer,1986). As well, I describe the how resistance works as a strategy of power (Kendall & Wickham,1999) in moments where tensions arise between contradictory discursive positionings.

Yeatman's (1994) writing on power as capacity is helpful in considering how the subject is interpellated through discursive formations as an active subject. Her writing helps me to see how the category of patient becomes something that the patient does rather than something the patient is. The patient can be understood as performing his/her identity as the patient, through the construction of identities that are negotiated and contested within these discursive formations. The subject has the capacity to

perform his/her identity beyond that of an oppressed subject who is paralysed within the gaze of medicine. Outside authorities are taken up, or not, as the subject's own concern through techniques and practices of self examination and self improvement. The goals towards which the self forming activities are directed include freedom and self mastery. The methodological approach this study shows how writing as inquiry has become a process of identity formation for me, where I take up discursive positionings in the telling of the story, constructing my own identities as I struggle (Blacker,1998) to locate myself and my practice in these stories.

Developing narratives of the self

In developing this study, I am aware that I have become a border traveller where I have brought together the methodological approaches (Walker,1997) of genealogical analysis, autobiography, and writing as a method of inquiry (Richardson,1998). I am working in border spaces where the ground is inherently unstable and constantly moving, and where conversations and engagements in the text are always ongoing, partial and unfinished (Walker,1997). I have used autobiography as a means of transforming the relationship between the texts I create and my subject positions within them. Within this circular process of speaking, listening, writing and reading, I examine my own positionings within these intersections of personal histories and professional and societal knowledges. In Kosta's (1994) terms, these narratives of self-discovery have become their own textual productions arising out of this experience of crisis and inquiry. They are like an archaeological exploration uncovering the past as sites of struggle between my own personal histories and my relationships with professional knowledge and the social and cultural inscriptions and practices surrounding life threatening illness.

The method of developing narratives of the self, which I have named "talking back to myself", developed out of a desire to create a textual richness that did not seem

possible in simply writing down events, thoughts and feelings. Sitting at the computer and writing seemed to produce rather linear accounts, which had beginnings and endings. I decided to audiotape myself talking about the experience of being in these events, recalling my thoughts and feelings, and using the journal notes I had kept at the time as prompts. I then listened to the audiotapes while writing back to them on the computer. At first listening to my own voice seemed strange. But as I became used to it, and allowed myself the freedom to experience responses to the stories I was telling, things came out in the text of the narratives in this conversation with myself that I had not realised were there.

This process of “talking back to myself” created a textual richness with many more layers and connections and opened up my writing approach to create something which was much more connected with myself. This engagement and exploration of my own experiences may have, in Gaddow’s terms arisen out of a desire

..... to make the little known comprehensible by journeying there, becoming involved in a relationship within it there is no option of detachment; vulnerability is constant. There is a risk of not finding a way back to the familiar. There are maps, of course, that could be studied and the look of the land extrapolated, instead of going there personally. Once there, however, even with maps, even having been there before, the land transcends every schema, every recollection and prediction. It is inexhaustible, different each time. It can be summarised at a distance, but a summary is useless for living there (Gaddow,1995 p.212).

Through this process of thinking, speaking, listening and writing, I again became deeply emersed in particular moments of this experience and was able to write with a much more passionate connection with it. My journal notes provided the maps to return to locations, which in turn were developed as audiotapes. Written responses to these audiotapes were kept as a journal on my computer. As well I kept an exercise book as a further journal, noting events, ideas, references and my own responses as they came to mind, and sometimes this was after conversations with close friends. The techniques I have developed in ‘talking back to myself’ create narratives of the self through engagement with my own evocative writing (Richardson,1998). Thinking

and speaking about these times has created meeting places for the personal and professional, the inside and outside of my own experiences, where being and knowing have come together (Gaddow,1995) to create a sense of what it is like to live in this land of life threatening illness. The journey back through these experiences has surfaced emotional responses that require an ongoing 'minding' through reflection and conversation to find safe and ethical paths through them.

Finding safe ethical ground for the study

I believe this study to be a morally sustainable project in that it provides unique insights into the ways in which nurses might work to mediate the boundaries of socially inscribed bodies in moments of profound vulnerability. It also reconstructs the 'theorising' on the patient's experience of life threatening illness as socially produced representations of the structure and form that the patient's experience and the nurse's practice with the patient could take. It documents the ways in which theory about, and practice with, patients experiencing life threatening illness are bounded by particular ways of knowing that are connected to the values and practices of particular times, places and disciplines. In laying open the experience of life threatening illness this study creates conversation spaces through the text which may support other nurses in considering alternative readings of their own practice.

As a personal exploration of the relationships between technologically oriented health care, nursing practice and the patient's socially inscribed body, this study presents some critical ethical challenges that at times have almost paralysed it. As Lightfoot (1983, cited in Clandinin & Connelly,1998) suggests, there is a need to pay attention to the inquiry process where personal data enters the public realm. This involves taking care of oneself within the texts created about oneself.

When I was a very small child my older brothers and sisters told us stories about these very scary creatures, called "Warkies", who lived in the depths of the lake bordering our parents' farm. Warkies

resembled something like a Taniwha and particularly liked to eat little children who went too near the water where they lived. So I grew up with this idea of Warkies being the scariest thing possible and the story did keep the little kids away from the lake (most of the time anyway). Every night before I went to sleep mum and dad had to check to make sure there were no Warkies hiding under my bed.

In attempting to work with ethics situated in a poststructuralist methodology where the outcomes of the inquiry process are inherently fragmented and unstable, I am aware the (ethical) water I am leaping into

.... is not just deep, but uncharted. We are not even at the crossroads; for there to be crossroads, there must first be roads. Now we know that we **make** roads - the only roads there are and can be - and we do this solely by **walking** them (Bauman,1995 p.17).

To imagine this study as too ethically problematic is not to attempt to walk the road in terms of undertaking this personal inquiry. I am always/already situated in this turbulent and dangerous water through my discursive positionings as the wife/nurse, and the “Warkies” are already under my bed. What may be required here is a new perspective for inquiry approaches and the ethical considerations involved in using poststructuralist methods. As Johnstone (1999) suggests, such an approach can be seen as creating new ways of working with moral problems. She cites Bauman as suggesting postmodern approaches to ethics involve “tearing off the mask of illusions; the recognition of certain pretences as false and certain objectives as neither attainable, nor for that matter, desirable” (Bauman,1993 p.3).

The ethical difficulties in the study arise out of the crossing over of the borders between my professional work as the nurse and my private experience as the patient’s wife. In bringing out this private experience in to the public domain of knowledge I am potentially rupturing the fabric of academia, and in doing this I am likely to find myself in difficult ethical territory. The risks inherent in the approach to this study are summed up by Lincoln in her reference to the ancient maps of unexplored territories where certain areas were labelled with the caption, “Here ther be beastes and

monsters” (Lincoln,1997 p.51). As she suggests, the creation of new forms of textual representations break new ground, and we have to make our tactics and approaches up as we go along. There have been times when I have thought it would have been easier to follow a route that was already clearly marked out to avoid the agonies of writing on the edge. It may be that to follow already made up rules is easier than

one’s own untested project; the consequences are less difficult to bear, sufferings are easier to endure, the pangs of conscience are muffled, the salt of responsibility is not rubbed into the wound of failure (Bauman,1995 p.19).

Having let what felt like ‘Ripley’s Alien’ loose into the fabric of academic inquiry, I was left to deal with the tensions between listening to criticism (with a judicious ear) and not feeling paralysed by it. In the following journal entry where I wrote about this concern, I attempt to situate my own untested project within an ethic of care for myself which recognises my own strengths and the possible pitfalls in undertaking this inquiry.

I have written this proposal from within my 26 years experience as a nurse. I think I probably learned to deal with this notion what I would now call the “abject” as a seventeen-year-old nurse. Many other nurses of that time would have had similar experiences to those I encountered as a first year student nurse, working on wards where the patients were mainly elderly and dying. I have considered these feelings in my previous writing where I worked to understand that some things were inevitable beyond my control, and the best that I could do as a nurse, was my best. I understood I could not save these people from the outcome that would be inevitable for them in terms of their dying, but I could make a difference to their experience of this I think this has become an important guiding philosophy over the years in my work as a nurse and certainly informed my work with Kevin when he was dying. While I recognise the emotional risks to myself in undertaking this inquiry, I think it is important to understand how I am positioned in it. That is, in terms of my work as a nurse and my work with Kevin, and in particular, the sense of my own agency that I have as a person.

The clinical work that nurses do in their everyday contact with patients constitutes an inherently relational practice where nurses bear witness to the patient's experience of suffering (Liaschenko,1998). The nurse is always/already constituted as having corporeality in common (Wiltshire,1998) with the patient and the recognition of this humanness of one another is central to the professional nursing relationship. It is this permeability of body boundaries which potentially creates the abject subject positioning of the nurse with the patient (Rudge,1998). Rudge (1998) draws on Kristeva's (1982) work to illustrate the subject positions of people who experience or witness wounding. The effects of such discursive positionings depend upon the ways, in which the subject takes up and acts the effects of abjection, in other words, the strategies they may use to manage it. Nurses may become emotionally strategic knowledge workers in order to manage their (sometimes everyday) practice experiences of nursing wounded patients. For example, these strategies may involve shifts in the permeability of body boundaries, where in certain moments the patient may be constructed as 'Other' in order to carry out a particular practice (Rudge,1995).

In this sense, I believe nurses may take up or act within specific discursive positionings to carry out elements of their relationships with patients and with themselves. I understand my ability to carry out this inquiry as an emotionally strategic knowledge worker, who is not always aware of what will appear, but that I am astute enough to recognise it when it does appear. Finding a safe ethical path through this crossing over between personal and professional has involved setting aside time for critical reflection on my own responses to thoughts and feelings that have been surfaced through the inquiry. As well, I negotiated a pastoral relationship with a chaplain who was involved with both Kevin and I during his illness to be available to me to discuss any issues, which arose.

My first intentions with this study involved developing it as a research project using people who were involved in the events of Kevin's illness as participants. However, this approach became problematic when I began to understand how ethically difficult

this would become. I think the idea of working with these people arose out of a desire for openness in an inquiry process, where the voices of other people who were significantly involved with Kevin could be heard. Ethical issues of confidentiality, anonymity, informed consent, coercion and freedom from harm became overriding concerns as I recognised I could not put sufficient ethical safeguards in place, within the study or in the ‘aftermath’ of it (Lightfoot,1983; Clandinin & Connelly,1998) to protect these people.

It was in order to manage the ethical problems that I developed the study as an inquiry rather than a traditional research project. As a process of academic reflection and inquiry, the study thus moved to being centred on my journey through these experiences of caring for Kevin, from within my unique personal and professional positionings as the nurse/wife. Finding modes of ethical conduct with this approach has also required considerable reflection. In bringing private experiences into the public place of this study, I am aware that I am unable to seek the permission of the other people involved in the context of Kevin’s care and my own experience of his illness. However, this is also my experience which as Lawler (1997 p.183) suggests “affected me, involved me by my ... presence and my witnessing”. In other words, this study tells the story of my own experiences, which I have related in my own terms.

In using my own personal experiences, however, I am still concerned with the other people who may be affected by the situations that are discussed. I imagined writing about this experience as an extension of the caring work that was situated in the relationship between Kevin and I. There was an ethic of care that extended to family members, and others involved in his care, and which remains as a central concern in the aftermath of the study. I see confidentiality as central to this writing about intimate details of a relationship, within this ethic of care. Certain events were not explored for reasons of my own, and others, personal safety and a desire to keep some things private. I have also drawn on Clandinin and Connelly’s (1998) work in

protecting the unique identities and anonymity of people involved in situations by fictionalising elements of the events that are described in the stories.

The possibility of tensions between the privacy of practice moments with health professionals and the potential to appropriate them for another purpose within the study has also been an important ethical consideration. I wished to respect the other people who were involved in Kevin's care as I believe their practice was motivated by compassion and their desire to do their best for us. Moments of practice described in the study which include factors which were unique to particular times or places have been fictionalised and unique identifiers changed. As well, I felt the need to be sensitive to the reality of nurses' practice contexts when relating what seemed to be inappropriate responses or lack of responses in specific situations. I believe it was important to take account of the marginalisation of nurses within the power relations of healthcare institutions. This is significant in terms of respect for colleagues and considering another person's specific location within these power relations and the values that inform their practice. I believe this study should not disadvantage those who are already marginalised within their institutional workplace.

The anonymity of people involved in events has also been protected by not using their names in the narratives, which were developed through the process of 'talking back to myself'. However, there are unique identifiers still contained in the situations described in this data. I have protected these unique identifiers by ensuring that I am the only person who has access to this material on my computer, and changing possible unique identifiers before sending work to my supervisors. I will destroy tapes, transcripts and notes, which could potentially identify other people, on completion of the study.

Writing in "liminal" spaces

The methodological considerations for the study offer new possibilities in framing the narrative voice, and moving beyond what are generally understood as the traditional boundaries of the personal and professional (Ellis, 1997). In undertaking this study, I am working in what Edwards and Ribbens (1998) call a liminal space. This liminal space is situated betwixt and between the personal and professional where the dominant academic approaches will always tend to pull me away from the subjective representation of personal experience. This has been another struggle in the study, especially in demonstrating the utility of academic reflection on a personal experience. My struggle to manage the tensions experienced between the need to respect traditional academic approaches and my desire to undertake 'cutting edge' work in the boundary spaces of this study is illustrated in the following entry from my research journal.

I am not sure how I can present this inquiry in a way that captures the uniqueness and importance of these positionings in giving voice to a story from a particular location..... I think there is a risk that I will be constructed here as the grieving widow who is unable to distinguish between her roles as a grieving spouse, nurse and academic inquirer. I find this interesting in that the discursive intersections between these so called different roles are such a critical element in this inquiry..... What I am also saying here is that I refuse constructions of the traditional grieving wife, because my experience does not fit with any theory in the textbooks I have read. To construct my experience with Kevin as negative and threatening is to disregard the complexity and contextual wholeness of it. While the events of this time were not something I would have wished to experience, I have drawn from these events a sense of hope, connectedness and a belief in the power of caring as a nurse.

In attempting to speak from my own personal experience, I risk my own construction as incompetent to do this work, given my emotional involvement with it. This personal involvement denies the possibility of objective representation of experience, which seems centrally important to trustworthy research at the postgraduate level. It seems that I am required to demonstrate the utility of personal experience methods, even though these methods have become an important focus for contemporary nurse

writers and practitioners in articulating their own practice experience as nursing knowledge. As I read the work of other nurses and women writers I began to see that I was not alone in experiencing this phenomenon. As Ribbens (1998 p.24) suggests

For private perspectives and understandings to be communicated, and formulated as public knowledge, they first have to be articulated in a personal voice. Yet, given the power of public bodies of knowledge, we may struggle to find a voice that can express more private ways of being.

Finding a place to speak about this personal experience involves bringing in outside referent points in order to connect the study to other academic work and substantiate my approach. Lumby's (1997) work on the feminised body in illness supports the idea of using a perspectival approach where how one is positioned in relation to events makes a difference to how that event may be understood. Fassett and Gallagher's (1998) text *Just a head, Stories in a body*, tells the story of the patient's experience of life threatening illness and the uniqueness of the nurse's personal journey with her. Rudge's (1995) writing on *Nursing wounds: subjectivities, nursing practice and postmodern bodies*, shows me how it is possible to weave together the narratives of nurses and patients to deconstruct the discursive practices in their work. In surfacing the politics of the context of this relationship, she demonstrates how it is possible to undertake an alternative reading of events in a way that created something other than a coherent, essentialist explanation of personal experience.

The writing of sociologist Carolyn Ellis (1997) provides some profound connections to my own experience. She relates how she came to write *Final negotiations: A story of love, loss and chronic illness* (1995) as an autobiographical account of her partner's illness and dying. The telling of this story challenged the boundaries of her scholarship. Ellis (1997 p.127) describes how

.... the mode of story telling fractured the boundaries that normally separated social science from literature; the episodic portrayal of the ebb and flow of relationship experience dramatized the motion of connected lives across the curve of time and thus resisted the standard practice of portraying social life as a snapshot; and the disclosure of hidden details of private life highlighted

an emotional experience and thus challenged the rational actor model of social performance that dominates social science.

This autobiographical approach to her research violated many of the taken for granted assumptions of traditional social science research. She came to understand that traditional ways of writing were insufficient to speak authentically to other people who had experienced such events, as well as lacking the means to convey the significance of such events to an academic audience. In writing evocatively, she invites the reader to participate in the event she describes where the outward gaze turns inward, creating a story of the self, and the inner workings of the self are analysed in a reciprocal relationship with the reader (Ellis,1997). Richardson (1998) calls this form of evocative writing, a narrative of the self where a personalised, revealing text uses strong images, metaphors, subtexts, and allusions to call the reader into an emotional reliving of events with the writer.

Ellis (1997) suggests that the validity of such an approach can be determined according to how it evokes this sense of authenticity in the reader. Generalisability is related to the reader's engagement with the story and the ways in which it evokes the reader's own experience in similar situations. Richardson (1998) sees the partial and local knowledge of situated speakers as valuable in representing unique understandings of the world, which may connect with many different audiences. As he suggests, the important thing may not be to "get it right", but rather to get it "differently contoured and nuanced" (Richardson,1998 p.354) for these different audiences. Consequently, the stories related in this study should be understood as texts, which could be subject to multiple interpretations rather than containing one inherently 'true' or confirmed reading of events. Furthermore, these stories should not be considered as a means of factually representing particular situations (Crowe,1998) or to hold out one mode of acting as more moral than another in a prescriptive sense.

In drawing on elements of genealogical analysis, autobiography and writing as inquiry as methodologies to guide this study, I am concerned with the ethics of how I produce

knowledge about the experience of life threatening illness. My writing in this thesis has a self conscious modesty (Foucault,1986 cited in Blacker,1998) where I am concerned with the breadth of my own knowledge claims, the consequences of the knowledge claims I am making, and the interest of those for whom I am speaking. I am required to be self conscious about my own positionings within the stories that are related to the reader and what the implications of such positionings might be (Blacker,1998). This requires the rigorous practice of honesty in analysing my own responses to events and the values and beliefs that may have informed these responses. I also need to consider how my telling of the stories represents the actions and voices of others.

Summary of the methodological considerations

The methodological approach for the study blends elements of Foucaultian genealogical analysis, autobiography, and writing as inquiry to create a form of narrative analysis. It weaves together ideas and values from my personal life and professional practice with theoretical concepts drawn from poststructuralism. The analysis focuses on the relationships between technologically oriented health care, nursing practice and the socially inscribed bodies of the nurse and the patient, which enter the discursive web of connections that constitute the knowledge and practices of healthcare. Events in the narratives are understood as the result of the complex, inseparable, and ongoing interaction of discourse and materiality where the non-discursive is always already constituted as an object in discourse. Subjectivity is constituted through the relations of power in the discursive space between the visible and the sayable, and this subjectivity constructs individuals as active subjects who perform, negotiate and contest discursive positionings. In telling the stories in this thesis, I actively take up discursive positionings, as narratives of the self through the process of 'talking back to myself'. In doing this I create my own identities in the moments where I locate myself in the stories.

As a personal exploration of the boundaries between my personal life and professional practice, this study raises some ethical challenges. Bringing out private experiences into the public domain of knowledge creates tensions between knowledge that is usually left unspoken in formal discourse and the supposedly 'clean bounded' professional knowledge we utilise in our everyday practice. I have a responsibility to be sensitive to the ways in which others and myself are portrayed in the study, particularly in relation to the potential outcomes, or the aftermath of it. I am aware that as the following chapters on the analysis of events develop, there is a tendency for formal knowledge to cover over representations of private knowledge. I have utilised the methodological considerations to manage the tensions between traditional academia and 'cutting edge' theorising in these boundaries between personal and professional knowledge.

The analysis in the following chapter explores the tensions arising from contradictory discursive positionings for the patient and the nurse in entering discursive fields where the patient is diagnosed with primary cancer. I explore the experience of being always/already the nurse, as Kevin became the patient. Living with the probability of a future diagnosis of cancer marked his 'patient's body' in ways that included him as well as excluded him from certain discursive practices. Finding the secondary melanoma two years later raises the stakes in living with life threatening illness. The discussion highlights the tensions between the discourses of the closed and open body following the diagnosis of metastatic melanoma. It makes visible the ways in which Kevin and I, as the patient and the nurse, negotiated paths through these contradictory discursive positionings.

CHAPTER FIVE

ENTERING THE FIELD - THE DIAGNOSTIC INSCRIPTION

Introduction

The analysis in this chapter considers the tensions arising from the multiple and contradictory discursive positionings of the patient and the nurse in entering discursive fields where the patient is diagnosed with primary cancer. I explore how I was always/already the nurse as Kevin became the patient. I consider how living with the probability of a future diagnosis of cancer marks the patient's body in ways that included him as well as excluded him from certain discursive practices. I relate how the diagnosis of secondary melanoma two years later raises the stakes in living with life threatening illness. The discussion highlights the tensions between the discourses of the closed and open body following the diagnosis of metastatic melanoma. I also identify the ways in which Kevin and I, as the patient and the nurse, negotiated paths through the tensions between these multiple and contradictory discursive positionings.

Entering the field, becoming familiar with the landscape

I will always think Kevin found the primary melanoma by chance. He was walking up the stairs one day at work, having a conversation with a friend. The mole of the back of his leg must have become noticeable while walking and he mentioned it to this doctor. The mole really was very inconspicuous, as it had normal skin colour and was only slightly raised. After looking at the mole while they stood on the stairs, this doctor told Kevin that he should have the mole removed as soon as possible. Though it was not typically melanoma, she thought it could be. Kevin duly made an appointment to have the mole removed. The GP didn't think it was suspicious at all, and Kevin had the impression that the mole was removed to humour him. It could also be said that Kevin didn't really think it was that serious at the time, but about a week later the pathology report came back positive for melanoma. I remember Kevin coming in and saying, "Guess what? That mole was a melanoma. The doctor wants to see us tonight." I don't remember

much of the conversation with this GP except that it focused on a referral to a surgeon.

This text makes visible the discourses of medicine, cancer, and health. The diagnosis of cancer creates the entry point for the previously healthy subject's constitution as a diseased subject within medical discourse. Medicine, as a discourse, represents a body of knowledge where the regularity of statements is contained within scientifically proven objective 'facts'. The diagnosis is the product of the relationship between the sayable, medical knowledge about cancer, and the visible, or the things that are used in the production of this knowledge - technology and the cells, which are identified as being cancerous. As Cassell (1996) suggests technology extends the power of human action beyond the capability of the individual user of that technology. In this case technology enhances the relationship between the sayable and the visible, and produces the ability to inscribe particular cells, and the patient's body, with this diagnosis of cancer. Entry to the discourse of medicine as the cancer patient is predicated upon the diagnosis. The diagnosis can only be stated when specific, clearly determined biochemical characteristics (Cassell,1996) are read as being present in the patient's body. Technology defines what counts as knowledge in this relationship between the patient's body and the discursive statements of medicine.

There is a tension here between wanting to be diagnosed with the disease and not wanting to be diagnosed with it at all. With the diagnosis, the person is called into being as the patient with a body in need of intervention by medicine. In Kevin's case, he willingly sought out a medical opinion and gave consent for this access to his body on the understanding that medicine may diagnose and hopefully cure this disease - it seemed the common sense (Crowe,1998) option. This notion of common sense in seeking medical diagnosis and treatment demonstrates how this power is predicated upon the ability to cure. As Starr puts it

Modern medicine is one of those extraordinary works of reason: an elaborate system of specialised knowledge, technical procedures, and rules of behaviour. By no means are these all purely rational: our conceptions of disease and responses to it unquestionably show the imprint of our particular

culture, especially its individualist and activist therapeutic mentality. Yet modern science has succeeded in liberating humanity from much of the burden of disease. Few cultural relativists, suffering from a bad fever or a broken arm, would go so far to prove a point as to trade modern medicine for a traditional healer. They recognise that in medicine the dream of reason has partially come true (Starr,1982 pp.3-4).

Technology supports this power relation between the discursive statements of medicine and the patient's body. In making the pathology visible, the patient is induced to give consent to intervention to reduce the probability (Deleuze,1988) of the cancer spreading further into the body.

The consultation with the surgeon the evening following our visit to the GP was to be the beginning of a journey with this disease and its intrusion into our lives. It was to be the first of many consultations with doctors; with doctors that we almost always knew as colleagues. The consultation that evening centred on discussion of the pathology report and treatment options. The surgeon quoted research that suggested melanoma tended not to metastasise until the primary had reached a depth of 1.5 mm. The pathology report recorded the depth of Kevin's lesion as 0.8 mm and so had been diagnosed moderately early. The surgeon recommended a wider excision of the site. He also examined Kevin's other moles as he believed Kevin had a type of mole dysplasia, which predisposed to melanoma.

We left this consultation feeling that Kevin had a good prognosis as we had been told that probably less than 20 percent of these lesions developed secondaries. The next week Kevin had a wide resection of the primary site and removal of several other moles as a day stay patient. At this primary stage the threat of cancer seemed to far outweigh the risks of surgery. This seemed to be a bit of a "brush" with life threatening illness - it was not serious yet, and the hope for a cure far outweighed the alternative which was to leave the primary as it was. So there was really no contest between these choices.

Choosing the surgical option for a wide excision of the primary site was the reasonable thing to do once the diagnosis had set the discursive boundaries within which the patient should perform. The subject's agency as the patient lies in deciding whether to consent to have the surgery or not. Kevin chose to perform his identity as the patient by undergoing this surgery, taking up the authority of medicine in offering

the potential for a cure as the right thing to do. The goal of these self forming activities in becoming the patient and undergoing the surgery could be understood as directed toward self preservation. If the ethical substance is the desire to preserve oneself from this disease, the mode of subjection becomes faith in the ability of medical knowledge and practice to cure one's pathological body. The obligation to take up this moral code can be understood as implied by reason, as to do nothing within this diagnosis of melanoma may well result in the subject's own erasure. In western cultures moral duties to oneself, where they are mentioned by ethicists, generally include prohibitions against harming oneself through self mutilation, suicide or behaviours that are likely to impair one's health. As well, the ethical self regulating subject is expected to actively participate in health promoting exercises to further develop his/her own physical and mental capabilities (Davidson,1986). Self preservation through subjection to the discursive practices of medicine becomes a self forming activity aimed at freeing oneself from the threat to life, which the pathology represents. Self preservation thus becomes ethical self conduct as a form of self improvement.

Discourses of the personal and professional

Within this diagnosis of malignant melanoma, Kevin and I were always/already positioned in discourses of medicine and health care. Kevin's work within the field of medical electronics, and in particular with the high powered technology of linear accelerators, placed him inside a health care institution where he worked closely with health professionals and patients in the every day practice of his professional work. We talked of how he found it increasingly difficult to manage working in the areas where patients were treated. He said it had been difficult enough before when he could just concentrate of doing his work, but since the diagnosis, these people always reminded him of his own illness. Whenever possible he chose not to work on radiotherapy equipment except for those times when no one else was available and he felt patients would be disadvantaged by his absence.

This practice in the hospital setting positioned Kevin as an insider who was personally known to people, who were bearers of power in this institution, through

their access to the knowledge and practices of medicine. As a health professional one's own body enters the discursive field of health care practice in certain ways, often as a tool for carrying out bio-mechanical tasks on the patient's body. The body of the patient becomes an object within the discursive statements of medicine, which is produced through institutional practices where the body is worked on as a bio-mechanical entity. As this bio-mechanical entity, the patient's body is detached from the life of the patient and physically managed through institutional practices (Chambliss,1996). The creation of this gap ensures that the patient is understood as the one with the disease, and the healthy bodies of the staff enter the discursive field as tools, which are integrated into their practice on patients. The staff may manage their interactions with patients, whose existence is threatened by disease, by constituting himself or herself as immune, separate from and outside the disease. This constructs a physiological and depersonalised view of the patient's reality, a vision of the patient as the 'Other' in order to do the work (Chambliss,1996).

The rules of conduct within medical discourse thus create professional boundaries, which tend to exclude the personal. The rules that delimit the sayable within medical discourse make one's own body unsayable in diseased terms as the health professional's body is already specified and governed within clear boundaries of performance. The relation to oneself, as the self governance which health professionals practice, is produced through the folding inward (Deleuze,1988) of the power that is exercised over the patient. But there are limits to this objectification of the patient and the maintenance of the discursively produced gap between the patient and the health professional. When these practices are challenged by tensions between the materiality of our own bodies and mortality, we understand the threat to another person who is like us. When there is a connection between the identity of the (soon to be) patient and the health professional's own identity, there may be occasions when the unsayable surfaces to allow some permeability in the boundaries between the personal and professional.

In this way, the human being behind the medical object surfaces with some kind of personal identification (Chambliss,1996) with the status of both insider and outsider. This insider/outsider positioning gave Kevin access to early diagnosis of this disease as the authority of the doctor who suggested he have the mole removed. This doctor's opinion carried weight in terms of already having constructed his body inside the discursive knowledge and practice of medicine. He was already understood as a patient who may be at risk. However, I think there is a cost to this personal identification and recognition of the 'Other'. Some health professionals could not act with Kevin in a professional capacity and referred him to another person stating that they preferred to maintain a personal relationship with him. These people could not manage the tensions between the discursive positionings of the personal and professional. Since there were other people who could provide the professional services that Kevin needed, they were able to some degree, distance themselves from his status as a patient and reconstruct some continuity with him in a relationship of collegiality and friendship.

This new status as an insider/outsider also affected Kevin's professional practice working with radiotherapy equipment. I think he had managed to do this work on the machines used in the treatment of cancer by distancing himself from the patients who used this service. By understanding his body as healthy and positioning his body as a tool in the completion of technical tasks, he was able to create his own subjectivity in relation to the cancer patient. This subjectivity was taken up within a form of specification as a technician, and thus set clear discursive boundaries for his own performance. At the point of his diagnosis with melanoma he had entered the discursive field of cancer and increasingly found himself unable to maintain this separateness from patients whose bodies were inscribed with similar diagnoses. The anxiety produced by the tensions between the insider/outsider positionings of his practice as a technician and his diagnosis as a patient with cancer at times became unbearable. When this happened Kevin reassigned himself to work on other equipment that was not directly used in the treatment of cancer. It seemed that he had

difficulty in maintaining the depersonalised vision of the patient as 'Other' when working in the areas where patients were treated.

Working in these spaces which patients with cancer inhabited was a painful reminder of his own mortality. The vision of these patients created a collapsing of space, a closeness (Savage,1997) where he was constantly called into being as the patient through the knowledge of his own diagnosis of cancer. Keeping himself together in his work environment seemed to involve a process where he actively contested his identity as the patient by clearly demarcating the boundaries where his body entered the discursive fields of medicine and technology. In doing so Kevin reconstituted his identity, 'normalising' himself as a technical knowledge worker outside this diagnosis of cancer, in locations where he was not required to share space with patients. In a sense he covered over his marked body in order to reinstate his professional positioning as the person who managed the equipment for the surveillance and treatment of the 'Other' body (Frank,1991).

Challenging personal and professional boundaries

Tensions between my own discursive positionings as the wife and nurse surfaced as Kevin entered this discursive field of medicine as the patient. These tensions were felt in ways, which challenged the prior clean bounded notions in my thinking about the personal and professional roles of the nurse.

The day following our consultation with the GP I had gone to the private clinic armed with the referral letter. The receptionist at the clinic told me we would have to wait six weeks for a consultation with the surgeon. I remember standing in front of this reception desk and coming to the realisation that I couldn't wait that long and that I was sure Kevin wouldn't want to. I think that was a moment when I understood the potential seriousness of this diagnosis and that if further treatment was available then it should be carried out as soon as possible. I went back to my office, phoned the surgeon at the hospital, and told him the length of time we were expected to wait.

After listening to my explanation, he suggested that we come to his private rooms after hours, at 6pm that night.

The existence of the pathology and the perceived need for medical intervention were taken up as my own concern through the discursive positionings of the wife/nurse. The relationship between the sayable or medical knowledge about melanoma, and the visible, the cells in Kevin's body, had inscribed his body with this disease. This inscription of his body produced my discursive positionings as both the wife and nurse and Kevin's subjectivity as the diseased patient. In the moment when the receptionist informed me of a six week wait for consultation with the surgeon, my understanding of the pathology produced tensions between the institutional practices of the health care agency and my recognition of the threat the pathology represented. My positioning as the nurse placed me inside these institutional practices and yet my refusal to accept the authority of the receptionist arose out of my insider status. I had taken up the authority of the diagnosis where the unambiguous (Cassell,1996) results of the biopsy had legitimated medical access to the body. Furthermore, this access to the body was predicated upon the understanding of the potential for the discursive practices of medicine to offer hope of a cure. Knowledge of the pathology informed my anxiety about the need for rapid surgical intervention to reduce the possibility of the disease spreading beyond the primary stage. My anxiety here was about gaining early medical intervention to contain this disease within the primary stage.

Almost without realising what I was doing, in that moment standing at the desk in the clinic, I found myself taking up the discursive positioning of the nurse as the patients' rights advocate. My refusal to accept the authority of the clinic arose from my understanding of the constructedness of institutional practices which set limits and prescribe certain activities for the behaviour of patients as discursive subjects (Kendall & Wickham,1999). My resistance to the idea of waiting six weeks for consultation was informed by my knowledge of the pathology as the nurse and the potential loss, which the pathology signified within my personal relationship with the patient as the discursive subject. My resistance in this moment was an effect of power

(Walzer,1986) where, in refusing the governance of the institution, I exercised my own capacity to choose an alternative path that I knew may be accessible to me as an 'insider'. My thinking outside this governance was based on my own knowledge and practice inside such institutions and was always/already a point of resistance, where as Deleuze (1980 p.90) suggests "...the thought of the outside is a thought of resistance". In collapsing the boundaries between the professional and personal through this thought of the outside, I created an alternative subject positioning that encompassed both.

Resistance, as the "counterstroke to power" (Hunt & Wickham,1994 p.83), challenges the rules which delimit the sayable within discursive statements and is productive of the subject's agency in recognising that there are other possibilities for action. Exercising power as resistance enabled me to perform my identity as the wife while maintaining a 'closeness' with the patient as the nurse. In thinking about my practice experience as a nurse, I realised that this permeability of boundaries was always/already a way of managing situations with patients. In a sense, this was the genealogy of my practice in the moment of refusal to comply with the institutional practices of the clinic.

I remember an occasion when I called the house surgeon to see a patient whom I believed had developed a compartment syndrome in a limb following surgery. I knew this patient well as I had nursed him from the time of his admission. I knew that what I was seeing was a compartment syndrome because of the history of the event, the clinical signs that the patient displayed, and his emotional response to this increasingly intractable pain in his limb. Even as the house surgeon assessed this patient, I could see that he didn't believe my diagnosis of the problem and, despite my protestations, suggested that I continue to monitor the patient. As the house surgeon left the ward, I phoned the consultant because I knew that the patient would quickly develop further ischaemia in the muscle compartment which, given more time, would probably become irreversible. On widely opening the cast and palpating the muscle as the consultant suggested, my diagnosis of compartment syndrome was confirmed and the consultant arranged emergency surgery for fasciotomies to reduce the intracompartmental pressure.

As the professional nurse I always/already knew how to push the boundaries of professional relationships through a personal appeal to a bearer of authority in the institution. On rare occasions, I have employed this approach in clinical situations when I believed further action was warranted to ensure the patient's wellbeing. For me, the confidence in using this strategy arose out of what Savage (1997) calls 'closeness' as a way of knowing for nurses in their practice with patients. She suggests the nurse develops a familiarity with the patient and his/her context through physical and emotional involvement, where the nurse comes to know the patient's experience by practising in that person's local and immediate environment. Gaddow (1995) refers to a similar phenomenon in describing nurses as explorers who know the patient's body as a locality with its own topography of experience. For me, these notions of closeness and locality create the potential for the "thought of the outside" (Deleuze, 1988 p.90) where resistance becomes the spark connecting the subjectivities of the patient and the nurse with alternative possibilities. In this 'thought of the outside' the perpetual horizon of the discursive statement is disrupted, producing new and different readings of the patient's body as a discursive object. The implications of such readings are understood in terms of the capacities of the patient and the nurse in performing their respective identities.

The patient as the 'special case'

Phoning the surgeon was an act of resistance. This moment of resistance represents an example of the strategic devices that nurses employ to manage the micropolitics of power in health care institutions. Walzer, quoting Foucault states

power is exercised from innumerable points.... At every moment, power is in play in small individual parts employed and exercised through a netlike organisation If power is exercised at innumerable points, then it has to be challenged point by point..... there is a plurality of resistances, each of them a special case (Walzer, 1986 p.54-55).

The nurse makes the patient's situation 'a special case' in order to construct what Gadow (1995 p.212) calls a "safe and honorable passage" for the patient. The agency of the nurse is performed as advocacy; a discursive strategy that is used to push boundaries that have been put in place by "blockages" (Deleuze,1988 p.70) produced through the exercise of power by agents of the institution. At times, these strategies may be used to challenge practices that are consistent with the discursive statements of medicine in order to support the patient in constituting themselves in alternative ways. On other occasions the nurse may work to remove institutional blockages that impede the patient's access to medical practice.

Through this idea of making the patient's situation a 'special case', the nurse enters the discourse of patients' rights (Johnstone,1999), where the sayable includes statements concerning the patient's vulnerability as a recipient of health care. These statements are connected to and supported by other statements in discourses of bioethics and human rights. The statements within the discourse of patients' rights work to inscribe the patient's body with the moral capacity of the subject as a human being who is capable of action and choice within his/her own life circumstance. The recognition of the vulnerability of people as recipients of health care marks a "personal extension into the lives and values of other human beings" (Johnstone,1999 p.247) on the part of the nurse, and produces the requirement for particular actions to reduce this vulnerability.

The self forming activities of the nurse as the patients' rights advocate are constructed through the self's relation to the self. The meeting place between the morally relevant actions of the self, and the moral code which is taken up as an outside authority by the self, represents a folding of the outside to the inside where the subject constitutes him/herself as an ethical agent (Deleuze,1988). The advocacy I performed in phoning the surgeon was constituted through my understanding of what I considered to be moral behaviour in my practice as the nurse as well as in my positionings as the patient's wife. The ethical substance of this action, or the relevant domain for ethical

judgement (Davidson,1986), could be understood as my practice as the nurse. In this positioning of self as the practising nurse I had the desire to produce the best outcome for the patient according to my knowledge of the best practice in the circumstances.

The mode of subjection illustrates how I recognised and took up outside authorities as constitutive of my own moral obligations. Deleuze (1988) explains the mode of subjection as the fold of the relation between forces where the outside (authority) is bent back to become a relation to oneself. I took up the authority of the rights of the patient as a moral code, reflecting ethical practice for myself as the nurse. As well, I held up the authority of the medical diagnosis, and the threat the pathology represented to the life of the patient, as condoning the actions that were needed to obtain early intervention. The self forming activities, which Deleuze (1988) describes as the fold of knowledge or truth to our being, involve the ways in which we change ourselves to become ethical subjects. For me, these self forming activities were performed through the construction of myself as the nurse advocate. The nurse advocate had the capacity to ‘move things about’. I had the capacity to challenge institutional practices and appeal to the authority of medicine to bring about change, even though such challenges involved pushing the boundaries of what was sayable within the discourse of professionalism.

Deleuze (1988) describes the goal of self forming activities as the fold of the outside, which creates the interiority of expectation. Through this fold the subject becomes an ontological being, creating the moral conditions under which the self governs the activities of the self. For Foucault this involves a will to power, where the subject achieves a self regulated dissolution into the world and power over the one’s actions and their results (Blacker,1998). As Blacker (1998 p.363) explains, the subject becomes a “privileged junction” through which power is directed. In my practice as the nurse I became a conduit through which power was directed towards new possibilities. My self forming activities as the nurse were directed towards producing the conditions for the recovery of the patient. As well, the goal of these activities was

to create the freedom for the nurse and the patient to choose and act for themselves within the discursive practices of health care. My appeal to the bearer of authority relied upon the surgeon's recognition of my integrity as a moral agent with this best outcome for the patient as the goal of my intervention.

The marked body and the notion of the stranger

Kevin returned home after a brief stay in hospital for a wide excision of the primary site. He was keen to recover from the surgery and get back to his usual activities of work, fitness and hobbies and I encouraged him to get back to a normal life again. He also attended ongoing clinic visits on a three monthly basis. During these visits he was thoroughly examined for further signs of melanoma, though I don't think either of us really considered there would be any development of it. The disease was something that was always at the back of my mind, but normal life sort of overtook it as a possibility. We were also, probably rather naively, surprised by the fact that Kevin was unable to take out any further insurance and medical insurance for overseas holidays excluded any treatment for melanoma.

Despite our desire to return to a normal life after this diagnosis and treatment for melanoma, we were to discover that Kevin's body had been reshaped by its entry into the discourse of medical pathology. The knowledge and practices of medical pathology (the sayable) had inscribed his body (the visible) as different from normal through its classification with this disease (Rafael,1996). This system of classification works to divide the normal from the normal and through this classification, the subject takes up the discursive positioning as the diseased patient who is encouraged to perform his/her disability. This notion of the disease as disability became apparent when Kevin attempted to take out a loan with life insurance. To his dismay, he found himself disqualified from participating in these previously taken for granted activities, which he had engaged in as a healthy person. The classification of his body as diseased meant that, within the discursive practices of banking and insurance, he had transgressed outside the boundaries of what was considered to be economically productive.

Kevin found himself a stranger, inhabiting a body, which was contaminated with the danger of disease (Lupton,1994) and inscribed with decreased capital value. He had become an outsider with only partial citizenship in the world of economic production. The administration of the social spaces of economics reflects the ways in which Western societies manage the notion of the alien/stranger. As Bauman (1995 p.180) suggests

... We throw the carriers of danger up - and away from where the orderly life is conducted; we keep them out of society's bounds - either in exile or in guarded enclaves where they can be safely incarcerated without hope of escaping.

I am using Bauman's concept of the stranger as an example of the ways in which social spaces become ordered through the classification of the subject. The statements in discourses of immigration have clear rules of conduct for the admission or exclusion of people according to their capacity to become 'normalised' within the cultural practices of the particular nation-state. The rules of exclusion are effective because they are supported with the threat of expulsion and serve to inspire conformity as "long as the hope of admission is kept alive" (Bauman,1995 p.180). The subject takes up this authority of what is classified as 'normality' as the mode of subjection with the idea of inclusion forming "an interiority of expectation" (Deleuze,1988 p.104). Inclusion becomes the goal towards which self forming activities are directed, in terms of doing things to oneself in order to produce a change in behaviours or capacities. Within the discursive statements of banking and insurance, people are understood as good or bad risks according to their perceived capacity to perform in an economically productive way. As the subject inscribed with pathology which signified difference, Kevin represented a bad risk who was unable to play this "game" (Bauman,1995 p.180) according to the rules of differentiation set by those who govern such economic practices. He was always/already understood as the diseased subject, and in the sense of being a bad insurance risk, had lost his utility as an productive member of this particular economic community.

Raising the stakes in living with life threatening illness

This notion of the stranger was important in my understanding of Kevin's struggle to come to terms with this pathology inside his body. The discovery of the lump in his groin represented the progression of the disease to the secondary stage.

I will always remember the morning Kevin discovered the secondary while undertaking his "everyday" activity of having a shower. While we had both checked the lymph nodes in the groin area proximal the affected leg on a regular basis, I don't think either of us really believed the disease would progress to the next stage. I think I knew what the lump was from the moment I palpated it, and I remember hoping that it wasn't what I thought it was. I suggested to Kevin that he talk to his colleagues at work and get a biopsy organised. This was done immediately on his arrival at work and of course it showed melanoma cells present.

To have the diagnosis confirmed was shattering to us both. Kevin was a very even-tempered person who took most things in his stride. This was very different. We both understood that this diagnosis of melanoma would have profound consequences for Kevin's life. It is difficult to describe how devastated Kevin was to have this word cancer connected with his own body. In those first hours and days, I saw his understanding of himself turned upside down and inside out. It was as though his whole life had suddenly been shaken to the core and he was helpless in the face of this disease that had silently moved through his body. In the following four days while he waited to be admitted to hospital for the removal of these lymph nodes, I saw him slowly begin to manage the impact of this word cancer, and begin to speak about it.

As I supported Kevin in coming to terms with this diagnosis of the secondary melanoma, I understood that his body had become inscribed with the disease in some new ways. This second entry into the discourse of cancer had developed an increased intensity through its associated mortality. The visibility of this scientifically proven fact of the presence of the disease in a new location in his body, represented the knowledge that the disease had progressed. This progression was physical in terms of cells having grown in a new location, but I think the major progression was in

Kevin's emotional response to this knowledge. Looking back over the whole period of his illness, I think this was probably the most difficult time for us in an emotional sense because it was the first time we both recognised that he could die from this disease. In this sense, Kevin had entered a discourse of life threatening illness; a subject positioning that threatened his body, his life, and his sense of self.

I understood the impact of this entry into the discourse of life threatening illness on Kevin's experience several different ways. I had a sense of his feeling that his body had been colonised by a disease, an intimate and alien enemy, which had the potential to move through his body in a way that was out of his control. Nandy (1983 p.3) suggests that "as a state of mind, colonialism is an indigenous process released by external forces". The external forces in this case were the medical technologies that inscribed his body with the disease. The self forming activities that Kevin undertook within this new subject positioning as the patient, whose life was threatened, seemed to be concerned with the process of creating and transforming a new relation of the self to the self. In the days that followed the secondary diagnosis I saw him struggle to come to terms with the meaning of the knowledge of this diagnosis.

The ethical substance (Deleuze,1988) of this new relation of the self to the self seemed to be concerned with the intactness and normality of his previously healthy body and his desire to survive this life threatening illness. A mode of subjection (Deleuze,1988) was established as Kevin took up the diagnostic representation of his body as diseased through the outside authority of medicine. It was this relation to the self, which represented such a threat to his wellbeing. At the same time this threat to self called him into being as a subject with certain obligations to act for himself in terms of undertaking self forming activities which would help to mediate the progression of the disease. The struggle for Kevin seemed to be in coming to terms with the dread this disease called up in relation to his life, where the diagnosis held a close association with death inside the discourse of cancer. This new understanding of his body encompassed the notion of an alien presence inside his body that has silently coexisted with him in his daily life and from which there was no asylum. It seemed

there was no place to seek refuge from these stigmata of future degeneracy that was written on his body through this diagnosis (Glover,1997).

I think for Kevin the sense of being colonised (Frank,1999) through being pulled into engagement with the discursively produced representations of the disease was powerful. Nandy (1983 p.3) describes the culture of colonisation as one where “the ruled are constantly tempted to fight their rulers within the limits set by the latter”. The sense of being taken over by the disease through medical representations of it created his body as a battleground (Martin,1994) where the disease was likely to progress relentlessly. His ongoing engagement with the discursive practices of medicine held certain resentment, particularly in terms of the changes medical intervention produced in his body such as scarring and loss of nerve function. This was always to be a thoroughly contested and negotiated relationship with periods of time in the following months when Kevin withdrew from contact with doctors. As well his relationship with the disease was to become a fight to retain the bodily function that it threatened, and finally in incremental stages, did take from him.

The lure of active intervention and the promise of a cure

In retrospect I see Kevin’s decision to consult with a surgeon as a self forming activity (Deleuze,1988) where he recognised that medical intervention offered the best expectation of surviving the disease.

By the afternoon of that same day Kevin had found the lump, we had an appointment with a surgeon which had been arranged by one of Kevin’s colleagues. I was not sure what to expect from this consultation but I was grateful that Kevin’s connections as an employee in the health service seemed to have facilitated such a prompt response. I think we were looking for guidance on how to proceed with this diagnosis. It is probably fair to say that we went into the consultation with a fair degree of anxiety, because the disease Kevin had felt like a death sentence.

My overall impression of the consultation was that the surgeon instilled a reasonable degree of hope in us. While he was very clear about the seriousness of the diagnosis he said that this did not mean Kevin was going to die next week. The surgeon talked with us about the pathology and quoted mortality statistics in people with this disease. He related the stories of other patients with similar diagnoses, stressing that the only good thing about metastatic melanoma was that it was unpredictable.

The surgeon went on to outline the options for medical intervention in this disease. The only real options seemed either to do nothing or to have the lymph nodes surgically excised. Radiotherapy and chemotherapy had no value in a curative sense, but he said that it might be possible to excise the affected tissue and thus prevent further spread of the disease. He drew a diagram of the lymph nodes in the groin and explained that excision of the tissue in this area would result in some loss of sensation from lateral to medial midlines on the anterior aspect of Kevin's leg; from the groin to about the level of his knee. As we discussed this option, Kevin said he thought there wasn't really any other option apart from the surgery unless we were to do nothing.

For Kevin, the decision to submit his body to surgery was not an easy one. As a self-forming activity (Deleuze,1988) this decision involved the recognition of the truth that surgical removal of the lymph nodes offered a possibility for action through submission to the discursive practices of medicine. The notion of survival in recognising the expertise of medical discourse to work on his body exerted a very strong pull at this stage. It constructed an interiority of expectation (Davidson,1986) around mediating his own erasure as the subject.

Medicine was a familiar discourse for both Kevin and I. Our experience working in health care settings made medical intervention a logical choice, given that at this time not to treat the problem seemed unthinkable. Medicine had identified the need to intervene and offered the means to do so (Bauman,1995), the certainty of immediate and active intervention, and the promise of a cure. It could be said that we confined our understanding of this metastatic cancer inside the regular and systematic statements (Kendall & Wickham,1999) of medicine that were, given our experience, familiar and trustworthy. The logic of the regularity of the discursive statements and

Kevin's recognition of his moral obligation to ensure his own survival through medical discourse, closed off the possibility of thinking about other options. Medicine also represented a belief system where Kevin's subject positioning in the discourse of cancer was mediated by his, as well as my own, sense of hope in the belief that the surgery would go some way to controlling the effects of the disease. However, I think Kevin's compliance with medical treatment was not that of a passive subject dominated by the medical gaze, but rather a freely chosen way of acting by a subject who was aware of the implications of taking up this offer of medical treatment (Lupton, 1997).

The hope that I felt was also taken up as a way of acting with an awareness that it was something that we both needed to feel at this time. It may be that this sense of hope energised our transition through the difficult stage of recognising the fact that Kevin's life was threatened. I remember reading the narrative by Visnick (cited in Peterson, 1994) and coming to understand that there would always be hope. It might be fragile and contingent upon the circumstances of the moment and might change with time, but in living this experience with Kevin, to be anything other than hopeful would have been unthinkable.

In later months I wondered whether we should have been less hopeful about Kevin's diagnosis. However, a consultation with a doctor who was not familiar to us led me to believe that we had been managing this situation as best we could, just a bit at a time. This other doctor very clearly spelled out the consequences of Kevin's diagnosis in a way that left us in no doubt that he was likely to die within the next couple of years. Looking back I think this doctor almost fractured the fragile fabric of hope that we had wrapped around ourselves. We already knew the threat to Kevin's life, but to speak of it openly, in such clinical terms and without warning was very difficult to manage. I felt angry that this doctor had been so blunt and simply left us to manage our own responses. Given the knowledge we both had about the implications of the diagnosis, I felt it was unnecessary to speak to us in these terms.

At this stage, the possibility of Kevin dying from this disease seemed to be something of which we were both aware, but we did not speak of it. It is possible that knowledge about the effect of such a prognosis may be subjugated within discursive construction of the patient, and what health practitioners think they need to know. Krisman-Scott (2000 p.51) writes that the patient's capacity to make end of life decisions depends on access to information about prognosis within an "adequate and timely disclosure". However, Rogers, Karlsen and Addington-Hall (2000) relate how patient dissatisfaction with communication about prognosis was an important theme in their study of patient satisfaction with hospital care. Patients in this study were concerned with the way information was given, and in some cases, with the fact that the information was given at all. The patients' were concerned about the impact of giving bad news about a diagnosis when patients and their families had not prepared themselves to receive it. They also believed some health professionals were immune to the impact of knowledge about the prognosis. Some participants in the study had expressed the desire not to be told about their diagnosis, but had been told anyway. Rogers et al (2000 p.770) relate the following from a family member's story.

.... (she) understood enough about her illness to know the prognosis was poor. It was clearly not necessary to spell it out and it undermined my morale at a time when it was important to give Elizabeth encouragement.

I think Kevin and I always/already understood the life threatening potential of this disease. It was a possibility in an intellectual sense, but to connect this knowledge with the reality of the disease was more than we were capable of enduring at this time. This notion of enduring is described by Morse (1996 p.80).

When *enduring*, all the person's energy is required for trying to maintain control, to get through a situation. The person focuses intensely on the present and does not have the energy or the courage to see the future, which is irrevocably altered, given the present accident or incident to *endure*, to last through the experience.

It was as though we could take a sideways glance at this pathology and its consequences, but to look it full in the face was too terrifying. In retrospect, this was like seeing a picture that is made up of dots, where the form of the image is not discernible until one takes a pencil and draws lines between the dots. To draw the lines and construct an image that made Kevin's death visible in the light of the pathology that we knew was present in his body was more than we could endure. As a self-forming activity we constructed a boundary around this knowledge of the pathology where his dying, at this point, was unspeakable. Containing this knowledge was about existing in the present, just getting through each present day.

The discourses of the closed and open body

The notion of enduring highlights the tensions between the discourses of the closed and the open body. As Liashenko (1998) suggests technological imaging turns the body "inside out" moving the gaze of both the health care practitioner and the patient towards externally constructed realities which signify a problem with the body. The closed body seemed to signify living while the open body was read in terms of its pathology. The hope that Kevin and I felt was taken up as a mode of subjection in the discourse of the closed body. As a self forming activity, the closure of body boundaries allowed us to contain our vulnerability in terms of our own emotional responses (Rudge,1997) to the pathology. It allowed us to elide, or move away from, the possibility of erasure of the subject, at least for the moment. This closure offered a temporary place of refuge from the 'alienness' and dread of the disease. It was as though we played a game; introducing some distance between cause and effect of the pathology, perhaps in order to manage a gradual and gentle movement towards the idea that Kevin might die.

The consultation with the doctor uncovered what I think of as the 'abject' by speaking in the discourse of the open body. Groz (1989) sees the abject as representing the subject's failure to suppress their own corporeality and mortality through the

delineation of body boundaries. These body boundaries mark the inside and outside of the body and the space between self and other, which are preconditions for the construction of the speaking subject. The abject is the unthinkable other existing outside the limits of the bounded body, but which threatens to overwhelm and terrify it. In speaking about the pathology and its representation of death, the doctor invited Kevin to conceptualise something that I believe was unimaginable in terms of his relation to himself. To insist that this patient participate in the discourse of the open body was to construct the notion of rational death.

Kevin had always said that if he had had a traumatic injury rather than a diagnosis of cancer, he believed there would have been counselling made available to help him come to terms with it. However, perhaps counselling in the case of traumatic injury is offered as a self forming activity that the patient may take up, arising from medical discourse and the rationality of future survival as a productive or useful person. It seems the patient's subjectivity is constructed between the sayable and the visible in the discourse of the open body through the pathological inscription of the body. Where the patient has a diagnosis of cancer and the prognosis for survival may be seen as limited. Self forming activities in the discourse of the open body may be illustrated by behaviours such as coming to terms with one's own mortality and putting one's affairs in order. For Kevin, I think the diagnosis represented the lack of his own ability to control his body which had become defined by a circular and self referential discourse (Tester,1993) where medicine represented an authority which spoke about how he should understand, experience and regulate his body (Lupton,1997). In the discourse of the open body his life was understood in terms of his potential mortality. As a rational and autonomous individual who possessed a static and unitary sense of self (Lather,1991) his obligation, in terms of this notion of rational death, seemed to lie in bravely and knowingly accepting the future vision of his own erasure.

I think the doctor's reading of the future through the discourse of the open body (Liashencko,1998) subjugated Kevin's experience of his own body and his desire to live a life. The disciplining of his body through surgical intervention to remove the disease was perhaps negotiated within a 'taking back of his life' as the subjugated knowledge (Lupton,1997) of his own experience created resistance to the discourse of the open body. On the one hand he voluntarily chose to collude with the disciplinary practices of medicine in undergoing surgery. On the other hand he resisted the power of this doctor in defining his life and his future. This simultaneous positioning, in and 'flight from', the dreadfulness of pathological representations in the discourse of the open body created an ambiguity in our lives. Living with this ambiguity, or 'knowing and not knowing', seemed to enable us to endure (Morse,1996), or live through this time. Ambiguity was preferable to defining things in specific terms one way or another, because it left space for Kevin to continue to live his life in some continuity with his 'healthy' existence prior to the diagnosis. By this I do not mean reunification with his authentic prior self. Rather, that he chose to manage the strangeness of this life threatening illness situated in the context of his own life and the sense that his body, though pathologically inscribed, remained healthy in his everyday experience of it.

Summary

The discussion in this chapter makes visible the discourses of medicine, cancer and health and the constitution of the patient's body as a battleground in the struggle between these discourses. The patient, as the discursively produced subject, finds himself living in what feels to be his own healthy body in his everyday experience of it, but at the same time called into being as a stranger. The lure of the active and immediate intervention offered by medicine in the discourse of the open body seems the common sense option to effect a cure. Healthcare technologies support the power relations between the discursive statements of medicine and the patient's pathologically inscribed body. The contradictory discursive positionings of the

personal and professional are contested and negotiated by both Kevin and I, as the patient/health professional and the wife/nurse. Our relationships with other health professionals are negotiated within the context of personal/professional boundaries, which have been altered by the vision of the pathology and the implications of it in the discourse of the open body.

For the person who is living a life, speaking in the discourse of the open body uncovers a dreadful and terrifying image of mortality through the visualisation of the body interior which is contingent with the subject's own erasure. The discourse of the closed body offers some refuge from the abject pathology through the reinstatement of body boundaries to, at least partially, cover over and move away from the image of mortality. This movement enables the containment of the vision of the body interior and allows us to find some emotional space to manage the implications of the diagnosis. At the same time the vision through the open body always/already exists at the margins of the closed body. The simultaneous flight from, and subject positioning in, the discourse of the open body creates a contradiction. The ambiguous knowing and not knowing is more bearable in the locality of our lives than the clear vision of mortality, which threatens to engulf both the patient and the wife/nurse.

The analysis in the following chapter considers the discourses surrounding our movement through the experience of surgical intervention and subsequent health care events. The discursive production of the subjectivities of the nurse and patient are explored in relation to this where I become the private nurse, and Kevin, the cancer patient. I explore the development of a new relationship with him as the patient through my discursive positioning as the 'private nurse'. The fragile identity of the 'private nurse' encompasses a borderline professional capacity across the boundaries of insider and outsider, and allows my entry to privileged spaces. I consider the ways my presence as the 'private nurse' mediates the entry of this patient's body into the discursive practices of healthcare. As well, the implications of working between personal and professional boundaries are explored in relation to discourses of

pollution and bodily control. Finally, I consider discourses of care and abjection and the potential for nursing in understanding and negotiating such intense and intimate relationships with the patient.

CHAPTER SIX

DISCURSIVE PRODUCTIONS - THE CANCER PATIENT AND THE PRIVATE NURSE

Introduction

The analysis in this chapter will consider the discourses surrounding our movement through the experience of surgical intervention. The discursive production of the subjectivities of the nurse and patient are explored in relation to this and subsequent health care interventions, where I become the private nurse, and Kevin positioned as the cancer patient. I consider the development of a new relationship with him as the patient through my discursive positioning as the 'private nurse'. I examine how the discursive positioning of the 'private nurse' produces a borderline professional capacity across the boundaries of insider and outsider. I illustrate how I use this professional capacity to cover over my private body, resisting the discursive construction of (my) self as the confessing subject in the role of the patient's wife, and take up a new positioning in the discourse of enduring. I become subject to control by other nurses as the ambiguity of my multiple positionings as the private nurse threaten the institutional classifications, which separate health professionals from their patients. I consider the ways my presence as the 'private nurse' mediates the entry of this patient's body into the discursive practices of healthcare. As well, I explore the implications of working between personal and professional boundaries in relation to discourses of pollution and bodily control. Finally, discourses of care and abjection will be analysed in relation to the potential for nursing in understanding and negotiating intense and intimate relationships with the patient.

The cancer patient and the private nurse

There was very little time between the diagnosis of the secondary melanoma and Kevin's admission to hospital for surgery. One day was

taken up with diagnostic tests such as bloods, CT scan and Xrays. Before we knew it we were in the lift going up to the ward. We thought we had arrived in plenty of time for Kevin's pre-op preparation, but we met a friend who told us Kevin had been moved to first on the list. We arrived in a ward that was very disrupted for a variety of reasons and I had the impression the nurses on the ward were very pleased to see me. I was drafted into preparing him for theatre, which I was still completing when the theatre orderly arrived. After Kevin had gone up to operating theatre, I roamed the hospital for several hours. I avoided explaining the reason for my presence in the hospital, I think because the situation was too emotionally intense to discuss with anyone on a casual basis.

I thought a great deal about this new relationship I had developed with Kevin. I had become his professional nurse as well as his wife and the ward staff actively supported this role. While I think this acceptance of my role as the professional nurse was mainly for workload reasons and the fact that I was well known to them, I would also like to think they were professional nurses who had an understanding of the significance of this experience for me. They joked about Kevin having a "private nurse" that he could take home with him.

In the chaotic circumstances of the ward, I was an extra pair of hands as the professional nurse and quickly co-opted into preparing Kevin for surgery. The invitation to be involved in his care in a 'borderline' professional capacity was extended throughout this hospital stay. This degree of involvement in his care initially arose by default and thus was not defined in any professional sense. In situating myself in the ward with Kevin, I acquired an insider status, which was like coming home to a familiar place of safety (Blackford,1997). My face was familiar to many of the ward staff. My sense of belonging in the ward arose from my previous employment in this setting and my professional practice as a clinical nurse educator. The chaos of the ward pushed the staff into extending the boundaries of normal practice, inviting me to inhabit a space that crossed over the clearly demarcated boundaries of the professional insider and private outsider.

Within the discourse of the private nurse I was constituted as having particular attributes, such as the necessary knowledge and skill to practise professional nursing. My positioning in the discourse of professional nursing was produced through the

relationship between the sayable (professional knowledge about nursing and what nurses do) and the visible (the things that are used in the production of this knowledge). The visible was the recognition of my presence by other nurses as my previously demonstrated capacity to undertake the work of nursing. My body, and therefore my presence, was inscribed with this capacity. The construction of this identity as the private nurse moved my position within the ward to allow my active entry to spaces (Purkis,1996) that were not usually accessible as the patient's wife. I was allowed greater proximity to the patient's body, increased scope to move into professional areas in the ward such as the dispensary. My readings of the patient's body were accepted on the basis of taken for granted understandings about my ability to practise as the professional nurse. This capacity for action, in a setting where the wife would generally have the status of a spectator, enabled my active engagement in the discursive practices surrounding the treatment of Kevin as a patient with a life threatening illness.

Discourses of endurance and confession

In "making oneself involved" (Purkis,1996 p.109) as the professional nurse, I was able to cover over the intensely private nature of this experience. My presence in the hospital often went unquestioned as it was assumed I was undertaking professional duties.

During the time Kevin was in hospital I did not discuss my private reasons for being there with nurses in the tearoom or with nurses I met in the corridors. While Kevin was in operating theatre, I wandered the corridors of the hospital, avoiding the ward nurses too, because I knew they would be sympathetic. It is difficult to describe the emotional intensity of the feelings that I experienced at this time. I now knew Kevin was going to die from this disease but to speak of it openly, and in clinical terms, was more than I could bear. I found myself sitting outside operating theatre, waiting for Kevin, as the professional nurse, marking students' assignments. Inside myself, I was inconsolable. I don't think anything anyone could have said, or done, at this time would have made any difference. I simply needed to live the moment.

I was able to appeal to the discourse of professional nursing to hide the reasons for my presence and cover over the “private body” (Williams,1997 p.15) and thus my own vulnerability. This movement of the private body seemed to involve a resistance to the gaze of health care professionals who would encourage my ritual confession of feelings about the meaning of Kevin’s diagnosis and hospitalisation. The ritual of confession is the ceremony of objectification within the panopticon professional gaze, where the subject of this gaze comes to know themselves within the sovereign knowledge of health care technologies (Dreyfus & Rabinow,1982). As Foucault (1979 p.59) suggests

The confession plays a part in ... the most extraordinary affairs of everyday life, and in the most solemn rites: one confesses one’s crimes, one’s sins, one’s thoughts and desires, one’s illnesses and troubles One admits to oneself in pleasure and in pain, the things it would be impossible to tell anyone else ... Western man has become a confessing animal.

Thus, private thoughts and feelings derived from one’s own self examination become subject to, and controlled by, external discourses of science, medicine and psychology. For example, discourses of coping in psychology support the confession of private feelings. Discourses of crisis and crisis intervention (Infante,1982; Aguilera,1994; Hoff,1995) construct the person experiencing a major emotional event as moving through stages of crisis, from pre-crisis to crisis, and post-crisis. The notion of crisis involves a period of intense disintegration and disorganisation of the previously rational emotional state. Resolution of crisis occurs through the restoration of the individual’s prior level, or a higher level of functioning where the emotional work upon oneself facilitates a rational understanding of events. Dreyfus and Rabinow explain how the individual works upon her/himself in this discursive production of the confessing subject.

This cultural desire to know the truth about oneself prompts the telling of the truth; in confession after confession to oneself and others, this ... has placed the individual in a network of relations of power with those who claim to be able to extract the truth of these confessions through their possession of the keys to interpretation (Dreyfus & Rabinow,1982 p.174).

These are the techniques, which invite the discursive construction of the subject through technologies of the self. The discursive subject becomes an object of knowledge that works on her/himself to perform in the light of that knowledge (Dreyfus and Rabinow,1982). These confessional technologies of the self are an important element of nursing practice in work with patients, and as professional technologies of the self. Nurses are well used to eliciting biographical data from patients and their relatives using data gathering techniques such as the patient history. Observation and measurement techniques are used to collect objective measurements of the patient's health status. As well notions of reflection (Johns,1995; Boykin,1998; Jasper,1998) have become centrally important to professional nursing as a means of self examination which is closely associated with notions of ethical practice. As Boykin (1997 p.47) writes, "Reflections shape the moment (of practice) and influence the nurturing response of the nurse". Reflection is understood as a means to create more authentic and caring practices with patients and their families.

It is possible that attempts by nurses to elicit confessions of my feelings about Kevin's illness were motivated by notions of professional caring and compassion. However, my insider status as the professional nurse, and covered over private body, provided a means of avoiding such confessions. The closure of discursive boundaries surrounding private feeling of loss, and my resistance to invitations to confide my feeling about this experience signalled my positioning in a discourse of endurance. The ethical substance (Deleuze,1988) of this subject positioning in the discourse of endurance concerned my own cultural beliefs and values about managing such events. There seemed to be some important values for me in terms of the desire to preserve myself as emotionally intact through this experience.

Morse (1995) describes enduring as closely associated with suffering and bearing emotional pain, and a time when the sufferer exists intensely in the present (Morse,1996). Frankyl (1959/1992) speaks of the will to live in suffering where human beings are creative in reconstructing the experience of tragic events. He identifies the idea of tragic optimism for survivors, where it is possible to move the

experience of suffering into the actualisation of future possibilities for action. Stories of enduring are also associated with courage in the face of extreme circumstances, such as the knowledge of impending death. Robert Scott's letter from the Antarctic expedition in 1913 (Bowles,1995) exemplifies the idea of enduring in the face of an ultimate struggle. For me, this narrative connects enduring with notions of hardiness, courage, and bearing the pain of what was to be an inevitable outcome, and the loneliness and fear experienced in coming to such an understanding.

I think the mode of subjection (Deleuze,1988) in this discourse of enduring was a belief in my own ability to practise as the professional nurse as a means of living through or expressing my feelings about the threat to Kevin's life and the impending loss of our relationship. I felt an obligation to care for him in both capacities as his wife and nurse. I think this obligation was derived from the history of our relationship and my belief that no matter how difficult this situation become for me, it was worse for him. He was the one facing the ultimate struggle. My professional nursing work with him seemed to provide a means of keeping us both together. Thus self preservation through the discursive practices of professional nursing became a self forming activity (Deleuze,1988) as a means of containing the threat to my own sense of self which Kevin's illness signified. The self forming activities undertaken in the discourse of endurance mediated the boundaries of my private body to avoid interpellation as a 'feeling' subject.

Such containment denotes Morse's (1995 p.959) concept of "holding on", where in order to endure, all emotional energy is channelled into maintaining control to get through the event. This is a state

where individuals consciously decide how they are going to behave with respect to others.... this semblance of normalcy and the selective disclosure ... enabled individuals to act as if everything was "normal"...emotional pain reflected on the face of others accentuated the emotional pain (Morse,1995 p.959).

Morse develops these notions of enduring and suffering further in a later article. She relates the story of a woman whose husband was undergoing a heart transplant where nurses were trying to help her get through the experience.

The staff felt that if she would only cry her response to the situation would be more normal; thus all their interactions with her were sympathetic and overtly caring, aimed at giving her the opportunity to release her feelings. The nurses did not understand that she was enduring the only way she could get through this experience and support her husband. If she cried she feared she might emotionally disintegrate and would not be able to control her sobbing. Then she would not be able to support her husband (Morse,1996 p.80).

In the state of enduring, the focus is on managing the present and lasting through it. Emotional responses are suppressed because the situation is too much, too painful to comprehend in terms of its future implications. The goal of self forming activities in the discourse of enduring seems to be self mastery in terms of keeping control and holding on to emotional responses. If this control were lost, I sensed that I would literally leak all over the floor like the burn patient in Rudge's (1998) study. This patient's description of himself concerns the notion of his body falling apart and becoming "just a blob on the floor" (p.234). As Rudge suggests this patient felt his body was disintegrating. His 'falling apart' body seemed to have lost its normal boundaries and was thus understood as beyond his control. I felt I couldn't afford to "lose it" (Morse,1995 p.961) because this would have involved breaching the boundaries containing very intense emotions. I was afraid that if this containment of feeling was lost, I might not be able to put myself back together.

It was soon after I realised that Kevin was probably going to die from this illness that I sought counselling, because I thought it was the right or perhaps responsible thing, to do. I actually thought it might help me get through this. But during the one session I did attend, I realised that either I was very resistant to the actual experience of counsellingor perhaps I didn't really need to do this putting my personal feelings out there. As Kevin's illness progressed I didn't have the emotional energy to expend on such personal therapies. Even my own reflective processes were directed towards getting through each day with him.

Looking back, I did not think about whether this containment or 'self mastery' of my own emotions was a healthy response or not. Within the intensity of these events psychological discourses about emotional responses in coping with crisis had little meaning. I worked to simply hold myself together and get through the demands of the present. I think I did what seemed consistent with my own positionings within these events, rather than subjugating my own knowledge to what 'expert' psychological discourses said I should be doing or feeling.

Fragile identities and the acting discursive subject

The discourse of enduring was an important subject positioning for the identity of the private nurse, especially in maintaining a capacity for action, however this identity was fragile. Williams (1997) identifies the vulnerability of the professional nurse as the patient, or object of care within the discursive practices of health care institutions. This vulnerability arises from the lack of signifiers, which represent the professional nurse's authority and power. My positioning as the private nurse was open to challenge on the ward as I lacked the protection of uniform and other cultural artefacts such as medals, which represent the authority to provide nursing care. My access as the private nurse relied upon the informal recognition of my simultaneous positionings as the professional nurse and the patient's wife.

On one occasion, the door to Kevin's room was closed when I returned to the ward from a meal break. There were two nurses standing in the corridor outside the room with a drug trolley. When one of the nurses saw me opening the door she said, "You can't go in there". The other nurse quickly clarified the situation for her saying, "It's her husband".

One of these nurses recognised me only in my capacity as a clinical nurse educator. The mistake was understandable as my surname was different to my husband's and I was wearing the same civilian clothing suitable for doing nursing work that I would wear in my professional capacity. My ability to 'pass' as a member of the hospital community left me open to challenge. The second nurse had inside knowledge of my dual positionings as the wife and nurse and was able to smooth over this moment of fragility by reinstating my access. This fragility was to arise on other occasions during

subsequent admissions to hospital. In the following narrative, the nurse's response seemed to be motivated by a desire to protect me in my capacity as the patient's wife by restricting the activities I undertook with Kevin.

This event occurred later in Kevin's illness, when he had become so fatigued that he needed help with showering and other basic activities. We had been having a bit of a tug-of-war with the nursing staff on this ward over things like showering. They liked to have all the showers done by a certain time and if I wasn't right there sometimes the bath attendant would take Kevin off for a shower in spite of his protests that I would do it when we were both ready. On this particular day, Kevin and I were walking across the corridor to the shower when a nurse came a long with some towels which I had asked her to get as there were none left in the bathroom. She stood in front of the bathroom door saying that the attendant would shower Kevin as I "needed to look after myself".

I remember standing in the corridor feeling so frustrated. Here she was arguing with us when Kevin was so fatigued he could hardly stand. I wanted to tell her that Kevin was dying - soon, and this was one of the few intimacies left to us. His daily shower had become a comforting ritual for us both. I was silenced - unable to speak because I simply did not have the emotional energy to discuss it with her. I reached out and took the towels from her hands, pushing past her into the bathroom while supporting Kevin. Later, Kevin gleefully told anyone who would listen that I had grabbed the towels out of the nurse's hands. I felt ashamed that I had been unable to use the interpersonal skills that we teach so well to first year nursing students.

My insider/outsider status blurred the boundaries of the professional nurse with my status as the patient's wife in a way that may have challenged the values and beliefs of some nurses. This nurse may have found the ambiguity of my simultaneous positionings difficult to manage as my presence in Kevin's care contradicted traditional notions of distance and objectivity in professional nursing relationships. According to Morse (1991), this loss of distance, or over-involvement, with patients occurs when the nurse chooses to care for a patient with extraordinary needs and the nurse and patient spend extensive time together. The nurse's commitment to the

patient as a person is seen to over-ride the treatment regime and other institutional practices.

There is a discourse of protection that mediates the proximity of health care professionals to patients. This discourse provides prescriptions, which control the conduct that occurs within professional relationships. Therapeutic boundaries are seen to protect both the clinician and the patient from behaviour that is seen to detract from the provision of care. These boundaries establish the limits of ethical conduct by prescribing conduct in professional relationships particularly in relation to such things as the roles of the clinician and patient. The time and duration of the relationship, the space or setting in which clinical practice is undertaken, and the degree of emotional involvement with the patient are also seen as important considerations in maintaining professional distance. Physical contact should be specific to the therapeutic role and violates the patient when it is used for the clinician's personal gain. Regardless of who initiates it, sexual relationships between the clinician and patient are considered unethical and in violation of professional codes of conduct (Gutheil & Gabbard,1993; Gabbard & Nadelson,1995; Chadda & Slonim,1998).

Codes of conduct in professional nursing practice (New Zealand Nurse's Organisation,1995) do not specifically refer to boundary transgressions, but in practice, the culture of the hospital ward provides significant sanctions against the nurse who becomes 'over-involved' in caring for a patient. Claims of loss of objectivity about the patient's case are significant in interpellating the errant nurse where professional subjectivity tends to be pulled towards the discourses of scientific rationality that operate in the culture of health care institutions (Chambliss,1996). These discursive practices are embedded in the way nurses work together and negotiate relationships with patients in their care. As Morse (1991 p.459) suggests, other nurses see the "over-involved" nurse as having clouded judgement. S/he has lost the objectivity required for safe and competent professional practice. Furthermore, over-involvement is seen as a threat to the notion of teamwork where the nurse lets

her colleagues down by valuing the relationship with patient over collegial relationships. The proximity of the nurse to the patient in the hospital ward setting has historically constructed the nurse as the keeper of the patient's physical and moral health. The capacity of the nurse to control him/herself is seen as an important qualification of the nurse's character and thus indicative of the nurse's ability to exercise control in relationships with others (Rafferty,1995).

This discourse of protection constructs the control of professional conduct as a hygiene practice. The concept of hygiene is useful in understanding the systematic ordering of elements in a social system and the classification of matter as threatening symbolic systems of purity (Douglas,1980/1966). The hygienic mediation of professional boundaries protects the patient but is also significant in protecting the nurse, by keeping things in place through the systematic ordering of relationships. Conduct which transgresses the symbolic boundaries of the professional relationship (that is, pollution behaviour) defiles notions of professionalism because it contradicts "cherished classifications" (Douglas,1980/1966 p.36) which separate patients and health professionals. My dual positionings as the private nurse challenged these symbolic boundaries for some nurses. As Douglas (1980/1966 p.105) suggests,

... people living in the interstices of the power structure ... (are)... felt to be a threat to those with better-defined status. Since they are credited with dangerous, uncontrolled powers, an excuse is given for suppressing them.

My positioning as the private nurse was ambiguous. I had an undetermined or anomalous status in the symbolic order of professional nursing. My presence on the ward created an element that did not fit into the given cultural set of the professional nurse. I was ambiguous because my presence was capable of two simultaneous interpretations. In my reading of this event, the disciplinary conduct of the nurse (which seems at first glance to appeal to a discourse of protection) was for me, informed by a discourse of control. This control was aimed at the coercion of the private nurse into inhabiting the subject position of the wife. While there are other possible readings of this nurse's behaviour, I felt drawn into these discourses of

protection and control. This fragile positioning and the desire to manage my own emotional responses as a means of getting through these events silenced me. The separating out of the simultaneous positionings of the wife and professional nurse was to become a strong theme in responses from some other nurses as Kevin's illness progressed.

I remember one occasion when we were meeting with a group of health care professionals about Kevin's care after discharge from hospital. We were sitting in this consultation and this statement just came out I didn't see it coming. This nurse said, "You will need to remember that you are Kevin's wife and not his nurse". I said nothing in response to her statement but I felt as though I was on slippery ground. There was no arguing with this statement within the confines of that room in the hospital but at the same time the idea that I could separate myself in this way did not make sense inside the intensity of this situation and the reality of our lives. She missed the point that I needed to be what ever it was that Kevin wanted me to be, that my professional practice as a nurse really made a difference for him.

The protection behaviours that nurses perform seem to be associated with metaphors of nursing work as emotionally arduous, draining and burdensome. Froggatt (1998 p.336) relates how the hospice nurses in her study used strategies of emotional control to avoid becoming drained by their work with dying patients. They used emotional distancing terms such as "switching on and off" between work and home, "hardening" or creating an impermeable emotional barrier, and "standing back" or holding oneself distant. Rudge (1995) also identifies how nurses working with burn patients separated themselves out from patients. They avoided getting too involved with patients by keeping a professional distance and controlling themselves, physically and emotionally, to do burns dressings.

These descriptions of distancing and control conflict with notions of closeness between the nurse and the patient. Closeness suggests an intimacy, which is central to therapeutic relationships. Savage (1997) sees the concept of closeness as a way of knowing in nursing that is implicitly emotional, and it is through closeness that the therapeutic potential of the relationship is realised. The collapse of social space is

central to this development of closeness, where 'common space' arises through the dismantling of emotional boundaries. Interpreting these concepts as clean bounded and static prescriptions for protection or total emersion in the patient's situation, which are tied to the identity of the nurse, is potentially disabling. On the other hand, these notions of distance and closeness imply movement of the discursively constructed subject reflecting the agency of the nurse to act in her/his own, and the patient's interests. Emotional protection implies the idea of boundary containment as an important strategy in keeping the nurse together. However, the prescriptive application of protection potentially disables the capacity of the nurse in carefully orchestrating her/his movements in harmony with possibilities presented in moments of engagement with the patient.

Appealing to discourses of protection or intimacy as prescriptions for the conduct of nurses denies the potential of nursing by subjugating other possibilities. The nurses who spoke on my behalf denied my moral agency in constituting me as a protected person. In constructing themselves as expert knowers about nursing relationships these nurses uncover the notion of power as the 'dominium', or the 'master's authority'.

These models identify power with the prerogative of the lord, master, household head and employer to demand obedience from their subordinates in return for protection. What the lord, master, household head and employer have in common is the prerogative of *dominium*, namely the right to rule and control all that come within their jurisdiction of command The rationale for this rule and command resides in the pursuit of what is taken to be the interest of all that come under the specific jurisdiction (Yeatman, 1994 p.80).

This thinking legitimates the domination of people who are constituted as weak and unable to care for, or make ethical decisions for themselves (Yeatman, 1994). It equates good nursing with the patriarchal protection of colleagues and patients. A further quote from Yeatman is useful in considering the capacity of the nurse in performing her/his identity.

When a conception of power as action and capacity is operative, we come to understand Foucault's point that a discursive formation interpellates us not as passive subjects of power but as specific kinds of agency or capacity (Yeatman, 1994 p.94).

The exploration of such capacities enables an understanding of the possibilities for multiple and performed identities that arise in particular contexts or moments of practice. In considering power as capacity, the identities of the nurse and the patient are understood as performed something we do rather than something we are, and neither static nor clearly bounded identities. The idea of capacity in performing identities creates the opportunity for new self forming activities. It suggests the possibility of negotiation and contestation of the social boundaries governing interactions between people.

Agency, as the capacity for action and movement within social boundaries, is an important consideration in nursing practice when the nurse faces uncertainty about how to proceed. People, as acting agents in the construction of their social world, have the capacity to understand what they are doing, even as they do it. It is this capacity that creates the continuous flow of activities in everyday interactions (Giddens, 1984, cited in Purkis, 1996). My discursive positionings as the private nurse enabled the production of the actively participating subject in spite of the tensions experienced as I was drawn into other discourses surrounding the conduct of the professional nurse. This agency provided the means for going on (Purkis, 1996); being able to find a path even when the way forwards was unclear. The 'doing' of nursing practice with Kevin uncovered private, discursively redundant, subjugated knowledges (Cain, 1993). As well, this 'doing' provided an important means of expression for me in getting through each day.

In retrospect, I was grateful to these nurses for bringing out the tensions between my positionings as the nurse and wife. Their challenges made me think carefully about my practice with Kevin they made me think carefully about making clinical decisions. It wasn't about being rational or having clouded judgement. It was that making a wrong decision in the context of the relationship between Kevin and

I would have been devastating ... it would have had a very high cost. I promised myself that I would not take action on major issues without talking things over with other nurses working with us..... with some things like medications and wound care, I needed a safety net.

Ritual inscriptions of the patient's body

My presence as the private nurse, and Kevin's always/already existing occupational status as a technician, mediated the "stripping of self" (Goffman 1969, cited in Gammon,1998 p.85) that occurs as the person moves through the rituals of entry to hospital and takes on the status of the patient. For the patient, entry to the hospital ward denotes both a personal and a territorial passage where the person moves from one state to another (van Gennep,1960). The personal passage involves states of liminality where there are rites of separation from life outside as the person enters the discursive fields of the hospital. New discursive positionings within the technological practices of health care reconstruct the person's relationships with themselves, as their old identity moves towards the new identity of the patient.

There are new social groupings to be initiated into on the ward, where certain status is attached to how the person's body enters the discursive field. The patient's body is often clothed in garments that are generally worn in bed and which provides easy access for health professionals to work on the body. Health professionals wear uniforms, or clothing that denotes a uniform, and carry the cultural artefacts of their practice and status. The street-ware worn by family members denotes their status as visitors with only limited access to the patient. In the rites of separation, families become entities who exist outside the primary focus of the discursive practices, which interpellate the person as the patient. The usual validation of identity and the sense of self and belonging that this validation from friends and family brings, is disrupted by this exclusion (Warren, Holloway & Smith,2000).

The rites of transition (van Gennep,1960) into the status of the patient encourage self forming activities that move the person into this new identity. These self forming activities undertaken by the patient involve physical rites of subjection to the gaze of

health care technologies. The body is reconstituted as a biomedical entity through participation in surveillance in the form of medical examinations, blood and urine tests, Xrays and scans. In this phase of transition, the private body is put out for public scrutiny and the felt experience of the body moves towards an objective, clinical understanding of its functioning, where the patient is constructed as an object of care (Chambliss,1996). The ritualised nursing practices of preparation for operating theatre further enhance this status as an object. They involve stripping the body of its usual attire, taking readings of the body involving technological devices such as thermometers and oxymeters, and conducting disciplinary practices involving body hygiene. The body is further catalogued, medicated, confined, and moved according to pre-operative protocols. The emotional vulnerability experienced in this transition phase is often recognised by nurses as associated with the experience of liminality; the sense of fear in feeling out of place and not knowing what to expect, and the anxiety involved in moving from one state to another. However, the discursive rules of engagement in health care practices reward stoical behaviour such as “putting on a brave face”, “giving full co-operation”, and “not being a bother” (Warren et al,2000 p.230).

Patients become fully incorporated into the ward only when they have actively subjected themselves to these discursive practices and learned to manage their place in the social order. The rites of incorporation (van Gennep,1960) invest the patient’s body with the full status of the patient. The discursive inscriptions of health care technologies are written on the body in forms such as the surgical wound. These inscriptions invite further work of the body as giving medications, doing wound dressings, confining the body to the bed or within the restricted space of the ward, and assessing the patient’s movement towards healing and recovery. However, Warren et al (2000) argue that the patient is actively involved in interpreting the rules of social engagement on the ward, and interprets fitting in with such practices as being for his/her own good. Fitting in should thus be understood as an active process for the

patient where. In gaining expertise about the way the ward functions, patients learn how to 'work' the system to get the best out of it for themselves.

The movement of the patient through surgery and hospitalisation can also be understood as a territorial passage from one domain to another. This movement involves physical rights of entry, waiting and departure (van Gennep,1960) where the person moves from the private domain of self care to the public domain of institutionalised care. Operating theatre is a useful example of the way the power of self care prior to admission moves to the exercise of expert care. The patient literally puts themselves in the hands of health care professionals as thus resides in the dominium of this expert care. Starr (1982) explains the importance of such expert knowledge to patients who are fearful of death as having a special need for the professional reassurance of such professional expertise.

....practitioners come into direct and intimate contact with people in their daily lives; they are present at critical transitional moments of existence. They serve as intermediaries between science and private experience, interpreting personal troubles in the abstract language of scientific knowledge. For many people, they are the only contact with a world that otherwise stands at a forbidding distance. (Starr,1982 p.4).

Patients enter the dominium of expert care because they recognise the need for the authority of medical and scientific knowledge in interpreting the body and the capacity for such knowledge to change the circumstances of their illness. The ritual of departure from this expert care occurs only when the patient is seen to be competent to resume self care. In moving through the domain of the operating theatre, Kevin's body simultaneously entered the discursive fields of health care in different ways. As the patient, his body was the object of surgical intervention to be worked upon. At the same time he had intimate knowledge of the abstract language of science and had worked with operating theatre staff on the technological apparatuses used to work on the patient's body. In this sense Kevin had always/already entered the 'dominium' (Yeatman,1994) of this field of practice where his body, with its authoritative scientific inscription, was understood as a tool for carrying out bio-mechanical tasks

on other patients' bodies. For some operating theatre staff, Kevin's prior work as a colleague within their domain of practice produced an understanding of him as a colleague and friend. These connections between the identity of the patient and the health professionals' own identity produced seepage between the boundaries of professional practice and personal friendship.

Co-extensive spaces of the interior and exterior

The following narrative explains the ways in which the lines between these discursive boundaries, the public and private body, and Kevin's identity as the patient, colleague, and friend became blurred.

During the time Kevin was in operating theatre, some nurses who were good friends and colleagues were involved in caring for him. When he came back to the ward, several things appeared with him that was outside the usual prescriptions for care. A large piece of chocolate, covered in gold foil, was taped to his pillow. Beside it was a note with the inscription, "This is for being such a good boy!". Shortly afterwards a large teddy bear arrived complete with an intravenous line and bandaged leg with tubes resembling redivac drains. For me, these things were artefacts of love and care from colleagues who fully understood the implications of Kevin's illness. These operating theatre nurses moved across the boundaries of professional care and personal friendship to offer us comfort and emotional sustenance.

In moving through operating theatre, Kevin's rites of transition in this "critical moment of existence" (Starr, 1982 p.4) were simultaneously informed by discourses of scientific rationality and discourses of friendship and care. The metaphor of a 'metropolis' helps me to understand how power circulates through institutions to inscribe the body as a discursive object, where the inside is constructed in relation to the outside. The borders of the metropolis seem clearly bounded, but there are multiple crossings in the activities of everyday life that go on inside these boundaries. Just as health care workers come and go each day from home to work in the hospital; they also move their professional and personal identities. The dominium of public authoritative knowledge always/already contains private spaces within the interstices of the institution.

For these nurses, the domain of expert scientific care became continuous with the domain of personal care and intimacy in the reading of Kevin's prior inscription as a friend. The emotional boundary constructed by the notion of professional distance was mediated by personal investment, which is signified by the game of 'being a good boy'. The placing of items on Kevin's bed signified "matter out of place" (Douglas,1980/1966 p.36). As tokens of friendship, these items can be understood as a form of pollution, which threaten the classifications of professional conduct and its implications for professional distance. In threatening such classifications, the boundaries they construct can be both visualised and articulated where they usually disappear into the discursive fabric of the institution and remain invisible to us because of their 'ordinariness' in daily practice.

The inside and outside of boundaries involving the containment of emotional energy can be understood as the fold of subjectivation (Deleuze,1988) which nurses develop as they are called into being in the discourse of professional nursing. The folding of subjectivity is an effect of the self on the self, which creates an interiority of expectation, or in Foucault's (Davidson,1986) terms, the goal of self forming activities. However, as Deleuze (1988 p.108) suggests, "as long as the outside is folded, an inside is co-extensive with it". In this sense, the inside always/already co-exists with the outside, denoting a relation of continuity between concepts such as similarity and difference rather than a binary opposition. In conceptualising the formation of subjectivity as the "mobius strip", Grosz (1989 p.160) describes how the inside flips over to become the outside, and the inside turns over to become the outside. This creates a continuum of interacting planes, flows, linkages and intensities of subjectivity. The continuity implied in the Mobius strip enables movement through the inside to the outside of subjectivity without leaving the inscriptive surface.

Discursive subjectivities are constantly forming and reforming. The movement implied in the actions of the operating theatre nurses, in shifting the boundaries

between professional and private conduct, indicates the active involvement of the nurse in her/his interpellation into competing discourses. This capacity for active involvement in the formation of subjectivity occurs through thinking in the space between seeing and speaking. As Deleuze writes

To think means to experiment and to problematize. Knowledge, power and the self are the triple root of a problematization of thought. In the field of knowledge as problem thinking is first of all seeing and speaking, but thinking is carried out in the space between the two, in the interstice or disjunction between seeing and speaking..... The problematical unthought gives way to a thinking being who problematizes himself, as an ethical subject..... To think is to fold, to double the outside with a co-extensive inside.... The inside condenses the past in ways that confront it with the future that comes from the outside, exchange it and recreate it (Deleuze,1988 p.117-119).

The active interpellation of the nurse as a discursive subject creates pliability in the moving of these boundaries of emotional containment where thinking enables the nurse to experiment in binding seemingly different elements of practice. The recognition of rigidly applied professional boundaries of containment as restricting creates a vision for the expenditure of 'personal' emotional energy in practice as something the nurse may freely choose to do in certain moments. It perhaps denotes the potential for movement through a continuum of possible relationships, when the nurse considers such movement to a new positioning supports the relationship with the patient. The recognition that boundaries are confining arises out of an understanding that past practices may not be sufficient in this patient's circumstances. The 'thinking' nurse works on a moveable scale of containment and loss of containment, where boundaries work to both construct the self and to avoid loss of self. This nurse is also an acting ethical subject whose self forming activities are directed towards the goal of care for self and others.

I think this idea that nurses could successfully negotiate the boundaries of personal and professional relationships was significant later when we realised that a personal friend was going to be centrally involved in Kevin's care. I was concerned about negotiating such an intense relationship across personal and professional boundaries.

When I discussed this with Kevin his response surprised me. He said, "She will be one less stranger". As she skilfully worked with Kevin's body and the equipment required for his care, I knew she was everything a nurse should be..... I did not realise she was such a good nurse.... she negotiated these boundaries, blending elements of the different relationships. Sometimes she appeared at our house in different capacities in the same day but she always knew exactly what her purpose was in being there. Even several years later she doesn't speak of our experiences together in these times directly, we have no need to do this but sometimes in our conversations I can hear the whisper of it in her voice.

The 'thinking' nurse pays attention to the detail of the patient's existence where understandings of the patient's transition through stages of illness are informed by the nurse's ability to travel with the patient, for at least some of the journey. The permeability of containment boundaries enables a deeper immersion in the illness experience with the patient and a more passionate connection with the patient's concerns. The nurse's body enters the discursive fields of health care in ways that are co-extensive with the inscriptions of the patient's body and yet retain the capacity for disengagement.

Managing the 'other' – visions of the 'English Patient'

The understanding of this co-extensive relationship came to me as I was watching the film *The English Patient* some months after Kevin's death. I suddenly found the images of the nurse working with the patient very difficult to watch as it brought the memories of working with his body to the surface. As a representation of nursing, the story of *The English Patient* portrays elements of the nurse's co-extensive relationship with the patient who moves through phases of engagement and withdrawal. The story of the nurse, Hana, and her encounter with the English Patient represents possible ways of understanding the sharing of human experience in abject conditions (Welch, 1997).

She pours calamine in stripes across his chest where he is less burned, where she can touch him. She loves the hollow below the lowest rib, its cliff of skin. Reaching his shoulders she blows cool air onto his neck, and he

mutters. What? she asks, coming out of her concentration. He turns his dark face with its grey eyes towards her. She puts her hand in her pocket. She unskins the plum with her teeth, withdraws the stone and passes the flesh of the fruit into his mouth. He whispers again, dragging the listening heart of the young nurse beside him to wherever his mind is, into that well of memory he kept plunging into during those months before he died. (Ondaatje,1993 p.5)

This passage from the novel *The English Patient* (Ondaatje,1993) captures the co-extensive positionings of the bodies of the patient and the nurse, where both participants recognise the humanness of one another. Through the practice of nursing, the body boundaries of both the nurse and the patient move, allowing an exchange that is something more than simply feeding the patient or dressing his wounds. Welch (1997) suggests that this scene brings to mind the sensuality in nursing work and the ‘uncomfortable ambivalence’ that professional nurses feel in this sexualization of the nurse as a woman. It contradicts historical notions of the nurse, as the nun working through her vows of service, inside the ruins of this monastery.

The tensions between these subject positions were apparent in the way other nurses encouraged me not to sleep in the same bed with Kevin when he became really ill.

Sometimes nursing friends would come over and suggest that they would sit with Kevin while I went to sleep in another room I mean nurses don't sleep with their patients, do they? When I did this on one occasion, Kevin was upset. "Where were you?", he said when I appeared the next morning after having slept very badly. I sometimes used to worry about what I would feel if Kevin died during the night while I was sleeping next to him. I thought about this quite a lot, and then decided that it would be OK. This was the context of our relationship.

Living with the unexpected is an important element of nursing where as Welch reminds me nurses do live in the world of the unexpected, “Where there is a constant reminder of the irrationality and unpredictability of life and death” (1997 p.276). He further suggests that the reward in living life on this edge with patients is the sharing of extremes of human experience. I could not move away from the ‘on the edge’ aspect of this experience because there was always/already a high emotional cost to be

paid. To disengage my presence from Kevin's would have been more difficult than remaining with him. I had to hold myself inside the relationship with the 'listening heart' that Hana's attentive gaze signifies and give my able bodied responses to compensate for the needs of his disabled body.

A further passage from this novel illustrates how the abject subject positioning (Rudge,1998) of the nurse is constructed through the permeability of body boundaries.

The Englishman was asleep, breathing through his mouth as he always did, awake or asleep. She got up from her chair and gently pulled free the lit candle held in his hands. She walked to the window and blew it out there, so the smoke went out of the room. She disliked his lying there with a candle in his hands, mocking a deathlike posture, wax falling unnoticed onto his wrist. As if he was preparing himself, as if he wanted to slip into his own death by imitating its climate and light. (Ondaatje,1993 p.62)

In this scene, the nurse senses the movement of the English Patient across the border between life and death. This is a moment when she is witness to his wounding and the patient becomes the abject as she senses his mortality and her own. By removing the candle and moving to the window, Hana withdraws from her attentive watchfulness of the patient and constructs him as the Other in order to delineate his body from her own.

As Wiltshire and Parker (1996 p.24) note, the work of nursing sometimes involves the "dissolving of autonomous subjectivity..... and that nurses respond to the visceral with the visceral". When the patient's body is situated in a way that is continuous with that of the nurse, the patient's body may become a conduit of distress across the boundaries between inside and outside. Hana's movement from the bedside can be read as representing an effort to contain her own emotional response to the patient by distancing herself in that moment. As Montgomery (1994) suggests, nurses experience emotional responses and connections to other people, as this is the nature of our work. The whisper I hear in my friend's voice reminds me of the need to care for oneself and others in the aftermath of such intense relationships. Abject elements

of the professional relationship, and the memory of the struggle to negotiate such difficult events, still exist at the margins of our personal interactions.

Co-extensive discourses of care and abjection

Being able to participate in caring for Kevin on the hospital ward, and later at home, seemed to be important in managing, or getting through, my own intense emotional responses to his illness. The following narrative brings to light the tensions apparent in the discursive positionings of the private nurse as I struggled to manage the giving of professional nursing care in ways that were co-extensive with our personal relationship.

I was profoundly concerned with the idea that Kevin retained the capacity to choose who would do specific tasks for him. When I questioned him about this, he would often say that he preferred me to do things for him. The first time I remember experiencing moments of panic when I realised I would have to do something for him that moved across the boundary between personal and professional care. Often these moments involved doing 'technical' things with his body, such as doing wound dressings or removing redivac drains. While these were skills that I had performed many hundreds of times on other peoples' bodies it seemed quite uncanny to perform it on my husband.

In doing this work with Kevin, I remember thinking about an occasion when our son had been admitted the emergency department with an unspecified illness. The medical assessment had involved taking haematological specimens. The nurse asked him if he would like mummy to do this. To my horror he said yes, and I said that of course I would do it for him, and thought, "Oh God, can I actually stick a needle into my own child?" In the end, I did this for him, forcing myself to overcome the feeling of "taboo" that I felt I crossing the boundary between personal care as a parent and my professional practice as a nurse. When I asked him why he had wanted me to do it, he said, "Mummy, I knew you wouldn't hurt me any more than you absolutely had to". His response took my breath away.

This experience with our son was a critical motivating factor in my willingness to perform such activities for Kevin. This desire to care both drew me towards practising professional nursing care and pushed away from it. Discourses of care and caring are

central to contemporary notions of professional nursing practice although they co-exist with discourses of rationality, objectivity and control within healthcare institutions and suffer a marginal status.

The concept of caring is closely associated with professionalism in academic nursing discourse where an attitude caring is seen as governing the professional work of the nurse (Mackintosh,2000). One may argue that there has been a concern with the patient as a person, and the subject of professional nursing care, for as long as nurses have been writing theories about nursing. Nightingale (cited in Pfettscher, de Graff, Marriner Tomey, Mossman & Slebonik,1998) constructed the ill person or wounded soldier as a human being in need of intervention, and used her skills in the analysis of morbidity and mortality statistics to show that intervention in the plight of these people was beneficial. In this sense she made the patient visible to the governing bodies of communities or societies, as the subject of care, and a worthy investment for resources to prevent illness or promote recovery. It may also be argued that Nightingale's (1969) writing made visible the effects of illness for the person, and the work of the nurse in managing such effects of illness, through her detailed descriptions of the techniques of nursing care.

The construction of relationship between the patient and the nurse, with caring as a central concern in the professional nursing encounter, is seen in the writing of Travelbee (1971), Watson (1988) and Benner (1984). The theoretical underpinnings of these theories are diverse. Travelbee's (1971) human to human relationship model is informed by Victor Frankl's (1992/1959) theory of logotherapy, which was derived from his experiences as a concentration camp survivor. The human to human relationship describes the activities of the nurse as directed towards helping people to cope with, and find meaning in, the experience of illness and suffering (Rangel, Hobble, Lansinger, Magers & McKee,1998). The relationality of Travelbee's theory constructs an attitude of compassion and caring in the therapeutic use of self, that is representative of deontological ethics (Barker,2000). The nurse is understood as guided by his/her moral duties that are owed to the patient within the professional

relationship, and as having the ability to distinguish between activities that are virtuous and those that are held to be vicious (Johnstone,1999).

Watson's (1988) philosophy and science of caring and Benner's (1984) model of excellence and power in caring both lay claim to existential and phenomenological approaches. In a sense they created what has been described as a paradigm shift from the empirical and scientific, to interpretive understandings of being-in-the-world, derived from the work of Heidegger (1962). Heideggerian phenomenology challenges the epistemology of Cartesian dualism as a way of understanding the world. Instead, an ontological approach has as its central concern the question of what it means to be a person (Leonard,1989). Both the nurse and the patient are understood as being in a constant process of becoming (Barker,2000) where the self is both constituted by, and constitutive of the world. As Leonard (1989 p.44) suggests people are understood as beings "for whom things have significance and value", and are self-interpreting, based on their own understandings of particular situations.

In defining caring as the essence of nursing (Barker,2000) nurses construct an ethics of care where the nurse owes the patient certain duties in terms of how s/he acts. These discourses of caring concern 'being with' the patient, while expressing behaviours such as concern, solicitude, caution, positive regard, fondness, attentiveness (Stevens & Crouch,1998), friendship and even nursing 'love' (Appleton,1994). Caring is seen as the 'gift of self' in being there with the patient (Appleton,1994). This 'gift of self' situates the nurse in the discourse of caring where there is an ethical requirement for attentive reflection on one's own beliefs and knowledge to enable an inspiring, supportive and comforting relationship with the patient. Caring thus becomes a self forming activity where the subjectivity of the nurse is constructed through techniques of self that are thought to produce this virtuous image of the 'good nurse'. Johnstone (1999) describes the virtues that define the good nurse as fidelity, benevolence, effacement of self interest, compassion and caring, intellectual honesty, justice and prudence. Tuckett (2000) similarly identifies

what he calls virtuous principles for the contemporary nurse where s/he lives 'an ethical life through cultivating virtues or character traits that would have them described by others as being "a good person". (MacIntyre cited in Tuckett,2000 p.107) Virtuous caring is seen to be synonymous with, and the means through which to meet the moral end of professional nursing.

There are numerous critiques of this construction of professional nursing as synonymous with a moral imperative to care. Caring can be seen as an essentialist way of knowing for women, which coerces or disciplines women and nurses into working in ways that are caring and subjugates the potential for other responses. It also serves to prescribe the relationship between the patient and nurse in predictable ways (Crowe,2000) that may not take account of specific contexts of nursing practice or the agency of the nurse and patient. Pinch (1996) suggests that caring associates the practice of professional nursing with the private sphere of conventional women's work in the emotional caretaking of family members and thus perpetuates the interpellation of women as subservient, self sacrificing and self denying. Caring practices may not provide women, who care for others in spite of the threat to their own safety, with the capacity to perform in different ways. Crowe (2000) makes the point that caring produces strategies that discipline both the nurse and the patient through this discursive production of subjectivity. Within the discursive practices of health care institutions, the effect of caring may be to render nurses docile, and thus productive and useful in the management of patients.

I am ambivalent about caring as the moral intent of nursing. Caring calls the nurse into being in ways where his/her body is co-extensive with that of the patient, however, the nurse does not seem to have the means to control the permeability of body boundaries. In giving the self (Appleton,1994) to the patient there is no accounting of abject moments where the nurse withdraws his/her self from the patient to avoid being engulfed by the connection with the patient. I believe the discursive production of the caring nurse could be further explored using Foucault's ideas. I am

thinking about Deleuze's (1988) explanation of the moment of Foucault's theoretical break with Heidegger and phenomenology. He suggests we can consider the differences between Heidegger and Foucault

..... only by taking as our point of departure Foucault's break with phenomenology in the 'vulgar' sense of the term: with intentionality. The idea that consciousness is directed towards the thing and gains significance in the world is precisely what Foucault refuses to believe..... All intentionality collapses in the gap that opens up in the 'non-relation' between seeing and speaking. This is Foucault's major achievement: the conversion of phenomenology into epistemology. For seeing and speaking means knowing..... Everything is knowledge..... there is nothing beneath or prior to knowledge. But knowledge is irreducibly double, since it involves speaking and seeing, language and light, which is the reason why there is no intentionality. (Deleuze, 1988 pp.108-109)

This is the point where Foucault moves from Heidegger's ontology of the intentional gaze, to an epistemology of strategy through the interlacing of the sayable and the visible. The mutually sustaining power relation can be understood as the mechanism or strategy "which keeps things going" (Kendall & Wickham, 1999 p.49) through sites of discursive practice. Force is the element that comes from the outside in constituting the self's relation to the self, so that the outside creates an inside that is co-extensive. The three dimensions of knowledge, power and self are always present with one another but are only identifiable in their specific historical contexts, that is, as an effect of power (Deleuze, 1988).

In undertaking caring activities with my own child in the Emergency Department I was interpellated as the caring professional nurse and mother as I struggled to manage the tensions between these discursive positionings. Van Manen's (1999) conceptualisation of care as worry pushes the boundaries of the discursive construction of care in the nursing literature. Rather than being the moral intent of nursing, care becomes something the nurse does as an effect of recognising the patient's vulnerability. Van Manen (1999) makes the idea of care as worry visible through a parent's eyes where he illustrates the power of the parent, in taking on the worry of the child. Worrying is an active ingredient of parental attentiveness where

the parent is constantly present with the child, and monitors or constantly goes back to check on him/her. Worry, rather than a duty or obligation, is a way of staying in touch with the child who is the subject of the parent's fears. The face of the Other addresses the subject and calls her/him into being as responsive to the Other's vulnerability. The face of the Other creates this worrying mindfulness as an active response where a threat to the Other is recognised in a person who is co-extensive with the self. Care is something that is borne by the nurse as the one who is charged with responsibility to alleviate harm through caring activities.

The ethical substance of my positioning across these discursive boundaries was concerned with my own moral values about what was required to manage the situation where my son wanted me to do a vene-puncture for him. In this sense I recognised my own skill in this technique as well as my desire not to harm my own child. The discourse of professional nursing invited me to recognise my obligation to care for my child beyond the usual boundaries of parental care by doing the vene-puncture. The self forming activities undertaken in order to do the procedure involved managing the abject (Rudge,1998) element of 'actually sticking a needle into my own child' where I felt his wounding. In the moment of putting the needle through his skin, I delineated his body from my own, pulling back from the abject to avoid witnessing his wounding and being cast into uncertainty and chaos (Rudge,1998). I used my body as a tool to complete the procedure as I had many hundreds of times before, and in doing so, covered over the moment of wounding.

The discourse of care as worry constructs the subject by making the other continuous with self. Worry is the power that connects the patient's face as the visible, and the sayable as the knowledge and skills of professional nursing. The body of the nurse becomes a container for emotions as s/he bears the weight of this relationship with the patient, but the nurse withdraws in certain moments by "switching on and off" (Froggatt,1998 p.335), as a strategy for the containment of self. Caring may be understood an effect of worrying just as caring is an effect of nursing. It is something

that happens as the result of nursing praxis, the practice of nursing, which constitutes the link between past and present, as the nurse engages in transversal and immediate struggles in the patient's situation (Deleuze, 1988).

Summary

The discussion in this chapter considers the discourses surrounding our movement through the experience of surgical intervention, undertaken in an attempt to contain the spread of metastatic melanoma. The discursive production of the subjectivities of the nurse and patient are explored in relation to this and subsequent hospitalisations, where I become the private nurse, and Kevin is positioned as the cancer patient. The development of a new relationship with him as the patient is explored through my discursive positioning as the 'private nurse'. The analysis shows how the fragile identity of the 'private nurse' encompasses a borderline professional capacity, which allows my entry to privileged spaces. In using this professional capacity to cover over my private body, I resist the discursive construction of (my)self as the confessing subject in the role of the patient's wife, and take up a new positioning in the discourse of enduring.

At the same time I become subject to control by other nurses as the ambiguity of my multiple positionings as the professional nurse and the patient's wife threaten the institutional classifications which separate health professionals from their patients. My presence as the 'private nurse' mediates the entry of this patient's body into the discursive practices of healthcare. The interior and exterior spaces of the healthcare institution become coextensive as the boundaries between Kevin's public and private bodies, and his identity as the patient, colleague and friend, become blurred. My work as the private nurse, between personal and professional boundaries makes discourses of pollution and bodily control visible in the work of professional nurses. Finally, discourses of care and abjection are seen as co-extensive and show the potential for

nursing in understanding and negotiating such intense and intimate relationships with the patient.

The following chapter analyses the discursive production of life threatening illness and the work of the private nurse where the patient is dying. I relate how Kevin works to manage his leaking, altered body, and return to a “normal” life and level of fitness following discharge from hospital. The relationship between technology and the patient’s body is further explored as Kevin undergoes radiotherapy and ongoing surveillance through CT scanning. I relate my journey through managing personal and professional boundaries in my work as an educator as well as finding ways to express the experience of my journey with Kevin through my teaching. Finally, I consider the discourses present in the care of the patient with tertiary stage melanoma as Kevin and I struggle to find a path through the inevitability of his dying.

CHAPTER SEVEN

RUNNING IN THE DARK - LIVING WITH LIFE THREATENING ILLNESS

Introduction

The discussion in this chapter analyses the discursive production of life threatening illness and the work of the private nurse where the patient is dying. Running in the

dark becomes a metaphor for the mediation of body boundaries as we both recognise the limits of medicine in treating this disease. The stories show how discourses that produce self forming activities related to health and fitness become privileged as Kevin attempts to live his life in the shadow of life threatening illness. An intimate relationship with the technology of radiotherapy extends the discourse of the open body across the personal and professional boundaries of Kevin's life. The rituals of monitoring and surveillance serve to maintain the privileged vision of the pathology until the point when a tertiary diagnosis is confirmed with the discovery of the tertiary stage lesion. The experience of living with life threatening illness finds expression in my teaching as I struggle to manage the boundaries between private experience and professional practice. Finally, I consider the discourses present in the care of the patient with tertiary stage melanoma as Kevin and I struggle to find a path through the inevitability of his dying. Discourses of hope, denial, acceptance, and suffering are considered in relation to the pathological body and the self's relation to the self.

Running in the dark – living with life threatening illness

I think the metaphor of 'running in the dark' describes what it was like to live with this life threatening illness where we did not know how the progression of the illness would unfold.

I knew Kevin was going to die from this disease. Though he didn't speak of it, I think he probably knew this as well. But what neither of us knew was what it would be like to live in this land of life threatening illness, how the effects of the illness would unfold, how this would impact on our daily lives, and how we would manage. Furthermore, the unfolding of this disease was something that was too painful to look at in an 'up close and personal' sense. We could only find a path to walk day by day and manage the effects of the illness as they presented. 'Running in the dark' also uncovers how Kevin ran after dark because he was a patient with an illness who was not supposed to run. He also had consultations with health professionals in private places, which often took place after hours.

For us, the metaphor of running in the dark was about finding paths through the uncertainty about the future that the diagnosis of metastatic melanoma had inscribed on Kevin's body. Biomedical, psychosocial and lay discourses on life threatening and chronic illness tend to construct the patient within certain normalising categories of what are reasonable and rational responses for the individual who is diagnosed with a disease. In this sense, the idea of a healthy body with a certain future becomes a normalising discourse where the ill person hides the stigmata of illness to "ass themselves as normal" (Wellard,1998 pp.49-51) and live a life. Living with life threatening illness involves undertaking self forming activities to make oneself healthy "in a world of health centred people" (Wellard,1998 p.51). An example of this was the way Kevin worked to contain his leaking body following the removal of lymph nodes in his groin.

We hadn't realised how much lymphatic ooze there would be after the redivac drains were removed. Kevin had wanted to go shopping in town. However, while he was walking the wound suddenly oozed copious amounts of fluid. Fortunately I was carrying some wound dressings and was able to change the dressing, but he found the sensation of having the wound suddenly ooze very distressing. What we also didn't realise was that once the wound stopped oozing, that the lymphodema would begin. As the lymphodema began to appear, Kevin began to work to get it under control. He found a local compression garment supplier on the internet and wore this garment on his leg constantly unless he was in bed. Over the next few months the lymphodema seemed to gradually subside. It was then that I realised he was running again. He would go out after dark when he thought no one would see him. He tried to pretend that he hadn't been running when he came home, and also didn't tell me that he had returned to working out at the gym.

Containing the leaking body and returning to his normal life and fitness were clear goals for Kevin in the months following surgery. Managing the leaking wound, and subsequent lymphodema, removed the stigma or markings of Otherness from his body. This investing in and working on the self becomes a means of decreasing the sense of alienation that is produced through the diagnosis and symptoms of the illness (Leenerts & Magilvy,2000).

The ethical substance of this work on oneself is the recognition of one's own capacity to influence the experience of the body in illness and to try to limit the progression of the disease. The mode of subjection, or the basis, from which self relation is produced (Blacker,1998), is normalisation within discourses of the health where the body is seen to have a clearly defined future. The self forming techniques and practices Kevin participated in involved rigorous practices of the body. He was absolutely consistent in wearing the compression garment and exercising his whole body to regain his prior level of fitness. As well, the hiding of these health-promoting activities seemed to cover over his attempts regain normality (Leenerts & Magilvy, 2000). The ultimate goal of self forming activities could be understood as self mastery in gaining control over his body and living his life. Frank (1999) describes this feeling when he was diagnosed with lymphoma.

Running on the stairs, experiencing the strength I still had gave me a feeling that my body was still doing what it wanted. Through exercise I began to discover what I wanted. Exercise was a way of keeping myself at centre stage of my illness..... a way of telling myself that I would come back from cancer, that my body was still worth taking care of I did not think exercise was any part of a cure. It was the way I wanted to live out my life with illness Exercise was my expression of wonder at the body (Frank,1999 p.226).

As Herzlich (1973 cited in Madjar,1997) suggests, healthy bodies are organically silent. We pay little attention to our bodies, taking function for granted until the body ceases to do what is required of it. Illness makes the body visible in a way that stimulates a deep-seated desire to have the familiar, working body returned (Madjar,1997).

The hope of the return of the healthy body is an interesting element of subjectivation within discourses of normality. Wilkinson (1996) suggests hope is a considerable motivating factor in staying healthy and banishing disease. It is often linked with survival and a person's ability to overcome life threatening situations. Psychosomatic

discourses on illness see the mind as having a relationship with the body through biological processes affecting body systems such as the management of pathogens by the lymphatic system. In these discourses, the mind becomes visible as working on the body to produce positive or negative outcomes in the form of health and illness (Samson,1999). Illness is thus socially produced through stressful events, which impact on the mind, and in turn creates unbalanced states in the body. The repression of emotions is seen to be a central element in the personality of the cancer patient (Levin,1999) who is interpellated into 'feeling' discourses, and carries out self forming activities as the confession of his/her repressed desires. People are seen to have the capacity to prevent or heal illness through their own behaviour and state of mind (Samson,1999). This connection of the mind and body within psychosomatic discourse tends to support and extend bio-medical understandings of self and the relationships between health and the self. Maslow's model of self actualisation illustrates this idea of self mastery, and rational control, where a person overcomes basic physiological cravings to be not only a better person, but to have better health (Samson,1999).

Biomedical discourses construct the body as a territory (Gaddow,1995; Bauman,1995; Frank,1999) to be worked upon in the presence of disease, or illness. The aim of biomedical discursive practices is to effect a cure, or at least to minimise the effects of the disease. As Miles (1996 p.166) suggests, technology has

... made the approach of death telescopically visible from a distance. Few persons die young. Far fewer die suddenly. The vast majority of people bear medically recognised and treated signs of impending death in the form of the gradual onset of a chronic disease such as cancer.... we peer forward to the scientifically recognised sequence of chronic disease even as the natural and personal mortality, that lies at the end, and beginning, of that process, is obscured.

While the cancer patient is concerned with how the body feels, biomedical discourses map out the trajectory, shape and predictability of disease (Wellard,1998). This classification of disease stages constructs the patient as a biological entity and host for

the disease, the progression of which can be mapped through the body and outcomes predicted in terms of changes in physiological functioning. This conceptualisation of the patient's body invites ongoing surveillance to monitor the progression of the disease through technological imaging, such as Xray and CT scanning. The patient complies with this surveillance as a self forming activity in the hope of 'remaining clear' of the disease, or having early intervention if further evidence of the disease is found. However, if further intervention is not possible in a curative sense, this continued surveillance may become ethically problematic (Cassell,1996).

I didn't really understand how traumatic undergoing the CT scan was for Kevin. I went with him because I thought it was the right thing to do. I wanted to be there to support him. Even though I had cared for patients undergoing such procedures in my professional practice as a nurse, what I didn't understand in his case was that he was literally waiting for a death sentence. If I had been able to see this, I think I would have cautioned him against having the scan.

Cassell (1996) sees such technology as creating unambiguous values, which is fundamental to good science, and has significant utility in a curative sense. However, the representations of the pathology risk becoming the illness for the patient within a self-referential discourse where looking, seeing and acting on the pathology subjugate the patient's knowledge of him/herself to this expertise. There is also the potential to create more certainty about the disease than the patient may wish to know, as person who is dying but still living a life. In this sense, as the discursively produced objects of science, patients risks losing themselves as spectators in their own drama. For the patient who has an 'incurable' disease it becomes very difficult to 'stop the war' waged against the cancer cells (Lupton,1994; Sontag,1999), which biomedical discourses perpetrate on the patient's still mainly healthy body. Such surveillance and treatment approaches may still have utility, but only in a palliative sense. However, as Seely (1999) suggests, palliative care shows both the strengths and pitfalls of technological healthcare. He believes that, given the aim of palliative care to reduce suffering and promote the quality of the patient's life, therapeutic approaches should have a vision of moving beyond technology to achieve this end.

Boundary seepage in the practice of the ‘private nurse’

As Kevin and I struggled to manage the implications of ongoing treatments and monitoring while living in the shadow of this illness, I continued working as a nurse educator. However, I was unprepared for how this experience with Kevin was going to impact on my teaching.

I was very careful not to talk about what I was experiencing in my private life in the classroom with students. I believed that the scope and content of my teaching practice needed to be educationally sound. I thought that talking about my husband’s illness directly would cross a boundary that was not appropriate. It would burden the students with my story, when they were in the classroom or clinical practice setting to learn about how to care for people who were ill. While I sometimes discussed my feelings with colleagues, I clearly separated myself from students in this respect.

The telling of my personal story to students would have had the potential to draw me into discussions that could rupture the boundaries I had constructed to manage the personal implications of Kevin’s illness. It could potentially result in a loss of control and containment of emotions that for me would have been unprofessional. The construction of distance between the students and my own experience ensured the maintenance of boundaries. The clear demarcation of this boundary in face to face contact with students signals my positioning in a discourse of protection as a mode of subjection (Deleuze,1988). The ethical substance of my conduct derived from my beliefs and values about professional relationships between students and educators. I believed the clear demarcation of this boundary had significant ethical utility. As a self forming activity, my positioning in this discourse of protection was a hygiene practice (Douglas,1980/1966) that was significant in keeping myself together, but also avoided burdening students with what I believed was pollution behaviour. The self forming activities (Deleuze,1988) involved keeping silent about my personal experience and at the same time, speaking in discourses of professional nursing which made the patient’s face visible as the recipient of care.

In retrospect, I can see how my experience with Kevin clearly informed the development of these new teaching approaches in acute care. I had finally found a way to conceptualise acute care beyond bio-medical discourses of pathology and disease.

I had been looking for a way to break out of teaching acute care approaches which had traditionally been taught using a body systems approach with the nursing process. I had felt constrained by such approaches for a long time, but had not been able to conceptualise other possibilities. Following Kevin's surgery, I developed a five-week programme, which was completely different from my prior approaches to teaching acute care nursing practice. My teaching moved to a process based approach rather than focusing on body systems as content. After completing the four study guides, the students had a session with a burn survivor, who told the story of her prolonged recovery from major burns. She showed graphic pictures of her wounds through progressive stages of recovery. She brought the human face of trauma and the patient's story of life threatening illness into the classroom with herself as an actor taking the centre stage. She illustrated her courage and a capacity to manage such trauma in a very personal way. Reading these study guides now, I can see how I was profoundly influenced by my own experience during this time, but this influence remained unspoken in my face to face presence with the students.

In these study guides, bio-medical nursing discourse is disrupted by making other discourses visible, which in turn makes the limitations of bio-medical discourse visible in relation to the care of acutely ill patients. These ideas, derived mainly from interpretive and critical nursing literature, served to make the patient's experience visible to the students. Discourses of hope, loss, vulnerability, trust, empowerment, caring and safety were illustrated in the nurse's work of caring for patients who had experienced trauma or illness. I renamed pre and postoperative care as preparing for surgery and healing from surgery. Cohen's (1995) interpretive research study was used to show how people undergoing surgery have unique responses to this experience. She illustrates the tensions between the patient's desire to know what will happen during the surgical experience and being afraid of having this knowledge. She

further explores how the majority of participants in her study were afraid of dying though very few talked about this idea directly. These patients seemed to want nurses to understand this fear but did not necessarily want to talk about it.

The final study guide that I developed used discourses of disability and chronicity in an attempt to show how patients struggle in coming to know and live in an altered body. The effect of bringing these discourses out into the classroom discussion created the potential for “the thought of the outside as a thought of resistance” (Deleuze, 1988 p.90), in the production of each patient as a ‘special case’ representing the human face of trauma and illness. Bio-medical nursing became one of the many discursive positionings that the student could take up within a self-conscious awareness (Blacker, 1998) of one’s own responses to the demands of the patient’s situation.

Technological interventions and the ‘techno-man’

Biomedical discourse, and its technologically produced vision, has the potential to draw the eye of both the health professional and patient towards the pathology. In doing so, it makes visible the potential threat of this pathology to the patient’s sense of self. However, technology had a central place in Kevin’s life. He lived his life engaged with technology in ways that produced the capacity to think and do things in new ways.

I think Kevin was probably the original ‘techno-man’. Technology had always been a part of his life, from the time he had been a young child. His mother once told me that she refused to clean his room when he lived at home, because she feared for her life in the myriad of equipment, wires and aerials that were intertwined through the space of his room. This was also a concern in the relationship between Kevin and I, but as the years passed, the presence of technology became an ordinary part of our lives. Kevin had a very familiar relationship with technology. He used it as an extension to his body. He thought in technological terms. He created technological devices in such prolific ways that I had ceased to notice their presence in our lives.

It was after Kevin died that I discovered he had made certain devices that I thought were quite ordinary, were not so ordinary. He had made some automatic garage door openers after his surgery as he found it difficult to bend down to physically open the garage doors. When the mechanism for one of these devices broke I had to get an engineer to fix it, because it wasn't possible to buy the broken piece. That should have warned me. I took the remote control to a garage door firm because it had stopped working. But the man in the office said, "This isn't a remote control for a garage door opener". "Oh, but it is", I said. "Well", he said, "It doesn't look like anything I've ever seen". "That's entirely possible", I said, and took it to a friend of Kevin's who ran an electronics business. I needed to find someone who thought the same way he did.

Kevin's way of living his life with technology involved more than just the simple application of scientific knowledge to solving problems. I think technology was something he used as other people might use literature. It was central to his thinking and ways of doing things in his life. There was a continuity between his sense of self and technology that implied "the possibility of human action and technology (as) being co-extensive" (Braidotti,1996 cited in Munster,1999 p.120). His ability to think and work with technology resembled more of a craft than the mechanistic application of principles, where empirical knowledge is applied to the solving of problems in practice. As Sandelowski (1997 p.221) suggests, technology "has a close relationship to art and craft by virtue of its emphasis on design, non-verbal practices, aesthetic vision and skilled making'. Working with technology involves what she calls a complex and dynamic relationship between human agency and objects where both technology and the outcomes of human agency are constantly reformed.

For Kevin, I think the ethical substance of the self's relation to the self (Deleuze,1988) in these discursive positionings with technology was creativity and inquiry. He pushed the boundaries of his own knowledge and experience with technology to explore new possibilities and new ways of living and working. In this sense, he saw technology as providing a means to do things differently. The mode of subjection (Deleuze,1988) in discourses of technology involved his ways of moving around objects of inquiry from the margins, where things were never forced into

place, but meticulously and incrementally coached into place. Kevin was not a person who was at the centre of things, in a social sense or a practical sense. The military metaphor did not work for him. He was not a fighter, but perhaps more of a strategist. Rather than attacking a problem ‘head on’, he would work from the sides, around it, and finally, through it. The self forming techniques (Deleuze,1988) Kevin undertook in this process resulted in a technical ‘know how’ (Sandelowski,1997) which (re) produced his body in this complex interplay with technology. This co-extensive relationship with technology produced his activities as human agency through the destabilisation of finite boundaries containing the person and machine. The opening of body boundaries produced visions of possibility for working in new spatial, temporal and kinaesthetic ways, or as Munster (1999 p.125) suggests, it bridges “both the formal and material hiatus between organic and silicon processes”.

Kevin’s decision to subject himself to radiotherapy treatments and CT scanning was to have a profound effect on both his sense of self and his relationship with his colleagues.

Kevin worked on the radiotherapy machines and CT scanner as part of his job. They were part of his life. He tended them and coaxed them into life, and made them work when they failed to do so. It was so uncanny going into the room with him when he was to have radiotherapy. I had seen him in this room with this huge machine in pieces. He knew how it worked. He knew what it did to human tissue. Kevin also knew that the intended effect of the radiotherapy was palliative, to prevent any further development of metastases at the operated site. He had arranged to have his treatments after hours and specifically chose the treatment radiographer. I think he chose someone who he knew would be clinical rather than affective. He did not want to be seen by other staff when he was having these treatments. Both the staff and the machines were too close to him.

Kevin’s presence in the hospital as the radiotherapy patient disturbed the classifications between health professionals and patients. It surfaced the patient’s body as an object of treatment across the boundaries of insider and outsider, collapsing the space between the professional body and the management of the

patient's diseased body through institutional practices. I think the conditions Kevin set around his radiotherapy treatment concerned the re-ordering these classifications in a way that denied the possibility of pollution behaviours (Douglas,1980/1966) and re-established the delineation of professional and personal boundaries. Although other people may have known he was having these treatments they did not actually see him in the department, and thus were not brought face to face with him as the patient. In being treated 'after dark' Kevin covered over his patient's body, making it invisible and therefore unsayable in the discourse of the open body (Liaschenko,1998) during day light hours.

As well, the medical equipment, such as radiotherapy machines and CT scanners, became continuous with Kevin's body in new ways. Before his subjectivation as the cancer patient, Kevin worked with this equipment in ways where his body entered discursive fields with a form of specification as the technician. He used his body as a means of completing technical work. In this new discursive positioning as the cancer patient, the equipment was used to work on him. It made the abject (Kristeva,1982) diagnosis of cancer visible as a threat to his 'self' in ways that he was unable to contain. There was a sense of involuntary participation in this new relation with technology, which threatened to engulf his sense of self through its capacity to surface the face of the cancer patient as his own. He was unable to delineate his body boundaries in relation to this technology because it uncovered the cancer as the intimate enemy, the monstrous 'Other' as the fearful entity that always/already existed within himself.

The tertiary stage diagnosis and the 'ambiguity game'

The diagnosis of tertiary stage melanoma was a critical point for us as we continued to live our lives in the shadow of this illness and its rapidly progressing pathology. The technological imaging had provided the means for biomedical discourse to inscribe Kevin's body with a new map (Wellard,1998) which showed clear "down hill" (Froggatt,1998 p.335) trajectory in this fight with cancer. The incessant onward

movement of the disease into new areas of his body held the promise of changes in physiological functioning, and the prediction of death.

Kevin had been ambivalent about getting the results of the last CT scan. One afternoon at work, I had a phone call from Kevin. He had finally decided to drop by the clinic while he was at work to get the results. But as I spoke to him, I could hear the break in his voice. "They found something on the CT scan. In my chest", he said. This was the only time I had not been with him to a consultation, and I was angry with myself that he had had to hear this alone. He was devastated by this result and subsequently refused to go to see the doctor again, even when invited to a consultation at the doctor's private clinic. He steadfastly refused to have any more scans or treatment. A few days after this new diagnosis he insisted on running the half marathon that he had been training for. "Do you think I should run?" he said to me.

In the end Kevin sent me to see the doctor, but told me that he did not want to know what the doctor said. I found this consultation with the doctor very difficult, but our discussion, and the way the doctor mapped out the likely progression of the disease to me, was helpful. I now knew what I was likely to be dealing with in the future. At least in terms of the changes to Kevin's body and the way he would be able to function. It was clear to me that Kevin was going to begin experiencing symptoms within six months and might live until the end of the following year. Strangely enough, this clinical map gave me some direction and purpose in how I might support Kevin. It was good to have had this information at this time. But I was not the one with the disease.

This was the beginning of a new phase in managing Kevin's illness, where, as the private nurse, I held the knowledge about things that he did not want to know about. In a sense, I became the minder of this knowledge for him as I helped to guide and support him through the following months. This construction of the private nurse as the keeper of knowledge produced contradictory discursive positionings between my professional knowledge and my desire to support Kevin in living his life on his own terms. When he told me he wanted to keep running, I found myself thinking in biomedical discourses of physiology and pathology as I envisaged him collapsing on the side of the road with a pneumothorax. I was ambivalent about him putting such

stress on his body, but simultaneously recognised the benefits for him in a discourse of wellness, where he was able to feel the power of his still healthy body. At the same time, I felt silenced by being unable to speak to him about his body in biomedical terms. I did not know whether he could make an informed decision without knowing the implications of this pathology in his body.

I also struggled with the idea that I could read his body within biomedical discourses in a way that Kevin had made unavailable to himself through his desire not to be told about the pathology. As the private nurse, and thus the mediator between Kevin's body and discourses of pathology, I was contradictorily positioned between ethical discourses of autonomy, veracity and informed consent. Discourses of autonomy were attractive to me as a means to subjugate my own concerns to Kevin's expressed wishes. As a self governing and rational individual (Johnstone,1999), his right not to be told about the pathology needed to be respected. Furthermore, I believed that to force information on him 'for his own good' would be harmful. The avoidance of harm to Kevin as a person who was experiencing vulnerability seemed to be an overriding moral obligation. I think this was the point where I began to question the notions of insight in psychological discourses which nurses sometimes feel compelled to use in moving patients towards a rational understanding of their health state.

The patient's refusal to look at the implications of pathology may become visible as denial in the psychological discourses of insight and rational acceptance that is present in the nursing literature. Nurses, who have been exposed to her work as an almost universally accepted grand theory on death and dying, have taken up the writing of Kubler-Ross (1969) in highly prescriptive forms. As well, such prescriptions are linked to ethical sanctions against withholding information about the patient's prognosis. The following quote from Barry (1996 p.443) represents one such example.

The dying patient's ego will maintain denial of unpleasant reality until its more mature defences are able to cope with troubling thoughts and feelings

about dying The persistence of strong denial of more than a day or two indicates that the awareness of impending death is terrifying to him or her test denial gradually and gently in order to assess its strength. The answers patients formulate in response to nurses' questions can help in a gradual acceptance of the reality of their illness at their own pace.

The patient is progressively lead towards the rational acceptance of the vision of the pathological body and its inscription of death, through self forming activities undertaken with health professionals, where he/she is talked through the door of denial (Barry,1996) and moved toward self actualisation in the form of acceptance. The patient is understood as being in denial until he/she manages to adapt to the situation using more mature coping responses. A persistent state of denial is seen as a maladaptive response, which is likely to lead to psychosomatic responses and disrupted relationships with family members (Barry,1996).

I believed I could not coerce Kevin into this kind of understanding. I saw such coercion as refusing the recognition of his unique capacities to manage these events within the multiple and contradictory discursive positionings we were both subject to. The recognition of alternative discourses arose from the way Kevin's responses tested my professional knowledge. His refusal to look at representations of the disease or discuss his illness made me question the value of psychological discourse which construct the patient as subject to the expert power of health professionals. My recognition of Kevin's agency in finding his own path through this life threatening illness signalled the beginning of my subject positioning of the private nurse as the bodyguard who patrolled these boundaries between professional knowledge and Kevin's body.

As Kevin began to experience 'possible' the symptoms of the illness, we worked together to create new strategies to contain these boundaries. For Kevin, this involved the closure of body boundaries to the medical gaze where he refused the discursive positioning of the patient. He repositioned himself in discourses of health, wellness,

and work. I became complicit in these repositionings as I developed something I called ‘the ambiguity game’.

From the point of the tertiary stage diagnosis, Kevin did not see a doctor or have any diagnostic tests for over a year. When he started to experience symptoms, I began to work with him to mediate the effects of these symptoms, such as the irritating cough, and later, the pain associated with coughing. He continued running until the coughing made this impossible, and I think he decided it was better not to run, because he was unable to sustain his prior times. It was later, that I found the notes in his diary, where he kept a record of his times for his usual run. As his times began get longer he stopped recording them. It was then that we started walking together in the evenings. As the symptoms developed Kevin would ask me what I thought was causing them. “What do you think?” he would say to me. “Well”, I would say, “It could be the melanoma, but on the other hand, it could be”, as I uncovered a number of other options to choose from.

As Frank (1999) notes, the construction of the patient within biomedical discourse involves the ceding of the body as territory to the expert gaze of medicine. While medicine offers relief to the patient who is suffering, it also colonises the body in ways, which separate the everyday knowing of the body from the rest of the patient’s life. If the treatment of symptoms and a possible cure is attainable, then patients may consider this ‘trade-off’ worthwhile. But as Frank (1999 p.221) suggests, it is “... dangerous to allow them (health professionals) to hog centre stage in the drama of illness”. While the patient’s body is present at centre stage, the person is sent off into the audience to become a spectator, as the drama of his/her own life unfolds. For Kevin, the closure of body boundaries signalled a taking his back of his body, where the re-positioning of self in the telling of his own stories screened his body from the gaze of others.

My reading of Hutchinson’s (1997) writing on postmodern film theory helps me to understand how the ‘ambiguity game’ worked with Kevin. It used techniques of “.... rupturing the chain of causation upon which character and plot motivation depend, spatial or temporal fragmentation”, and the introduction of “.... alien forms of

information” (Siska,1979:286 cited in Hutchinson,1997 p.36), and thus worked as a means of producing discursive disruptions. It simultaneously destabilised biomedical interpretations of Kevin’s body within the dominant discourse and interpellated the patient as subject into new possibilities. The production of these new possibilities challenged the notion of a coherent, continuous and autonomous subject, who should participate in universal and essentialist understandings of the world (Hutchinson,1997) and the dying patient.

The ‘ambiguity game’ refused the obsessive search for wholeness in the acceptance of dying. It surfaced the possibility of uncovering the multiple and contradictory discursive positionings of the subject as a way of containing the view of pathology inside the body. It made the nature of the ‘real’ problematic in relation to Kevin’s stories of his everyday life, through the construction of “dialogic doublings” (Hutchinson,1997 p.38), which challenged the historical character of particular connections between Kevin’s body as the visible, and the sayable, or the knowledge used to interpret his body. This discursive destabilisation created changes in prior historical categories and generated new discursive features that contradicted previous ones. In doing so, the ‘ambiguity game’ worked to ‘curtain off’ the view into Kevin’s body and left the performance of pathology going on ‘behind the scenes’ (Hutchinson,1997). Within the discursive constructions of his body as the cancer patient, he enacted his own ‘private life’ in spaces where the viewers of the pathology could not see. He merged fiction and reality in these ‘behind the scenes’ spaces, and constructed his own biographies in the telling of his stories about his relationship with his body. The pathology remained as a ‘querulous’, but absent presence. In ‘curtaining off’ his body to the gaze of biomedical discourse, and his own subjectivation as the cancer patient, Kevin was produced as “a wilfully absent subject, one who refuses to be subjected to the discourses and representations of others any longer” (Hutchinson,1997 p.41).

Discursive productions of the dying patient

There are times when I am still ambivalent about whether my complicity with Kevin's refusal to look at the implications of the pathology was the right thing to do or not. Discourses on death and dying that were so embedded in my professional practice and thinking pulled me toward the idea of rational acceptance. It was my understanding of Kevin's responses, and a desire to respect his unique way of coping with this illness, that challenged my positioning in professional discourses and drew me into supporting him in ways that were consistent with his expressed wishes of 'not wanting to know'. I think my complicity with his 'denial' was produced through my own unique response to his vulnerability, and my distrust of meta-narratives as prescriptions for practice that did not fit with Kevin's way of living his life. In my reading of the literature since that time, I have come to think that the work that I did with Kevin surfaced a compassionate response in my own practice with him, where I saw his 'denial' of the pathology as his way of living his life through this.

Kevin steadfastly refused to talk about dying with doctors, colleagues, friends, family, and other health professionals. And yet, I later discovered that he had spoken to the bank, his life insurance agent, and had also talked with our lawyer about his will. He had gone around talking to all of these people, putting things in place to make sure everything was ready in case he died. He also bought a new car to replace the one I was driving, because it was beginning to need some mechanical work.

Psychological discourses on death and dying create the expectation that the patient will work on themselves through self forming activities in discourses of rational acceptance, such as the well published theory of Kubler Ross (1969). Doka (1995) reminds me that meta-narratives can only ever be an approximation of the human experience of living and dying. Techniques or models that represent processes of dying can never really capture what it means to die. Benner, Hooper-Kyriakidis and Stannard (1999 p.391) relate the following comments from a dying patient.

All that nonsense written about stages of dying as if there were complete transitions – rooms that you enter, walk through, then leave behind for good. What rot. The anger, the shock, the unbelievableableness, the grief – they are part of each day. And in no particular order, either. Who says you work your way eventually to acceptance – I don't accept it! Today I can't accept it. Yesterday I did partly. Saturday I was there; kind of in a trance, waiting to die. But not now. Today it is the fear all over again. I don't want to die. I'm only 33; I've got my whole life to live. I can't be cut off now. It isn't just. Why me? Why now? You don't have to answer. I'm just in a lousy mood right now.

As this patient's narrative illustrates, representations of death and dying as linear and progressive stages of denial, anger, bargaining, depression, acceptance, and hope, Kubler Ross (1969) offers a psychological prescription for dying, where acceptance is constructed as a 'healthy' means of coping.

Doka (1995) challenges these discursive productions of dying as not taking account of the unique ways in which people may respond to the threat of death. In producing a narrow range of potential responses to life threatening situations, he suggests Kubler Ross' (1969) theory separates the coping responses people use in their everyday lives inside the notion that dying is somehow a separate experience from living. The dying patient is constructed within a narrow range of coping responses, which are closely linked to the psychological notion of insight. Doka (1995 p.120) suggests, "... living with life threatening illness recognises that all previous challenges of life ... remain an ongoing part of the larger struggle of life and living". He sees the strategies that a person uses to cope with life threatening illness as being derived from previous experience of life, and his/her own cultural interpretations of appropriate responses. As well, there may be significant factors related to the unique circumstances of the disease and treatment, and the degree of social support and other unique factors in the patient's life.

It is interesting that Doka (1995) challenges the way this theory of death and dying has been taken up as a normalising discourse in healthcare and popular literature, with little empirical support according to the rules of knowledge construction in bio-

medical discourse. He suggests that Kubler Ross was a charismatic psychiatrist who produced romantic and nostalgic visions of death (p112), with little basis for her ideas in research. However, I believe the work of Kubler Ross (1969) has been theorised and taken up as an overarching metanarrative in the form of a prescriptive and linear process of dying. As I read her original work (Kubler Ross,1981) rather than secondary sources, which refer to her ideas, I sense her recognition of patient's unique responses in the stories she writes. She relates a narrative about visiting a woman who is dying but in denial. In this story Kubler Ross (1981) refers to the need to understand the symbolic language patient's use when they are unable to talk about dying and how it is possible to communicate with the patient through this symbolism. She states

It is very important that you do not tear down this denial, that you respect the patient's needs and the patient's defences. But even those who maintained denial to the very end were able to talk about the awareness of their impending death in symbolic verbal and nonverbal language (Kubler Ross,1981 p.31).

I believe Kubler Ross' theory has been co-opted into the discursive practices of healthcare in a prescriptive form with little attention to the ideas, which underpinned her original writing. If I had insisted that Kevin accept his dying through the self forming activities of popular and biomedical discourse, I would have denied his agency in negotiating his own responses at a time of profound vulnerability. In my reading of Kubler Ross (1981), she understood this. The discursive tensions I experienced were the result of my own recognition of Kevin's unique ways of coping, and my belief that discursive productions of a rational death were insufficient to understand the reality of our situation. The simplistic representations in nursing texts produce the patient as a rational and autonomous individual who should be making insightful decisions about his/her own health. Perhaps my own complicity in Kevin's 'denial', was consistent with the way Kubler Ross would have worked. However, these tensions between my thinking and my practice as the private nurse were to surface again as I struggled to help Kevin manage the effects of this illness.

We eventually sought help because we needed to manage the pain and the other symptoms of the disease like shortness of breath and fatigue. With some ambivalence, I convinced Kevin that he needed to have a chest Xray so the doctors could see what they were dealing with. He eventually agreed, reluctantly, and put some conditions on having this procedure, such as having the Xray at a private clinic after hours, when he was the only patient. He told the radiographer who was an old friend that he did not want to know anything about what was on the Xray. Kevin had a similar approach with the next doctor we saw. I watched this doctor choose his words so carefully. He skilfully avoided mentioning the actual pathology while telling Kevin that he needed a referral to another service, which specialised in the management of such symptoms.

I think having this Xray was probably the right thing to do at the time in order to access the right interventions, but for Kevin, opening his body to the surveillance of biomedical discourse was difficult. Even when it was becoming obvious that Kevin was dying, tensions remained between the discourse of the open body (Liaschenko,1998) with its “scopic drive” or impulse to look inside his body (Braidotti cited in Grace,1997 p.85) and Kevin’s desire not to look. The covering over of the pathological body remained an important strategy in protecting his now increasingly fragile sense of self. However, within the normalising rationality, which is so prevalent in the discursive practices of institutions, some health professionals did not recognise or understand this need to not look.

What we wanted was help in managing the pain. During the admitting consultation the doctor said he wanted to do a bone scan to see whether there were any secondary sites. Kevin was horrified. He gave the ‘help me here’ look that I had come to know so well. I explained to the doctor that Kevin had only had one Xray in the past year and would prefer not to have any more diagnostic tests unless they became absolutely necessary for his care. The doctor agreed to this, however, following discharge from hospital, the book Kevin was given with his prescribed medications set out, had a note beside one of the medications. “For bone pain”, it said, which was an assumption Kevin clearly did not want to know about.

Even in the absence of 'hard data', health professionals continued to inscribe Kevin's body with the markings of the pathology. Furthermore, it was assumed that he wanted these inscriptions on his body mapped out in the instructions for taking medication. I think this represents the failure of some health professionals, who privilege notions of rational insight and universalise informed consent as the norm, to recognise the utility of denial for a patient facing such a threat to the self. In the local world of the patient such practice by health professionals seems unthinking. It risks tearing down the fragile fabric of the patient's life by assuming that the patient is able to articulate threats to self, and covers over the possibility of other responses that may support the patient's control over such a threat (Russell,1993).

There are significant tensions in the nursing literature between discourses of denial and hope, and what is considered to therapeutic and ethical practice with patients who are dying. Russell (1993) suggests that discourses of rational insight into death are derived from religious discourse where denial of impending death is seen as blocking the forgiveness of sin and making amends for one's past transgressions. Psychiatric discourses also require the 'patient to work on themselves' to move beyond denial and show insight that is 'reality' based. These discursive practices are predicated upon the notion that self-perceptions should be externally constructed according to the expert truths defined by health professionals. In this discursive production of the patient's internal reality, a healthy self-perception accurately reflects representations of his/her external world. Russell (1993) argues for the preservation of the integrity of self, and a personal sense of control over one's own destiny, as critical elements in managing the implications of threats to the self. He believes that a sense of optimism and control is important in buffering the patient's sense of self against such threats. As Alsop (1973 cited in Russell,1993 p.940) puts it, "... hope is vital and threads of illusion, however threadbare, should not be stripped away". This subjectivation in discourses of hope could be understood as being so significant that to challenge this positioning could be to threaten the patient's life itself (Hall,1989).

The ethical substance (Deleuze,1988) of self forming activities in discourses of hope is concerned with living a life with some kind of meaning and the belief in a future. The mode of subjection (Deleuze,1988) involves living the 'felt' body (Yates,1993) rather than biomedical representations of it, thus recognising oneself as a person who is living a life and capable of participating in a future. For Kevin, I think the self forming techniques (Deleuze,1988) in discourses of hope involved the practice of illusion. Rather than necessarily denying the pathology, the practice of illusion (Ersek,1992) involved alternative readings of the 'facts' that were presented to him that created the pathology as an absent presence. It was there in his body but it was not significant to his everyday experience of his 'felt' body. The symptoms that Kevin eventually experienced were interpreted as having multiple possible histories, and it was through these histories that he controlled interpretations of his body and his sense of self. The 'help me here' look was the signal for the 'private nurse' to help him draw this curtain of illusion over his body. The ultimate goal of these self forming activities was to avoid being 'set aside from the living' (Hall,1989) as a person who is beyond hope.

The 'prisoner of war' as the suffering patient

A sense of control over representations of the 'disintegrating' body was significant for Kevin in containing his life in a way that moved beyond the pathology. As the symptoms began to impact, he continued living his life by working out new ways to manage activities in spite of the pain and loss of function.

He set about finishing house renovation projects that he had begun before his illness, even though this sometimes involved hard physical work, and we had to figure out new ways for him to do things. He would plan to take his medication at times that allowed him to manage the pain of doing these things. He kept going to work until he was physically too fatigued to walk around the hospital. Even then, he kept driving the car until the pain became too much.

Having a sense of control over one's life and covering over the 'disintegrating' body were centrally important themes in Lumby's (1997) stories of women with life threatening illness. Like the women she describes, Kevin fought to maintain a sense of his own agency in his life; stubbornly refusing to give up doing things until the point that he no longer had the physical capacity to do them. It was during a brief hospitalisation not long before he died that he began speaking in metaphors about losing this sense of control.

Kevin had become very distressed about being in hospital. There were several events that occurred which I found troubling. One afternoon while an elderly male relative was visiting, Kevin said to him, "John, you must know how to get out of places like this. You were a prisoner of war". When I explored this comment with Kevin, he told me about a dream he had had. He said that he had dreamed he was on a train and the train was going into a tunnel. He told me how he had tried to get off the train but he couldn't and it was getting dark. He said he was afraid that the train was his body and that he was going into the dark and was helpless to stop this happening.

The metaphor of the 'prisoner of war' signified this loss of control. The use of metaphor is significant in producing interpretations of the body and illness. Through imagery and symbolism, certain aspects of experience are brought out into the open while others remain hidden (Malone,1999) and unspeakable. Metaphor institutes a resemblance between one story and another through a process of substitution, where the metaphor is used as a vehicle to move away from something, but at the same time retain the capacity to speak of it (Eco,1979). Speaking through metaphors of the 'prisoner of war' and the 'night train' allowed Kevin to tell the story of his sense of capture within discursive constructions of his body and sense of self as the dying patient. This imagery gave voice to this feeling of capture and suffering while allowing containment of body boundaries. I think this is the symbolic language Kubler Ross (1981) refers to in her story of the dying woman who used the image of flowers, which she said had been sent by her husband. These flowers signified the love and care she needed to cover over her loneliness and isolation when the stark reality of her situation was too much to bear.

In biomedical discourse, the suffering of the dying patient often goes unrecognised, beyond clinical understandings of physical pain. Suffering, as emotional distress seems to be something, which is outside the responsibility of healthcare practitioners. The discursive construction of the patient as an object of science privileges biomechanical interpretations of the body in a way that human responses to illness may be seen as residing outside this field of practice (Cassell,1991; Rabow & McPhee,2000). While it could be argued lay people may consider that the relief of suffering is an important aim for healthcare practitioners, actual teaching about this concept may be almost non-existent in professional education (van Hooft,1998). Discourses of suffering are derived from both religious and philosophical values, where it is understood as part of the human condition. Sacrifices are made in the name of one's country or God, and bravely borne by the suffering person (van Hooft,1998). Such constructions illustrate the tensions between biomedical, ethical and religious discourses where the meaning of events for this patient may have been overlooked as having significance for his sense of self.

The construction of meaning is important in integrating or bringing together a sense of the self, where goals that define and give meaning to existence are formed. We define ourselves through the self forming activities and goals, which are taken up in living. As van Hooft (1998) suggests the body is not simply a vehicle in which we live life, it is our expression of life. In this sense, the dying patient's suffering is connected with the loss of control over a sense of the self and the expression of life.

I thought it was time to get Kevin home again. I could sense that we were running out of time. He was becoming so fatigued that he found it increasingly difficult to avoid having diagnostic tests. He was particularly distressed one afternoon when I arrived back on the ward after lunch. The staff had taken him off to another department for a diagnostic test. I was surprised that this had been done. When I asked him how this had happened he said, "I was too tired to say no. It didn't seem worth the effort". While some of the care Kevin had received was very beneficial, such as intravenous anti-emetics, his presence on the ward seemed to invite intervention.

The more fatigued Kevin became during this hospitalisation, the less resistance he was able to offer against the pervasive diagnostic tests and examinations, which he had expressly stated he did not want to have. While the aim of healthcare with the terminally ill is to alleviate the patient's suffering, healthcare technologies remain central to the discursive practices of palliative medicine. These technologies may afford considerable relief to patients in the form of high-powered pharmacological approaches, and technical devices which simplify and improve the management of symptoms quite dramatically (Seely, 1999). However, the presence of such patients in healthcare institutions means that they are accessible as subjects of pathology within the discourse of the open body (Liaschenko, 1998).

The 'private nurse' as the body guard

It was the afternoon of what was to be Kevin's last full day in hospital. I was sitting by the side of his bed when a young doctor came in and sat on the edge of the bed. I can't remember exactly what it was the doctor had come in to see Kevin about, but I do remember the moment when he noticed Kevin's eye. I had noticed some changes in the way his eye looked the previous day but I had said nothing. I sat there thinking, please don't say anything about it to him, like you can have ten out of ten for assessment skills, but just don't say anything. In the next moment the doctor said, "Kevin, are you able to see normally out of your right eye?" and proceeded to assess his vision. "Your right eye does look a bit different to the other one. I think we should get some tests done just to see what's going on", he said.

This doctor was blissfully unaware that he had sailed into 'monster territory'. As I followed him down the corridor I thought about the ethics of what I was about to do. I had to explain to this doctor that Kevin had read about another patient with melanoma who had become blind as the disease metastasised. I knew Kevin was afraid of going blind before he died. I also knew that diagnostic tests would serve no purpose for Kevin, but at the same time I could not discuss this with Kevin because I knew it would distress him to bring it out into the open. The moment I explained this to the doctor, he saw what I meant and cancelled the tests.

I have no doubt that to have undertaken tests and examinations on this eye would have distressed Kevin by constructing clear lines between the pathology and changes in the appearance and function of his body. These inscriptions of his body, together with his increasing fatigue, signalled his going 'down hill', and I believe this connection would have destroyed the illusions he had built around his body. The diagnosis of further pathology in the eye was also significant in producing ethical tensions for the doctor, and for my own practice as the 'private nurse'. The doctor could not continue to look at the pathology, because the utility of this looking could not be supported in the patient's best interests. Continuing with the diagnostic tests to illuminate this pathology would result in the patient being used as a means to an end, that is, to satisfy the impulse of the scopic drive (Braidotti, cited in Grace,1997).

As the 'private nurse', there were also tensions between having access to readings of these pathological inscriptions, and my capacity to act on this knowledge, without Kevin's consent. In closing off this doctor's attempt to construct Kevin's eye within the discourse of the open body (Liaschenko,1998) I had developed a new discursive positioning as the 'body guard' where I patrolled the margins of his body to fend off incursions beyond the limits Kevin had previously defined. Such interference with the autonomy and liberty of another person is generally understood as paternalistic in the practice of professional nursing. In ethical discourse, paternalism is assigned a negative moral value unless significant benefit can be shown to result from such actions. Discourses of informed consent thus require "a heavy burden of justification" (Johnstone,1999 p.232) for such conduct. Begley and Blackwood (2000) argue that there are times when the withholding of knowledge about pathology may be justifiable in situations where such knowledge would significantly harm the patient's sense of self. While I believe my actions were justifiable in preventing harm to Kevin in his significantly vulnerable state, I think the ethical tensions in these circumstances were derived from the compulsion to look at and read the pathology. There does not seem to be any justification in looking at all if there is no contribution that this looking can make to the wellbeing of the patient.

And so I returned to Kevin's hospital room. Of course he was out of bed, looking at his eye in the mirror. "Do you think its melanoma in my eye?", he said. "Well, it could be", I said. "But then again it could be", as we began to play the ambiguity game, drawing the curtain of illusion over the pathology and leaving it to play on behind the scenes.

To be at home during that final week of Kevin's life did indeed feel as though we had returned to a sanctuary. The battles of the world carried on outside the door away from this private space, which we inhabited together. I think the memory of this feeling of sanctuary and intimacy was what I found so unsettling later when I watched the film *'The English Patient'*.

I think I will always remember the sensations of caring for Kevin during this time. He was still able to walk to the bathroom and enjoy long baths. As I washed and dressed him, I could read the inscription of the pathology on his body. There was a wound on his head that was not healing. His sclera had taken on a yellowish hue, as had his skin. I knew I was seeing the beginnings of liver failure and I also knew this meant he was dying. But our long days together were filled with quiet conversations about his comfort and the other immediate concerns of our daily lives. It was a time when I ministered to his body and his mind, smoothing over and compensating for the activities he could no longer undertake for himself. I took comfort from my own ability to touch and position his body in ways that supported his breathing and his comfort. I learned to respond to the specific ways he liked to have things done for him, as he thought out meticulous plans of action in moving and positioning himself.

This sanctuary was uncluttered and unfettered by discursive practices that drew attention to the pathology. The battle of the pathology had ceased as we worked in the discourse of the closed body (Liaschenko,1998) where 'felt' responses of the body were privileged. My 'secret' readings of the pathology were silent, and unspoken in the space between us. However, the day before Kevin died I found myself once again positioned in the role of the 'bodyguard' where I felt compelled to make a clinical decision in the light of my uniquely situated personal knowledge with him.

The nurse wanted to give Kevin an enema. He had been telling fibs about his bowel movements for a few days now. It seemed he had been found out. When he gave me the 'help me here' look, I was surprised by the intensity of my own response to this suggestion of an enema. It felt like that moment in the film 'Alien' when Ripley defends the little girl against the monstrous and fearful alien being. He was too fatigued. I knew it would distress him and cause him the most incredible pain. Who knew where the pathology had infiltrated and what his physical response might be to this procedure? I couldn't bear it. Even the thought of it tore me apart. "Over my dead body", I thought as I said, "I think Kevin's a bit tired for that today, don't you? I'll make sure he takes his medication tonight".

This narrative illustrates how the language of Kevin's suffering was silent within the discursive practices of healthcare. The secret language of suffering was communicated between us by the 'help me here' look, which drew me in to covering over his body, while simultaneously speaking in the discourse of bowel care. The risk rupturing the fragile fabric of Kevin's illusion and serenity through subjection to this procedure, that I knew had caused him so much pain before, was not something I was prepared to live with. There was no ethical dilemma for me in making this choice, even though his body became visible in my mind with images of bowel obstruction and surgical intervention. In my discursive positionings as the 'private nurse' the justification for this decision was simple. He was dying – soon. As the 'body guard' standing at the foot of his bed, my reading of his body constructed the potential for bowel obstruction as the lesser evil. The refusal to participate in this ritual of bowel care was derived from my recognition that intervention in the discourse of the open body (Liaschenko,1998) was futile and therefore beyond consideration (Cassell,1991). My promise to the nurse that Kevin would be a 'good patient' signalled the closure of boundaries and the strategic withdrawal of the body, knowing it would be only a matter of time. Looking back, I am profoundly grateful that I privileged the subjugated knowledge of Kevin's suffering, thus avoiding the indignity of being drawn into these discursive practices, which now had little meaning in the context of this patient's life.

Endings and beginnings, finding a path

I should have known when Kevin was going to die. I am sure he knew. The night before he died, he was reluctant to go back to bed. He just sat there hugging me with all his still considerable strength, saying, “I love you, I love you”, again and again. I was fooled by his strength and the fact that there were none of the changes that I had seen in other people who were dying. He simply went to sleep that night and when I woke beside him the next morning, he was still sleeping peacefully. I called a family member, who came over, because I had recognised some kind of change in him, but there were no Cheyne Stokes respirations or any other signs. Eventually, he simply stopped breathing. So quietly that we hardly noticed the change.

My prior experience with dying patients had allowed me to know when they were going to die and call relatives to the bedside. As the ‘private nurse’ I had positioned myself in the discursive practices of pathology and read the body for the impending signs of death. In doing this I covered over my personal and contextual knowing as a means of flight from what I did not want to see. Subjugating my own situated knowing allowed the covering over of Kevin’s impending death as something that I was unable to look at. But in retrospect, nothing could have prepared me for the moment of his dying.

Some time after Kevin died, I asked a family member to call the funeral director that had been chosen. The arrival of this funeral director brought a new phase – that of managing Kevin’s body through the rituals surrounding death. I remember sitting in a chair next to the funeral director, with family seated around me. We went through the formalities of arranging what was to happen next - making funeral arrangements. This seemed to be an enormous shift from my work just a few hours previously, when I had been caring for his living body. Within this shift in thinking, I worked hard to make connections with family and Kevin’s past, to plot a path through the intensity of these events and produce a plan that would be ‘safe’ for all of us. When it came time to move Kevin’s body, I felt a powerful moment of resistance. I knew I couldn’t be involved in moving his body. The vision of seeing his body moved would be too powerful. I remember looking at my hands and thinking that I wanted to hold the feeling of his living body in my hands. So other family members helped to move Kevin’s body, and this represented the moment of my separating from his body to keep this sense of being with him.

When I thought about my resistance to this vision of Kevin's body, I realised I had positioned myself in a way that signalled the closure of my work with him as the 'private nurse'. Newman's (1986) writing on expanding consciousness and pattern recognition helped to interpret the way I had taken up a new discursive positioning, where holding the pattern of Kevin's living body was a self forming activity in a discourse of life rather than death. I think the ethical substance of this new positioning was the recognition of this patterning of his living body in my hands and that this 'remembering' held was important in keeping my connection with Kevin. Living and dying became co-extensive in constructing this relation of the self to the self, where I simultaneously let his dead body go and 'held' his living body. In creating this space within myself to preserve the sense of his living body, I moved beyond the time of his death and constructed his life as part of, and co-extensive with, my own. The effect of this was allowing my relationship with him to survive as a way of mediating the loss of his physical presence.

I do not believe this way of mediating the experience of death should be read as denial or holding sameness in a static sense of time and space. I think I covered over aspects of Kevin's death as a way of moving into the future, while holding his presence with me. Shortly after he died, a friend sent me a message. It said, "*Where there is love, there is life, for love endures love remembers love survives*". I think this was very good advice from someone who had 'been there'. The reality of Kevin's death is something that has taken me years rather than months to negotiate - and to begin dreaming of him again. At first, I believe did protect myself from it. I took it out and looked at it a bit at a time, as I was able to manage it. As Hedtke (in press) suggests, had I subjugated my own responses to dominant discourses of grief and death I might have missed this moment? These dominant discourses insist on the separation of the living from the dead. The bereaved are encouraged to take up self forming activities such as saying goodbye to a loved one, and treasuring but not living the memories. They are warned of the potential to get stuck in the grieving process by fending off emotional responses that are too difficult to bear (Martocchio, 1985). Such modernist constructions privilege the idea of facing the reality of death, getting over the loss and

moving on (Vickio,1999 cited in Hedkte, in press), covering over and making illegitimate the continued presence of a loved one. It disallows the continuity of relationship, which does not necessarily have to die with the person (Hedtke, in press). As nurses, the critical engagement with alternative conceptual possibilities may allow us to form new discourses about how to speak of death and our own responses to it.

It is three years today since Kevin died. As I visit the cemetery and look towards the mountain in the west, I feel I have such a strong connection with him in this place. I know that I did everything I could have done to live this journey with him as we ran together in the dark. The artful practice so carefully and painstakingly crafted within and between the boundaries of our personal and professional lives, could only be seen in retrospect. Still, it is a good feeling. I now have a new life that I live, in a sense alone, and yet the relationship with him remains with me. And why should I want it any other way. For Kevin will always be a part of who I am.

Summary

Running in the dark is a metaphor, which relates how living with life threatening illness encompassed a journey through unfamiliar territory towards and 'unknown' destination. The mediation of body boundaries was a strategic element of containing the self; for Kevin as the 'cancer patient', and for my practice own practice in the discursive positionings of the 'private nurse'. Technological interventions and dominant discursive productions of the dying patient threaten Kevin's fragile sense of self by uncovering the cancer as the intimate enemy. The ambiguity game helps Kevin to mediate his body boundaries and contain a sense of self. This game of discursive disruption draws a curtain of illusion over his body, leaving the pathology to play on

behind the scenes as an absent, but querulous presence. The 'help me here' look draws the 'private nurse' into the discursive positioning of the body guard, who patrols the margins of the body in order to maintain the curtain of illusion. The metaphor of endings and beginnings describes the journey of the 'private nurse' through the discursive practices surrounding death and grief. The discursive positionings of the 'private nurse' are relinquished to recreate Kevin's life as co-extensive with my own in ways that allow my relationship with him to survive.

The following chapter on genealogies of practice forms the conclusion of the thesis. The genealogies of the thesis are discussed as paths that have been negotiated through the telling of the stories where the whisper of other voices appear at the margins, and through the gaps in the texts. The philosophical and contextual positionings of the nurse as a border traveller are explored in relation to the idea of the nurse as the specific intellectual. This is the thinking nurse, who critically engages with the experience of her/his own practice to form new discourses derived from local and contextual 'truths' about illness, suffering and dying. Finally, I consider the agency of nurses, and professional nursing, in bringing our practice into harmony with the discursive productions in the patient's local world are considered in terms of what might constitute ethical practice.

CHAPTER EIGHT

GENEALOGIES OF PRACTICE

Introduction

The discussion in this chapter forms the conclusion of the thesis. Writing an ending for this thesis is no easy task, as there are in a sense no endings to the stories that are related here, or to the multiple possibilities in the interpreting them. Rather than an ending, I offer some possibilities about how nursing practice with patients experiencing life threatening illness could be shaped in the localities of my own stories. The genealogies of the thesis are explored as the negotiation of paths and unfolding of ideas in relation to the stories and my reading of them, in relation to the literature. I explain the experience of reliving these private stories in the telling of them, and how the thesis weaves them into the fabric of scholarship. The idea of 'talking back to myself' is considered as the means to construct narratives of the self where my own voice shifts and changes in the text, and other voices whisper at the margins.

The philosophical and contextual positionings of the nurse as a knowledge worker are explained through genealogies of practice and the specific intellectual work of the nurse. The thinking nurse is a specific intellectual, who critically engages with the context of her/his own practice to form new discourses derived from local and contextual 'truths' about illness, suffering and dying. The idea of harmonising nursing practice with the self and the patient's local world through contingent and thinking responses, and the recognition of one's own agency as the nurse, are considered in terms of what might constitute ethical practice. Local and contextual epistemologies are explored as ways of theorising nursing practice through personal knowledge surfaced through the critical analysis of contextual positionings and the process of

writing as inquiry. The capacities for vision, that are developed through the stories in the thesis, are explored as having the potential to present new possibilities for the practice of professional nursing.

Negotiating paths through the thesis

My journey through the writing this thesis has been interesting. As the stories unfolded in the telling, I developed new relationships with my own experience through the processes of thinking, reading and writing as inquiry. Overall, I think I have had a good relationship with the stories through the telling of them. At the same time I have had to manage the tensions that have been produced in laying open such personal stories. I have surprised myself in undertaking this study as I have always thought of myself as a rather private person. In retrospect, I think it might have been easier to do a more personally distant study, situated within more formal boundaries of scholarship, rather than enduring the agonies on writing on the edge, doing what Bauman (1995 p.19) calls “one’s own untested project”. The agonies in such writing concern one’s own frail self esteem as an ‘untested’ writer who is as yet ‘unproven’, and the very real prospect of failing in such an undertaking.

And yet, I was always already situated in the parallel and intertwining journeys of academic work, professional practice and my private life. I knew this story of Kevin’s illness and dying, and my experience of being with him, would inform my thinking, reading, and writing in the years following his death. Writing this thesis as a method of inquiry has brought my reflection and thinking about these events into sharper focus than I think would otherwise have been possible. It has allowed me to create nursing knowledge as self forming activities in new discourses of academia and professional practice. I do not believe that undertaking this thesis has necessarily been therapeutic, as this would be to make it visible within the language of psychoanalysis. I think I began exploring this experience because I was curious about the ways people involved in events had responded, and the feeling that my previous academic work

had formed an important element of my own histories in these responses. In this sense, the thesis represents a means of expression for the 'private nurse', in speaking of and exploring events where there is a bringing together of my private relationship with Kevin and my professional practice as a nurse.

The contextual positionings of the study were developed through a substantial review of the literature. However, the exploration of the stories in the analysis led me to new writers as I searched for theoretical tools to make sense of events. Through this process of reading, writing and reflection, I found myself constantly drawn into new literature, which took me beyond the chapter on contextual positionings. There were times when I went back and wrote newly discovered authors such as Cassell (1996), Douglas (1966), Lupton (1994), and van Genep (1960) into this chapter. As the analysis progressed I began to think that this reaching out into the literature might be a part of the process of writing as inquiry. I was torn between letting the thesis unfold with these new references to the literature, which reflected the histories of its genealogy, and my desire to respect the conventions of scholarship. I think my 'walking through' this literature alongside my own reflections has extended my vision in ways that would have been impossible to predict in the original literature review.

While I struggled with some of the methodological considerations for the thesis, writing as inquiry was a familiar theoretical approach in my scholarship, and thus worked more easily within the thesis. The initial difficulty I had was in finding theoretical tools in Foucault's original writing to guide the analysis. There seemed to be some significant theoretical and methodological shifts from his earlier writing in *The Birth of the Clinic* (Foucault, 1975), and his later work on the genealogy of ethics (Foucault cited in Dreyfus & Rabinow, 1982) and techniques of the self (Foucault cited in Martin, Gutman & Hutton, 1988). His later writing on the genealogy of ethics seemed to provide some of the detail I wanted to use in undertaking my own analysis. Reading Deleuze (1988), Walzer (1986), Kendall and Wickham (1999) and Blacker

(1998) extended my understanding of Foucault's writing and seemed to provide some actual theoretical tools to work with.

The method of analysis developed through 'practising' it as the thesis progressed. I realised I was relying heavily on secondary sources and that my own interpretations, informed by the work of writers other than Foucault, may have produced some tensions with his original ideas. It was at this point that I stopped calling the study a Foucaultian analysis and began to write that the thesis was informed by ideas drawn from Foucault's writing. Perhaps I have paid too much attention to this detail of the theoretical basis of the thesis, and this may have constrained my voice and my thinking in the writing of it. As well, I am aware that I created a shift from calling the thesis research in my first conceptualisation and naming of it, to a knowledge based theoretical study centred on my own personal reflections. This shift has served to re-establish the discursive lines between what is considered formal research and practice knowledge, which could be considered as informal, private and outside the boundaries of academia. While I am complicit in re-establishing these boundaries, I believe this thesis represents a unique and valuable view of nursing practice and scholarship, and my accommodation in the naming of the thesis may serve to the avoid 'thorns' in it catching on the fabric of academia.

Narratives of the self

The process of 'talking back to myself' has involved positioning myself in discursive statements where I become visible with the inscriptions of the 'private nurse'. These positionings uncover my own voice as the self's relation to the self, as I undertake self forming activities in various discourses. The analysis has required a self-conscious awareness of the multiple possibilities being played out the context of particular moments in the stories. The analysis also offers readings of the histories of these possibilities, however I am aware of the tensions that arise in these readings where I have taken up contradictory discursive positionings. My reading of the possibilities

presented in these discursive positionings is informed by my own histories in terms of values, beliefs and cultural and professional practices. For this reason, I may have covered over other possible interpretations. I am also aware that other people who are excluded from the text or exist as nameless shadows at the margins of these stories. This exclusion represents one of the ethical tensions I have experienced in the thesis. I have been torn between wanting to situate the stories within the connections to people that were part of this experience, and the ethical requirement to protect the identity of these people. In a methodological sense, these people have been excluded from contesting my own interpretations of events, where the 'push and pull' of other interpretations may have supported the negotiation of alternative and richer readings.

I have worried about the implications of putting these stories 'out there' into the fabric of academia where they will remain accessible to whoever may want to read and engage with them. As I realise there is no possibility of taking the stories back once the thesis is submitted I worry about whether my interpretations are credible and if I have done the stories justice. I am aware of how I have been pulled into particular discursive frames in interpreting the stories and that both strangers and friends may read this work, and interpret these events differently. The writing of the stories has also involved reliving my experience of being with Kevin. I found this to be an interesting experience in that it was not entirely possible to predict my own responses before I experienced them. By this, I mean that I have found the reliving of experiences connected me to them again in the telling of them, and this reconnection felt good even when I had to take time out to carefully work through what I was feeling. I have found writing the stories much less arduous than managing some interactions with other people in my everyday life, where sometimes well intentioned people have attempted to draw me into events that are likely to surface feelings of loss. The difference in telling the stories in the thesis is that I have control over my own writing and how I wish to address an audience. I am able to write, or take time out from writing as I wish, whereas in my interactions with other people there is always the potential for coercion which might take me beyond my own desire to

speak of things. Within the thesis some events have been covered over because they were too private where the need to “mind myself” in the “aftermath” (Lightfoot,1983 cited in Clandinin & Connelly,1998 p.169) of the study through the setting of personal boundaries became an over-riding factor. For me there has been a very real tension between telling the stories as a means of informing nursing practice and the need to consider whether certain moments should be included from the conversation.

In relating intensely personal moments, such as the story of Kevin’s death, I risk trivialising profound aspects of human life, and yet this story uncovers something important for the practice of nursing. I could not have predicted my own response to this moment of Kevin’s death, where I chose to withdraw from my positioning as the ‘private nurse’. This withdrawal from the vision of his body could have been interpreted as lacking continuity with my prior work with him. And yet, my own unpicking of the genealogy of this withdrawal uncovered it as a means of holding myself together in a way that was continuous with his living body. Other discursive readings of this moment may not have recognised the self forming activities of my own unique positionings. There is also the potential for the discussion of private practice moments with health professional to be seen as appropriating their practice as a means to an end in telling the stories. However, I think the utility of these readings of Kevin’s responses, and my own, is in explaining the genealogies of these responses as the self forming activities of uniquely positioned subjects. The reader’s engagement with the reading of these responses may encourage self forming activities that take account of the patient’s histories and produce new possibilities for professional practice.

I am aware that this thesis has created Kevin’s story as my own, where he is present only through my interpretations of the text, which may or may not have been consistent with his interpretation. I have worked through the telling and analysis of the stories with a self-conscious awareness of knowing Kevin and have made certain assumptions about what may have been important to him. I have agonised over

naming Kevin in the thesis because this naming uncovers his identity and intimate details of his life. My decision to use his name was derived from a belief that the stories needed to be situated in the relationship between us to retain their “evocative power” (Ellis,1995 p.328) in drawing the reader into his/her own interpretations. In doing this I have risked using Kevin as a means to an end in writing the thesis, however I remind myself that these are also my stories of my witnessing and presence (Lawler,1997) with him. It is possible that fictionalising Kevin’s identity would have reduced his presence to that of an off-stage shadow, when for me he was a central actor in these stories who had a clear understanding of his own agency in keeping himself centre stage in his own life drama.

There is a further difficulty arising from this notion of ‘talking back to myself’, which concerns the drawing of conclusions from the stories. My thinking about this has been informed by my reading of Ellis’s (1995) story of her husband’s illness and dying where she shows how she struggled over ending and making sense of the events she had related. In the light of her discussion, I realise I cannot close the stories off by constructing themes or categories from the analysis as this would generalise the particular in ways that would be inconsistent with the methodology of the thesis. As Ellis (1995) suggests to me, this study cannot be wrapped up neatly. To some degree the stories need to be left in a state of open endedness where the reader is able to bring her/his own histories into making sense and meaning from them. Therefore, in this concluding chapter I have worked to bring together the context of events and my own interpretations of them, as the relations of the self to the self. In tracking the potential for movement within discursive positionings, I show how subjectivation occurs as an active process, which provides the means to transform the sense of self. The identity of the nurse can be seen as produced through doing nursing, where subjectivation is negotiated and contested through discursive formations, and certain authorities are taken up as the subject’s own concern within the immediacy of the local context of nursing practice.

Genealogies of practice

The stories related in the thesis are strategically important in unsettling the taken for granted and universally accepted practices in healthcare settings. The tensions arising from contradictory positionings for Kevin as the cancer patient illustrates how he brought his own genealogies to the discursive field of healthcare practices. The diagnostic inscription of cancer threatened to disrupt the boundaries between Kevin's positioning as the cancer patient and his practice with cancer patients in medical electronics. His new identity as the cancer patient collapsed the distance between insider and outsider positionings in the field of radiotherapy practice which kept health workers from being engulfed in the suffering of cancer patients. This story shows the unique demands for Kevin in taking up the identity of the cancer patient when some degree of distance from such patients was a central element in allowing him to undertake his own professional practice. The limiting of his scope of practice with cancer patients following his own diagnosis became visible as a distancing strategy in removing himself from the patients' location to do other work where the patients were not visible.

Kevin's history as the cancer patient marked him as a stranger. He was living life on the margins of normality, seeking readmission to his former life through his engagement with the discursive practices of healthcare technologies in the hope that his previously healthy and normal body would return. His histories of exercise and fitness and his own professional practice informed the ways he negotiated paths through the experience of life threatening illness. He created a new relation to himself through the self forming activities of health and fitness to strategically manage the telescopically visible shadow of disease in his body. In finding his own agency in living with the implications of the disease he became a "wilfully absent subject" (Hutchinson, 1997 p.41) of pathology. He ran after dark and out of sight of other people, in order to call himself into being as a healthy person.

The evocative power of these stories calls into question the procedural doing and established patterns of work in healthcare institutions, which does not take account of the histories of patients and other people involved in their care. Within the normalising discourses of health and biomedicine, the patient and the nurse participate in previously scripted and formalised healthcare activities. The formal prescriptions that are implicit in these normalising practices do not take account of the patient's agency in responding to threats to the self. Nor do they allow for the nurse's agency in crafting unique practices to meet the patient's specific needs, wants and desires. This 'blind' obedience to universally accepted practices refuses the agency of the patient and the nurse in forming new discursive positions, which may support ethically sustainable practices within the patient's local world. In uncovering the potential for the contestation and negotiation of discursive positionings, I make visible other possibilities for action in the formation of new discourses.

A more specific approach to nursing practice might take account of the 'microphysics' (Blacker,1998) of power in the production of subjectivity and the multiple and contradictory knowledge positions which discursive subjects may occupy. With this in mind, nurses need to consider how they represent the interests of the patient, in terms of whom they claim to speak for, and the theoretical ground on which this capacity to speak is based. In positioning ourselves within specific healthcare discourses, nurses should question the assumptions that they make in taking up particular knowledge positions in the light of what might constitute ethical practice in the patient's world. Responsible strategies for the production of knowledge are concerned with the critical analysis of the ways in which we have come to govern ourselves and others through our 'expert' knowledge and practice, which allows or denies certain knowledge as true or false (Blacker,1998). In finding one's voice as an intensely local knowledge worker, the nurse ceases to be an expert speaking about the patient's case. Instead, the nurse addresses the local and immediate effects of nursing practice, and other healthcare activities, within the patient's specific location.

Notions of what is ethical practice becomes negotiated and contested through local conversations which privilege the capacities of the patient and the nurse in taking up other discursive positionings as alternatives to those prescribed through the sovereignty of expert power. In the local and contextual world of the patient, visions for practice may be negotiated moment by moment through careful exploration of discursive tensions and the critical appraisal of the utility of alternative possibilities. This development of local knowledge relies on the ability of the nurse to explore and trust her/his own judgement and nursing responses in situations where visions for practice may not be clear. In 'un-picking' and 're-sewing' the stories related in the analysis of the discursive production of the cancer patient and the private nurse, it is possible to imagine new possibilities for the ethical substance of nursing. This ethical substance creates the potential for new conceptualisations of practice, where nurses and other health professionals take responsibility for the effects of their activities with patients. In this 'un-picking' of the stories, I am concerned with the discursive positionings that are taken up by the patient and the health professional in the story. I identify the means through which subjects become visible in discursive statements and the effects of these subject positionings on specific moments of practice with the patient. The 're-sewing' of events involves the telling of alternative stories, negotiated between the actors in the events, to produce a more ethically desirable outcome in the specific context.

I believe the doctor who revealed the implications of the pathology in a brief conversation with us, in that moment fractured the fragile fabric of hope that we had built around ourselves. It is possible that this doctor took up this disclosure as a self forming activity in the discourse of the open body (Liashencko,1998). The ethical substance of this discursive positioning may have been the recognition of himself as the 'expert' knower, in terms of seeing himself as responsible for ensuring that Kevin and I developed insight into this life threatening diagnosis. As we had never met him before, this doctor had little understanding of the genealogy of Kevin's and my own responses to this experience of life threatening illness, and therefore how we might

respond to the giving of this information. The disclosure of his readings of the pathology seemed based on assumptions about what patients should be told in these circumstances. Drawing the patient into this discourse of insight about his death did not consider the aftermath of giving of such information, because the patient's suffering was not visible as a professional responsibility in this moment. The inscription of the body with this map (Wellard,1998) of the pathology and its potential down hill (Froggatt,1998) trajectory felt inescapable and intensely frightening. As the patient, I think Kevin became a bystander in drama of own life, and in this moment, his capacity in finding his own path through the experience was denied.

Other possibilities for practice in this moment need to take account of suffering in response to threats to the self (Cassell,1991) and control over representations of the disintegrating body (Lumby,1997) as important elements of the patient's agency. When the patient's body is constructed as an object within discourses of biomedical science, suffering moves beyond the sayable as it is simply not visible in discursive readings of the pathology. An alternative story might see the doctor introducing this patient to others who have similar diagnoses, either in person, or by telling their stories. Such stories could include discussions about how some people have lived with the same illness for long periods of time. As well, stories about other patients who have died soon after diagnosis or have lived for a longer time would fulfil the obligation to ensure the patient does recognise that the disease could result in death. The telling of these stories would leave the interpretation of the pathology with the patient to make sense of it in the location of his/her own life. In bringing suffering into the light of professional practice, the aftermath this telling of bad news becomes visible (Cassell,1991) as something the patient and the health professional negotiate through engagement with one another. The patient retains the capacity to be the central actor in his life and the doctor becomes the story teller who opens up various possibilities for the patient to create scripts for his/her own drama.

The moment when the 'private nurse' became the bodyguard is useful in illustrating how resistance may constitute ethical practice through the telling of an alternative story. The doctor's desire to carry out diagnostic tests on Kevin's eye shortly before his death was located in the discursive reading of the body for the presence of pathology. As the 'private nurse' who was living this illness with Kevin, I recognised the potential for the examination of his eye to uncover the pathology as a threat to self in the form of blindness. The doctor was located in a different story where the examination of the eye would be considered as ethical practice in identifying disease in order to re-institute the normal functioning of the patient's body. What the doctor did not see was the potential effect of the threat to self for Kevin in uncovering the pathology when there was no hope of cure. My resistance in this moment was concerned with the ethical utility of the doctor's proposed actions when he had not recognised the suffering such an examination could create. When I invited the doctor to participate in an alternative reading of the story of the eye and its connection with blindness and terror, the patient became visible in new ways. I had encouraged the doctor to take up suffering as the 'thought of the outside' (Deleuze, 1988) which made his prior prescriptions for practice unsustainable. The doctor's new discursive positioning privileged suffering over intervention through this shared reading of Kevin's histories in relation to his own.

The story of the eye shows how attention to the events in the local world of the patient requires an unpicking of the structures, which support the knowledge that participants bring to events. In the busy doing of everyday work, procedures such as investigating the pathology of the eye become so familiar and prescribed that health professionals are often unaware of the knowledge informing their practice. We may not consider what we know, or how we have come to know certain things in our practice, because the discursive positionings we engage in make these practices invisible to us. Paying attention to the detail of events through the stories that patients and others involved in their care might tell, supports the blending of the fine detail of personal experience with the straight seams of professional knowledge and practice.

The contestable readings of events and the construction of new discursive positionings with the patient may sustain a vision of ethical practice where the nurse works to support people to live their lives with the capacity for action and choice.

The ‘thinking nurse’ as the specific intellectual

The discursive analysis of nursing practice in this thesis uncovers the light and language of nursing in the present moment. It makes visible our capacity for resistance and the possibilities for entry into new discourses. As subjectivity is formed through multiple and contradictory discursive positionings, the nurse comes to see what can be done, what s/he knows and thus who s/he is. The analysis of the stories in this thesis shows how nurses may bear witness to, and participate in, the production of new subjectivities (Deleuze,1988) in local sites of practice with the patient. The ethical substance of the ‘thinking nurse’s conduct with the patient, and others involved in his/her care, is concerned with the specific rather than the universal (Blacker,1998). The part of our conduct that is relevant for ethical judgement is the nurse’s practice with the patient. For the ‘thinking nurse’ there is a critical self awareness of the scope of the practice environment and what is happening within it. This ‘thinking nurse’ recognises how healthcare institutions work as sites of knowledge production and the impact of such knowledge in the place where patients and nurses interact with one another.

The ethical substance of my practice as the ‘private nurse’ can be seen in my refusal to accept a six week wait for a consultation when I knew surgical intervention should be undertaken at the earliest opportunity. It is also visible in my practice with students where I set boundaries around my private experience of living with life threatening illness to avoid what I considered pollution behaviour in the classroom. Negotiating discursive productions of the dying patient in playing the ‘ambiguity game’ shows how I recognised that formal representations of grief and loss were insufficient to manage the complexities of my situation with Kevin. His refusal to look at

representations of the pathology or to speak about dying challenged my own thinking in a way, which led me to consider other possibilities for ethical practice with him. A further example is illustrated in the moment when the nurse wanted to give Kevin an enema the day before he died. The ethical substance of my positioning in a discourse of suffering made this practice unethical, as Kevin's suffering became visible.

The mode of subjection for the 'thinking nurse' is concerned with recognising his/her relation to the rules produced by discursive statements and how the nurse chooses to position him/herself as obliged to put them into practice. The mode of subjection for the specific intellectual is harmonisation (Blacker,1998). The nurse brings his/her ways of speaking and acting into harmony with the patient's location, paying attention to how particular interests are represented in discussions about the patient's care. There is a concern with whose interests are represented and how the nurse's ways of speaking and acting are implicated in constructions of the truth. Emancipatory practice occurs through the shifting of the ground of knowledge where there is the thought of the outside (Deleuze,1988), which is the moment of resistance. The nurse's attention is directed toward the power/knowledge arrangements in the locality of practice with the patient, and how these arrangements of power create obstacles or enable capacities.

The mode of subjection is visible in my practice as the 'private nurse' in my moment of refusal of the receptionist's appointment time when I already knew there were other possibilities. With the thought of the outside, which produced the possibility of new discursive positionings, this wait of six weeks was open to challenge. The seepage between my work as an educator and my positionings as Kevin's wife and nurse also produced the thought of the outside as resistance to biomedical constructions of life threatening illness. My former use of singular and overarching biomedical metanarratives became insufficient in my teaching because of my new awareness that they failed to represent the concerns that patient's might have in his/her experience of illness or trauma. This approach had also disallowed recognition of the local and

immediate capacities of both the patient and the nurse in choosing their own uniquely situated ways of participating in healthcare activities.

Kevin's refusal to look at the implications of pathology also challenged my previously taken for granted assumptions about how patients ought to respond to situations where their lives are threatened by illness. These assumptions were also derived from my own positionings in dominant discourses, in this case metanarratives of grief and loss. The 'ambiguity game' is an example of an attempt to harmonise my practice with Kevin's location. I recognised my own relation to the rules produced by discursive statements as the need to support Kevin's capacity to interpret knowledge about his illness in ways that enabled representation of his concerns. I think the motivating factor for me as the 'private nurse' was to help Kevin maintain a sense of integration of self that included hope for the future. The confrontation of his own erasure in conceptualising his own death may have constituted unethical practice with him in disallowing his capacity to create his own understandings and responses to this illness. My refusal to participate in the discourse of bowel care with the nurse is a further example of how I recognised my own subjectivation in a discourse of suffering. This recognition of the potential for a procedure to cause pain and distress in circumstances where there was little positive effect to be gained for the patient. This refusal illustrates how the discursive statements of suffering informed my thinking about what constituted ethical nursing practice in this moment.

The self forming activities of the 'thinking nurse' include attentiveness, honesty, and competence as the means of ethical self transformation (Blacker,1998). The self forming activities of my practice as the 'private nurse' show how I paid careful attention to the detail of the Kevin's location. I attempted to make my own practice ethical through debate, negotiation and accommodation of activities and outcomes for nursing care with Kevin, and with nursing colleagues who were involved in his care. In attending to what concerned the patient, I critically evaluated the utility of knowledge in the light of its history of production (Deleuze,1988). I engaged with the

multiple possibilities derived from different theoretical positions, and from my own practice experience, but remained suspicious about the potential effects of knowledge within Kevin's unique location. The practice of honesty involves a critical self awareness of one's own ways of understanding and living in the world and the recognition of alternative ways other people may choose to respond in particular circumstances. Critical self awareness also concerns the careful consideration of the effects of one's own professional practice, in terms of how others are affected by the activities we undertake.

Competence is the skilful practice of nursing where the nurse moves in concert with the patient, offering nursing responses negotiated within the patient's circumstances. The nurse may create a new category for the patient as the 'special case', as I did in approaching the surgeon to ensure Kevin did not have a six week wait for a consultation. As the 'special case' I moved Kevin's positioning as the patient within the institutional practices of the healthcare agency, to accommodate his specific needs and interests. The ability to undertake this re-categorization relies on the recognition of the nurse as a competent and respected practitioner, especially by other bearers of power. The use of alternative networks of power is derived from the nurse's ability to use power as a means to call others into being with new discursive positionings. The ability to use formal and informal communication networks facilitates access to people who are bearers of power in the institutional networks. The recruitment of such people to the cause of the patient may allow the nurse to move things in a new direction in the interests of the patient. The 'thinking nurse' also utilises theoretical tools drawn from multiple locations through rigorous engagement with the published literature. As well, the critical consideration of my own professional histories with patients in similar circumstances, surfaced personal practice knowledge which was important in finding local solutions to local problems.

The goal of these self forming activities of the nurse, as the specific intellectual, is self mastery over one's own practice where the nurse takes responsibility for the

effects of his/her conduct with other people. Self mastery involves attempting to regulate the entry of self into discursive practices by paying serious attention to one's own professional world and being committed to self conscious practice (Blacker,1998). It also concerns the use of self as a conduit for power where nurses emancipate themselves in their practice with patients through their capacity to recognise, move within, and use networks of power. Such activities require the nurse to be politically astute in knowing when to make oneself visible as the speaking subject in challenging institutional practice which deny the patient's freedom, and knowing when to work behind the scenes in covert action. I believe nurses become nurses by acting with the recipients of healthcare in order to move themselves and their patients towards wellbeing and the freedom to live life on one's own terms. In taking the centre stage in the drama of their own practice, nurses may find a 'will to power' (Foucault,1979) and the means to work in ways that are emancipatory.

I do not believe the idea of the 'thinking nurse' as the specific intellectual necessarily offers new ways of working for experienced nurses, as I think elements of this approach were always/already visible in my practice with Kevin. It is also possible that local and immediate ways of working with patients were already present in the other histories of my practice, and I believe I have also seen them in the practice of other experienced nurses. I think there are reasons why nurses choose not to work in these local and specific ways with patients. While local responses may best support ethical practice in the patient's location, economist and legalistic notions of what constitutes nursing practice may drive the normalising practices in healthcare institutions. The 'thinking nurse' may be situated in a turbulent space between these normalising practices and the patient, where the nurse negotiates a path between the patient's interests and those of the institution. The creation of new discursive positionings for the nurse as the specific intellectual invites the nurse to engage with the patient in ways that may challenge previously held assumptions about what constitutes ethical nursing practice.

Harmonising nursing practice with the self

Blacker (1998) explains the ethical substance in the work of the specific intellectual as bringing one's practice into harmony with the location in which one is working. This harmonisation involves the recognition of the agency of the nurse and the patient in performing discursive positionings, where identity is formed through the 'doing' of subjectivity. Developing local responses to local problems in practice creates the nurse in new ways, which challenge how the subject is always/already positioned in other discourses. Choosing paths for practice in the unique circumstances of the relationship with the patient is likely to produce discursive tensions for the nurse. In creating the patient as the 'special case' the nurse may occupy a liminal (van Genneep, 1960) space with the patient. While this positioning may offer new capacities for practice by producing the ability to 'move things about' for the patient within one's own knowledge and networks, this liminal space may also be a dangerous place to stand. It makes the nurse visible as resisting the normalising practices which produce the classification of subjects within healthcare institutions.

My practice as the private nurse brought together my professional knowledge and experience with my private positioning as Kevin's wife. In this space, my vision for appropriate responses in the context of our lives extended beyond the usual capacities of the nurse in relationships with patients. This vision enabled me to harmonise my practice with Kevin's location through my personal relationship with him, however it also produced my positioning in a liminal space 'betwixt and between' the boundaries of public practice and private life. My presence was not signified with the authority of the professional nurse employed by the institution. Rather it relied on my prior status as the professional nurse, which was open to challenge in these circumstances. The covering over of my private body through professional practice was a means of harmonising the self's relation to the self by participating in discourses which made my presence visible as the professional nurse rather than the wife. My participation in a discourse of endurance avoided the possibility of having to confess my private

feelings to other nurses when such disclosure would have exposed my own vulnerability. Covering over the private body avoided sympathy from other nurses, which would have been unendurable as the wife. Thus harmonising practice with the self sometimes involved denial of other discursive positionings in the public theatre of healthcare. My personal performance as the wife was played out in private spaces with Kevin and other people whom I trusted.

My refusal to position myself in a discourse of confession also signified my reluctance to participate in metanarratives of crisis and crisis intervention. For me, harmonising practice with the self required openness to multiple possibilities for discursive movement and the capacity to respond 'in the moment' according to what felt appropriate for me in the circumstances. This represented a refusal to subjugate my own knowledge and experiences to the prescriptions that my participation in expert psychological discourses would have produced for my own responses. My mode of subjection in the discourse of enduring was the belief in my own ability to choose ways of living through, and expressing the threat to Kevin's life and the impending loss of our relationship. The desire to care for him was derived from the histories of our relationship and my recognition of his suffering. My participation in the discursive practices of professional nursing provided a means of containing this threat to self, which the loss of the relationship signified. The self forming activities undertaken in the discourse of enduring mediated the boundaries of my private body and harmonised the self's relation to the self by avoiding interpellation as the feeling subject. The goal of these self forming activities of boundary containment was self mastery over the expression of my own feeling responses.

Harmonising nursing practice with the self involved doing what was consistent with the recognition of my own capacities produced through my unique discursive positionings. However, these positionings were fragile in that it was sometimes difficult to hold my own performance together in the face of boundary transgressions into the space of my 'private body' by other nurses. Some nurses attempted to create

distance between the personal and professional aspects of my performance as an actor with multiple parts in this script for professional practice. It is possible that the nurses, who reminded me that I was Kevin's wife and not his nurse, were operating in a discourse of protection, which clearly demarcates space between the clinician and the patient. This demarcation equates distance from the patient with rationality and the ability of the nurse to make objective judgements about how s/he will undertake professional practice. My presence as the professional nurse and wife was ambiguous because it threatened these systematic and hygienically ordered relationships (Douglas,1980/1966) within the normalising discourses of the healthcare institution. It collapsed the space between the nurse and the patient in a way that denied the potential for clean professional boundaries and objective judgements about the patient's case.

However, one may argue that the professional nurse always/already exists in an ambiguous position in the nursing relationship with the patient and that the notion of clean boundaries is a fiction. The collapse of social space is a critical element in the development of closeness (Savage,1997) between the nurse and patient, where the occupation of common space through the 'doing' of nursing activities requires some degree of emotional investment by both participants. Boundary containment is an important strategy in holding the nurse together in an emotional sense, to avoid being engulfed in the patient's suffering responses. The agency of the nurse lies in the capacity to move between distance and closeness, and engagement and disengagement with the patient. This movement enables the nurse to harmonise her/his own responses with the possibilities presented in moments of engagement with the patient. Discourses of protection legitimate the domination of people who are constituted as too vulnerable to make decisions for themselves (Yeatman,1994). While there may be times when the protection of vulnerable people to avoid harm does constitute ethical conduct, it also denies the capacity of the nurse to make expert scientific care continuous with personal care and intimacy. It denies the unique potential for the

nurse to work in ways, which skillfully negotiate the boundaries between professional and private bodies.

The demarcation of boundaries between professional practice and private life creates space between the inside and outside of public and private bodies. However, this inside always/already co-exists with the outside, denoting a relation of continuity rather than separation. This conceptualisation of continuity enables movement through the inside to the outside of what is classified as professional or private without leaving the inscriptive surface of the body (Groz,1994). Harmonising practice with the self involves working between containment and loss of containment of emotional boundaries. The nurse binds these seemingly different elements by freely choosing to invest emotional energy or not. The bodies of the patient and nurse enter discursive fields in ways that are continuous and yet retain the capacity for disengagement. This disengagement is important where extremes of human experience with life and death (Welch,1997) are encountered by nurses in their everyday practice with patients. The permeability of body boundaries creates the potential for the nurse to witness the wounding of the patient (Liaschencko,1998) in ways that may surface the abject, as the nurse senses the mortality of her/himself and the patient.

The vision of the patient's wounded body is an effect of power (Deleuze,1988) in the form of the abject. The covering over of the patient's wounded body in these abject moments is also an effect of power, which contains the nurse's own emotional distress. In this way, harmonising practice with the self involves negotiating the tensions between caring for the patient and the strategic management of the nurse's own emotional responses. The ethical substance of the nurse's positioning across discursive fields of care and abjection is an effect of how the nurse comes to recognise her/his responsibility to intervene in the patient's situation. This recognition informs the ways in which the nurse locates her/himself in the patient's context as a person who possesses the necessary capacities to intervene effectively to relieve the

patient's suffering. Intervention in the patient's situation becomes something the nurse does as a way of bringing her/his own values, beliefs and practice into harmony with the self through nursing activities.

Surfacing local and contextual epistemologies for nursing practice

Harmonising practice with the self is the effect of seeing and speaking (Deleuze,1988) in the locality of nursing practice with the patient. The nurse becomes the nurse as s/he constitutes the self's relation to the self through doing the activities of nursing practice. The stories I have told of my practice in the thesis records these processes of subjectivation and thus the conditions, which govern how, the relation to the self constitutes nursing. Writing and talking about nursing practice situates the nurse within specific contexts where the construction of subjectivity occurs through the interlacing of power between the sayable and the visible (Deleuze,1988). It is this space between the sayable and visible that creates the unique capacities of the nurse to practice in the light of local and contextual knowledge within the patient's situation. Writing the histories of my own nursing practice using genealogical methods of inquiry has surfaced these local epistemologies of practice. Harmonising practice with the self is an effect of recognising this local knowledge, bringing professional interpretations into harmony with it, and being concerned with the effects of nursing practice for the patient and oneself.

For me, one of the most challenging aspects of harmonising practice through this recognition of local knowledge was managing my own responses to Kevin's interpretations of the pathology. In particular, this concerned his desire to 'pass himself as normal' by covering over the Otherness of his body. I had to come to terms with his responses in the light of my own knowledge of the disease and the prediction of death I knew it held. The ethical substance of harmonising practice with the self involved my belief that Kevin should live his life in ways, which were consistent with self mastery in his relation to himself. This self mastery included having some control

over interpretations of his body and the freedom to choose how he would live his life in relation to these interpretations. My own self forming activities in the light of this local knowledge necessitated managing the tensions between my professional knowledge and Kevin's interpretations of his body. My ambivalence about holding this knowledge about his impending death, and remaining silent about it, was mediated through my recognition that speaking of pathology and death would constrain Kevin's capacity to respond to these events on his own terms.

The techniques of self I employed to mediate this ambivalence included playing the 'ambiguity game' where I offered multiple representations of the symptoms of the disease to bring out the possibility of local interpretations beyond the dominant discourse of pathology. In surfacing local epistemologies to inform interpretations of these symptoms, I satisfied my own desire not to withhold information from Kevin. At the same time, I ensured he retained the capacity to undertake self forming activities in ways, which supported his ability to harmonise his relation to himself. In destabilising the metanarratives underlying representations of his body as pathological, I supported Kevin's potential to call himself into being through discursive positionings affording new capacities for self-interpretation. His choice to 'curtain off' the view into his body was a self forming activity where he merged 'fiction' and 'reality' to construct new stories about his relationship with his body. My desire to respect Kevin's unique ways of situating himself in relation to knowledge about this illness challenged my positioning in professional discourses on death and dying. This challenge moved me to the recognition that metanarratives offering normalising prescriptions for patient's responses to such situations were insufficient to support nursing practice in the context of my relationship with Kevin.

I began to read Kubler Ross' (1969) writing in new ways, which led me to an understanding of her ideas as literature rather than as an empirical model. This recognition surfaced my own capacity to engage with her profoundly moving stories and move beyond my prior understanding of her writing as a model which factually

represented the stages of dying. Instead, I read the stories in the light of their connection with my own experience and the implications they held for my understanding of the events surrounding Kevin's illness. In one story, Kubler Ross (1969) relates how a dying woman used denial as a means of alleviating her own suffering and loneliness. The woman did this by imagining that there were flowers in her room sent by her husband. It was the situatedness of local this knowledge that connected with my own experience and showed me that this understanding of denial as a means of harmonising the self's relations to the self was always/already present in her work. My reading of secondary and abbreviated sources of her writing had covered over the genealogy of these concepts, which I now see in her interpretations of patient's stories and her own experiences. The tensions between my own location and theories of death and dying were mediated by the potential for new self forming activities that became visible through the unpicking of this genealogy.

My prior experience of moments when I had collapsed the boundaries between professional practice and personal relationships had always/already created a subject positioning that encompassed both. In the therapeutic space, which developed between Kevin and I through living this illness together, these local epistemologies of practice informed my responses to him. My memories of performing a venepuncture on my own child in the emergency department surfaced in my practice with Kevin as the thought of the outside (Deleuze,1988), which was already a point of resistance to the restraint of my discursive positioning as the patient's wife. My recognition that Kevin wanted me as the professional nurse as well as his wife was the ethical substance for the construction of my subjectivity as the private nurse. The thought of the outside (Deleuze,1988) was the power or interlacing between the visible and the sayable for the discursive construction of the private nurse. It provided the capacity for me to move beyond the call of normalising practices, which separate public caring from the private caring within family relationships.

My recognition of Morse's (1996) concept of enduring as having resemblance to my own experience provides a further example of how literature may inform local epistemologies, through the significance of a story in one's own location. I recognised the story Morse (1996) tells about the patient's wife outside the intensive care unit who is existing intensely in the present because she is unable to look into the future. My recognition of my own positioning in relation to this story was profound. My response to it shows how other people's stories may be taken up as local epistemologies when they connect with our own stories. It was a moment when I responded to 'the visceral with the visceral' in situating myself with this woman in the story. This recognition of my own positioning provided a way of making sense of my relation to the self as the patient's wife, where I needed to keep myself together in order to get through these events. It offered me the discursive positioning as the 'enduring' wife where I was able to live through my own suffering, which I expressed in my practice as the professional nurse. Enduring, as a local epistemology, made the constraints of discourses of protection and control both useful and problematic. Protection of the self and control over my own expressions of suffering were an important element of my own self mastery. At the same time, the protection or control exercised by other nurses on my behalf was sometimes constraining, because it lacked connection with my own responses. They were, in this sense, unable to read the story of my movement and suffering through these events, and because of this, there were no conversations about how we might engage together.

Exploring the light and language of nursing practice

As Maeve (1994) suggests, telling the stories of our work with patients is a time-honoured tradition in nursing. It is the space where we create nursing practice knowledge in telling the stories of what we do and who we are. Through these conversations about nursing practice, we create visions of possibility, connecting ourselves with our past and envisioning possibilities for our future. This thesis represents a place where I have brought moments of nursing practice into the light of

this conversation. In laying out the stories of my practice with Kevin through this experience of life threatening illness, I have explored the paths I have chosen to follow and the ways I have constituted myself in relation to them. These explorations began before I had thought of writing the thesis. They are present in the journals I wrote at the time these events were unfolding.

The local epistemologies that surfaced through this experience have informed my teaching practice. This local knowledge about my practice has surfaced through my writing of events, both at the time they happened, and in the analysis of events through the thesis. While I do not speak of my personal experience with students in the classroom, this knowledge profoundly influences my teaching practice. This influence was first apparent in the way I felt drawn to epistemologies which surfaced the patient's experience of illness and trauma in my teaching of acute care nursing. It uncovered the possibility of multiple ways of knowing and experiencing healthcare events, which moved me beyond the metanarratives of the biomedical model. My own local epistemologies made biomedical constructions of the nurse and patient insufficient to explore what I now saw as a multi-faceted experience.

My own experience has also profoundly influenced my teaching practice with undergraduate students and registered nurses in nursing knowledge classes. Looking back through my journals and my notes for these classes, I can see how I have encouraged both new and experienced nurses to tell the stories of their practice and their lives in the classroom. This classroom has become a conversation space where I encourage students to see and feel the light and language of their practice. As I listen to these stories I hear the genealogies which form the students' practice, and see how they are both constrained and constituted with capacities through the self forming activities they undertake in their practice. As I work with the students, I encourage them to explore the ethical substance, self forming activities, and techniques of self which are embedded in their stories and to consider the outcomes of their practice for their patients and themselves. At the same time, I encourage them to explore the

genealogies of nursing theories to consider the significance and utility of empirical models and literature in the locations of their own practice.

In speaking about their own practice, I believe these students come to understand what holds certain knowledge about nursing in place, in theory and in practice. They are able to explore the genealogies of their own assumptions, especially in terms of how their participation in the discursive practices of healthcare create these assumptions. Through these conversations about nursing practice, it is possible to see both the utility and limitations of formal theory, and to locate nursing knowledge and clinical decision making within the relationship with the patient. The processes through which we form ourselves as nurses become visible as the active participation in practice with patients. At the same time, it is possible to recognise the implications of nursing practice events for our relation to ourselves as nurses, and for the patient's life. These implications also concern the need for nurses to consider the effects of telling our own stories, for both the others and ourselves, who are situated in them. There is a need to care for one another, in the process of this telling, and the potential aftermath of it.

Envisioning possibilities for further inquiry

The journey through my husband's illness and dying related in the thesis illustrates the tensions between the multiple and contradictory discursive positionings in my work as the 'private' nurse. The capacities of the nurse to engage in contextual responses in the immediacy of the patient's situation are developed through the stories in the thesis. The exploration of these stories where I am positioned as the 'private nurse' show how it is possible to present new forms of inquiry into the practice of professional nursing. Having undertaken this inquiry, I now see the potential for other explorations into the ways other patient's have experienced this journey through life threatening illness. Writing this thesis has challenged my own prior assumptions about the ways in which patients experience life threatening illness. I am now less

likely to make assumptions about how patients should respond in the light of knowledge derived from grand theories of grief and loss, and death and dying. Furthermore, I am interested in how registered nurses might engage with, and make sense of, their own experiences of working with these patients.

While my own experience of caring for my husband informs my thinking about how patients might respond, I now realise that their responses are likely to be much more unique than I had previously imagined. I think it is important to explore the situated and unique responses of people who experience these events, where patients tell their stories of what it is like to be diagnosed with a life threatening illness, and how they live their lives with this knowledge. A further inquiry could explore how patients construct themselves in relation to such an experience, according to their own values and beliefs about themselves and their lives. This inquiry could explore the subject positionings that patients take up and perform in the discursive practices of healthcare, and the genealogies of patients' responses to specific knowledge about their bodies. This would make visible the ways in which patients develop and employ strategies to mediate body boundaries and the self's relation to the self, and show how they engage with health professionals through this experience of life threatening illness. Patients' stories of life threatening illness would illustrate how they negotiated their relationships with healthcare technologies and how they interpreted and managed such relationships. An inquiry guided by the methodological approaches in this thesis would extend my own exploration of the patient's subjectivation through the experience of illness and healthcare interventions. It may also challenge my own interpretations of my husband's experience, and highlight the multiple possibilities and alternatives in the unique responses of other people.

I think it is also important to consider the experience of nurses who care for patients in the circumstances of life threatening illness. Given my own struggle to understand and work with my husband's unique ways of negotiating life threatening illness, I am interested in how patients and their families become visible to nurses within the

discursive practices of healthcare. How do nurses work to mediate the boundaries of relationships with patients and families in these circumstances, and how might they manage the aftermath of such relationships in the self's relation to the self? What does the relationship between the nurse and the patient look like when the nurse acts as the specific intellectual? How does this relationship work? How does the nurse read the patient's genealogies and how does the nurse respond to the patient and family? What self forming activities do nurses undertake in response to readings of the patient's body? What is the ethical substance of the discursive positionings, which the nurse takes up, and how are the goals of the self forming activities of the nurse contingent with the goals of the patient? What histories can be seen in stories of the nurse's practice and the patient's responses? How does the nurse negotiate with colleagues and other health professionals to move things about in the patient's interests? What are the professional, ethical and legal implications of the nurse's work as the specific intellectual when moments of refusal manifest as resistance? How does the nurse manage the turbulence and danger of practice in this space with the patient, when ethical nursing practice invites resistance to institutional practices? What are the implications of resistance for the nurse within the normalising practices of healthcare institutions? How do nurses recognise and practice their own moral agency, and what are the ethical and professional limits of this agency?

An analysis of nursing and other professional texts relating to life threatening illness would examine representations of life threatening illness in the published literature. The data used to create such texts could include the published writing of nurses on cancer as a life threatening illnesses, and texts from other professional disciplines that are used as authoritative sources of knowledge for nurses. As well, nurses' written narratives, about the experience of caring for patients with cancer, could provide access to 'unauthorised' local and contextual histories, which are not visible in the published literature. A life history approach may be useful in making visible the patterns and effects of caring over significant periods of the working life of a nurse, especially in terms of patterns of engagement and withdrawal from caring work.

Artifacts and artwork that depicts the experience of nursing and nursing relationships at the historical locations of nurses' narratives could also be useful. Such artifacts would allow the representation of cultural practices and social and health policies, which have affected the practice of professional nursing in New Zealand at given historical points in time.

The methodological approach could draw on the contextualising method of data analysis identified by Jaques (1992) in his study of nursing practice. The data collected in this study could be 're-interpreted' using the following approaches. The study could situate representations of nursing practice and nursing relationships within the context of New Zealand healthcare settings and values and beliefs about who nurses are and what they do. It could involve an exploration of the production nurses as discursive subjects through textual analysis, and compare the representations of nursing relationships within these texts. The data analysis techniques for this research would include reading between the lines to ask what makes the text possible, and identifying discursive practices within particular historical and contextual locations. Other data analysis techniques would involve making connections to other discourses, seeking points of discontinuity in the use of representations in particular discourses, connecting the discontinuity with changes in other discourses, and seeking the different entities populating the different discourses. The goal of this analysis would be to show how ways of talking about nursing practice and nursing relationships constructs how they are seen to exist, and to explore representations of 'normal' experiences with nurses as participants in healthcare practice.

My journey through the writing of this thesis has also made me think about how other women who are nurses might understand this experience of being both wife and nurse with a partner who has a life threatening illness. An exploration of how other women negotiate and live with this experience of working within and between the boundaries of their personal and professional lives would extend my own analysis, by surfacing

possibilities for other uniquely situated responses. I would like to understand how other nurses might negotiate and accommodate subjectivities within the multiple discursive positionings of wife and professional nurse, and how they recognise their own agency in taking up particular ways of acting. A further element of this inquiry could develop Ellis' (1997) idea of evocative autoethnography as a method to consider how nurse/wives reconstruct their lives following the death of a partner. In particular, the effects of discursive constructions of grief, loss, bereavement and widow-hood could be explored in the stories told by the surviving partner, and considered in relation to the unique capacities that these women may represent in their own stories of survivorship.

Summary

The philosophical and epistemological positionings of the nurse a specific and local knowledge worker have been explored through the analysis of stories in this thesis. The negotiation of paths through the thesis has taken me on journeys through my own nursing practice. The process of 'talking back to myself' has uncovered my positionings within discursive statements where I became visible as the private nurse. The thesis gives voice to the practice of the 'private nurse', in speaking of and exploring events where there is a bringing together of my private relationship with Kevin and my professional practice as a nurse. The stories related in the thesis are strategically important in unsettling the taken for granted practices in healthcare settings. The evocative power of these stories calls into question the procedural doing in the normative institutional patterns of work in healthcare institutions that do not take account of the histories of patients and those involved in their care. I advocate a more specific approach to nursing practice, which does take account of the discursive production of subjectivity and the local epistemologies arising from new subject positionings of both the nurse and the patient. In 'unpicking' and 'resewing' the stories of the cancer patient and the private nurse I have imagined new possibilities for the ethical substance of nursing. I have come to see ethical nursing practice as

negotiated and contested through local conversations and practised through the capacities of people as discursive subjects who understand possible alternatives to the subjection of self to the sovereignty of expert power.

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