

**NEGOTIATING BOUNDARIES: THE NURSE FAMILY MEMBER CARING  
FOR HER OWN RELATIVE IN PALLIATIVE CARE**

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## Abstract

This research illuminates the challenges of living well within one's own family as a nurse caring for her own relative who is dying of a cancer-related illness. Developing a deeper awareness of the consequences of this caring work has been the central focus for inquiry in this research. Nursing requires epistemologies that encompass new ways of understanding how we live within our own families and communities and practice as nurses. The theoretical framework that guides this research interprets the French Philosopher Michel Foucault's (1926-1984) critical history of thought as an ethical project for nursing. It uses conceptual tools developed in his later writing and interviews to draw attention to how discursive knowledge and practices constitute subjectivity in relations of truth, power and the self's relation to the self. The first aspect of the analysis, *landscapes of care* examines the techniques of discourse as relations of power and knowledge that constitute nurse family members as subjects who have relationships with their own families and other health professionals. The second aspect analyses *care of the self and others* as self work undertaken to form the self as a particular kind of subject and achieve mastery over one's thoughts and actions.

Nurses are called to care because they are present within their families with knowledge and expertise that makes a difference to how a dying relative experiences palliative care. Caring discourse positions nurses with responsibilities to their own; responsibilities that require sensitivity in knowing how to negotiate the relational spaces that constitute relationships with other family members and health professionals. Family discourse calls nurse family members to care as daughters, daughters-in-law, wives or mothers within normative understandings about the obligations that families have to care for their ill or dependent members. The discourse of expertise in knowing as a nurse positions nurse family members as interpreters of information for their families and observers who use their inside knowledge of how the health system works to watch over the ill person's clinical care. This expertise, which becomes visible as the exercise of

professional authority in practising nursing, challenges the normative frameworks that classify and demarcate professional and lay roles in caring for the dying person.

As an exploration of the complex and contradictory subjectivities of the nurse family member, this research illuminates the forms and limits of nursing practice knowledge. It shows how nursing is practised, and the identity of the nurse is created, through intellectual, political and relational work, undertaken on the self in relation to others, as modes of ethical engagement. Within this ethical engagement, nurse family members work to transform the self into discursive subjects, with the knowledge, skills and other capacities that are necessary to honour their commitments and responsibilities for care of another person. The experience of caring for their own relative transforms nurse family members' previously held values about how nurses ought to be with others in their professional work, creating a deeper sense of interest in and concern for the vulnerability of other people in palliative care.

**Key words:**

*Nurse family member, palliative care, care of the self, nursing ethics*

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## **Chapter 1**

### **Framing my curiosity**

Curiosity is a vice that has been stigmatized in turn by Christianity, by philosophy, and even by a certain conception of science. Curiosity is seen as futility. However, I like the word; it suggests something quite different to me. It evokes “care”; it evokes the care one takes of what exists and what might exist ..... a readiness to find what surrounds us strange and odd; a certain determination to throw off familiar ways of thought and to look at the same things in a different way. (Foucault, 1984/1994 p. 325)

Foucault (1984/1994) saw philosophy as a way of reflecting on the values and beliefs that we hold to be important in how we live our lives and practise our professions. He believed that philosophy ought to be practised as ontology for the relation one has with oneself; an ethics of the self that provides techniques and strategies for people to govern themselves as active moral agents, where the search for one’s own wisdom and truth is a constant practice (Foucault, 1984a). Curiosity is a way of thinking that is concerned with care of the self and its inherent responsibility to free oneself from truths that dominate one’s thinking and choices about how to conduct oneself in the world. It requires an ability to withhold judgement about the truths that are presented to us in the knowledge about the world that we take for granted as self-evident. Instead an ethics of the self requires people to work on themselves to maintain an interest and inquisitiveness about how they find themselves positioned in events, conversations and relationships with others.

### **Framing my curiosity**

The inspiration for this research was grounded in my curiosity about the experiences of other registered nurses who had, like me, been involved in palliative care for their own dying relatives. This doctoral research aims to create a space for other nurses to speak about their reflections on similar experiences and in doing so, unfold knowledge for

nursing about the unique challenges of living as a nurse within one's own family and community. My interest in the topic for this research is concerned with the idea that, as a nurse, caring for a person who is dying from a cancer-related illness is quite an ordinary thing to do in our professional work. It is familiar; something we as nurses already know and understand (Ceci, 2003a). Similarly, caring for family members who are ill or dying is probably a relatively usual thing for women to do in the New Zealand social context when the need arises. Like other nurses I have found myself drawn into the care of my own relatives when they are ill (Hurliman, 2004; Mills & Aubeeluck, 2006; Monahan & Hopkins, 2002; Read, 2003; Rosenfeld, 2007; Ward-Griffin, 2004). While caring for others was so much a part of my world that knowing how to be with a dying relative was something that I did almost without thought, finding oneself positioned as a nurse family member was a new experience that was both frightening and intriguing.

As I entered early middle age a number of my close relatives were dying of cancer or needed care because of age-related illnesses, including my husband, parents and parents-in-law. The first of these relatives was my husband; Kevin, aged forty-five, was diagnosed with metastatic melanoma at the beginning of 1996 and died in October 1997. Inspired by Carolyn Ellis' (2005) book *Final Negotiations*, I had written a thesis for a Masters degree in nursing as a 'narrative of the self' that documented a detailed exploration and analysis of this experience of caring for my husband (McClunie-Trust, 2000). This exploration of my own experience illustrated how I practised care of the self while situated in parallel and intertwining journeys of academic work, professional practice and the profound events in my personal life. The analysis of these stories showed me how I made this intertwining of my personal and professional lives habitable by coming to understand that my knowledge, experience and identity as a nurse had profoundly influenced my thinking and actions in caring for a dying relative.

I was involved in the events surrounding Kevin's illness and dying, as someone who already had the knowledge, skills and capacities of a nurse. I found myself reaching into the depths of my nursing experience in response to Kevin's, and my own, need for care as his illness progressed. What struck me during this time was both the degree to which nursing informed how I engaged with and responded to these events and the

expectations of other nurses and medical staff that I would participate in his care as a nurse. Kevin was often discharged from hospital early because the staff knew I was a nurse and would be able to manage his care until district nursing and other services were in place. The fact that he would have palliative care as an outpatient and die at home was something everyone involved in his care took for granted.

Nursing knowledge, and the ability to practise as a nurse, offered me a particular way of enduring (Morse, 1996) one of the most challenging experiences of my life. It gave me entry into life events and clinical situations with particular capacities; a specific kind of power to express my love and care given that I was already an experienced nurse who could not deny what I knew. Looking back, providing palliative care on a full time basis, albeit with the support of an excellent palliative care team, was an undertaking which I entered into thinking it was a very obvious thing for me to do. And yet, “What nurses know and do.... is view the world through the prism of ....human vulnerability and capture, in their glance, the dangers of the ordinary” (Gordon, 2002, p.59). As Gordon suggests, nurses encompass this vision in their ability to understand the complexity of illness and be with people in ways that are healing, comforting and supportive. This sense of ‘already knowing’ was present in my ability to know what to do and how to relate to people in particular ways, but caring for my husband also showed me that nursing knowledge is always partial in relation to the experience of life-threatening illness. My prior experience of caring for dying people in their own homes provided a vision of the sort of care that Kevin might need but it did not prepare me for my involvement in it as his wife. This was a different landscape.

I believe nurses have a long deep view of what it means to be human. Nurses are intimately involved with people facing illness and death in circumstances that most other people do not experience. They know how situations are likely to unfold and have some idea of the degree of emotional endurance that it takes to get through them for people, families and themselves. Nurses have to learn how to manage their own responses to the sometimes traumatic effects of the situations that they are involved in order to contain themselves in the face of such experiences, but I did not know what it meant to be the wife of a dying person until I experienced it. The loss experienced in the

death of a close family member is something nurses might be able to conceptualise but they do not have to live with the consequences of it. As Gadow (1995) suggests, one can conceptualise certain aspects of a landscape from a map, but knowledge of what it is like to live with life-threatening illness can only be gained from experiencing it oneself or with a loved one. Nursing knowledge might have afforded only a partial view but it created a particular kind of familiarity that helped to inform my understanding of what I was experiencing.

In certain respects, from my standpoint as a nurse, I already knew what a diagnosis of metastatic melanoma signified. Knowledge of pathology and my own nursing practice experience created a vision of the likely progression of this disease in Kevin's body and the consequences of it. As clinical signs emerged on his body, I was able to interpret them. I could say that this knowing was both valuable and challenging. It was valuable because it gave me the capacity to understand how events were likely to unfold and prepare myself for the challenges they presented. On the other hand I could never 'not know' the consequences of this disease for his life and mine. But as Ceci (2000) suggests, "knowing is deciding" (p. 65). I knew I could choose how I engaged in representations of Kevin's body as an object of scientific discourse. Scientific knowledge called me into being as a nurse; it informed my practice in moving and positioning him as the disease impacted on his ability to move and made him increasingly short of breath. It contributed to my clinical judgement in administering morphine via the various routes that it was prescribed and managing its side effects. I knew when to call the palliative care team to assist when complications occurred that were beyond my ability to manage, or when I chose to have someone else intervene.

Asking how we are related to what we think we know is an important task for nurses to consider (Ceci, 2000). Our social, cultural and physical worlds are interpreted from particular standpoints and things are meaningful to us only if we know how to interpret them. Our interpretations of what we experience in the world lead us back to ourselves "in a deeper, less innocent way" (Caputo, 1987, p. 97). Our interactions with the world are mediated by prior knowledge and experience that are always already situated within

particular social, temporal and geographic contexts. What we can see and the ways in which we make sense of things are both enabled and constrained by this situatedness. As Ceci suggests, if we understand that a range of ways of knowing about the world are available then it is possible to grasp the implications of particular points of view that we hold for nursing as a profession, the nurses who practise it and the people whose lives are mediated by it.

### **The research approach**

This research examines the discourses that govern the conduct of nurses as family members in the clinical field of palliative care and explores how these nurses participate in and negotiate their subjectivities as family members and health professionals through discourse. It seeks to understand why certain discourses are dominant in the construction of knowledge about personal and professional identities and to consider the implications of these discourses for nurses who are required to negotiate the boundaries between them. It aims to trouble what we take as self-evident to critically evaluate contextual knowledge that might work to inform how nurses think about the challenges of living as a nurse within one's own family and community. In order to do this work, the methodological approach for this research draws on Foucault's (1984/1992; 1984/1990) later writing on ethics as a method of critical inquiry to analyse how nurse family members constitute themselves as subjects of the various discourses that call them to act in particular ways. The theoretical framework also uses Foucault's later definition of discourse, as a site where knowledge and power intersect to create certain ways of speaking within a particular formation of knowledge (O'Farrell, 2005).

Foucault's approach to ethics analyses the historical and cultural effects through which we construct ourselves as subjects of discourse. Using his theoretical tools, the concept of curiosity informs this critical inquiry to examine how female nurse family members constitute themselves as gendered subjects of the various discourses that are made available to them in the accounts they offer about their experiences of caring for a dying relative in palliative care. As stated earlier in this chapter, curiosity is understood as a way of thinking that is concerned with care of the self and its inherent responsibility to

free oneself from truths that dominate one's thinking and choices about how to conduct oneself in the world (Foucault, 1984/1994). The first aspect of the analysis identifies the verbal traces of discursive knowledge and the effects of power relations that individualise, discipline and order the thinking and actions of nurse family members, and explores the points of resistance that are apparent in moments of tension that arise between the subject positions that they are called to occupy. The second aspect of analysis uses Foucault's theoretical work on the subject in ethics, where he conceptualised the constitution of subjectivity as an ethical practice. The constitution of subjectivity is critically examined using the four elements that Foucault (1984a) developed as the ethical substance, mode of subjection, self-forming activities and telos of the work undertaken to create oneself as a subject of discourse. Other theoretical sources that interpret Foucault's writing, including Butler (2002, 2005) and Cooper and Blair (2002) are also used to inform my interpretation of Foucault's theoretical tools for the research.

The specific objectives for the research were to explore six female nurse family members' experiences of caring for their own relatives in palliative care in order to

- analyse the subjectivities that are created through competing discursive positionings that arise in the text of the stories
- explore the subjectivities and relations of truth, power and self that are constituted by and constituent of knowing in competing discourses about caring within the family and professional practice
- give voice to subjugated knowledges that inform professional practice in the context of private space with one's own family members
- consider how nurses negotiate the boundaries between self and professional practice and construct themselves as the nurse family member through practices of the self.

The research questions are framed as:

- ◆ What are the discourses that construct nurses and nursing and how do they show up in nurses' stories?
- ◆ How do nurses negotiate the boundaries between their professional practice and personal lives while caring for their own family member in palliative care?

For the purpose of this research, a family member or relative is defined as someone related by blood, legal, cultural or other ties, or a person who is significant within the family of the nurse, such as a close family friend. A private space is that which is normally considered to be within the realm of the family or outside the public or professional gaze. Gender is understood as a way of representing the subject positions that are available to women within discourse (Ceci, 2004). It is used as an analytical category in this research to explore social norms about what women ought to do in given situations (Butler, 1990). While this research focuses on the experiences of women as particular kinds of discursive subjects, it does not seek to devalue the contribution that male nurse family members make to their families and communities.

### **Rationale for the research approach**

Nursing has a need for new epistemologies to inform the development of knowledge for practice that occurs in increasingly complex informational, technological and cultural worlds. The knowledge that nurses use to inform their practice is a complex matrix of understandings derived from research and literature, professional experience acquired through clinical practice, and personal life (Higgs & Titchen, 2000). But personal knowledge is often undervalued in nursing, framed and dismissed as subjective and biased knowing. Will (2001) argues that life-informed knowledge has been excluded from nursing knowledge and the empirical knowing of scientifically constructed theories has been privileged in striving for professionalism. Consequently, nurses have been encouraged to separate their own experience of life, illness and suffering from the lives of people with whom they work in a professional capacity. Carper (1978) brought life experience back into nursing knowledge in her seminal work on patterns of knowing in

nursing. She encouraged nurses to value the differing patterns of knowing that arise from blending knowledge through scholarship, practice and experience. She made the nurse visible as a person within the context of her/his own life and learning.

Contemporary nursing needs epistemologies that encompass different ways of knowing and create new relations to the truths that inform what we know and influence how we come to know. Nurses require theoretical frames and conceptual processes to critique the norms that inform nursing practice, to seek deeper understandings of themselves and others beyond the discourses of science and economics that dominate contemporary health care (Georges, 2003). Research approaches that are influenced by postmodern thinking have the potential to construct multiple perspectives and broader conceptual frames for nursing enabling new and different analyses of nursing practice and relationships (Dzurec, 1989). These approaches surface alternative and potentially creative ideas that are derived from local histories containing previously excluded or disenfranchised knowledge. Where there is little known about a particular phenomenon these approaches may illuminate new avenues for further inquiry by problematising current theoretical approaches and interpretations (Porter, 1997). Foucault's later work is important for this study because it enables an exploration of choices that nurses have made in wanting to 'do the right thing' while caring for their own family members in palliative care. This focus on subjectivity as an ethical relation to the self illustrates how the moral agency of the nurse is accomplished through the subjectivity of the self-as-nurse (Georges, 2005).

This exploration of moral agency of the self-as-nurse is important because as Gadow (1999) suggests, nursing is concerned with moral ends. Modes of subjection to ethical theory need to be explored and understood in ways that encompass the self as the connection between theory and practice (Georges, 2005). Universal ethical principles can disenfranchise both the nurse and the client because these discourses invest moral value in an act or outcome rather than in the ethical substance of a reflective and morally responsive subject. Conceptualising ethics as a practice of the self subjectivises the self-as-nurse with a critical relation to ethical discourse in the context of practice. While ethical codes can command caring, Gadow argues that engagement cannot be ordered by



principles. Caring addresses the nurse as a person situated with concern for the other within practices that have no neutral moral ground, because nursing practice already exists within value-laden and contested relations of truth.

Cody and Mitchell (2002) agree that the ability to articulate the ethical basis for practice is essential in contemporary health care environments that call nurses to account for who they are and what they do. Nursing is concerned with people's rights, as individuals and communities, to live in the world and experience health and illness on their own terms. Nurses cannot participate effectively in supporting clients' quality of life if they do not understand what values and beliefs influence clients and communities, and the sociopolitical factors that impact on their ability to live well. As Cody and Mitchell suggest, disparities between the values that nurses hold about their practice, and the capacities they have in enacting these values are mediated by the power of dominant discourses in health care that call nurses to practise in ways that are other than what they desire. This disparity between actual practice and their own beliefs about nursing is a potential source of dissonance for nurses who value themselves as ethical beings. For this reason, nurses need to recognise the moments when their own voices are silenced and the self-as-nurse is rewritten and coerced into knowing in alien ways (Georges, 2005).

### **Negotiating professional boundaries**

In caring for their own relative, the nurse family member is positioned in an ambiguous space, betwixt and between professional and lay caring roles, with the need to define their own authority and responsibilities for care. The idea of negotiating professional boundaries is central to the research, as the site of struggle for knowledge that defines the professional authority and capacity to practise. Foucault (1982/2003a) argues that the practices one is required to conduct on the self within discourse potentially alienate the self from the self. The values and beliefs that construct the normative framework (Butler, 2005) for professional discourse create criteria for the inclusion of people who are eligible to practise the discourse, and the exclusion of those who are not. Furthermore, the rules that define what can be said in relation to what is held to be true

within the discourse limit what can be said about certain things (Kendall & Wickham, 1999). Professional discourse works to shape those who have earned the right to call themselves professional according to its rules, but this right divides the self from the self in that only certain representations of the self can be made visible. The most obvious of these distinctions is the professional/lay dividing practice, where knowledge that is not held to be authoritative is marginalised as “unrigorous, undisciplined and unprofessional” (Agger, 1992, p. 126). Expert knowledge and the ability to practise as a professional person define the difference between the provider and recipient of the service and in doing so mark out the territory that is encompassed by professional practice (Paternelj-Taylor, 2002).

The professional relationship is bounded by lines that demarcate this difference in knowledge and skill and the conditions under which the relationship is practised. Professional norms construct this relationship as the means to deliver a service in ways that respects the autonomy and self-determination of the participants. It is typically shaped by distance, objectivity and the authority of professional expertise to define and manage problems on another person’s behalf (Mellow, 2005) and act in their best interests (Penfold, 1998). Boundaries are the primary concept used to define appropriate professional relationships. They are seen as one of the most important competencies for nursing in providing therapeutic frames for professional relationships (Paternelj-Taylor, 2002). Therapeutic frames are seen to facilitate clarity of purpose within professional relationships, conserve physical and emotional energy and order the spaces between their professional work and private lives, and protect both the nurses and the people they work with (AARN, 2005; College and Association of Registered Nurses of Alberta, 2005; Nursing Board of Tasmania, 2005; Nurses Board of Victoria, 2007; Nursing Council of New Zealand, 2001; Nurses and Midwives Board New South Wales, 1999).

Boundaries are a site where discourse is practised in calling people to modify their own actions and those of others. Exclusion of those who are outside the normal “is an effect of power. It is a putting away”, (Hacking, 1986 p. 30) that signals transgression. Boundaries create expectations about the kind of trust, security and protection that clients using health services are entitled to (Martsolf, 2002; Morrissey, 1997; Sheets,

2001). ‘Crossing the line’, ‘overstepping the mark’ and ‘going over the top’ (Nurses and Midwives Board New South Wales, 1999) are metaphors that characterise inappropriate behaviour as boundary crossings. According to the Nurses and Midwives Board, New South Wales, a zone of helpfulness is characterised as a continuum of professional behaviour that is therapeutic. ‘Over involved’ behaviour is defined as caring about rather than caring for the client. The idea of over-involvement suggests an emotional investment in the relationship with the client with the potential to obstruct the therapeutic value of the professional relationship by allowing personal involvement to take priority over clinical judgement. Therapeutic relationships that cross boundary lines become ambiguous in ways that threaten the normative framework for the discourse of professionalism. In caring for her own relative, the nurse family member transgresses the limits set by these boundaries by constructing what is represented in the discourse of professionalism as a dual relationship.

The strength of normative frameworks in calling attention to boundary incursions arises partly from their connection with discourses of risk management (McLaughlin, 2003). Risk reduction requires the regulatory control of professionals by external bodies to arbitrate what is considered to be appropriate conduct (Kemshall, 2000). It brings the regulatory power of the law into play in ways that affirm or negate particular behaviour (Graham & Slee, 2005). While the importance of therapeutic integrity in protecting vulnerable populations cannot be denied (Paternelj-Taylor, 2002), the problem for nursing is that thinking in boundary terms creates dividing lines that close down rather than invite inquiry into the meaning and effects of rules that are expected to guide behaviour. Zubrzycki (2003, p.1) argues that the conceptualisations of professional boundaries as “narrow and cautionary, focusing on boundary incursions” limits creativity in relationships where professionals deal with the overlapping influences of their personal and professional lives.

Mellow (2005) also draws attention to how rural nurses, who live within the communities where they practise, have to manage situations where the lines are not so clearly drawn between their personal and professional lives. The emotional and geographical distance between these nurses and the clients they work with are reduced

when people are their neighbours or relatives, and while these relationships were challenging for the nurses and other professionals in Mellow's study, the normative framework that defines professional conduct did not realistically help them to address the complexity of the situations that they experienced. Rural nurses are not able to compartmentalise their places within communities because they are under constant scrutiny (Miller, 1981) from those who live around them. The nurse caring for her own family member is similarly positioned within her own family even if not acting primarily in the professional role.

Nurses are called to care within their own families and communities as people who possess knowledge and expertise in caring for others. Boundaries are spaces where the inside and outside of our relationships are mediated; points of sensitivity and tension that might be experienced and negotiated (Nedelsky, 1991) in relation to, and with, others. In caring for their own relatives, nurse family members have already entered the discursive field of professionalism in a new way that destabilises the knowledge informing previous normative prescriptions for conduct, enabling other ways of knowing, thinking and acting to be explored and negotiated (Butler, 2005). Mellow (2005) suggests that it is possible that being professional may mean different things in different locations. Situations and relationships that create boundary transgressions can be managed ethically by carefully attending to power differentials and role conflicts (Brownlee, 1996).

### **Transgressions and limits**

This idea of boundary transgressions and limits came alive for me one day while I was driving to visit my elderly mother. One of my siblings had phoned early that morning in February 2007 and asked me to visit her because she was feeling quite unwell. In these circumstances I am never just a daughter. I bring professional knowledge and assessment skills to my visit with her, and take responsibility for knowing when to call the doctor. I was also in the midst of data collection for this research and had spent a great deal of time thinking about nurses' relationships with their family members, particularly the call to care that I was currently experiencing. While driving, I heard a radio interview with a New Zealand nurse turned euthanasia campaigner, and the Chief

Executive of the Nursing Council of New Zealand, Marion Clark (Radio New Zealand, 2007). In 2003, intensive care nurse Lesley Martin was convicted of the attempted murder of her terminally ill mother following the disclosure of actions that she maintained were intended to accelerate her mother's death.

A recent High Court ruling had seen Martin struck off the register of nurses following her conviction and subsequent imprisonment in 2003. She argued that she had acted as a daughter in caring for her mother, and not in a professional capacity as a nurse. Marion Clark stated that Martin's removal from the register of nurses was important to protect the nursing profession's reputation and ensure that the New Zealand public had confidence that nurses would uphold the sanctity of human life. Despite her claim to be acting solely in the role of a daughter, the Nursing Council's view was that she had used her nursing experience and skills and was in fact nursing her mother. She was answerable for her conduct in this matter under the Crimes Act 1961, but as a nurse, was also subject to the extraordinary responsibilities of being 'fit and proper' and competent to practise as a professional person within the regulatory requirements of the Health Practitioners Competence Assurance Act (HPCA Act<sup>1</sup>) 2003. The key factor in this decision to revoke her registration was her fitness to practise in the light of such a serious conviction and the lack of remorse shown for her actions. Martin had stated that she would act in the same way again in similar circumstances (NZNO, 2007). Marion Clark stated in this radio interview that the public needed to have confidence that nurses would uphold the sanctity of human life (Radio New Zealand, 2007).

This case is relevant to this research in that it shows how caring for a family member as a nurse/relative is a complex, difficult to negotiate and sometimes, professionally onerous activity. It illuminates the boundaries of the professional self through an act of transgression that placed Martin outside norms about what constitutes professional conduct. Transgression is an action that shows the limits or lines of the boundary and "forces the limit to face the fact of its imminent disappearance, to find itself in what it

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<sup>1</sup> The HPCA Act 2003 provides the regulatory framework for all health professions in New Zealand. The principal purpose of the Act is to protect the health and safety of health care consumers through mechanisms that ensure health professionals are competent to practise.

excludes” (Foucault, 1963/2003 p. 446). The Nursing Council of New Zealand reinforced the limits of professional conduct by deregistering Martin and excluding her from the profession on the basis of public confidence in nursing. In doing so, the Council has highlighted the registered nurse’s regulatory responsibilities in always being accountable for practice, whether that practice occurs as part of paid employment or in a voluntary capacity within one’s own family or community.

Nurses are drawn to use their professional knowledge and skills to care for their own relatives and may be encouraged to do so by other health professionals and family members (Ward-Griffin, 2004). However, the nurse who is called to care for their own relative exists in a marginal professional space without the authority of the nurse assigned to a case within a work role, and as such practises in an ambivalent space where lines about responsibilities are not always clearly drawn. As a nurse, I find myself drawn to interpret my mother’s health events in the light of my clinical knowledge but seeking appropriate health care for her, as an elderly person, is sometimes a struggle. I have often found myself pulled into the gap between the care that the health care service provides and that which she actually needs. This interview about Lesley Martin’s case highlighted my concerns about being involved with my mother as a nurse, sometimes by default, because there is no health professional with constant oversight of her care. On occasions when I have expressed concern over this complex positioning as a nurse and daughter to other health professionals, I have felt ‘disciplined’; pushed away from using my clinical knowledge, but at the same time expected to fill gaps in the provision of health services.

Professional and public perceptions of how nurses are positioned within their own families and communities often lack understanding about the reality of nurses’ lives; both in being drawn to care for other people and the encouragement they receive from others to do so.

Donald Stevens QC, defence lawyer for Martin stated that Martin “should never have been left to look after her mother because she was too close to her mother”. He suggests that “one of the principles of palliative care is that a health

professional should not be expected to look after his or her loved one (The Dominion Post, 2004).

This statement shows how the normative framework for professional discourse constitutes nursing relationships in ways that establish the limits of possible action and thought (Ceci, 2003b) about caring for family members as a nurse. It draws attention to the idea of dual relationships as relationships that transgress professional norms, positioning the nurse-relative as a lay person who ought to divide the professional from the personal self. The division between the personal and professional invites nurses to separate their lives into public and private spheres, where women as family caregivers are relegated to the private domain of the family. This separation simplifies and reduces complex relationships into two discrete environments (Gerson & Peiss, 2004), which reinforce norms about professionalism as a universal standard rather than allowing for the negotiation of boundaries as permeable and flexible entities. On the one hand the nurse as the family caregiver might be encouraged to participate in their own relative's care beyond the capacity of the lay person, but on the other s/he is constrained by a lack of authority to speak as a nurse in the public sphere.

### **Lay and professional caring**

The nurse may be invited to participate in the care of their own family member but at the same time find themselves contained by other people's assumptions about what constitutes and differentiates lay caring from professional nursing practice. Boundaries between lay caring and professional nursing practice are by no means clear and may be subject to negotiation with families in the context of care (Pickard, Jacobs & Kirk, 2003). In recent times of fiscal restraint in health care services and health policies that emphasise health care at home (Ward-Griffin & Marshall, 2003), some aspects of nursing are transferred from professional nursing roles into unpaid family caregiving 'amateur nurse' roles (Glazer, 1990). This means that family caregivers are likely to be asked to undertake practices that have been traditionally considered to be within the realm of professional care. Pickard et al. found that lay carers in their British study were involved in complex health tasks that went beyond those usually associated with normative caring within families. Ties of duty and reciprocity, and perhaps the desire to

keep their relative at home, encouraged these caregivers to engage in tasks that were far in advance of what they had previously considered themselves capable of doing.

The differentiation between skilled and unskilled caring fades in the light of learning complex skills but an epistemological divide remains between formal and informal caring systems. Nurses acting within their professional role retain the power to negotiate more complex caring activities with families (Pickard et al, 2003; Ward-Griffin & Marshall, 2003). Nurses are professionally accountable for the tasks delegated to the 'amateur nurse' within the family (Nurses' Association of New Brunswick, 2002) and the appropriateness of this delegation within a given context. Pickard et al. found that the knowledge of lay caregivers was interpreted by health professionals as experiential and individual as opposed to the propositional and generalisable knowledge that is the hallmark of professional practice. While lay carers might become skilled in particular procedures, they do not necessarily have holistic knowledge of the broader context of the client's situation. The nurse acting in the professional role retains responsibility for health assessment, and overall planning and supervision of care.

The simultaneous positioning of the nurse as a family member, who is both inside and outside the professional role, challenges the limits of family caring within these lay boundaries. The nurse as a family member has the capacity to step across this epistemological divide between formal and informal systems of care by exercising her/his capacity for clinical judgement. While this judgement may be seen as clouded by emotional involvement with the client or ill person, it potentially inserts the nurse as a family member into clinical situations in ways that may challenge the power of the nurse who is acting in the professional role. Furthermore, as Marion Clark (Radio New Zealand, 2007) suggested in the case of Lesley Martin, all nurses are subject to the regulatory requirements of the HPCA Act 2003 to practise competently, even when acting in situations that primarily involve a voluntary or informal role. This means that nurses functioning in any capacity are likely to be held accountable for a standard of practice that represents the level of skill and the registration they possess (Vermont State Board of Nursing, 2003). The point here is that the nurse family member is not necessarily visible as a nurse because s/he is not practising in a formal role (Ward-



Griffin & Marshall, 2003). And yet despite any real authority to practise professionally in this ‘informal’ space, nurses remain accountable for their practice within the context of family caregiving. This is something that of itself is in need of explanation (Ceci, 2004).

### **Significance of the study**

This research explores an issue that has implications for the professional practice and employment of nurses. The demands of family caregiving have been shown to impact on nurses’ work role capacities and choices in paid employment (Gryzwacz, Frone, Brewer & Kovner, 2006; Rosenfeld, 2007 Scott, Hwang & Rogers, 2006). It is argued as one of the main reasons that nurses reduce their hours of employment, change work settings or leave nursing (Gould & Fontenla, 2006; Hurliman, 2004; Reineck & Furino, 2005). New Zealand Health workforce data show that of the 34,660 registered nurses actively practising, 90.9% are female and 64% are aged over 40 years. The largest concentration of nurses (73 percent) is aged between 30 and 50 years old. Half of all actively practising nurses work close to or over fulltime hours per week (NZ Health Information Service, 2004). Most care family caregivers, including nurses, are female and middle-aged (Frederick & Fast, 1999), with responsibilities to both children and parents (Brody, 1990). This means that family caregiving may be an important factor for workforce planning as particularly middle-aged nurses reduce hours in paid employment or leave work altogether to manage multiple work and family commitments.

This research is also an important project for nursing because there is little research on how nurses negotiate the boundaries between the knowledge and skills they acquire in professional practice and how they live within their own families and communities. Nurses who care for their own family members transgress the limits of normative frameworks that guide nursing practice. In doing so, they demarcate and illuminate these limits as sites of interest for the profession to critique the relation to the professional codes that it expects its members to take up as their own. Researching the moral agency of nurses is a relevant task for nursing as a profession that is concerned with moral ends and social justice (Gadow, 1999). Knowledge about what kind of people nurses are, and

how they practise and live in the world, requires interrogation about the kind of self it requires us to be. The stories we tell about ourselves and our relationships with other people show what kind of persons we wish to be and how we work on ourselves to become ethical. The analysis of stories about caring for a relative as a nurse family member has the potential to challenge existing interpretations about what constitutes ethical conduct as a nurse by inviting nurses and other people to think critically about how they apply rules of conduct in the relationships they have with themselves and others. New knowledge about this topic might help to free other nurses to act according to their own ethics; to be able to practise an ethical relation to themselves, the profession and their family members and to be able to live well within the experience of caring for others.

### **The structure of the thesis**

This chapter has set out the historical positionings for the research as grounded in my curiosity about the experience of caring for a relative in palliative care. It introduces the reader to the central ideas that arose from reflections on events involving the care of relatives in my own family, which have informed my curiosity about the experience of other nurses in similar situations. As a nurse, there is a sense of ‘already knowing’ that informs one’s involvement in an illness event with one’s own family member, but this knowing is in some ways out of place. It constructs new and complex subjectivities as the nurse family member that are difficult to negotiate and sometimes professionally onerous, given that the boundaries between lay and professional caring, and professional accountability for practice, are not always clearly defined for the nurse as a family member. The following chapter presents the theoretical positionings for the research, using ideas that have been derived from conceptual tools that the French philosopher Michel Foucault (1926-1984) developed in his later writing and interviews. The discussion explores how, as a critical history of thought, Foucault’s philosophy draws attention to the historical fields of knowledge that constitute subjectivity in relations of truth, power and the self’s relation to the self. The theoretical positionings for this research use aspects of Cooper and Blair’s (2002) interpretation of Foucault’s

conceptualisation of how subjectivity is constituted through the self's relation to the self, as a conceptual lens to guide the research process.

Chapter Three explores contextual representations of family caring in analysing the literature that informs the professional, social, political and cultural landscapes of the nurse's 'call to care'. It offers a critical analysis of representations of nursing and lay subjectivities in the literature that inform nursing, palliative care, and lay or home care in New Zealand as well as drawing on relevant literature on these topics from the global context. The discussion in this chapter explores the historical emergence of nursing subjectivities that have constructed caring within professional discourse, which classify and divide subjects, and recognises them as professional or not on the basis of their knowledge and skill. The call to care is examined as an effect of the relational sets of rights and relationships, and their inherent obligations that position women and nurses in particular in family discourse as subjects who are responsible for the care of ill relatives. The influence of health policy in constructing a discourse of informal family care in palliative care is also explored as a contributing factor in calling the nurse family member to fill the gaps between their ill relative's need for care and the health services that are available.

Methodological considerations for the research are explained in Chapter Four as the strategies I have developed to operationalise analytical techniques derived from Foucault's (1984a) ideas about how subjectivity is constituted through the self's relation to the self in discourse. The discussion of methodological considerations argues that nursing requires epistemologies that encompass new relations to the truths that define what we know and inform how we practise as nurses. The approach to data analysis had two aspects that focused on how the participants came to constitute themselves as subjects of the discourses that were available to them as nurse family members. The first aspect, *landscapes of care* examined the techniques of discourse, or the relations of power and knowledge, that worked to constitute the participants' subjectivities as nurse family members who have relationships with their own families and other health professionals. The second aspect analysed *care of the self and others* as the self-work undertaken to form the self as a particular kind of subject and achieve mastery over

one's thoughts and actions. Ethical considerations for the research are identified in the process of seeking ethical approval from the Victoria University of Wellington Human Ethics Committee and managing ethical challenges that were experienced in conducting sensitive qualitative research with participants who had the potential to re-experience the emotional distress of losing a loved one in telling their stories for the research. These considerations also included managing the potential for my own emotional responses to working with the participant's stories.

Chapter Five presents an analysis of the first storyline that appeared in the *landscape of care*, which was conceptualised as the discursive knowledge and practices that constituted the nurse family member's call to care for their own relative. The analysis in this chapter identifies the discourses that became visible in the participants' stories and examines how they engaged with the call to care to become subjectivised in the discourses of caring, family and expertise in knowing as a nurse. Care of the self and others is explained as an effect of the self-forming activities that the participants performed as the ethical substance of intellectual, political and relational work that constitutes the subjectivity of the nurse family member. In this process of transforming themselves with modes of subjection as particular kinds of relation to the self in discourse, nurse family members created their own authority to speak about and practise nursing within their own families. However, the analysis also shows how the relation to self that subjectivises them as nurse family members also sets them apart from their own family members and positions them uniquely in relation to other health professionals.

Negotiating boundaries was the second storyline to emerge in the *landscape of care* that became apparent as the limits that are negotiated at the margins of 'normal' subjectivity. This is the focus of Chapter Six. The analysis of the participants' stories shows how subjectivity of the nurse family member is constituted through 're-making' the self's relation to the normative frameworks that classify and demarcate professional and lay roles in discourses on caring, family and professionalism. These classifications establish the limits for the relation to normative frameworks that define limits for inclusion and exclusion, classifying the subject according to their conformity. Degrees of normality are expressed in practice as normalising judgement that calls the nurse family member

to account for themselves according to the limits that characterise professional and lay subjectivities and formal and informal care. The tensions between professional authority and care that is delegated to families by health professionals are analysed as an effect of the subjectivity of the nurse family member, who is positioned with knowledge and skills that extend beyond the usual capacities of lay carers or other family members. Returning to work creates further tensions as the nurse family member finds that there is no return to the subjectivity of the former self. The 're-making' of the relation to the self in practising as a nurse becomes a priority in care of the self in attempting to reform a new modes of subjection to professional discourse.

The final chapter reflects on limits and possibilities in summarising the findings and implications of the research. The ideas surfaced from the discussion of limits and possibilities are examined for their potential to conceptualise an ethical framework for care of the self as intellectual, political and relational work. The implications of the findings of the research for professional self-governance of individual nurses and nursing as a professional community are considered in relation to the discursive knowledge and practices that inform and regulate practice. Limitations of the research are offered as reflections on the positioning of it as a qualitative study that locates its findings within a particular practice context and geographical location. These limitations are explored as points of departure for new opportunities for critical inquiry on the relationships between nurses, their families and the professional and regulatory discourses that construct normative frameworks for nursing practice.

## **Chapter 2**

### **Theoretical positionings**

#### **Introduction**

The theoretical framework for this research draws on later writing of Michel Foucault (1926-1984). As a critical history of thought, Foucault's project encourages us to think differently and to understand that things can be otherwise than how we find them. His work maps historical fields of knowledge and draws attention to historical productions of the self that can be used to examine current issues and concerns (Besley, 2005). For Foucault, social justice as a concern with the capacity for people to exercise choice is an essential element of any critique of social relations. It constitutes a particular kind of ethical deliberation of the effects of one's actions on others and others actions on the self (O'Farrell, 2005). Ethics, subjectivity and social justice are central concerns in this research, which seeks to understand how nurses come to know themselves as nurses and family members, and recognise the responsibilities that arise from these complex and sometimes contradictory subject positionings that call them to act in particular ways.

The means through which people come to recognise themselves and their professional and moral obligations is an important ethical consideration in critical inquiry for nursing because nurses need to be aware of how they are situated in social contexts and construct themselves through their relationships with clients, their own family members and other health professionals. The bipolarity of thinking in medicine that classifies and juxtaposes the normal and the pathological (Foucault, 1973) has constructed a particular kind of gaze in health care; one that extends the normalisation and regulation of users of health services to include those providing the service. As health professionals, nurses are expected to be particular kinds of people whose actions represent the norms of professionalism and it is this relationship between nurses and the relations of power that

construct their subjectivity that is the focus for this inquiry. As Boutain (2005) suggests, nursing has been inclined to focus on the individual rather than the social conditions that work to constitute both health and illness and our experience of the health care environment. Nursing requires theoretical tools and practices of critical inquiry to refocus its gaze on how the individual nurse's agency and discursively constructed subject positions intersect within the relationships and practices that play out in health care settings (Allen & Hardin, 2001; Crowe, 2005).

This research draws on theoretical tools developed in Foucault's work on ethics and subjectivity to examine the knowledge and practices that shape new subjectivities and constructions of the self for the nurse as a family member who engages in the care of her own relative. The theoretical positionings for the research focus on the idea of reflexivity recognising that how we know arises from relationships between the knower and what is known. Knowledge is always already situated within particular historical perspectives and normative values about what counts as reliable ways of speaking and acting within a specific discourse (Bonner, 2001). Our experience of the social world is interpreted in the light of these relationships between what we know and how we know it, and in relation to the sort of expectations that we have of ourselves and the demands that others make on us within our communities of practice and family circumstances. In exploring the self's relation to the self, the analysis in this research seeks to understand how the nurse family member, in turning a professional gaze across her own family members, constructs new relations of the self to the self, and in doing so, transforms herself as a subject of discourse (Carolan, 2005).

This ability to transform the self's relation to the self requires new ways of thinking about and relating to accepted boundaries for knowledge and practice within our social and professional worlds. The ability to negotiate one's own participation in the normative practices of established social orders relies on a capacity to reflect on one's actions and the conditions under which we have come to consider that certain ways of acting are appropriate (Danaher, Shirato & Webb, 2000). This capacity for reflection

and critique and the ability to ‘sculpt’ the self in certain ways (Peters, 2005) is what Foucault meant by freedom as the ontological condition of ethics (Foucault, 1984/2003); the means to make our own subjectivity the object of self-reflexive thought and to transform ourselves through the choices we make in everyday conversation and action. This chapter explores the significance of Foucault’s conceptualisation of the relations of knowledge and the self to the self in framing nursing inquiry. The discussion examines the importance and relevance of these theoretical perspectives in providing conceptual tools to examine the stories nurse family members tell about themselves, the consequences of fulfilling obligations to their families and profession, and relations of power involved in the choices they make. Butler’s (1990) analysis of how people come to constitute themselves as discursive subjects provides some further elaborations of Foucault’s thinking, particularly her writing on normative prescriptions for gendered conduct.

### **Thinking and the unthought**

When external referents are no longer available as a means to legitimise knowledge claims, persuasion must replace logic (Kvale, 1997). Persuading others of the importance of particular knowledge claims calls for a particular kind of self-consciousness about the partial nature of one’s own theoretical positionings and the potential consequences of our ideas (Blacker, 1998). As a nurse exploring Foucault’s writing and attempting to shape his ideas as a theoretical framework for nursing inquiry, I have longed for some certainty about how the world is organised and firm ground to stand upon in making knowledge claims. This is precisely what Foucault’s writing suggests I cannot do; stand within certain essential truths as lighting a path to knowledge of the world in transparent and eternal ways (Foucault, 2003c). He argued that scientific methods can be appropriate to conceptualise concrete elements of the natural world but they are not sufficient to explain the breadth and diversity of human activity in the social world. In challenging the modernist notion of value-free science, Foucault calls our attention to the political nature of knowing and the constitutive relationships between knowledge, power and subjectivity.



The theoretical positionings for this research, generally speaking, take a postmodern approach in terms of conceptualising modernism as concerned with thinking and postmodernism with what is unthought (Hoy, 1991). In broad terms, postmodernism refers to groups of diverse ideas or ways of thinking that challenge the assumptions of modernist thinking. Postmodern thought problematises progressive and linear interpretations of history, generalised categories of knowledge, and reason as the key to effective action and emancipation (Cheek, 2000). It refutes the social coherence and progress that are hallmarks of modernist societies, instead recognising and respecting diversity, plurality and social discontinuity (Bauman, 1992). In doing so, postmodern thinking challenges the convictions of modernist knowledge claims, such as mastery over nature, and progressive movement toward a utopian freedom (Tarnas, 1991) proposing instead diverse ways of understanding human experience and knowing about the world.

Hoy (1991, p. 15) uses the metaphor of spinning a web to conceptualise the shift from modernist ways of thinking to Foucault's attempt to reflect on the unthought. As Hoy suggests, "knowledge is not the progressive discovery of the nature of the things themselves, but the spinning of ever more subtle webs of beliefs and practices". In conceptualising this web, the positivist might want to chart the spatial dimensions of it and categorise the spider according to known species. The spider would know it is a spider because external referents in empirical knowledge define it as such. And if for Kant, a spider's web is the product of its own experience and representative of its ability to know itself in the world, then the spider's web might at first glance be seen to emancipate the spider because it is an effect of its existence; an expression of its life and labour. But Foucault might have said that the spider is not really free. The web confines and imprisons its ability to think because it cannot live without nor conceive of a world beyond the web. In short, it does not know how it knows what it knows. While knowledge might feel enabling, and is productive of labour, life and language, knowing is always limited and partial. It is constructed within a web of comprehension that is

surrounded on all sides by the shadow of the unthought (Foucault, 1966/1970); that is, the power that conditions knowledge (Hoy, 1991).

The relations between the knower and the known, knowledge and power, and the self and other are central concepts in Foucault's project. By this he meant that we are not transparent to ourselves as the Cartesian subject was held to be, because the assumptions, social practices and relations of power that influence us are not always apparent in our thinking. There is no essential essence of the self that can be interpreted through experience because we cannot necessarily know the unthought that lies beyond the horizon of our perception (Hoy, 1991). The important difference that I see between the modern and postmodern subject dwells in how to think the unthought, because as Hoy suggests, if reflection and self knowledge are characteristic of modern thought, Foucault's approach requires us to practise knowing differently. He would have us not only reflect on our experiences but most importantly, transform our relationship with that upon which we reflect, and thus our relation to ourselves. In Foucault's terms, the mode of enlightenment thinking that equates reason with emancipation (Best & Kellner, 1991) is no longer sufficient, ethically or conceptually, to explain ourselves in terms of what we do not understand and cannot see.

### **Situating Foucault's critical history of thought**

Foucault's later work is generally positioned as postmodern because he resists enlightenment thinking, offering instead an understanding of the constitutive relationship between knowledge, power and subjectivity. In his terms, what counts as true and false is the result of complex, contestable and contingent processes and relationships in the constitution of knowledge (Hoy, 1991). But I am ambivalent about naming Foucault a postmodern thinker as he himself sought to resist such classifications as modernist strategies to define and categorise knowledge within its own episteme (Foucault, 1983/1998). Whether his analytical approaches were modern or postmodern, structural or poststructural is a point that has been debated. Hoy suggests that Foucault himself never accepted the label postmodern as he saw these terms as too simplistic in explaining the transformation in thinking that the "recasting of the subject" (Foucault, p.

448) from an essentialist humanistic position might have signified. He believed his project might better be described as a critical history of thought; an analysis of the conditions under which subjectivity is produced in the interplay between the relations of power and knowledge. Hoy writes that Foucault did not embrace the idea of postmodernity in his writing, suggesting that we should not think our time in history as the point where one thing ends and another thing begins. That is, modernity should not be thought as a distinct period that comes between the premodern and the postmodern; rather we should be concerned with the attitudes that have shaped and challenged dominant cultures over time.

Foucault (1998) considered that his approach to a critical history of thought was best used as an eclectic ‘tool box’ for critical inquiry. There are three distinct periods in his writing that represent both shifts and continuities in his thinking. *The Order of Things* and *The Archaeology of Knowledge* were concerned with how people form themselves as subjects of knowledge. These two texts represent Foucault’s quasi-structuralist phase while the genealogical method used in *Discipline and Punish*, which examined how power is exercised by the subject to act on others, is more consistent with postmodern thinking. Genealogy in this sense is concerned with the social practices that contextualise language; in particular the relationships between discursive disciplines and social power (Hoy, 1991). The ethics of existence in his later works on sexuality explore the relation of the self to the self in terms of how people work on themselves to practise morality in living their lives (O’Farrell, 2005).

Hoy (1991) notes Foucault’s claim that the ethics of existence, in terms of “how human subjects and their historically variant subjectivities are constituted either by unthought social practices and discourses or by not completely thought-out ethical self fashionings” (p.27), have been a central and consistent concern throughout his work. In designing a theoretical framework for research, it is more helpful to focus on the shifts in emphasis and perspective around subjectivity rather than what appear to be radical breaks in Foucault’s work (Allen, 2003). As O’Farrell (2005) suggests, Foucault saw his writing as a work in progress where writing and speaking reflected his thoughts about

how things could be conceptualised; an autobiographical work in the sense that his ideas reflected concerns in life. He believed that discourses are constantly reinvented and that no writer can expect their ideas to exist through time without modification and interpretation (Foucault, 1981/2003).

### **Subjectivity**

Subjectivity can be conceptualised as “an emergent property of a historicized experience”, (Alcoff, 1988 p. 431) where the categories of woman and nurse become points of departure emerging from the shifting cultural, political and social contexts in which they are embedded. While the theoretical positionings for this research focus on Foucault’s later work on the aesthetics of existence, consideration of his prior work on subjectivity is useful in understanding how he came to his later conceptualisations about the relationships between knowledge, power and the subject. He describes his critical history of thought as “an analysis of the conditions under which certain relations of the subject to object are formed or modified, insofar as those relations constitute a possible knowledge...” (Foucault, 1998, p. 450). In this sense, the term subject has two meanings, first as being subject to someone else through control or dependence and secondly, subject to oneself through self knowledge (Foucault, 1982/2003b). Using different conceptual strategies over time, he sought to examine the historical means and relationships through which human beings are made subjects of knowledge. He explains these different approaches in his essay on *The subject and power*.

My objective.... has been to create a history of the different modes by which, in our culture, human beings are made subjects. My work has dealt with three modes of objectification that transform human beings into subjects. The first is the modes of inquiry that try to give themselves the status of sciences.... In the second part of my work, I have studied the objectivising of the subject in what I shall call “dividing practices”. The subject is either divided from him-self or divided from others. This process objectivises him.... Finally, I have sought to study .... the way a human being turns him – or herself into a subject.... have learned to recognise themselves as subjects.... (Foucault, 1982/2003b, p. 126).

Following Foucault then, subjectivity, or our sense of ourselves, can be thought of as socially and historically constructed through discourse and always in the process of being reconstituted as we think and speak. It is precarious and contradictory; the site of conflict and disunity as an effect of multiple and conflicting simultaneous positionings in discourses (Weedon, 1987). Archaeology conceptualised the subject as dispersed in discourse, while genealogy analysed the constitution of the subject in discourse. The ethical analysis of care of the self explored the subject constituted in practice (St. Pierre, 2001). These different conceptualisations of the subject from the three periods in Foucault's work are explained in the following sections on archaeology as the relation to the truth, genealogy as the relation to power and ethics as the self's relation to the self.

*The subject in archaeology – the relation to truth*

In his later archaeological work *The Order of Things*, Foucault presents the subject as a construct that is dispersed in discourse and the object of modern scientific investigation. The subject becomes an entity constituted through external forces as an effect of language, history and practice, albeit with the potential to resist and remake this construction. The conditions of possibility for knowledge formation are examined to show how specific rules operate to include or exclude particular ways of speaking and acting within discourse, as fundamental codes of a culture (Best & Kellner, 1991). From the seventeenth century, modernist thinking reconfigured knowledge from resemblances in the premodern age into discourses that arranged representations of the world in logical order around identity and difference (O'Farrell, 2005). *The Archaeology of Knowledge* showed how the episteme, or theoretical structures or systems ordering knowledge within a given society, could be seen in historical artefacts. Foucault saw that all aspects of human behaviour were ordered within these epistemes and this ordering was always already limited and contingent upon a particular context and subject to challenge from coexisting orders (Foucault, 1966/1970). Even though some ideas would have been scandalous in their time, the present ordering of thought in western societies has become so much part of our landscape of knowledge that its historical construction and effects are no longer visible to us. Foucault argued that ideas

that are thought to have been universal and seemingly eternal have resulted from “very precise historical changes” (Foucault, 1988, p. 11).

Foucault was interested in the gaps or inconsistencies between social histories and the history of ideas. As he suggested in an interview with Martin (Foucault, 1988, p. 14)

Social historians are supposed to describe how people act without thinking, and historians of ideas are supposed to describe how people think without acting.... the way people act or react is linked to a way of thinking, and of course thinking is related to tradition.

In his examination of sites of discursive practice and their subsequent breakdown, Foucault wanted to show how systems of representation between words and objects change over time, creating new traditions. His idea of differential analysis sought the demarcation points among systems of representation to identify their effects and the differences and intersections between them (O’Farrell, 2005). He employed the idea of discontinuity to show that in the shift from one episteme to another, things become perceived or known differently (Best & Kellner, 1991). At the point of discontinuity, something new can be seen; a new order with specific kinds of vision and different arrangements of knowledge, which closed off other ways of thinking and acting. Systems of representation, such as the use of particular words to convey the meaning of an object, are unique to an order and make things visible in specific ways (Kendall & Wickham, 1999). Recognition of these historical changes and their effects allows an appreciation of how certain things have taken shape as objects of knowledge and come to be constituted as normal and natural when these shapes are often the outcome of quite random occurrences (Foucault, 1983/1998). Understanding the random construction of these shapes and occurrences in how people have come to know, relate to and value their world, creates the freedom to see things differently.

This interpretation of structures and systems of knowledge and practice had some similarities with the ‘structuralism’ that took hold in post-World War Two intellectual

writing in France. Structuralism, as practised by writers such as Levi-Strauss, Saussure, Barthes and Althusser, was a radically new way of thinking about the social construction of societies at a time when new ideas were needed to create alternative social worlds from the values and beliefs that had permitted the development of Nazi Germany in Europe (Foucault, 1980/2000). Structuralism rejected the universal Cartesian subject as the centre of human consciousness and existence and sought instead to examine the relationships between particular things and their structures that systematised knowledge, language, culture and societal practices. The major difference with Foucault's approach was that he did not seek to establish a theoretical model that could be universally applied to different situations in a predictive or propositional sense (O'Farrell, 2005).

*The subject in genealogy – the relation to power*

Genealogy has a wider scope than archaeology in terms of being concerned with how subjectivity is constituted in discourse “through a multiplicity of organisms, forces, energies, desires, thoughts” (Foucault, 1980a, p. 105). In moving away from the juridical forms of power that had conceptualised the subject within sovereign or legal models, Foucault looked for a way of showing how power is legitimated at a micro social and political level, what Blacker (1998) calls the ‘worm’s eye view’. He was interested in the historical circumstances where the effects of power come into being and work to construct the subject in specific ways (Foucault, 1982/2003b). Foucault saw that a new way of thinking about power was needed to conceptualise the links between specific rationalities and the relations of power within fields of human experience; a conceptualisation that located resistance to different forms of power as its point of entry for analysis, to “bring to light power relations, locate their position, find out their point of application and the methods used” (Foucault, p. 128). In other words, to analyse how subject to object relations in discourse are shaped and modified within relations of power, or the antagonism of strategies, as Foucault termed it, to constitute knowing.

The genealogical approach undertakes a history of the present, using history as a way of diagnosing the present to disturb assumptions about what we take for granted in our knowing, what we know and how we have come know it (Kendall & Wickham, 1999).

Using methods of suspicion and critique, it unsettles our familiar postures of knowing (Hook, 2005), making problematic what has previously been regarded as unproblematic, common sense and normal (Blackler, 1998). As Foucault (1998) suggests,

the problem is to determine what the subject must be, to what condition is he subject, what status he must have, what position he must occupy in reality or in the imagination, in order to become a legitimate subject of this or that type of knowledge (p.459).

By this he means that in order to study fields of knowledge and practice that construct particular kinds of subjectivities, we must find what perspectives have been subjugated or excluded from them, and on what terms and in whose interests other perspectives have been legitimated (Meadmore, Hatcher & McWilliam, 2000). Thus genealogy is a mode of critique that offers a set of suspicions about our relationship to objects of knowledge and the methods of knowledge construction that produced them (Hook, 2005). Its purpose is to produce an analysis that accounts for subjectivities that have been produced within historical frameworks and their particular relations of power (Foucault, 1980b). In illuminating the outcome of an historical event as contingent, or even accidental, rather than predestined; as one possible result of a complex interplay of relationships between events, genealogical analysis shows how power has been exercised in a particular context (Kendall & Wickham, 1999).

Power is always present in social life in that its operation is related to particular ways of knowing and acting. The relations of power that produce specific kinds of subjectivity are located within the regimes of knowledge and normalising practices that define and control the constitution of subjects (Best & Kellner, 1991). Subjection potentially divides the individual from the self and ties subjectivity to a particular kind of identity that constrains and separates a person from what they are otherwise capable of being (Foucault, 1982/2003b). Dividing practices include or exclude people or groups in terms of their fitness to belong to a social group (Danaher et al., 2000). Foucault sees power, not as something that acts directly on others, but rather as an effect of actions on



the possible present or future actions of others; as the management of possible ways of acting. Furthermore, power can only be exercised when people have the option of acting in different ways, so the exercise of power is agonistic in terms of being a complex interplay of “incitement and struggle” (p. 139). It produces unequal relationships between people because it invites people to participate in certain practices but at the same time subjugates and constrains them (Cordoba, 2006).

Foregrounding the conditions for the production of subjectivity politicises these aspects of everyday life, making the implications of becoming subject to particular discourses apparent, as well as the potential for resisting practices that alienate the subject from themselves (Best & Kellner, 1991). While power subjugates and induces certain actions over others, it also constitutes subjectivity in ways that produce capacities (Foucault, 1984a). Power is productive in that it generates differing kinds of knowledge and social orders (O’Farrell, 2005). It produces self knowledge, which is the means through which social forces are generated and ordered, as people are encouraged to work on themselves in particular ways (Best & Kellner, 1991). This conceptualisation of subjectivity as an active calling or interpellation constructs the potential for agency in interpreting how to perform subjectivities (Yeatman, 1994).

Locating the subject within relations of power creates the possibility of critique, contestation and subversion in ‘doing’ subjectivity within a specific discursive field (Butler, 1990). As Yeatman (1994) suggests, power should not necessarily be conflated with domination. While there are always historical and social constraints on people’s actions, there is also a degree of freedom in being able to perform subjectivity differently (O’Farrell, 2005). Foucault was always optimistic that things could be changed because power is associated with contestation and struggle and as soon as relations of power exist, so does the potential for resistance (Best & Kellner, 1991). Self knowledge produces the capacity to choose how to perform particular subjectivities, and in this choosing, enables people to participate in a micro-politics of power where negotiation, confrontation or accommodation of individual forms of identity is possible

(Yeatman, 1994). So the potential for self transformation involves knowing how to modify constraints on the self by mediating the impact of others actions. This contextual framing of power relations in the production of knowledge, that is, what we know and how we come to know, enables the effect of intertwined and competing subjectivities to become visible as political and ethical practices where people are transformed and transform themselves through their relationships with others. This notion of subjectivity as practice is further developed in the following section on genealogical ethics as the self's relation to the self.

*The subject in ethics – the self's relation to the self*

Foucault's later writing conceived the subject as constituted through the self's relation to the self as an ethical practice (Bevir, 1999). This third conception of the subject appears in his second and third volumes on the history of sexuality, where Foucault extended his emphasis on how subjectivity is constituted through the coercive effects of power to an exploration of how the subject responds to, and works with and reinvents the self within these effects of power (Poster, 1993). He used the phrase technologies of the self to show how power is constitutive in providing techniques and strategies for people to govern themselves as moral agents (Foucault, 1984a). Technologies of the self involve taking care of oneself in order to know the self by permitting

individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality (Foucault, 1982/2003a, p. 146).

Foucault's approach to ethics examines the relationship between care of the self and knowledge of the self where one has to search one's own wisdom and truth as a constant practice, before being able to know the self. It challenges the idea of knowing the self in the Christian tradition of renunciation and subjection to external moral codes and laws, which are the dominant modes of social morality in western traditions. In care of the

self, the subject becomes an intersection between aspects of his/her behaviour that need to be worked on and rules of conduct for what ought to have been done. Foucault (1982/2003a) identifies three technologies in this practice of the self: disclosure of the self to the self, examination of the self and conscience, and remembering truth. These technologies of the self enable the subject to make adjustments between what was done and what ought to have been done. In disclosing to the self, and examining their conscience, people recover knowledge of about themselves remembering what they have forgotten about rules of conduct for their own behaviour. The subject becomes the site where rules of conduct come into memory, and reflection, as a retreat into the self, serves to bring these rules of conduct, the truth about the kind of ethical being one wishes to be, back into the memory. Reflection creates the conditions for a 'widening of the self' to be able to think about who one is by meditating on the effects of one's own actions and imagining different possibilities. Knowing the self comes to light through these practices of care, concern and respect for the self, where self modification as a constant process of learning about the self that occurs through practicing the self within discourse.

Knowing the self through these practices of the self constructs subjectivity as an active process, where the self participates in modes of action that create a practice-oriented subjectivisation within discourse. While the subject is still shaped by power through discursive effects of normalisation and constraint, care of the self involves resistance to and refusal of discursive positionings that ignore the individuality of people and determine them in particular ways. The self is a site of resistance that pushes back against the forces that work to regulate, normalise and limit and delimit capacities through subjugation (Hofmeyr, 2006b). Resistance involves refusing the coercive pull of discourses that interpellate people as passive subjects, and through this refusal, reinvent subjectivity in new and creative forms (Foucault, 1982/2003a). The subject is never outside power in this process, meaning that subjectivity is not an autonomous process as it is always governed by power relations, but the idea of resistance reveals the potential for people to characterise their own identity and practise strategies of freedom in

choosing to be different (Best & Kellner, 1991). While the subject draws on social practices and knowledge that exist prior to the self, subjectivisation as care of the self furnishes people with the capacity to be discerning in accepting or refusing patterns of behaviour and ways of thinking that are imposed or suggested as discursive positionings (Foucault, 1988).

As Hofmeyr (2006b) suggests, Foucault sees the subject as an agent who participates in ethical self-creation toward a particular end, not in the sense of knowing what the self will become beforehand but as a process of sculpting the self through a process of production. This is a pedagogical relationship where the self is able to learn through practising careful, repetitive and disciplined techniques of the self. Foucault's (1983/2003a) elements of self practice in these techniques of the self are conceptualised as ethical substance, mode of subjection, self-forming activities and telos.

The ethical substance, that part of oneself that is taken to be the relevant domain for ethical judgment; the mode of subjection, the way in which the individual established his relation to moral obligations and rules; the self-forming activity or ethical work that one performs on oneself in order to transform oneself into an ethical subject; and finally, the telos, the mode of being at which one aims in behaving ethically (Davidson, 1998, pp. 200-201).

The first step in determining the ethical substance, as the aspect of the self that requires care, involves problematisation of one's own behaviour. This is a kind of diagnostic thinking that inquires into what one presently is and how the limits of self might be transgressed to create a better, more ethical self by stepping beyond the norms and rules that discipline people as uniform subjects (Huijer, 1999). As St. Pierre (2001) writes, the self must be confronted with what we are in terms of what we think and do. Problematising the relationships between our thoughts and our actions requires the ability to unfasten or mediate the bonds between the self's relation to knowledge/truth and power, so that the relation to the self uses nodal networks of power within discourse but is not totally subject to them. Through problematisation and redefinitions of self in

relation to truth, the subject retains this capacity to resist normative subjectivities and reshape themselves in new ways (Foucault, 1981/1988; Hofmeyr, 2006a).

Critical and creative thinking establish the second step in care of the self as the mode of subjection, or relation to a normative code, in order to fix the problem that has been identified through reflection and self critique. The mode of subjection is practised either as fashioning a particular kind of subjectivisation in discourse as a unique ethical mode of being or choosing subordination to a specific norm (Infinito, 2003).

In this moral form, the subject does not come into being by elevating the rules for his conduct to the general rule, but by way of an attitude and quest that individualise and transform his action and can even add a special lustre to the individual by way of the rational and well considered structure it grants him (Foucault, 1984/1992, p. 73).

Thus rules for conduct are drawn from existing social and cultural patterns and applied because they fit the subject's aspirations for ethical conduct, or modified and reshaped, to allow the subject to function in well considered alternative ways. Hofmeyr (2006b) suggests that while desire is a potentially destructive force that has to be moderated through practices of austerity and self control, Foucault entrusts the subject with its own ethicality. The subject is an ontological entity capable of choosing between different courses of action (O'Farrell, 2005). Subjects are therefore moral agents who take responsibility for their own self development, constantly re-evaluating the self's relation to itself as the subject of its own actions (Foucault, 1984a), choosing and resisting modes of subjection whether they result from forces of the inside or outside (St. Pierre, 2001). The subject's capacity for freedom is played out in these repetitive practices of self positioning within discourse and evaluation of the effects of their conduct.

Self-forming activities are the third step in the care of the self where the person works to transform themselves into an ethical subject by bringing their behaviour into line with aspirations to maintain their identity in specific ways according to chosen rules or codes

(Hofmeyr, 2006b). As Foucault (1984b) puts it, “at every moment one must confront what one is thinking and saying with what one is doing, with what one is” (p. 585). Transforming and improving the self requires an ascetic attitude; a training of the self by the self through activities that exercise the mind to broaden one’s thinking. An ascetic attitude creates freedom; “not a freedom from power, but freedom through power” (Hofmeyr, 2006a, p. 227) as the capacity to change one’s existence through self-forming activities that transgress the limits of their experience. This does not mean that people are free of the limits of their current context but rather that they are able to recognise, identify and clarify limits that are constraining and work on themselves in this space between limits and transgression (Taylor, 2003). Taylor (p. 262) proposes that

Self creation is not an unconstrained activity; while one does indeed constitute oneself as a subject through self-practices, doing so does not extricate one from prevailing social, political and ethical conditions. While we are able to decide how, when and in what way we engage in a particular set of practices (our actions are ‘voluntary and intentional’), these decisions are always limited (though not determined) by our social context.

While the context of self-practice is simultaneously enabling and constraining, the ability to detach oneself from prior knowledge of the self and objectify one’s own behaviour, enables people able to experiment with new ways of thinking, speaking and acting (Huijer, 1999, p.77) or positioning the self in roles and relationships (Cooper & Blair, 2002).

This confrontation of the self is a socially situated activity in the sense of its relation to, and responsibility for the consequences of interacting with and having an effect, on others (Foucault, 1984c). The self and others exist in a state of tension within networks of power, appearing as relations of force “whose point of contact functions as the limit that separates them”, but these “limits of the self are enlarged to make room for the other as other” (Hofmeyr, 2006b, p. 122/123). The self’s relation to the self, bends and reforms power relations to create an inside of the self that is derived from the power of

the outside. Subjectivity comes into being as an effect of the outside in relation to the other (Deleuze, 1988), where the other exists as divergent from but still in contact with the self. Foucault saw care of the self as a social practice where people reflect on themselves within relationships of friendship, kinship and obligation (Infinito, 2003). As he suggests,

Care of the self requires a relationship with the other insofar as proper care of the self requires listening to the lessons of the master. One needs a guide, a counsellor, a friend, someone who will be truthful with you (Foucault, 1984/2003, p. 30).

While the self-forming activities undertaken in caring for the self create new subjectivities that exist in relation to and encompass the care of the other, care of the self takes precedence in ethical terms. The person who practises an ascetic attitude in taking care of the self will be able to act honourably in their relationships with others, because “it is the power over oneself that thus regulates one’s power over others” (Foucault, 1984/2003, p. 31).

The final step identified in the care of the self is telos; the goal at which self-forming activities are aimed (Davidson, 1986) which is to live an ethical life with moral value invested in care of the self. This is the kind of person that we aspire to be in order to act ethically because as Foucault advises (1984/1992, p. 28),

A moral action tends towards its own accomplishment, but it also aims to go beyond the latter, to the establishing of moral conduct that commits an individual, not only to other actions always in conformity with values and rules, but to a certain mode of being, a mode of being characteristic of a moral agent.

Care of the self culminates in critical and creative modes of being that represent the telos of the ethical subject where knowing one’s relation to the truth, and understanding the effects of differing truths on the conduct of one’s life, is the ultimate goal. Deciding

how one wants to live in the world through an ascetic attitude requires the formation of sensibilities: awareness, responsiveness and receptivity to the self and others (Hofmeyr, 2006b). Subjectivisation of the ethical subject is a process that develops the moral and mental capacities of people to their fullest potential and this potential is characterised by the vitality, strength and independence of their thinking. The formation of sensibilities also requires the cultivation of our own individuality, not as an end in itself, but as the means through which we can know ourselves as distinctive and innovative individuals who are capable of appreciating the self and others (Clifford, 2001). The following section explores the potential of Foucault's critical history of thought and ontology of the self's relation to the self as a theoretical framework for nursing inquiry.

### **Theoretical frames for nursing practice**

Practice knowledge is constructed within the multiple intersections of individual and collective experiences that inform how clinicians come to know and interpret their clinical world and their own lives (Mackay, 2008). While nursing draws on multiple theoretical perspectives and standpoints to inform practice, empirical knowledge is held to enable the clinical reasoning and decision-making that underpins professional judgement (Higgs & Titchen, 2000). Propositional knowledge, based on scientific and realist representations of the body and its functions, constitutes an important discourse in nursing practice knowledge (Georges, 2003; Georges & Benedict, 2008). The ability to define, classify and ascribe meaning to particular representations of the body using the scientific language of anatomy, physiology and pathology offers nursing access to the expert power that such knowledge confers. It positions nurses as speaking subjects within medical discourse (Liaschenko, 1998), with access to its privileged place in the hierarchies of belief that inform contemporary health care (Starr, 1982). And yet, nursing requires a broader range of theoretical perspectives to reveal different ways of knowing about health, illness, and the social, cultural and physical contexts for nursing practice (Dzurec, 1989). The ability to articulate diverse representations of practice, with a scepticism about what constitutes knowledge, is important for nursing (Flaming,



2004), as a dynamic profession practised within complex and changing health care environments and relationships (Zander, 2007).

Diverse conceptualisations of knowledge for nursing are important to avoid replicating and reinforcing phenomena in traditionally accepted ways that have resisted change (Munhall, 1995). Gilbert (1995 p. 870) argues that nurses need “to be able to identify the discursive practices through which they as nurses are formed. For it is these practices, and their associated norms and values, which nurses then carry with them into their everyday roles”. These discourses define how nurses, and other people, think and speak about nursing. An analysis of the social practices that construct knowledge about nursing illuminates the multiple, complex and shifting subjectivities produced in the discursive relationships between power, knowledge and the self that regulate how nursing is practised (Crowe, 2005). A critical appreciation of how nurses are positioned within professional and societal contexts encourages nurses to think more deeply and thoughtfully about their practice in making the familiar problematic (Street, 1997). A critical nursing gaze affords the ability to interpret people, things and events in particular ways to draw certain conclusions about what might be happening in a given clinical situation or social context. A nursing gaze is both constituted by and is an effect of nursing knowledge in relation to the patient as an object of discourse. It comes into play through the nurse’s ‘look’ as the nurse constitutes her/his subjectivity in relation to the patient as the other. The effect of that gaze depends on the unique positioning of the nurse and how s/he performs subjectivity in the relation to the self and the self and other. The following sections explore the intellectual, political and relational work that underpins nursing practice knowledge and the nurse’s gaze. This framework has been developed from my reading of Cooper and Blair’s (2002) conceptualisation of Foucault’s ethics.

### *Intellectual work*

Nurses are knowledge workers who need to develop a theoretical self-consciousness about how they interpret and employ the concepts, frameworks and research evidence that informs what they know and do in practice. A theoretical self-consciousness, using

an epistemology of critique, makes the positioning of the nurse explicit within the relations of power that have constituted certain truths and calls them to account for their own ideas and arguments (Cheek, 2000). This attention to the relationship between knowers and how they know is an epistemologically significant issue as all knowledge is situated, reflecting the values, beliefs and assumptions of the subjects who produce it (Ceci, 2000). Cooper and Blair (2002) identify intellectual work as the ethical substance of professional life where the struggle for knowledge and a will to truth serve as a possible mode of subjection. Problematisation and critique are self-forming activities aimed at the telos of self transformation and intellectual creativity. The ability to disturb tradition to open up new ideas was seen by Foucault as an essential element of the intellectual or knowledge worker's role (Brocklesby & Cummings, 1996). The uncritical acceptance or total rejection of modern reason, rational thought and empiricism, are equally threatening to ethical conduct. Foucault (1984/2003) believed that empirical constructs were important and necessary to human life, but that these constructs, and their effects in human social life, should be constantly and critically examined. Critical thought involves showing that what is taken as obvious is in fact not so obvious but is rather an historical construction that has come to be taken for granted as true (Foucault, 1981/2003). Butler (2002) explains Foucault's notion of critique as not evaluating whether something is good or bad but attempting to illuminate the truths that underpin the constitution of it. She invites us to consider the following points about our relation to knowledge.

What is the relation of knowledge to power such that our epistemological certainties turn out to support a way of structuring the world that forecloses possibilities of ordering? Of course we might think that we need epistemological certainty in order to state for sure that the world is and ought to be ordered in a given way. To what extent, however, is that certainty orchestrated precisely in order to foreclose the possibility of thinking otherwise? (Butler, 2002, p. 4).

The epistemological certainties that become embedded in our thinking over time as the right way to approach a particular problem work to constrain possible alternatives. The

ability to pose problems and questions creates ethical practices that are prompted by knowledge that is foreign to the self. Critique, as a critical relation to norms, is the practice of questioning the limits of our knowing, interrogating theoretical assertions and evidence to expose the boundaries and limitations of epistemological fields (Butler, 2002). As Foucault (1988 p. 37) suggests, “since these things (contingencies that present themselves as necessities) have been made, they can be unmade, as long as we know how it was they were made”. He proposes that intellectual work requires ascetic practice to challenge one’s own and others thinking using techniques of reflection and meditation to suspend judgment and enable openings for creative responses and alternative ways of knowing.

People working in professional roles have a particular responsibility to challenge their own thoughts and practice because they are not only involved in transforming themselves. Health professionals have a particular relation to others in terms of how they interpret other people’s circumstances and experiences, offer guidance and advice and conduct interventions on patients’ bodies and minds. Their identity as subjects of professional discourse is formed in relation to the subjectivity of the other with whom they are engaged in the provision of health care (Foucault, 2003b). An epistemology of critique is an important political strategy for nurses because it has the potential to free them to form their own relation to theoretical ideas and research evidence for practice. It offers the potential for a nursing gaze that encompasses space to manoeuvre within existing discourses, employing frameworks with a critical eye, according to the circumstances that nurses find themselves faced with in practice. Making certain truths problematic gives precedence to strategies of inquiry where truth can be contested in an interrogatory sense; where dialogue between people enables the limits of different ways of knowing to be explored and weighed for their value in a given context (Cooper & Blair, 2002). As Miehl and Moffatt (2000) suggest, knowing oneself and one’s own relation to particular truths enables respect for the experience of others, which avoids the indignity of speaking for them (Foucault, 1977b).

### *Political work*

Social justice is an important ethical consideration to be attended to in analysing and assessing the value of human ideas and actions in enabling or limiting freedom (O'Farrell, 2005). The relationship between politics and philosophy is complex because to care for others, in Foucault's (1984/2003) terms as a governing subject who is involved in the care of others, one must first take care of the self. Hofmeyr (2006a) sees the self's relation to the self as a political subjectivity; a new way of thinking about governance as a 'politics of ourselves' where resistance to the normalising power of dominant discourses is possible through subjectivisation (Butler, 2002; Foucault, 1977/1980). While Foucault (1984/2003, p. 42) was reticent about making the link between philosophy and politics too explicit, he suggested that warning of the dangers of power is "an important function of philosophy" in calling into question "domination at every level and in every form in which it exists". Freedom arises through taking care of the self where freedom is an effect of self-mastery. Freedom is also a practice, a way of doing things that regulates the self through sustained reflection on the self's relation to truth and the effects of our own truth on others. Hofmeyr believes that while the self's relation to the self involves individual action, it has the potential to cause bottom-up social change, creating freedom as both an ethical and political action through constant de-individualisation of normalising forces and re-invention of them in new ways.

People, who position themselves with an ability to articulate the truth, practise power in creating their own freedom to speak from particular subject positions (Foucault, 1984/2003). Speaking positions are political in the sense of requiring the subject to carve out and claim a space to speak, as resistance to other modes of being. The capacity to resist being overwhelmed by the force of others talk and actions is also a political act. Health care is a political activity in the sense that people who use health services struggle for the freedom to negotiate their experience of health and illness. "The therapeutic relationship is always a power relationship" (Silverman & Bloor, 1990 p. 5) and health professionals usually have the most power in determining the focus and boundaries of that relationship (Cheek, 2003). However, as Miehls and Moffat (2000) suggest, it is no longer possible for the health professions to ignore political struggles or

view them from a safe distance. New emancipatory discourses, such as the Health and Disability legislation and cultural safety, have become apparent in the governance of New Zealand health care in recent years. Emancipatory discourses offer counter representations of the interests of marginalised groups (Friere & Macedo, 1987), whose particular needs and interests are not encompassed within the normative frameworks of dominant discourse. In health care, emancipatory discourses represented by statements such as the World Health Organisation (WHO, 2004) declaration that health is the right of every person, challenge institutional practices that do not take account of health disparities between different populations and their specific health needs (Giddings, 2005). These discourses provide alternative subject positionings for both nurses and patients, recreating once docile patients as active and vocal partners in health care (Wepa, 2005), requiring nurses to be present with patients and marginalised groups in ways that are concerned with social justice.

This new 'politics of ourselves' has created political work as the ethical substance for health professionals in the social world of health care, where the struggle for rights and resistance to domination becomes the mode of subjection. Self-forming activities in political self-work become an ethic of resistance and critique, with the practice of freedom as the telos or desired outcome of these self-forming activities (Cooper & Blair, 2002). Calling forth one's own story, as knowledge of one's own relation to truth, enables us to understand our own historical and cultural positionings in relation to users of the services we provide. In this understanding we create a relation to ourselves and others that avoids overpowering and reconstructing the stories of others in accordance with our own truths (Miehls & Moffat, 2000). Political work creates a role for nursing in mediating the biopolitics of health care where dominant discourses make patients into passive objects of a medical gaze. An ethic of resistance to, and critique of medical discourse, enables other representations of patients to appear and provides the means to work with people on the problems and issues that concern them. By this I do not mean that nursing should abandon the scientific ways of knowing that underpin our understanding of pathophysiology. Starr (1982, pp.3-4) reminds me that

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 a modern physician for a traditional healer. They recognise, in behaviour, if not in argument, that in medicine the dream of reason has partially come true.

What I am advocating here is the idea of ‘gazing with’ rather than at patients (Georges & Benedict, 2008). Using science as a lens to help patients to interpret and understand the physiological impact of disease processes in relation to their experience of both illness and wellbeing subjectivises them within scientific discourse with strengths and capacities rather than maintaining their subjection as passive objects of it. The idea of ‘gazing with’ positions nurses in a creative relation to themselves and others. It creates the potential to build capacity with patients by working with them on the self’s relation to the self, establishing a pedagogical relationship that supports them in living with the effects of illness in ways that might enable them to attain self-mastery in relation to a particular disease process or illness experience. It positions nursing with a gaze that is relational, drawing the other into a respectful didactic and educational relationship where the nurse intervenes in ways that compensate for the lack of capacities where necessary, but ultimately aims to free the patient to live well through their own relation to themselves.

### *Relational work*

Relational work, as the practice of focusing attention on the self in relation to others (Miehls & Moffat, 2000), could be thought of as the ethical substance of the social aspect of our professional and personal lives, where differing degrees of intimacy, community and connection serve as the mode of subjection. Self-forming activities may be seen as working on oneself through relational practices that involve reflexive strategies. The telos or aim of relational work is to achieve greater fluidity in roles and relationships through the imaginative exploration of possibilities that create ethical ways of relating to others (Cooper & Blair, 2002). Relational work involves the relationship

that we ought to have with ourselves when we act in professional roles, not as adherence to a professional code of ethics, but as a critically thought out and individualised professional identity that is responsive to the situations and interactions that present themselves to us (Mackay, 2007). It is an attitude towards relationships that takes into account the experience of the other by attempting to think about and question what influences us to act in particular ways (Foucault, 1984a). As Foucault (2003c) suggests, a critical ontology of ourselves involves analysing and reflecting upon the limits that have been imposed on us and finding ways to move beyond these limits in our relationships with ourselves and others. His ethics are focused on a considered form of freedom that departs from the universally applied standards that inform professional codes and boundaries as the basis for judging appropriate action. In taking care of ourselves and others within relationships, he asks us to be curious, imaginative and interrogative of ourselves rather than judgemental of others (Cooper & Blair, 2002).

For health professionals, focusing attention on the self in relation to others is an important aspect of coming to know ourselves as others see us. Given that we construct our identities as people and practitioners through our relations with others, reflexive strategies reveal how power manifests in our relationships by illuminating the cultural capital of privilege, as the knowledge and expertise, that we bring to encounters with clients. Care of the self in relation to others requires recognition of one's entrenchment in the language and culture of health care and the taken for granted assumptions about what is normally considered to be self-evident. It involves the ability to explore the genealogy of our own decisions and actions with a suspicion about the ways sedimentation of knowledge in practice can create expectations for behaviour that can unknowingly result in harmful effects (Flaming, 2006; Harper, 2003).

Reflexivity creates the potential for relationships to become negotiated encounters where identities can be contested and recreated in more emancipatory terms (Cheek, 2003). To be reflexive demands a conscious awareness of the self in relation to others as a process of self scrutiny (Chiseri-Strater, 1996) where one's actions are carefully

looked over and scrutinised with a view to how they could be made more ethical. Perceiving ourselves as the object of someone else's gaze creates the possibility of seeing things about ourselves that only others can see (Hardin, 2001; Mackay, 2007). Recognising the effects of one's actions on others creates an intellectual space to think about the limits of how we present ourselves and to develop alternative ways of relating in future encounters beyond the normalised, essentialised and privileged modes of being that are constructed through subjection within dominant discourses (Moffat & Miehl, 1999).

### **Summary**

This chapter has explained my interpretation of Foucault's critical history of thought as useful tools to draw attention to historical productions of the self in the analysis of the subject positionings that nurses are called to and work through. In developing theoretical frames for the research, my interpretations of Foucault's writing are situated and partial (Ceci, 2000), according to my reflections on his work within the differing relations of truth, power and self that circulate as the discursive field of Foucaultian thought. As noted in my references to other authors, I have also been influenced by other scholars' interpretations of Foucault's written and spoken texts, which emphasise different aspects and periods of his project. In my reading of his work, I have presented the idea of a critical history of thought as similar to postmodern thinking but not necessarily entirely consistent with it, as Foucault preferred not to position his thinking within an overarching episteme or period.

The discussion in this chapter has explored the value of Foucault's later writing on genealogical ethics in providing theoretical devices or tools to critically examine how people are involved in shaping themselves through relations of the self as a form of ethical deliberation within discursive relations of power and knowledge. I have emphasised subjectivity in its differing forms through the subsequent periods of his writing to show how he conceptualised the subject as both constitutive of and constituted within discursive relations of truth, power and ethics. The self's relation to the self examines the historical construction of the subject through an ascetic attitude where reflexivity is practised as an ethical strategy to critique the self in relation to the



effects of the self on others. Care of the self encompasses care of the other through problematisation of the self; it is a search for wisdom as the constant practice of critique and reinvention of the self, albeit within the constraints of discursive relations of power.

Theoretical frames for nursing practice are conceptualised as encompassing intellectual, political and relational work, drawing on Cooper and Blair's (2002) interpretation of Foucault's ethics as ontology of the self. A critical nursing gaze, constituted through intellectual self-work, calls nurses to account for ideas and arguments as reflections of their own situated knowing in practice (Cheek, 2000). Political work presents the self's relation to the self as a politics of ourselves (Foucault, 1977a) where we regulate ourselves through reflection on our own relation to the truth and its effects on others. Freedom to practise as a nurse is imagined as individual action undertaken within the broader collective of the profession, which is taken up as resistance to normalising forces and reinvention of them in order to practise in new and more ethical ways. Relational self-work examines the potential to develop greater fluidity and creativity in the relationships we have with others while working in professional roles. It describes the relationship that we ought to have with ourselves in creating carefully thought out and individualised professional identities that acknowledge the limits of our knowing and encompass the conditions to know differently (Mackay, 2007).

The following chapter presents a critical analysis of the contextual representations of nursing and lay subjectivities in the literature on nursing, palliative care, and home care in New Zealand as well as drawing on relevant literature on these topics from the global context. The analysis examines the historical emergence of nursing subjectivities that have constructed caring within professional discourse, which classify and divide subjects, and recognises them as professional or not on the basis of their knowledge and skill. The influence of health policy in constructing a discourse of informal family care in palliative care is also explored as a contributing factor in calling the nurse family member to fill the gaps between their ill relative's need for care and the health services that are available.

## **Chapter 3**

### **Contextual representations**

#### **Introduction**

This chapter critically examines representations of nursing subjectivities in literature on family caregiving as a nurse from a variety of geographical, social and cultural contexts. My curiosity about other nurses' experiences of caring for their own relatives led me to explore the literature on this topic, but despite intensive literature searches via CINAHL, Proquest, Science Direct and Google Scholar databases, using search terms such as 'family caregiving', 'nurse as family member' and 'palliative care', I found very few articles relevant to my experience from the time I began to search in 1997. There is little research that explores the forms and meaning of caring work across home and work boundaries and the implications that simultaneous paid and unpaid caring has for how women live their lives (Gattuso & Bevan, 2000). It was this gap in the literature about how nurses live within, and involve themselves in caring for their own families and communities (Mills & Aubeeluck, 2006; Ward-Griffin, 2004) that encouraged me to explore how the subjectivity of nurse family member is constituted in the discourses that are made available to them. I realised little research had been published on this topic, particularly in the palliative care field of nursing practice.

Since the mid 1990s, research on the impact of nurses' family elder caregiving responsibilities on work performance (Monahan & Hopkins, 2002; Rosenfeld, 2007; Scott, et al., 2006), and nurses caring for their elderly or critically ill relatives (Hurliman, 2004; Mills & Aubeeluck, 2006; Rutman, 1996; Salmond, 2006; Ward-Griffin, 2004; Ward-Griffin, Brown, Vandervoort & McNair, 2005) has emerged in the nursing literature. Therefore the literature chosen to inform this chapter on contextual representations of nursing subjectivities within their own families draws on research from Canada, the United Kingdom and the United States of America. This literature

reports on research undertaken with nurses who have cared for their own aged relatives or in situations where a relative is experiencing a life-threatening illness. New Zealand contextual factors in the delivery of palliative care services are also considered in relation to the international literature on the nurse as a family member.

The discussion in this chapter draws on Foucault's (1984/1994; 1998) conceptual tools of curiosity and critique to examine the discourses that appear to constitute the subjectivity of the nurse family member in the literature. These discourses, and their relationships with other discourses and institutional practices, are identified as sites of difference where struggles about what constitutes the relation to truth, and what authority defines such truths, are played out (Rolfe, 2000). Assumptions about the appearance of differences between, and silences within, discourses on caring, family, professionalism, workforce and palliative care are made explicit as a way of 'troubling' or making problematic what appears to be normal and settled about these discourses and the knowledge and practices that they inform. In focusing on this interface between women's family and work lives as nurses, I surface some of the implications of a divided identity for women in performing simultaneous subjectivities as a nurse and family member. 'Troubling' this site enables me to examine the relations of power that create and sustain these discourses and offer alternative ideas as possible interpretations of boundaries as sites of tension and creativity (Powers, 1996).

Gender is used in the following discussion as a way of representing the effects of subject positions that are available to women within the discourses that are available to them. Women are conceptualised as called into being with multiple and sometimes contradictory subjectivities that are performed as within their family and work lives, women. The formation of these subjectivities both reiterates and challenges societal norms and values about the kinds of people women are and what they ought to do (Butler, 1990). Therefore gender is used as an "analytical rather than ontological category" (Ceci, 2004 p. 74); a category composed of the variety of subject positions that women are invited to inhabit rather than the ontology of an essential female subject

with inherently natural qualities. As such, the concept of gender makes the characteristics, behaviours and moral responsibilities of women visible as performances that are enacted in response to calls to participate in discursive practices as women. This participation is always mediated by normative codes that define subjectivity in terms of divisions; that is, in relation to what one is not (Rose, 1996b). Gender, in this sense, is an effect of discourse that can be traced to historical surfaces of emergence where meanings and assumptions have become visible in discourse, together with the power relations that have produced them (O'Farrell, 2005).

### **Historical emergence of nursing subjectivities**

Nursing subjectivities, performed in caring relationships with others, are informed by the dominant discourses that have shaped nursing and the position of women within the family (Crowe, 2000). These discourses define and differentiate caring activities within public and private realms of social life according to norms about how professional and personal relationships are constituted and practised. The historical emergence of nursing as a professional discipline, “transferred the skills and roles of taking care of others in the private realm of the home to the public realm of the clinical workplace” (Crowe, p. 964). It was a calling built on discursive constructions of women as innately caring that have been deeply embedded in family discourse, which positioned women and their family relationships and obligations within the private domain of social life (Eichler, 1988; Keddy, Gregor, Foster & Denny, 1999), albeit with particular civic responsibilities to New Zealand as a developing nation. Over time, family discourse has been informed by multiple, and sometimes competing, religious, feminist, scientific, civic and colonial military discourses that linked the health of the family to the state (Nelson, 2001). The religious discourse that informed the early development of nursing in Europe opened up nursing as a site for women's work in the service of God, drawing on subjectivities of mortification to allow women to enter sites of degradation and danger (Nelson, 1999). This religious discourse was mediated by secular discourses that linked civic reform with liberal feminist aspirations to professionalise nursing as a women's occupation, culminating in the statutory regulation of nursing as a distinct occupation with specific expertise (Nelson 2001; Wanhalla, 2007).

The creation of nursing as a profession heralded the construction of new subject positions for nurses as experts on the relationship between hygiene and health (Wanhalla, 2007). On the one hand, nursing drew on liberal feminist discourse to provide women with a standpoint from which to enter public life with a sense of purpose; to emancipate them to be able to function on equal terms with their male counterparts (Bashford, 1993). However, Bashford shows how nurse reformists who overstepped the boundaries of their role as women, by challenging the male authority of medicine in the late nineteenth century, were likely to be disciplined and removed from their positions of authority. It seems that the women's sphere was allowed entry to public life so long as women maintained the subordination of their public roles in relation to male authority as a mirror image of the relations of power within the family. Nurses were subsequently co-opted by the state to protect the health of the nation through their ability to call other women to account for themselves as women and mothers, primarily through discourses on hygiene, sexuality and mothering.

Wanhalla (2007) suggests that as the twentieth century progressed, public policy on health and social welfare focused on repairing damage to New Zealand's population from the decimation of two world wars by calling on women's reproductive capacity within the family. Nurses participated in the discursive practices of these times, including the social and moral surveillance of families and the education and discipline of women as practices that fulfilled notions of service and duty. A divided nursing identity characterised by the contemporary discourses on *caring for* and *caring about* (Ward-Griffin, 2004), has its origins in these historical events that have shaped the meaning of nursing practice over the past century. Caring discourses both unite and separate women, nursing and the family, bringing the emotional and nurturing work that women undertake within the family into the public sphere of professional nursing (Crowe, 2000). Ward-Griffin sees the dichotomy between public and private spheres of life, professional and personal knowledge, and paid and unpaid caring work, as an artificial boundary dividing nurses' work and knowledge from their family life. It

delineates and divides the knowledge and activities related to ‘caring for’ people in a paid professional capacity distinctly from the ‘caring about’ that defines personal or family relationships.

### **Public and private discourses on caring**

Caring is central to women’s lives (Gilligan, 1982), both as women and nurses and much of this caring work remains invisible within the family (Ross, Rideout & Carson, 1996). Caring discourse, in the form of the ‘careful nurse’, emerged from Nightingale’s (1859/1970) writing on ‘watching over the sick’, to protect and nurture those in need of care (Stevens & Crouch, 1998). A renewed emphasis on caring appeared in the nursing literature in the 1980s with researchers using predominantly interpretive approaches to explore lived experiences of nursing practice, health and illness (Euswas & Chick, 1999). Caring has been held to be the defining element of nursing relationships (Andrews & Roy, 1986), as a moral ideal and a unifying focus for nursing practice (Watson, 1988). It draws on moral discourses of duty and beneficence that focus the therapeutic work of nursing on relationships (Leight, 2002; Morse, Solberg, Neander, Botteroff & Johnson, 1990), with assumptions about service to others (Crowe, 2000) signified by terms such as presence, attentiveness, knowing the client, being concerned (McCance, McKenna & Boore, 1997) and being engaged in relationships (Davies, 1995).

Stevens and Crouch (1998) suggest that caring creates contradictions for nursing in that it articulates with traditional discourses that presume women’s ‘innate’ and biologically determined ability to care, where women have a natural “disposition towards empathy, kindness and self sacrifice” (Reverby, 1989 p. 7). On the one hand professionalism has given nursing knowledge particular kinds of authority and expertise (Thompson, 2008), but caring discourse has the potential to reinforce nursing practice as a mirror image of women’s work within the family and reiterate the hierarchical practices that have divided traditional male and female domains. Nurses are positioned at this interface of public and private caring practices that they undertake within their work and family life (Ward-Griffin, 2004). Ward-Griffin conceptualises this interface of nurses’ work and

family roles as degrees of caring for and caring about people. Her research with nurses, who were acting as family caregivers for elderly relatives, used a socialist feminist methodology to illuminate the connections and tensions between the public and private aspects of caring, what Ward-Griffin calls a false dichotomy or artificial boundary. The research draws on a Marxist structural analysis to show how the state extracts surplus value from women's labour within the family as a site that is concerned with reproduction and maintenance of the workforce. In this sense, power is seen as invested in structures rather than in relationships. However, socialist feminism also draws on the concept of patriarchy from radical feminist theory to analyse women's agency as purposeful actors (Wharton, 1991) in choosing to negotiate the performance of gendered subjectivities.

While it was conducted with a population of twenty nurses in Canada who were involved in the care of aged relatives, the findings of Ward-Griffin's (2004) research are relevant to this study in terms of how nurses recognise and enact their agency in negotiating their participation within particular events that are described in the study. She presents a discourse of *caring for* in a paid capacity outside the home as being informed by professional discourse that defines the requisite knowledge, skills and attitudes for competent nursing practice. It is delineated from the expressive and affective discourse of *caring about* (Ross, et al, 1996) that is connected with women's roles within their families. The discourse of *caring for* invites women to position themselves 'professionally' when they are practising in 'formal' roles involving paid employment. It draws on ideas of objectivity and distance where the subject of professional discourse divides the self from others to demarcate professional identity and status (McLaughlin, 2003) and enact normative responsibilities (Shirley & Padgett, 2004). Professionalism emphasises the technical aspects of caring as impartial and neutral services (Green, Gregory & Mason, 2006) carried out with the client in the belief that people are best able to be helped by someone who is not emotionally involved with them (Fook, 2000). While this position reflects the discursive practices of the dominant 'professional' discourse (Agger, 1992), it does not mean that personal experience and

emotional responses cannot usefully and appropriately inform professional knowledge (Osmond, 2005). As Ceci (2000) suggests, knowing is both enabled and constrained by situatedness. Working in complex situations of competing interests and locating oneself within particular contexts as a responsible social agent could be considered as elements of expertise that health professionals require (Fook, 2000) in contemporary health care settings.

Ward-Griffin (2004) notes the involvement of nurse family members in the care of their own relatives creates situations that can be very complex. Her research found that some nurses were able to blend caring constructs across professional and personal boundaries within their everyday practice and family care, while others chose to limit the degree of their participation in *caring for* family members. However, *caring for* family members was viewed by most of the participants as a natural extension of their professional caring work. As the nurse in the family, they felt obliged to be involved in the care of ill or aged relatives and had high expectations of themselves in doing so. Some of the participants in Ward-Griffin's study limited aspects of care that were too intimate and crossed the boundaries of cultural norms in family relationships. They also said that when invited to participate in clinical conversations with health professionals about their relative's care, they felt they could not express emotions and 'be clinical' at the same time. Mills and Aubeeluck's (2006) phenomenological study in the United Kingdom also noted the complexity of relationships for their participants who were involved in the care of their own family member in a situation of life-threatening illness. This study points to the idea that nurses interpret their professional and personal worlds as 'already knowing' subjects. Nurses move into situations involving the health and illness experiences their own family members with a body of knowledge that enables them to focus their professional gaze within a personal space in ways from which they may be unable to disengage.

The discourse of *caring about* is informed by notions of relationship, duty and emotional engagement that are the norm for women's role within the family. *Caring about* constitutes a paradoxical space for nurses who are required to engage with clients



in professional relationships but avoid being ‘over involved’ (Oakley, 1992; Scott, 2000). While it may be present in professional relationships, *caring* ‘too much’ *about* a client is seen as constituting a dual relationship, which is held to be potentially hazardous for both the nurse and client. Conversely, nurses are required to engage clients enough to appreciate the uniqueness of their situation (Gadow, 1999), and not caring enough is likely to be seen as a boundary violation in terms of under involvement (Peternelj-Taylor, 2002). These contradictory positionings require constant negotiation of both closeness and distance that do not necessarily account for the continuities in women’s caring work (Ward-Griffin et al., 2005) across different social spaces (Thompson, 2008) and the complexities of nursing in the community in which one lives (Mellow, 2005). The ability to *care for* another person in the professional sense thus requires a mode of subjection involving the appropriate normative distance. But Ward-Griffin et al. note the expectation from families and health professionals that women who are nurses ought to provide unpaid professional care to their own family members.

Feminist analyses see women’s commitment to care as deeply embedded in gendered arrangements of caring (Benoit & Heiting, 1998) that are created, maintained and contested within the family. The ‘caring self’ is a discursive construct that signals the performance of a particular kind of gendered identity within family relationships (Davies, 2003). Caring has been an important normative value for the ‘respectable’ and ‘responsible’ women whose labour has sustained social and reproductive relations (Skeggs, 1997) both within and beyond the family. This discursively constructed normative ideal of the ‘caring self’ perpetuates the belief that women are more emotional than men and therefore naturally better suited to undertake physical and relational work that involves emotional labour (Forssen, Carlstedt & Mortberg, 2005). Since caring is seen to be natural for women, the assumption that they do so effortlessly undervalues the contribution women make to families. Forssen et al. see women’s socially constructed sensitivity to caring as one reason why women may have difficulty setting limits on, or withdrawing from, caregiving responsibilities within the family.

### **Negotiating the call to care**

The call to care is premised on a sense of obligation. Caring for others is relational in the sense that it is bound to sets of rights and relationships and their inherent obligations (Sacks, 1967). The ‘long arm’ of the family has traditionally called women to care (Hoffman & Mitchell, 1998; Reverby, 1987) as wives, daughters and mothers with duties of service to others that transverse geographical distances and other life responsibilities, including paid employment. It could also be said that nurses are often called to care for their own relatives (Ward-Griffin, 2004) as an extension of the social generosity (Frow, 1997) that informs their paid professional caring work as nurses. However, in performing caring practices, both nurses and women maintain the capacity to resist, contest or transform how they care (Davies, 2003). Examining these sites of negotiation and contestation of boundaries illuminates the competence and agency of discursive subjects in negotiating their own actions and interactions with others (Anderson, 2004). As family members, nurses are uniquely invited to inhabit subject positions in discourses of *caring for* and *caring about* their family members and clients simultaneously. Women negotiate the subject positions available to them as active social agents (Thompson, 2008). In making this point I recognise that the subject positions nurses and women occupy are historically constructed within particular social relations (Skeggs, 1997) but as Anderson suggests, the circumstances that arise in people’s lives can move them to respond in new ways that disrupt normative expectations of taken for granted social positions.

Ward-Griffin’s (2004) conceptualisation of the provision of unpaid professional care to family members by nurses as ‘double duty’ caregiving indicates that nurses, who are in paid employment, fit responsibility for family care around their professional work. They are involved in similar activities in their professional work and family roles, albeit that in the public domain both the nurse and the client are replaceable (Crowe, 2000), and family relationships have deeper emotional attachments and commitments. The research on nurses as family members suggests that nurses respond to the challenges of being involved in the care of their family members in a variety of ways (Hurliman, 2004; Laylan, 2006; Mills & Aubeeluck, 2006; Salmond, 2006; Ward-Griffin, 2004; Ward-

Griffin et al., 2005). Central concerns for nurses in these studies involved the struggle to manage the self as a nurse and family member, using nursing knowledge and skills in the care of a family member and keeping watch on the quality of care that the family member received. Other concerns included managing the tensions and responsibilities in the care of a family member as a nurse, maintaining family and professional relationships and making sense of the whole experience.

The recognition of oneself as a nurse within family relationships challenges nurses in some unique ways when family members become ill. Nurses are positioned with their families and professional roles with specific ‘inside’ knowledge (Laylan, 2006) and find themselves challenged in negotiating roles and relationships across personal and professional boundaries (Mills & Aubeeluck, 2006; Ward-Griffin, 2004). In making their own family member visible within a nursing gaze, nurses are faced with objectifying a loved one within medical discourse that illuminates the person as a patient with a particular type of body, which in turn becomes a site of specific types of action (May, 1992). Crowe (2000) argues that nurses project their own subordination within the health care institutions and services that they work in onto their patients, where the patient is expected to be docile and grateful for the expertise that nurses and other health professionals provide (Fox, 1993). In this process, nurses become dissociated from patients; among them but not with them (Frank, 1991) in the sense of living the consequences of trauma and illness. In the public space of professional care, the relationship between the client and nurse is limited in terms of time and degree of involvement and is constantly renegotiated and replaced with other recipients of care.

Discourses informing nurses’ personal and professional lives collide in the moment of recognition of the ability to interpret a loved one’s body as pathological through readings of it within medical discourse. This discursive collision is both enabling and constraining (Crowe, 2000). Participating in the care of a loved one enables nurses to participate in illness experiences with family members with a deep appreciation of the meaning of these events and the suffering that is associated with them. It is an experience that has the potential to reshape the nurse’s professional practice and provide

for personal growth through reflection on profound life experiences (Mills & Aubeeluck, 2006) that illuminate one's own values and beliefs about life and nursing. However, it is also constraining in that nursing knowledge makes the implications of a diagnosis visible to the nurse family member in ways that may be disturbing and difficult to manage in the context of one's own family (Mills & Aubeeluck). Knowing the course of events for clients in life-threatening situations is often a difficult aspect of nurses' professional work with clients who are not previously known to them, particularly if they are concerned about medical interventions that may prolong suffering (Cronqvist, Theorell & Lutzen, 2004). This may be doubly difficult in the context of one's own family where notions of duty and responsibility to family are tested by having to live with the aftermath of making decisions about care.

Nurse family members are acutely aware of what can go wrong with their relatives as patients in health care services and act as the family guardian in overseeing care (Mills & Aubeeluck, 2006; Salmond, 2006). Similarly, Laylan (2006), in her American grounded theory study of ten registered nurses, called the nurse family member the 'watchful gatekeeper' whose nursing gaze oversees the quality of care to protect their relative from harm. Nurse family members are likely to be noticed by other nurses and health professionals when they are either known to health care providers or engage in conversations in ways that convey a professional level of knowledge about their relative's care. Salmond suggests that other nurses and health care professionals see the nurse family member as more active in the patient's care and more demanding of staff. They may also be challenged by the nurse family member's ill-defined status within professional and institutional practices that position discursive subjects with particular classifications and status that make their level of knowledge, skill and degree of authority immediately obvious.

Laylan (2006) calls balancing the multiple roles of the nurse family member 'walking a fine line'. Nurses are able to let go of their nursing role in the care of a family member to some degree when they have detailed information and confidence in the staff providing care (Salmond, 2006). However, dissatisfaction with aspects of care causes

distress if nurse family members are not able to communicate their concerns effectively to staff involved in a relative's care. Mills and Aubeeluck (2006) reported how all the participants in their study felt dissatisfied with some aspects of the care their relative received and were unsure how to respond in situations where less than adequate care was given. The concern expressed by these nurses about criticising other nurses showed how their positioning as employees and colleagues in the health care services that were providing care to their relatives mediated their ability to intervene in preventing the provision of less than adequate care.

Hurliman's (2004) descriptive qualitative study of eight female nurses providing care to their parents or in-laws in Alaska showed both positive and negative impacts of caring for their parents as a nurse family member. Hurliman found that the participants in her study had pivotal roles in providing care to parents because they were nurses and used their authority as a nurse to inform decisions about care. In some families where siblings did not participate in giving care to ill family members, nurse family members were left with feelings of anger and resentment that were destructive in their relationships with siblings. Families call on their nurse family members to interpret medical and treatment information, bestowing them with a particular kind of expertise in negotiating paths through illness events and involvement with health care services (Laylan, 2006). Nurses may have ambiguous positions within their own families where they are seen as being able to call on expert knowledge, experience and professional networks that other family members do not possess (Mills & Aubeeluck, 2006).

Being involved in the care of an ill or dying relative is a challenging and potentially life-enriching experience that enables family members to engage in relationships with each other and to find meaning in the events surrounding the person's illness or death. Following their study in northern England with participants receiving treatment for cancer, Chattoo and Ahmad (2008) argue that families exercise choice in both fulfilling and not recognising a responsibility to care and in choosing the most appropriate family member to participate in caregiving. They see caring for a family member as a practice that is embedded within already existing sets of relationships that have both moral and

material legacies (Finch & Mason, 1993) informing reciprocal obligations. Chattoo and Ahmad also see cultural frames as giving meaning to caregiving experiences within families. They suggest that within certain cultural ‘scripts’ caring has a moral purpose on its own account that is legitimised by the illness or incapacity of another and the cultural norms that are used to interpret conduct in the face of such life events. While the way these obligations are fulfilled within families can be as important as the obligations themselves, these authors make the point that people are differentiated from others in terms of knowledge, understanding and experience. Even within the same family, people may interpret normative responsibilities differently according to their own sense of self worth in the context of a family member’s illness.

### **The relation to self as ‘nurse family member’**

Caring for ill or incapacitated people within the family tends to be conceptualised as a burdensome experience where the caregiver has little control over their degree of participation in the care of a relative. The literature on female nurses and other health professionals identifies negative affects of family caregiving on women’s mental and physical health, social life and overall quality of life (Mills & Aubeeluck, 2006; Ward-Griffin, 2004). Women participants in these studies related a sense of being in overdrive where their own lives were disrupted by the constant demand for care of others. They found themselves constantly tired and neglected their own health needs in terms of exercise and health screening activities (Hurliman, 2004). Yet there is some evidence to suggest that women are inventive in reframing and organising caregiving responsibilities into opportunities for self growth (Wuest, 2000). Ward-Griffin et al. (2005) agree that the female health professionals in their Canadian study demonstrated agency in choosing how they would participate in caring for family members and demonstrated resilience in responding to the demands of care within the family. This study shows how women participate in the subject position of the ‘caring self’ that is discursively produced and reproduced within family and work environments.

As Davies (2003, p. 721) notes, people have the potential to transform themselves, for better or worse, through ‘doing’ subjectivity. She suggests that the actions of individuals

need to be understood within their social context where “there is a relentless and reflexive process of these other levels influencing individual action and individual action similarly constructing, maintaining and even altering .... structures, symbols and discourses”. Ward-Griffin (2004) and Ward-Griffin et al. (2005) show how nurses and other female health professionals engage in discourses of caring for and caring about with differing intensities according to the sense of obligation or duty that draws them to engage in caring for a family member. While some nurses reported high levels of stress and associated health problems associated with family caregiving, they were also able to negotiate strategies to manage the workload and responsibilities involved with it. Nurses, whose stories reflected they were primarily positioned within the discourse of *caring about*, were more able to contain expectations of family members and health professionals that they would undertake professional nursing work within the family. Others had a deeper involvement in the clinical care consistent with the discourse of *caring for*. This second group of nurses was able to blend emotional attachment with clinical care to the degree that boundaries between formal and informal caring roles virtually disappeared. The perceived sense of need in the family member and the nurse’s degree of confidence in providing clinical care were important factors that mediated this degree of involvement.

Wuest’s (2000) feminist grounded theory study on women’s management of caregiving demands shows how women develop strategies to organise family commitments in ways that reduce or overcome potentially negative aspects of caring demands. Women have few resources to take on additional work within the family when they are already working in paid employment and caring for children. Wuest suggests that the most difficult challenge for women is the changing nature of these caring demands and their own expectations about how to respond to them. Referring to Wuest’s (1998) idea of ‘precarious ordering’, Ward-Griffin et al. (2005) show how the women in their study set boundaries on caring demands and negotiated aspects of care. These authors identified three stages of intensity in family caregiving from periodic and manageable requests for assistance, moderately demanding expectations, and finally high expectations that required total immersion in caregiving activities. In the first stage, women were able to

set limits to contain the expectations of other family members and health professionals, but this ability to limit their involvement depended on the severity of perceived need for care, the degree of obligation felt by the women and the availability of others to fulfill caregiving needs. Ward-Griffin (2004) noted that women who primarily positioned themselves in the discourse of caring about were more able to limit their degree of involvement.

In the second stage, identified as ‘working to manage’, Ward-Griffin et al. (2005) noted that the women’s degree of involvement in caregiving work had increased over time to the point where they were doing more for their family member and strategies for limiting care were no longer as effective. They were also providing more care that moved them beyond what they considered their area of expertise or comfort zone. The lines between professional or formal care and informal care became increasingly blurred as they moved to fill gaps they recognised in their relatives’ need for care. In this stage, nurses, and other women who were caring for family members, made continual readjustments and accommodations to achieve balance in their lives. They used their professional connections with people and systems to ensure their family member had access to timely and appropriate health care and support services, particularly when they knew services were available but were being withheld. They delegated care to paid services or other family members when they recognised that the need for care had moved beyond their capacity to manage. The final stage of ‘living on the edge’ was seen more often in women who positioned themselves primarily in the discourse of *caring for* but may also have been apparent for women whose workplace and social supports were limited and the demand for care high. These women sometimes faced extreme exhaustion and withdrew from other obligations that impacted on family caregiving, such as paid employment.

Ward-Griffin (2004), Ward-Griffin et al. (2005) and Wuest (2000) show how nurses and other women constantly renegotiate the conditions under which they are prepared to care by resisting and contesting family expectations and accommodating the changing environment within the family. They capture how the women in their studies made



active choices about how they participated in family caregiving and in doing so demonstrated the necessary skill, foresight and ability to recognise their own capacities to respond to the demands of their families and other aspects of their lives. Foresight demonstrates knowledge of the potential for caregiving demands to move beyond their control and the ability to resist this potential by developing strategies to contain them. The ability to set limits on their degree of involvement shows how they recruited alternative resources to fill perceived gaps in care in the form of paid, voluntary or family help. Recognition of fraying connections, when the women saw the potential for the boundaries around their role to collapse, reveals their ability to see the need to care for the self in the face of exhaustion or their own health issues. It also illuminates how they actively chose which losses they were prepared to sustain, or put on hold for the time being, in the face of potentially overwhelming family caregiving workloads.

### **Research on family-work conflict**

In an early study, Ross, et al. (1994) identified tensions in the balance between nurses' personal and professional caregiving careers among a population of forty nurses providing care to children and/or elderly parents in Canada. This qualitative study found that nurses' lives involved a highly complex mix of work, family and study demands that created tensions and conflicts between competing demands for time and attention. A sense of being torn between two worlds was reported by the participants in providing care to both their families and clients, attempting to complete university study, and participate in community activities. These feelings were exacerbated when a family member was ill and required an increased level of care. Alternatively other nurses reported a sense of control in that paid employment gave them control over their financial resources and an increased sense of self worth and confidence through making a contribution to society.

Over the last decade, the relationship between family commitments and paid work roles has become the focus of increasing interest for researchers as nurses have become a scarce resource in health care settings. However, much of the research that reports on interactions between paid work and family life roles tends to draw on dominant

discourses that define modes of subjectivity, and thus position people, within predefined roles and norms that have the potential to limit women's capacity to negotiate these interactions (Runte & Mills, 2002). Runte and Mills argue that research on the interface between paid work and family life lacks a sustained analysis of the impact of gender. They suggest that dominant discourses construct paid work and family life as binary opposites separating the public and private domains of life. The interface between work and home becomes a site of competing interests, where employers and families each make demands for resources and conflict is inevitable. This conceptualisation of conflict is seen in the 'spillover' model (Barnett, 1994; Small & Riley, 1990), which in itself implies a normative separation between work and family. Dominant discourses on both work and family normalise gendered values about the position of women within paid employment and their primary responsibility for caregiving roles within the home. The disconnection of home from work is informed by patriarchal discourse that values work over family and male cultural models of workplace practice as the norm (Mennino, Rubin & Brayfield, 2005). In doing so, it also illuminates women's ability to balance their family and work responsibilities within the constant scrutiny of a gaze informed by male values.

Research on the relationship between nurses' family caregiving and paid work roles or double duty caring, highlights negative effects of spillover from home to work. The discourse of conflict assumes that increased demands in one domain of life will deplete the other. This depletion is conceptualised as either time-based or strain-based conflict (Runte & Mills, 2002). Studies on double duty caring have identified mental and physical fatigue, increased levels of stress, time away from work and less satisfaction with performance at work as 'spillover' effects of multiple caregiving roles (Grzywacz et al., 2006; Monahan & Hopkins, 2002; Rosenfeld, 2007; Scott, et al., 2006; Ward-Griffin, 2004). These effects become visible within the discourse of risk management as the potential to make a drug error or other mistake (Grzywacz et al.; Scott et al.), and productivity in terms of decreased work output and the lack of ability for these nurses to provide high quality care (Killien, 2004). Inflexible work rosters and a lack of understanding from managers and colleagues (Hurliman, 2004; Ross et al., 1994) about

the demands of family caregiving responsibilities is one of the leading reasons that nurses give for leaving their employment (Gould & Fontenla, 2006; Reineck & Furino, 2005).

Other research (Mennino et al., 2005) suggests that there is a relationship between the increasing demands of workplaces as ‘greedy’ institutions that are extracting more from employees in the face of health workforce shortages and fiscal restraint in the delivery of services. Scott et al. (2006) found that nurses with family caregiving responsibilities worked more hours on average than their colleagues, which they attributed to the financial strain of family caregiving. Gryzwacz et al. (2006) also found that nurses who worked the most hours in paid employment had the highest impact on their family roles but were not sure whether this was attributed to their own needs or the demands of their employers. In an already stretched and competitive workforce, colleagues are less willing to compensate for family-related work absences (Ward-Griffin et al., 2005). Furthermore, cutbacks in health services have the effect of more family care needing to be purchased privately, or being undertaken by unpaid caregivers. Ward-Griffin et al. see this situation as impacting on nurses by demanding more of their time to fill the gaps in health services to their own families, but at the same time being unable to take time away from work or feeling obliged to remain at work because of staff shortages.

Grzywacz et al. (2006), in their American survey of work-family conflict among 4,000 registered nurses in 29 states, found that 92 percent of their participants had experienced work interference with family responsibilities and 50 percent reported a chronic negative impact of work on family. This research indicates that spillover from work, in the form of fatigue and stress, is more likely to have a negative impact on the family, rather than family spillover into the workplace. Stress and fatigue are endemic in contemporary workplaces where employers demand that employees do more with less. Runte and Mills (2002, p. 28) argue that “the discourses of downsizing, global competition, profitability and the cult of efficiency are fundamental pressures that create work environments in which stress is maintained at such high levels that any additional strain (such as spillovers from home) become unmanageable”. Ceci and McIntyre

(2001) suggest that nurses experience more emotional impact and ill health from their work than other occupations. Canadian and American research supports this claim and its link to nurses' exodus from the workforce (IOM, 1996; Simon, Kummerling & Hasselhorn, 2004; White, 1999). It seems that nurses make active choices about their work and family lives; some exit from the workforce or change the type of work they do in order to accommodate the demands of double duty caregiving. Others who are able to manage a complex blend of caring roles across work and home boundaries, may be more satisfied with their roles than those who do not provide care to family members (Monahan & Hopkins, 2002). The following section explores health policy and the implications of the discourse of informal care for people and their families in palliative care.

### **Health policy and the discourse of informal family care**

As a family member, the nurse enters the complex mix of relationships and processes that characterise palliative care, with readymade knowledge and expertise about caring for ill people. Knowledge about how relationships and processes operate within the health system position this nurse with the ability to advocate for their relative's access to appropriate health care services. In a health service that relies on informal care to stretch health funding, their own families and other health professionals are likely to encourage them to 'fill the gaps' that occur between the ill person's need for care and the services that are available. Changes in the delivery of health services in New Zealand over the past two decades, like health reforms in Canada, the United Kingdom and Australia, were informed by a discourse of neoliberalism that promoted consumer choice and constructed health and health care as marketable commodities. Subsequent 'post-neoliberal' shifts in health care policy have reduced the focus on market strategies and the consumer as a user who pays for services, but elements of this discourse remain in contracting agreements and the notion that people are able to participate in making their own arrangements for health care (Prince, Kearns & Craig, 2006).

The surface of emergence for the discourse of neo-liberalism in New Zealand during the late 1980s and early 1990s was the political desire to contain growing public

expenditure in a health service that was perceived as fragmented, poorly administered and lacking the capacity to meet the health care needs of the population equitably or efficiently (Gould & Fontenla, 2000). Gould and Fontenla note that the 1993 restructuring was one of the most radical shifts in health policy seen in the western world and that it proposed radical solutions that in some respects were unworkable in the New Zealand context. Neoliberal discourse promotes a reduction of direct provision of health services by the state and the introduction of market relationships that are characterised by contracting, competition and choice (Kelsey, 1995). At the same time this discourse works to govern populations at a distance through the construction of new subjectivities in health care about choice, participation and equitable distribution of resources (Prince et al., 2006).

Since the late 1990s, subsequent governments have instituted a 'third way', moving New Zealand health policy into a post-neoliberal phase that has instituted programmes involving community collaboration and partnership (Craig, 2003); sentiments that were embodied in the New Zealand Health Strategy (Minister of Health, 2000). Consequently, the New Zealand Palliative Care Strategy (Minister of Health, 2001) affirms palliative care as an important entitlement for all people in New Zealand, particularly access to culturally appropriate care that is consistent with their health care and social needs. It identifies consumer choice, home care and the support of families to care for people as central strategies in its vision for palliative care. This community model of palliative care focuses the provision of care for the dying person in their own home with their family as active participants in that care. The provision of services within a hospice, or community facility such as an aged care rest home or hospital, is seen as a substitute for home care when this is not possible or not desired by the family. Primary health care services work as an adjunct to support this vision of care in the community, with the intention of sustaining clients in a place with people they know. Freedom of choice about how people and services will be located is consistent with the values and strategies that are advocated in the New Zealand Health Strategy (Minister of Health, 2000), in that people are understood as responsible for their health in partnership with their communities and government agencies.

Research conducted in the United Kingdom suggests that between 50 percent and 70 percent of people prefer to die at home (Higginson, 1999; Higginson & Sen-Gupta, 2000). In reality only 31 percent of people with cancer die at home in New Zealand, though the rates increase for <sup>2</sup>Maori (53 percent) and Pacific people (42 percent) (Minister of Health, 2001). Being at home is equated with dignity, comfort and some degree of control over events surrounding death and these ideas signify the difference from dying in hospital (Brown & Colton, 2001). The preference to die at home is also consistent with notions of consumer choice and the expectation that people ‘play their part’ in maintaining their own wellbeing and health (Prince et al., 2006). Consequently, home care is seen as a cost-effective alternative (Cosimo et al., 2003) in a restrained health care funding environment. It articulates with the discourse of informal care where keeping people at home becomes a viable strategy to stretch funding by reconceptualising health care as something done in the community by the community (Heaton, 1999). This notion of choice situates some of the responsibility for health care and consequently shifts part of the financial and human resource burden of the provision of health care services from the state to voluntary community services and the family. At the same time it aims to provide people and their families with the freedom to control aspects of their experience of life-threatening illness and dying.

The idea of dying at home within one’s own community creates the potential for innovative approaches to palliative care. Prince et al. (2006) cite the example of Maori Health Providers who resisted the first wave of neo-liberal reforms and used subsequent health reforms together with their own knowledge and expertise to create new models of health care services that were appropriate for their own communities. However, such initiatives require the capacity for communities to work together towards a common goal and the ability to access funding streams and other resources that are necessary to sustain their effort. Palliative care, as the care of clients whose illness is not responsive to curative treatment (World Health Organisation Regional Office for Europe, 1989),

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<sup>2</sup> Maori are the indigenous population in Aotearoa, New Zealand.

also has the added challenge of the outcome of care being secondary to the process through which it is delivered. In this respect it is less quantifiable or measurable in terms of its outcomes than some other services (Clark, Neale & Heather, 1995) and fits less well within a contracted funding model. While humanitarian values are an important mobilising strategy for communities and health care professionals, they do not provide the concrete reality of empirical data needed to argue for the cost benefit analyses that speak to the discourse of economics (Clark, 2007).

The ability for families to exercise choice assumes a discourse of informal care (Heaton, 1999), where ancillary care is provided by family members. This means that people who live with someone else are more likely to die at home (Bowling & Cartwright, 1982). According to Brown and Colton (2001), in the US state of Washington, more middle-aged men die at home from cancer-related illnesses than any other population group. These men are usually cared for by their female partners, who die later and more often in a care facility or hospital rather than at home. As Brown and Colton put it, the ‘good’ death at home for a middle-aged man may not be as good for his female informal caregiver. The New Zealand Health Strategy uses the idea of inclusion as the path to equitable distribution of health care services (Prince et al., 2006) but the Ministry of Women’s Affairs (2001) has clearly expressed the need for gender analysis in considering the impact of shifts in health policy, particularly those with the potential to normalise women in roles that remain invisible, albeit it within an emancipatory discourse of choice.

Further challenges remain to exercising choice, including the assumption that twenty-four hour support for palliative care will be available to dying people and their families. In this context, the capacity for choice is mediated by the complexity of funding models, the availability of services and skilled health professionals, and the adequate coordination of available resources. In 2003, the Report of the Palliative Care Expert Working Group to the Cancer Control Steering Group identified that

There is still some way to go in the development of palliative care services, particularly in ensuring that palliative care is available for all people who are dying of cancer. This is particularly important for people in rural areas where there are still major gaps in service provision. There is also a lack of service co-ordination between primary care, cancer treatment and palliative care services. This means that some people who are dying of cancer do not access the full range of palliative care services. Some people receive care from multiple agencies while others access services too late to be of much benefit (Ministry of Health, 2003, p. 8).

Drought and Koenig (2002) emphasise the importance of clients, families and providers of services being able to recognise that choice is an element of treatment and care decisions and that meaningful options are actually available to them. There are tensions between the ethical requirement to provide a humanitarian service within the collectivist principles stated within health policy and the reality of financial costs and consequences of home care approaches for palliative care (Ceci, 2006a; Read & Wuest, 2007). Canadian experiences have shown that the restructuring of health services has not always resulted in the necessary funding to enact the rhetoric of home care (Frederick & Fast, 1999).

### **Summary**

This chapter has presented a critical analysis of the discourses that construct the subjectivity of nurse family members who care for their own relatives. Caring is an effect of discourse that has emerged from the historical construction of nursing as a reflection of women's role within the family (Crowe, 2000; Lawler, 1991). It has been constituted variously within essentialist and gendered notions of women as innately expressive carers whose moral duty was to serve others and becomes visible in how nurses respond the call to for a family member who is experiencing a life-threatening illness. Ward-Griffin's (2004) research shows how professional boundaries work as discursive constructs that divide women's identity as nurses, shaping both the meaning and effects of their practice as nurses and family members. The 'caring self' is a



discursive construct that signifies a particular kind of gendered identity (Davies, 2003) with normative requirements for respectable and responsible women (Skeggs, 1997). As women, nurse's socially constructed sense of obligation calls them to care for their own family members, often doing 'double duty' between work and home.

Nurses are situated within their families with specific kinds of 'inside' knowledge about illness and dying that is derived from their professional experience (Laylan, 2006). This knowledge enables them to be involved in caring for their own family with a deep appreciation of the meaning of illness and suffering (Mills & Aubeeluck, 2006). But it also positions them with the ability to predict the outcome of life-threatening situations in ways that may sometimes be challenging when the object of a medical diagnosis is a loved one. Nurses walk a fine line between their own family members and other health professionals as they negotiate the complex roles associated with being the nurse family member. They engage in caring discourse with varying degrees of intensity depending on their sense of obligation and capacity to manage the demands of the situation they are faced with. Research on women's caring within the family shows that they are creative in their responses to the demands of caring; sometimes contesting expectations and 'reordering' family care and work responsibilities (Ward-Griffin et al., 2005; Wuest, 2000).

The demands of family caregiving impact on nurses' capacities and choices as health care workers (Grsywacz et al., 2006; Rosenfeld, 2007; Scott et al., 2006) and are the main reason nurses give for leaving paid employment or reducing their hours of work (Hurliman, 2004; Gould & Fontenla, 2006; Reineck & Furino, 2005). New Zealand health workforce statistics (New Zealand Health Information Service, 2004) show that most nurses in this country are over 40 years of age and that the majority work full time. At the same time, most family caregivers are middle-aged with responsibilities to both dependent children and parents (Frederick & Fast, 1999). The idea of informal care is integral to New Zealand health policy. It informs a community model of palliative care that focuses the provision of care for dying people on the family home, family as active participants in that care. This reliance on informal care positions nurses to 'fill the gaps'

that occur between their ill family member's need for care and the services that are available.

The following chapter explains the methodological considerations for the research. The methodological approach uses an epistemology of critique, drawing on tools for critical inquiry from Foucault's (1972; 1980; 1982/2003b; 1983/1998; 1984/2003) writing and interviews and Butler's (1990; 2005) writing on normativity, to make observations about how nurses are situated in social contexts and construct themselves through their relationships with others. Foucault's writing on the genealogy of knowledge is concerned with the political strategies that produce subjectivity through dynamic and ongoing relationships between power and knowledge (Davidson, 1986). Genealogical analysis as the self's relation to the self informs the methodological tools for the research. Butler's analysis of how people come to constitute themselves as discursive subjects provides a further theoretical frame for the research, particularly her writing on normative prescriptions for the relation to self in the constitution of subjectivity.

## **Chapter 4**

### **Methodological considerations**

#### **Introduction**

This chapter presents the strategies that I have developed to operationalise analytical techniques derived from Foucault's writing on ethics as a form of ethical deliberation within relations of power, knowledge and the self. The methodological approach reflects my subjectivisation within the discursive fields of nursing research, practice and education. It shows how I have positioned myself in relation to the participants as a nurse, researcher and a family member who has lived through similar experiences to them. Care of the self as a researcher is explained in relation to care of the other in interpreting subjectivities of the participants and myself as constitutive of and constituted by relations of truth, power and ethics. The discussion of methodological considerations examines the process of working through developing techniques for the analysis of the data and my reflections on the process of developing and working through these techniques. It also explains how the research participants were recruited and supported through the process of interviewing and the interpretation of their stories. Ethical considerations are explored in terms of the process of seeking ethical approval and some of the challenges that I experienced in conducting what could be considered as sensitive qualitative research with bereaved participants. The final part of the chapter draws on Wilkinson's (2007) ideas to examine the truth claims that I have made in accounting for the research process as ethical practices of the self.

#### **Methodological considerations**

The methodological approach for this research uses Foucault's definition of ethics as the relation one ought to have with the self, which demands a critical relation to the self in questioning what is seemingly natural and normal in the world and in doing so, to move beyond the limits of what has been known as the basis for the previously defined self (Lamb, 1995).

My thinking about this idea of a critical relation to the self in this research has been influenced by Flaming (2006, p. 221) who suggests that,

by thinking critically about the self, a person is free to develop as a particular human being because he or she is free from the inhibiting normalizing or dominating discourses.

Stories told about an experience provide the opportunity to see oneself as the subject of a specific kind of knowledge, enabling people to think about the effects of their actions and reclaim a voice in representing a relation to the self that has been silenced through subjection to discourse. Stories offer an account of oneself as a history of this subjection that shows how discursive resources were used to work on the self to establish a particular kind of relation to normative frameworks that regulate the practices of discourse (Butler, 2005). Accounting for the self as the history of one's actions is an ethical activity, a lived space that invites others to share an experience and in doing so enlarge their capacity to think and act in ways that are ethical. It creates the potential to contest the relation to the self by challenging how rules about what constitutes the relation to truth that one is called to occupy as a subject position in discourse have been constructed and applied (Frank, 1998). In doing so, the subject constitutes the self as an active agent in the 'manufacture' of knowledge revealing their relationship to the conditions of its production (Veyne, 1997).

Stories focus attention on the specific (Blacker, 1998), as a marginal view that draws attention to something that might not be visible from within the rules that define what is held to be established knowledge. As accounts of the self, stories offer alternative and competing interpretations of events in circumstances where no other reality might have been imagined, or have been considered relevant in relation to established knowledge. They illuminate ideas that are unspeakable within the boundaries of established knowledge because they transgress norms and values about what is held to be true.

Foucault believed that knowledge should not be taken as self-evident or definitive and that people should be aware of the limits of the systems in which they work. He saw curiosity and innovation as important elements of ethical work in the self's relation to the self, where each person is responsible for reflecting on the situation they find themselves in and choosing how they wish to participate in it (Foucault, 1980/1997; O'Farrell, 2005). An ethic of the self, practised as imaginative and creative responses to others (Foucault, 1988), is characterised by "a robust openness, curiosity and respect for difference" (Coles, 1992, p. 85) and the ability to free oneself from being too tightly connected with dominating truths (Flaming, 2006). The ability to think outside what is obvious in discourse creates the potential for desubjugation (Butler, 2002), where the subject resists being governed within the confines of the relation to truth that the discourse represents. Thinking outside a discourse is already "a thought of resistance" (Deleuze, 1988, p.90) that illuminates the relations between the knower and the known, by shattering the web of comprehension that subjection to discourse constructs for one's thinking (Foucault, 1966/1970).

Foucault's approach to ethics analyses the historical and cultural effects through which we construct ourselves as subjects of discourse. A discourse is "a way of speaking, arranging and presenting representations of the world in a logical order" (O'Farrell, 2005, p.41), the location where subjectivity is formed through language and practice. Foucault's (1966/1970) earlier use of the term discourse developed in *The order of things*, defined it as the artefacts and verbal traces left by history. The methodological approach for this research draws on Foucault's (1984/1992; 1984/1990) writing on ethics, developed in his last two books *The use of pleasure* and *The care of the self*, as a framework to analyse how nurse family members constitute themselves as subjects of the various discourses that call them to act on the self in particular ways. The later definitions understood discourse as a site where knowledge and power intersect to create certain ways of speaking that define a particular formation of knowledge (O'Farrell, 2005). A discourse is recognisable by the regularity of the statements that comprise its formation and the normative frameworks, or discursive practices that define rules for the

production of statements and the status of subjects who have authority to articulate and practise the discourse (Kendall & Wickham, 1999).

Drawing on the methodological insights of Heikkinen, Silvonen and Simola (1999), the analytical techniques for the analysis of data in this research has two aspects. The first aspect of the analysis seeks to identify discourses that are present in the participants' stories as *landscapes of care*; the verbal traces of discursive knowledge and practices that were available to them at the time they were engaged in the care of their ill family member. It also explores *the effects* of power relations that individualise, discipline and order the professional and family relationships that are apparent in the nurse family members' stories. The second aspect analyses *care of the self and others* as techniques of self to show how the participants have undertaken self-work to form themselves as particular kinds of nurse family members. In defining ethics as the relation one ought to have with oneself, the methodological approach for this research uses four elements of the relation to self that were developed in Foucault's (1984a) writing on the genealogy of ethics, to guide the analysis of how subjectivity is constituted in discourse.

1. Ethical substance: the aspect or part of the self or behaviour that is concerned with moral conduct
2. Mode of subjection: the way in which the self is called to recognise moral obligations or relation to a normative framework
3. Self-forming activities: the means or actions through which the self changes or transforms the self to become an ethical subject
4. Telos: self-mastery as the kind of ethical being the self aspires to be.

The first two aspects of these questions establish the subject's rapport or relation with themselves. The analysis of how subjectivity is constituted for the participants in this research attempts to uncover what these rapports are and how they have come into being to create "the subject as the subject of ethical actions" (Foucault, 1984a, p.352). Butler's (2005) writing on normativity is also used as a tool to examine how the relation to the rules of discourse, or its normative framework, are established as one's own relation to

truth. Self-forming activities or techniques of self describe the means through which people act on themselves to become ethical. Techniques of self are identified engaging in discursive practices such as reflection, improving knowledge and skills or presenting oneself differently (Owen & Powell, 2006). The final aspect, telos concerns the kind of ethical being we want to be (Davidson, 1986) or as Owen and Powell put it, to make oneself into a “useful, productive and ethically self managing individual” (p. 114).

### **Developing the research data**

The participants in this research were six nurses, aged between 30 and 60 years, who were registered and had worked as nurses in New Zealand. These nurses had been involved in caring for a person, who was defined by them as a family member, and with whom they were involved in a relationship as a nurse family member, where this person required palliative care at home or at home and in hospital in New Zealand. Five of the participants had cared for more than one family member in a cancer-related palliative care situation and three of them were no longer practising as nurses. They were recruited using a purposive sampling approach via advertisements in the New Zealand Nursing Review and selected community newspapers, and one participant recruited another. Six participants were recruited out of eight respondents. While I had only intended to recruit participants from a defined North Island area, there were two nurses who were accessible to me by travelling outside this area. The six participants who were chosen met the inclusion criteria, and were accessible to me for face-to-face interviews. All participants were Pakeha<sup>3</sup> women who were born and educated in New Zealand, as were all of those who responded to my advertisements to recruit participants. The focus on female Pakeha nurses in this research is part of its situatedness.

Data was developed from the verbatim transcription of audio-taped interviews to create the narrative texts for data analysis. I used what could be considered as an unstructured approach to the first interview, beginning with a request for the participant to tell me about themselves and their experience of caring for their family member. When

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<sup>3</sup> The term Pakeha is generally used to describe white settler descendants who were born in New Zealand.

participants asked for feedback about whether they were “telling me what I wanted to know” I assured them that any information regarding their experience as a nurse family member was useful. At times when participants became lost for words, I gently prompted them to continue speaking about what they thought might be important in their experience. All of the participants had particular things they wanted to talk about, whether it was something they had learned and thought other nurses should know, or they wanted to relate experiences that were memorable. The second interview was more structured in that it involved reviewing the previous transcript and talking about what would be included and excluded from the data. It also involved a greater degree of disclosure as they elaborated on their thoughts and feelings and clarified aspects of their experiences. As well, the participants talked in more depth about some experiences they had alluded to in the first interview, sometimes because they had had time to reflect on the memories that had been surfaced in the time between interviews. While I had intended to interview the participants up to five times in the course of the research, I found that two formal interviews were sufficient for the nurses to tell their stories. However, I later phoned and emailed them to ask questions and clarify aspects of their stories. They also gave written feedback on their interview transcripts, which I had posted to them. Each interview lasted between 60 and 90 minutes and was conducted either at the participant’s home or at a mutually agreed location. I transcribed the interviews myself, partly because I felt that some of the stories contained in the interviews were emotionally evocative and perhaps too demanding for someone who was not in a relationship with the participants and so could not hear the stories in the context of that relationship. As well, I could not be sure that a paid transcriber would have access to the emotional support necessary to manage the effect of listening to these stories. I also used the transcription process as an opportunity to reflect on and make journal notes about aspects of the nurses’ stories.

### **Techniques for data analysis**

The data analysis began with identifying stories within the interview texts that make a particular landscape of care visible as the practices and relationships that are apparent in caring for a family member in palliative care. The topography of each story line within



this landscape was mapped to identify the effects of techniques of discourse that appeared within them as discursive statements.

### *Landscapes of care*

Using aspects of the framework on techniques of discourse developed by Heikkinen et al. (1999), discursive statements were analysed in terms of how a discourse was put into action to interpellate nurse family members and make them subject to it as a specific relation to the self. The internal rules of the discourse were examined to identify relations of power exercised to control or normalise what could be said about certain objects. The bases for the authority of speaking and acting subjects that accorded them status or prominence within the discourse and worked to sustain their particular identities was also identified as mechanisms that regulated access to subject status (Foucault, 1970) including; verbal rituals determining accepted roles for speakers, rules for membership of the disciplinary community who are authorised to practise within and preserve the discourse, and the effects of dual subjection in constituting and being constituted by the discourse in a professional role. Power relations were identified as the historically constituted divisions that separate self from other, and establish differences between people. Procedures of exclusion were identified as the knowledge that was subjugated or silenced as soon as it was spoken as knowledge outside the discursive rules of engagement. These moments of silencing and exclusion pointed to the unthought or that which was not authorised to be practised within the discourse (Foucault, 1966/1970). It showed how these practises of division and rejection within discourse worked to marginalise subjectivities lacking in authority, and undermined that person's capacity to speak or act in a particular moment. The analysis of data in this section was guided by the following questions about techniques of discourse:

- What are the discourses that inform nurse family members' call to care and how do they show up in the participants' stories?
- How are the nurse family members bound up in relations of forces and individualised in their relationships with others?

- What constitutes ‘true’ knowledge about nursing and families and how is it spoken about and practised?
- Who is authorised to speak about nursing and palliative care and under what conditions?

### *Care of the self and others*

The analysis of the nurse family members’ stories illuminates how the nurses create and recreate themselves through the discourses populating the texts and how, in certain situations, particular subjectivities become privileged over others. Techniques of the self within the participants’ stories were critically examined to identify the genealogy of the forms of subjectivity that appear in their practice and interactions as nurse family members (Heikkinen et al., 1999). These subjectivities constitute the relationships that they have with themselves in constituting the self as the subject of their own actions (Foucault, 1982/2003b). The ethical substance of a particular subjectivity was illuminated as what attracted the nurse family member to care within the context of her own family; as that part of themselves that required care such as their ability to engage in the intellectual, political, and relational work (Cooper & Blair, 2002). The analysis has attempted to show how the requirement for self-work was recognised through reflection on, and problematisation of, their conduct and knowledge. Modes of subjection are established as the relation that is chosen to moral or normative codes that are drawn from the participants’ social, cultural and professional patterns of knowing and relating (O’Farrell, 2005). The mode of subjection was seen in how the nurse family members sought to engage themselves in the situations that they were involved in. It shows how the participants struggled to meet the obligations of commitment and care as a woman (daughter, wife or mother), calling on nursing knowledge and skills to create the optimum conditions for the care of their family member and to establish the kinds of intimacy and connection necessary for this work.

Self-forming activities were apparent in the self-work that was undertaken by the participants to transform themselves into the kind of nurse family members that they aspired to be in order to act ethically. This work of self-creation as a nurse family

member was identified in the activities the participants' described as they attempted to modify their behaviour according to the challenges that they experienced at different stages, and in particular moments of caring. Their self-work was illuminated in descriptions of how they experimented with different ways of thinking, speaking and acting as they assessed situations and positioned themselves within roles and relationships (Cooper & Blair, 2002; Huijer, 1999). The telos of the self's relation to the self was apparent in the participants' explanations of why they chose to act as they did. It identifies their relationship to normative values and rules as a nurse and particular kind of family member. The particular modes of being that were characteristic of themselves as moral agents (Foucault, 1984/1992) were seen in the capacities they developed as nurse family members, in creating the freedom to practise as a nurse in a private space, and in transforming their relationships with others to accommodate their subjectivisation. The data analysis in this section was guided by the following questions about the genealogy of subjectivisation:

- What are the relations of the self to the self that a nurse family member (daughter, wife, or mother) should aspire to practise?
- What self-forming activities do nurse family members perform and how do they transform themselves to act ethically?
- What are the effects of negotiating the boundaries between self and professional practice and practising relations of the self as a nurse family member?

### **Ethical sensibilities in the research**

Drawing on Wilkinson's (2007) interpretation of how Foucault's (1984a) genealogy of the ethical subject can be read as constituting the subjectivity of an ethical researcher, this section explores the self-work I have undertaken to meet the ethical requirements for conducting research. The ethical substance of my subjectivisation in this research can be thought of as ethical sensibility, a critical relation to self and the normative ethical considerations for scholarship and research with human subjects that determine the right action to take in caring for the self and others. The mode of subjection for

ethical sensibility has involved my own efforts in thinking critically about and accommodating ethical principles of beneficence, respect for human dignity and justice in the research. This positioning of the self has entailed careful reflections on what might constitute harm or benefits for me and the research participants in each stage of conducting the research. Ethical self-work has been guided by the Victoria University of Wellington (2007) Human Ethics Policy and the principles expressed in the New Zealand Nurses' Organisation (NZNO, 2001) Code of Ethics. Through this process of establishing relations of the self to these codes within the research process, I have endeavoured to cultivate the self as a particular kind of researcher who appreciates and respects the participants and the ethical requirements for scholarship.

Qualitative research requires us to be present with research participants; to enter their world, listen to their stories and co-create knowledge with them about the meaning of their experiences. Sensitive research presents particular challenges because it involves topics that are stressful and may cause emotional pain for both the participants and researcher (McCosker & Gerber, 2001) and it is these elements that define it as sensitive. The risk of harm or discomfort that is anticipated in this kind of research should not exceed that which participants would normally encounter in their daily life (Labott & Johnson, 2004). While the participants in this research were registered nurses who had substantial knowledge about emotional self-care, I informed them that exploring their reflections about caring for a dying family member might be distressing. Each participant signed a consent form before participating in the study. However consent was negotiated between the researcher and participants in the conduct of the research. They chose fictitious names for their identities in the research and some information containing unique identifiers has been excluded from the writing up of the research findings because it has the potential to identify a participant, though this inclusion and exclusion of data has been carefully negotiated with them. The process of consent in this study has involved ensuring that participants gave permission for the use of experiences as they appeared in the transcribed research interviews.

The ethics proposal for this research was approved by the Victoria University Human Ethics Committee in September 2005. Ethical considerations set out in the proposal included practical considerations regarding the emotional safety of participants. I suggested that they discuss their proposed involvement in the research with their family to assess any possible implications for them or their relationships with other family members. At the first interview I also assessed whether they had experienced any difficulty in negotiating their recovery from the events that they would share in the research. Ethical self-work included reflecting on my interactions with the participants to develop an appreciation of the effects of their participation in the research as they unfolded their experiences in the interviews. Participants were contacted one week after each interview to discuss their reflections on their experience of being interviewed. All of the participants said that the interviews had surfaced memories for them and I suggested that they might want to seek support from a critical friend, support person or counsellor to discuss feelings about those memories. However, none of the participants sought assistance for formal counselling support.

The benefits of this research for the participants have included the opportunity to speak about events in their lives, clarifying thoughts and feelings about caring for a dying family member. Three of them talked about how their involvement in the research had been beneficial in helping to explore aspects of their experience when they had not previously had the opportunity to speak about caring for their family member in such depth or detail. One participant said that she had not realised how much being a nurse had influenced who she is, and how she acts as a person. Another participant spoke of how the fact that I had experienced a similar event increased her level of comfort in being interviewed and made her able to disclose thoughts and feelings that she had not discussed before.

### **Positioning the self-as-nurse researcher**

This research has an ethical substance of political work (Cooper & Blair, 2000) in that it seeks to examine the relations of power that construct nurses as professional people living within their own families and communities. Through the process of gathering and

analysing data, and writing it up in the thesis, I have become subjectivised within a struggle for the rights of nurse family members in showing how they might resist dominant discourses or at least accommodate them on their own terms through practices of care of the self. My self-forming activities involve an ethic of resistance in speaking about the experience of nurses that are not visible in dominant discourses about nursing, and publishing my critique of these discourses in the thesis. This political work also informs relational practices of the self as an ethical substance that struggles for connection with other nurse family members and a broader understanding of their experiences within the knowledge that informs nurses thinking as a feminised profession. The mode of subjection in this relational work is the desire for the kind of empathy and connection that might inform a deeper understanding of the tensions nurses experience in turning their professional gaze towards their own family members. The creation of alternative kinds of relationships that might allow greater fluidity in roles and relationships is the aim that I wish to achieve in publishing this thesis. The struggles that I experienced in positioning myself as a researcher, nurse and family member are explained in the later section in this chapter that reflects on the relational aspects of the research.

A further relation to the self that is relevant for this research involves Foucault's notion of the author function. Foucault (1969/2003) sees the author as a process rather than an entity; the site where a complex web of discursive practices converge and shifting relations of power are enacted through relations of the self to the self in writing. As such, the process of 'authoring' is a practice that encompasses a range of subject positions and, through processes of subjectivisation in various discourses, creates representations of a writer's thinking as the text of a work (Barrett, 2006). Drawing on Foucault's notion of the author function, Nehamas (1986, p. 689) similarly sees both the author and the text as constructs where, "the author is produced jointly by the writer and the text, by work and critic; it is a character who is everything the text shows it to be and who in turns determines what the text shows". In this sense, the writer is not the same as the author. Writing can be thought of as a self-forming activity that has an ethical substance of intellectual work and a mode of subjection that struggles for knowledge as

representations of truth. The writer's subjectivities, as the author, are dispersed within the text and disappear as the text becomes an entity in itself. Readers interpret and reconstruct the text through their own subjectivisation, transforming ideas represented in it into new discursive forms through their own relation to the self.

The writing in this thesis has been a creative process of capturing the various subjectivities of the self as author, in relation to the data, and in speaking through specific discourses at different moments in time. It is a practice of the self in becoming through writing where I appear in the text as I work on myself to sculpt this work. Writing is a way of coming to understand ourselves and making sense of what we know (Rolfe, 2000). It is a creative practice, through which the self is constantly reworked in relation to what has been written, and new relationships are forged between the knower and what is known (Ceci, 2003b) as the unthought (Foucault, 1966/1970) is captured in the very act of writing. Writing creates the conditions to surface and express ideas not consciously thought about in this process of positioning the self within complex webs of discursive connections. It brings the self into new associations between discourse and the self through deep reflections on one's own relation to truth, using theoretical ideas and experience as building blocks to transgress and reform what seems self-evident and normalised in one's own thinking. I have found myself reshaping and reworking aspects of the text as I return to it and form new perspectives on what I have written. Rolfe (pp. 110-111), citing Woolf (1978) suggests, "The self who writes is different from the self who later reads what is written". As the text becomes objectified and separated from the self in the process of 'authoring', I constantly form a new relation to it.

As stated in Chapter One, I came to this research having already experienced similar life events to the participants. With this experience in mind I had identified counselling for myself in the ethics proposal as part of the self-work I would undertake during the data collection and analysis stages. My thinking was that hearing about the participants' experiences and working with their stories would be emotionally evocative for me. While I had carefully attended to these aspects in planning the research, I did not fully appreciate what it meant to practice ethically as a researcher until I experienced doing

the interviews. I was to find that being a researcher in this study was more complex than I had imagined particularly when the participants became distressed or talked about deeply moving events. All of them cried at some stage while being interviewed and counselling helped me to identify and work with my own emotional responses to them. This was to become a critical aspect of my self-work in the research as my own thoughts and actions were reflected back to me through the counselling process.

Counselling provided an external reference point for me in caring for the self as a researcher. The counsellor became the person Foucault (1984/2003) speaks of as the guide or mentor, who truthfully reflects the subject's actions back to them through critical questioning. While in my mind I had a strong sense of my role as the researcher, there were moments when I identified with the participants as colleagues and women, and empathised with their experience as a family member. These difficult moments moved me beyond the role of researcher and drew me to engage with them in ways that were supportive and therapeutic. But this desire to be supportive interfered with my ability to explore emotionally difficult aspects of their experiences because I became focused on their vulnerability and my sense of responsibility for their distress. As a nurse I also brought a professional gaze to the research interviews, where I was concerned with my own professional conduct and that of other nurses. In this complex positioning as a researcher and a nurse, I also found myself moving away from topics that were sensitive in the professional sense. Talking with my supervisors about my discomfort also helped to build confidence and strength to move back into the interviews in a stronger frame of mind. I came to see the participants as capable of freely choosing whether to tell me things or not.

Being able to think critically about how I responded to the participants enabled me to reframe my practice as a researcher. I recognised that I had developed a mode of subjection that emphasised protection as self-work and constrained my ability to act as a researcher by silencing the participants. But protection is in some ways an undemocratic concept because it legitimises power over others whom we see as too weak to take care of themselves (Yeatman, 1994). It also permits an uncritical relationship to an ethic of



care where ‘good’ nursing equates to doing for others in ways that may actually disenfranchise and silence them; and as Yeatman suggests, it may also evade the more complex politics of a negotiated relationship in such moments. Self-work through counselling and supervision enabled me to call forth my own stories; to situate them in relation to those of the participants with some understanding of the effects of my behaviour (Miehls & Moffat, 2000). Looking back at my actions, and thinking about the effect I had on the participants, I became aware of how I might have responded differently. I could see how my focus on vulnerability had ‘saturated’ my thinking to the point that I was unable to see them as resilient and deeply reflective women. I understood my own emotional resilience but had not been able to respect their right to engage in the research in ways that were freely chosen.

This new mode of subjection was concerned with respecting the participants’ freedom to speak on their own terms. I became sensitised to my own responses in the interview process with the ability to sense moments when I had not followed a story line or changed the subject. As I did the second round of interviews I became more aware of how I phrased questions, such as, *“I have another question and you don’t have to answer this if you don’t want to ..... but last time you said you couldn’t do some things that you wanted to do for your mother .....Can you tell me more about why you couldn’t?”* Representation requires the freedom to speak and requires a belief in the capacities of other people. ‘Holding the moment’, by dwelling in moments of uncertainty, keeps the conversation space open. In research interviews, ‘holding the moment’ requires managing the tension that asking a hard question creates and being open to how the participant will respond. This experience taught me that it is sometimes necessary to dwell in moments of uncertainty in order to be sensitive to the stories that others tell. When I found the courage to listen attentively I heard moving stories about nurses’ belief in themselves and the power of nursing. So my self-work as a researcher was to make myself present in a different way. Rather than calming my own anxiety by silencing the participants I had to recognise the potential that uncertainty holds to make the self open to the experience of others (Miehls & Moffat, 2000).

### **Evaluating the research process**

This research has involved locating an inquiry within particular discursive fields and practices and identifying gaps in knowledge that the inquiry sought to address. I have drawn on discursive apparatuses, operations and procedures (Foucault, 1969/2003) to create theoretical ideas and methods for the research design, which have situated the research, and its findings, within the field of nursing scholarship in specific ways. As an inquiry that is located within postmodern thinking, the research is positioned as partial and situated in my reading of theoretical ideas drawn from Foucault's critical history of thought (Ceci, 2003b). While I have attempted to trace the genealogy of my thinking, and the theoretical ideas that have influenced how my own subject positionings have been formed in relation to the research topic, as Ceci suggests, any reading of a scholar's work, and interpretations of our own and others' experiences, are always situated and incomplete. We do not always know what is not apparent to us.

In evaluating this research, validity should be understood as assessing how the analysis works to critique normative modes of thinking and acting that constrain people's ability to act ethically and whether it offers possibilities for new modes of subjection that might usefully be taken up by others. Rather than thinking about this thesis as an end-point or an entity in itself, it could be thought of as having a mode of existence that calls attention to particular discursive relations and subjectivities. It articulates potential modes of subjection that call other people to work on themselves as particular kinds of ethical subjects. In using Foucault's methods, validity might be less concerned with what I have said about the findings in this research and more concerned with their effects; whether "possibilities for thinking and acting are opened rather than closed" (Ceci, 2003a, p. 74; McWhorter, 1999). The research represents an attitude towards nursing knowledge and the experience of being a nurse family member that is informed by a curiosity about how it is possible to know in particular ways (Ceci, 2003a). This curiosity represents my concern about whether it is possible to know differently and in ways that transgress current modes of knowledge, so validity could be interpreted as the degree to which the findings of the research represent this transgressive potential (Gilmour, 2001; Lather, 1993). The utility of this research might lie in how well it

stimulates forms of inquiry that continue beyond the writing of the thesis as other people have the opportunity to read and engage with the ideas presented in it.

As Barrett (2006) suggests, the findings are not invented by the researcher but are constructed within specific relations of the self to the self and connected to other works and ideas. This process has involved developing a reflexive relationship with my own ideas and actions in the process of conducting the research. A research journal was used to record my thinking about ideas and the experience of interviewing the participants and working with their stories in the analysis of the data. Representing the experiences of others requires this attention to relations of power, with an ability think critically about how the self and others are situated in and interpret events and one's own behaviour (Coles, 1992). Reflexivity has involved a process of self reference, bending my own feelings and thoughts back on the self, and making the self and my own actions an object of inquiry (Bonner, 2001) in an attempt to maintain awareness, albeit partial, about the complex relationships between what I know and how I know. This reflexive work of thinking critically about the self was an important aspect of my self-work as a researcher as a means to transform my thinking beyond my own experience of being a nurse family member. As an ethical practice of the self, it called me to account for my actions in the research in representing the experiences of the participants in the findings it has produced.

## **Summary**

This chapter has presented methodological considerations for the research, which was grounded in my own curiosity about the topic. This curiosity has framed my thinking about the topic and the methodological approach to it as a form of inquiry that aims to disturb assumptions about what it means to care for a dying family member as a nurse and daughter, wife or mother. It signals a concern with social justice in terms of looking beyond what is obvious to us in an attempt to grasp what happens when a nurse becomes involved in palliative care for her own family member and to offer strategies to conceptualise this experience and its effects in new ways. This chapter also explained how I have worked to develop techniques for analysis from Foucault's critical history of

thought and the challenges I have encountered in positioning the self-as-nurse researcher in an inquiry that involves stories about experiences that were similar to my own.

The following chapter introduces the research participants within the landscapes of care that become visible in caring for a family member in palliative care. The story lines in these landscapes of care are mapped to show their topography as discursive statements that call nurse family members to subjectivise themselves in particular ways. The internal rules of discourse are examined to show how nurse family members become both discursive objects and at the same time subjectivised within relations of power that tend to normalise their responses. Moments of transgression are identified when the participants resist these normalisations and choose to act in other ways. Power relations are identified as historically constituted divisions that separate self from other and constitute aspects of people both within themselves and in relation to others.

## Chapter 5

### The call to care

#### Introduction

This chapter introduces the participants within their biographical portraits as nurse family members and explores the discourses and subject positionings that are visible as the call to care in this context. ‘Landscapes of care’ are conceptualised as the discursive knowledge and practices that became apparent as the participants spoke about their experiences. Storylines were mapped as conceptual topographies that appeared within these landscapes, illuminating discourses that the participants had become subjectivised within as they described their experiences and accounted for their actions. The conceptual topographies, as repositories of sets of discursive statements within the text of the stories, locate subjectivities within series of actions and ideas that reflect particular constructions of the self. Their subjectivities became stories of place as told by its inhabitants (Gadow, 1995), that make the nurse family member visible, located within the broader socio-political, cultural and professional contexts of nursing, health care and the family. While the idea of ‘landscapes of care’ is identified in nursing and feminist literature as places where people’s experience of health and illness are influenced by various cultural, social, economic and political factors (Carolan, Andrews & Hodnet, 2006; Dyck, 2005), the idea of place is conceptualised in this research as discursive positionings or locations that are both constituted by and are constitutive of subjectivity. These discursive positionings locate the subject within relations of truth, power and the self, creating a particular kind of vision and capacities for the participants in the situations that were related in their stories.

The call to care was the first storyline that surfaced in the complex and moving stories that the participants told about caring for their own family member in the palliative care stage of a cancer-related illness. The analysis in this chapter identifies discourses that became visible in this telling and examines how the participants engaged with the call to

care to become subjectivised, and simultaneously positioned in various competing discourses that constitute the role of nurse family member. Care of the self and others is explained as the relations of self through which the participants worked to transform themselves to be able to practice as the nurse family member. It shows their modes of subjection as particular kinds of relation to the self in discourse, where self-forming activities resulted in their ability to insert themselves into the spaces and relationships that formed their field of practice. In this process of transforming themselves, they created their own authority to speak about and practice nursing within their own families. The analysis shows how they possessed a particular kind of nursing gaze that set them apart from their own family members and positioned them uniquely in relation to other health professionals.

### **Portraits of the participants**

The six registered nurse participants who agreed to participate in the research named themselves as Michelle, Sarah, Jean, Maree, Robyn and Hazel. They were aged between thirty and sixty years at the time of being interviewed about their experiences of caring for family members with a cancer-related illness in palliative care. Some of them had cared for family members in areas other than they were located at the time of interview, although all of the events described in their stories had occurred in diverse rural and urban settings in New Zealand. Five of the six participants had more than one experience of acting in the role of the nurse family member over varying periods of time. Michelle, the participant who had cared for only one family member was the youngest in the study. The older nurses, Sarah, Jean, Maree, Robyn and Hazel, in their fourth or fifth decades of life, had experienced caring for at least two family members as daughters, daughters-in-law, a wife or mother.

I had originally set the criteria for inclusion of an experience of caring for a family member at no sooner than one year prior to be interviewed and no longer than ten years. These limits were set to enable sufficient time for reflection on their experiences, but also to elicit stories that were reasonably contemporary, reflecting current conditions in nursing and the health service. These inclusion criteria were challenged by my

experience of interviewing Robyn, who had two experiences fifteen years apart, where I considered the prior experience had contemporary significance. Three of the six participants, Sarah, Michelle and Robyn, were no longer working as nurses at the time of being interviewed, though the latter two in this group were working at the time of caring for their family member. Sarah, the one participant who had not worked as a nurse for twelve years prior to being interviewed, still thought of herself as a nurse and related how she drew on nursing knowledge and skills. Her stories contributed relevant information to the study from her experience of caring for two family members. The following section provides a summary of biographical data, and a brief overview of their experiences, for each of the participants. Some aspects of the clinical and personal data has not been specified in order to preserve the participants' anonymity.

### *Michelle*

Michelle was the youngest participant in the research and related the experience of caring for her middle-aged mother who had been diagnosed with cancer. She talked about how she had always wanted to be a nurse and entered a nursing programme at the local polytechnic as soon as she had met the entry requirements. Following registration Michelle worked in New Zealand and overseas hospitals. When she returned to New Zealand family circumstances encouraged her into district nursing because the location of the work and the hours suited her family situation with preschool children. She had been district nursing for about six years, specialising in palliative care, when her mother was diagnosed with cancer. Following surgery, her mother had been given the 'all clear', but just over a year later developed metastases and required palliative care. She survived for three months following this diagnosis. Michelle's mother was adamant that she wanted to remain at home in a remote rural setting, where she lived with her partner and other family, during the final stage of her life. Michelle soon realised that palliative care services were almost non-existent in this rural area as people who were dying generally went to the hospice in the small town some distance away. Michelle understood that there would come a time when she would need to move in to live with her mother, taking one of her pre-school children with her and leaving the others in the care of her husband. Moving in with her mother required an extended absence of about

seven weeks from work on sick leave, which she says her employer fully supported. Michelle returned to work in palliative care one week after her mother's death. She was not offered any formal support from her employer but sought grief counselling privately after a period of time. After three years, Michelle resigned from her position and has not worked since but related her thoughts to me about seeking an alternative career in the future.

### *Sarah*

Sarah, in early middle-age at the time of being interviewed, had also wanted to be a nurse from the time she was a young child. Her older sister had provided a role model as a nurse, which she had always wanted to follow. As a graduate, Sarah's experience included diverse fields of district nursing and intensive care, with some experience overseas. She left work to have children and had not worked in paid employment as a nurse for several years prior to taking up the role of nurse family member. Sarah cared for her mother-in-law intermittently over a period of two years, while she was having radiotherapy and chemotherapy. In the palliative care stage, her mother-in-law moved in with Sarah's family so she could be cared for in the family home. Eighteen months later Sarah again found herself in the role of the nurse family member, this time caring for her own mother with the help of her sister, extended family and friends and the knowledge gained from her prior experience of caring for her mother-in-law. The family lived in a semi-rural area close to a country town and within easy reach of a base hospital and Sarah's children were primary school age during both experiences. She relates how the first experience with her mother-in-law involved some fraught moments in relationships with other nurses, while the second time around was an entirely different experience that was characterised by strong professional support from palliative care services and her older 'nurse sister'.

### *Jean*

Jean, was also middle-aged at the time of being interviewed, had begun her nursing training in a hospital based programme after leaving school. She eventually left this programme because she felt she wasn't mature enough to deal with the challenges of



nursing at that stage. She returned to nursing, this time to complete a polytechnic nursing programme, and went on to specialise in intensive care nursing. Her most recent work had involved providing nursing services on an intermittent basis overseas. Jean described her role as one that she was passionate about, albeit involving very demanding work that required periods of time away from home. Historically, she had been involved in the care of her father, and her mother-in-law, both of whom had died of cancer. Each of them was nursed at home by family members; by Jean and her mother in the former case and Jean and her registered nurse sister-in-law in the latter. Over twenty years later, and four years prior to being interviewed, she found herself caring for her own mother who had been diagnosed with metastatic cancer and was adamant she wanted to die at home, in the city where she lived. While Jean did not necessarily want to go through another experience of nursing a relative, this time as a registered nurse, she felt obliged to honour her mother's request. While she had good support from a hospice service, she found caring for her mother more difficult than she had with her two other relatives. This experience was also complicated by what Jean characterised as a complex and sometimes difficult relationship with her sister, who in turn had a very close relationship with their mother. Following her mother's death, this sister was also diagnosed with cancer and Jean described how she has worked to re-position herself within this relationship, attempting to manage her role as a sister, rather than a nurse family member.

### *Maree*

Now aged in her fifties, Maree had also always wanted to be a nurse since she was a child, but was encouraged to study in another field by her parents. Maree eventually entered a hospital based nursing programme and completed two and a half years before leaving to get married, having been told by the matron of her training school that she could not be a nurse and be married at the same time. Her request to transfer to another hospital was refused so despite trying to return to training for several years, Maree eventually gave up the idea of becoming a registered nurse to have children. However, she later returned to nursing via a polytechnic nursing programme, although her children were still growing up. Maree's experience as a registered nurse included work in a

hospital that offered a mix of medical, surgical and elder care services, then a period of acute care nursing at a base hospital. She then went back to her rural town to work as a practice nurse in a health centre, where she loved the need to think on her feet to meet the everyday challenges of her work.

Maree found herself in the role of a nurse family member, nine years prior to being interviewed, when her daughter was diagnosed with cancer. Her daughter died at home eighteen months later. The experience of caring for her daughter was characterised by good relationships with many health professionals that she either knew personally or had worked with. She talked about her recognition of the emotional work that these other nurses and some doctors that she knew had to do while caring for her daughter. A few months after the death of her daughter, Maree had returned to work as a practice nurse in the rural town where she lived but then found herself involved in the care of her father who had also developed a cancer-related illness. Working in the small town community where she also lived was challenging for Maree, as many of the clients in the practice where she worked knew her family and the story of her daughter's illness. She eventually went to work at a practice in another small town that was within commuting distance, but after a period of time returned to work in her own town. She continues to negotiate this relationship between herself and her work in this context.

### *Robyn*

Robyn says she became a nurse by default because her parents had separated when she was sixteen and could not continue paying her private school fees. While her friends either stayed on at school or went to university, Robyn found herself training to be a nurse in a hospital system that she says she hated and says she did not learn to fully appreciate being a nurse until she was registered. Following registration, she went overseas for a year and then continued working as a nurse on a part time basis for about 30 years, to fit around her children and family commitments, until she stopped working three years ago. In that time she had worked in a variety of medical and surgical clinical areas, completed a nursing degree and spent some time working as a nurse educator. Robyn, aged in her fifties at the time of being interviewed, related how she was drawn

into the role of nurse family member over twenty years before, when her husband was diagnosed with cancer in his thirties. He had chemotherapy treatments for six months and then eighteen months of remission before it recurred and he had more chemotherapy. Robyn described how during these years she coped with working part time, managed a farm and young children and cared for her husband when he was ill and hospitalised for periods of time in a city some distance from the small rural community where the family lived. He died seven years later. In the final stage of his illness, she brought him home for the last two weeks to care for him with what she describes as very effective support from the local palliative care service.

Her second, more recent experience as a nurse family member involved caring for her mother who had been diagnosed with cancer a year after Robyn's husband died. Following surgery, her mother remained well for eight or nine years until she developed a recurrence of the tumour in the area of the suture line. A year later, following radiotherapy which had been unsuccessful in treating the tumour, Robyn knew that her seventy five year old mother was in the palliative care stage as she developed a pleural effusion and other complications secondary to the cancer. While she had planned to care for her mother at home, things deteriorated rapidly and because she was no longer mobile, and would not consent to using a commode, in the end Robyn's mother was cared for in a local rest home that contracted palliative care services. This experience was characterised by some fraught relationships with registered nurses, some of whom Robyn knew through prior professional relationships, as she attempted to get access to information about what was happening with her mother and ensure she was given adequate care. While Robyn had given up working as a nurse in the year prior to her mother's death, her experience during this time was pivotal in deciding never to return to nursing as a profession that as far as she is concerned exists within political and economic conditions that disable the potential to practice ethically.

### *Hazel*

Hazel is a hospital trained registered nurse from a rural area in New Zealand who became involved in caring for both her parents at different times as they were dying of

cancer-related illnesses. Her mother had been ill with various health problems when Hazel was a teenager and she suggests that it was her mother's appreciation of the care she gave her during those years that influenced her to become a nurse. Prior to caring for her parents in the role of a nurse family member, she had spent twenty years working overseas as a specialist palliative care nurse, some of this time caring for dying patients in their own homes. When her mother was diagnosed with cancer, Hazel resigned from her position as a palliative care nurse and came back to New Zealand to live with her parents and care for her mother in the final three months of her life. She had applied for another position overseas, but her new employer was willing to hold this open for her so she would have sufficient time to nurse her mother. Hazel's parents lived close to a rural town and a short distance from a hospital. This first experience occurred ten years prior to being interviewed for the research. It was characterised by what she termed a very difficult relationship with her sister, who had always lived close to her parents. These difficulties finally culminated in Hazel returning to work overseas before her mother had died. Several years later, when she had returned to live in New Zealand with her husband and children, Hazel's father was diagnosed with cancer. In the intervening years, she had worked to re-establish her relationship with her sister, but at times the relationship was again to prove difficult to negotiate during her father's illness. Hazel again resigned from her position to take up the role of nurse family member full time, but this time she had a home in New Zealand where she could go for 'time out' while her sister-in-law cared for her father.

### **The call to care**

The call to care was the first storyline that appeared in the landscapes of care that were related by all of the participants in their accounts of caring for family members. The analysis in the rest of this chapter explores what makes it possible for caring discourse to call someone to take up a mode of subjection that positions them with a particular kind of sensitivity that has as its moral end, the thoughtful care and comfort of another human being (Hultgren, 1994) who is also a family member. Being called to care involves naming the self as the one who cares and presenting the self as the person on whom others have the power to make particular kinds of claims. The call to care

subjectivises and thus positions the self within caring discourse creating specific forms of knowledge about who we are and what we ought to do in relation to others. As a relational practice, caring is lived out in community (Lashley, Nealm & Slunt, 1994). It is practised in relation with others, creating modes of subjection that encompass specific kinds of ethical engagement, commitments and responsibilities that arise from those relationships. While the different discourses that became apparent in the storylines were inter-related and at times contradictory, three discourses were visible as sets of regulated statements and associated practices that defined and differentiated the call to care and caring practices. The discourse of caring articulated with discourses of family and expertise in knowing as a nurse, and these discourses were the conceptual resources that the participants drew on in explaining how they engaged with their family members and positioned themselves in relation to them.

### *Caring discourse*

Caring is a dominant discourse in nursing that has been derived from interpretive philosophies about what nursing is and how nurses ought to practice nursing and develop relationships with their clients (Andrews & Roy, 1986; Euswas & Chick, 1999; Watson, 1988). It subjectivises nurse family members within an ethical substance of beneficence as the moral aim of nursing, where duty and service are the mode of subjection. Within this mode of subjection they undertake self-work to provide palliative care for their dying relative at home, particularly where they consider the service that is offered is considered to be insufficient or to ensure that the best care is provided in an alternative environment. This self-work requires them to make the self into a knowledgeable and expert presence, subjectivised simultaneously as both the nurse and family member. The outcome of this transformation of subjectivity is the provision of palliative care, often in collaboration with other family members and health professionals, which is uniquely tailored to the dying person's needs. For the participants in this research, caring involved a vision of the practice that they wanted to enact for their loved one as nurse family members, which seemed to reflect an ethical ideal of caring as a nurse.

For example, Michelle became involved in the role of nurse family member because she had quite definite expectations about what kind of palliative care her relatively young mother ought to have in order to die at home. Michelle's experience as a palliative care nurse meant that she was able to see rural palliative care services in her mother's region as limited by distance and geographical isolation. Her mode of subjection within an ethical substance of duty to her mother, involved a struggle to provide not only an adequate service, but the best care possible. She suggested that,

*When people die, they should be able to die how they want and have the support they need for as long as it might be and as much as it might be.*

Michelle cared for her mother at home because otherwise she would have been hospitalised, and while the idea of choice is apparent in the post neoliberal discourse that informs the idea of community collaboration and partnership in palliative care (Craig, 2003; Minister of Health, 2001), she was concerned that her mother's wishes would not be honoured unless she positioned herself in the role of the palliative care nurse. Hazel was similarly positioned as a palliative care nurse, though her parents lived in a semi-rural setting that was close to a base hospital, meaning they had better access to expert palliative care services. She explained how her knowledge and skills as a nurse informed the decision to care for her parents.

*It was so lovely to be actually able to do something for my parents and to do something that was appreciated.... I'd had all of this experience in London and I just slotted straight into it and knew exactly what was what.*

Her many years expertise of working in palliative care overseas influenced her decision to give up her job and travel home to New Zealand to care for her mother, and again several years later for her father when she had returned to live in New Zealand.

Sarah says that she took up the role of caring for her mother and mother-in-law, mainly because she was present and available and was a nurse; she "*had the experience, the knowledge, the ability, the capability of actually doing a good job for them*". The nursing practice associated with death and dying was an area that she had loved when

she was nursing so she felt she had a lot to offer her own family members. As the daughter and daughter-in-law, Sarah explained how she “*slipped straight into nurse mode*” when these family members were at the palliative care stage, which she saw as “*an automatic response*”. The way Sarah spoke about her desire to make the death of a relative a good experience for herself and her family reflects a mode of subjection to caring discourse that informs how she lives her life and relates to her family members.

*I think there's a huge link between love for that person and being a nurse, the fact that you want to care for them and keep them as comfortable as possible and do what is .... optimum for them.*

Maree at first considered her caring role with her daughter, who was diagnosed with cancer as a teenager, to be more the kind of care that a mother gives to a child. But at the second interview she suggested that on reflection, the fact that she was a nurse also influenced how she cared. Her mode of subjection to caring discourse involved doing her best for her daughter as the mother/nurse, drawing on her knowledge and experience as a nurse to get a diagnosis and ensure that her daughter received the best care possible. The self-work she undertook in this nurse family member role involved using her ‘insider knowledge’ to work the health system in facilitating effective care (Allen, 2001; Duke & Connor, 2008). She explained this way of knowing and functioning as a nurse in her story about struggling to get her daughter’s painful leg diagnosed. Having taken her daughter to a surgeon for a consultation, Maree was not happy with an inconclusive diagnosis and a prescription for rest and anti-inflammatory medication, because she knew something was seriously wrong with her daughter. In an attempt to get the right kind of intervention, in her words, “*to see if he could give us a different angle...*” Maree took her daughter to see a physiotherapist. She described how events unfolded in the consultation with the physiotherapist.

*.... and at that consult he said, just sit there, I'll go and ring (the Surgeon) because I think (he) knew immediately that there was something really wrong... so the next day we went back ... to see him. He did a scan and as she went through...I thought, Oh gawd, because... the uptake was just huge. You could see*

*this bright red patch on the screen. They didn't tell us at that stage... but being a nurse... get the books out and have a read... ... but I knew what it was...*

As surgical nurse and knowing her daughter's high pain threshold, Maree had sensed that something was seriously wrong and worked the health system (Allen, 2001) to ensure the problem was diagnosed, sooner rather than later. Her self-work within her subjectivisation as a nurse family member involved shifting blockages that she had encountered in gaining access to a diagnosis, which she eventually correctly interpreted for herself with the aid of her nursing textbooks. As time went on in events surrounding her daughters' eventual hospitalisation, surgery and palliative care, Maree made herself present as her daughter's nurse in hospital and at home.

These participants' stories show how they became subjectivised seemingly without hesitation as the nurse family member. They blended these roles in a way that seemed very normal to them, given their insider knowledge, and this seemed to be the right thing for them to do in the circumstances. They show how they simultaneously positioned themselves across the professional and lay discourses of caring for and caring about, that Ward-Griffin (2004) conceptualises as a public-private dichotomy in caring. While Ward-Griffin emphasises the discursive practices that divide the self from the self in the dominant professional discourse of caring in nursing, these participants' stories show how they collapsed this conceptual space to meet the moral end of the best care possible that they had envisioned for their dying relative. The following example from Robyn emphasises this point as she explains how it was impossible for her to separate being a nurse from her role as a family member and how she too researched her family member's illness.

*When my husband and my mother were dying everyone told me you're there as the wife, you're there as the daughter, you're not the nurse, but I couldn't separate the two. It wasn't possible. Part of who I am is the nurse and part of me goes into being.... they're mixed up and intertwined. I wasn't able to box the nurse in me when those two people I loved were dying.*



This was further illustrated in how she did an intensive search on her husband's diagnosis of lymphoma after being told by the consultant that

*.. if you're going to have a cancer, this is the best cancer to have and I knew that wasn't true... no cancer is the best cancer... so I found out all I could about it... median survival rates.... the treatment.*

Robyn emphasises how, given her insider knowledge and experience of the health system as a nurse (Allen, 2001; Duke & Connor, 2008), she was unable to separate and delineate the subjectivities of nurse and family member. She resisted normative expectations to position herself as a lay family carer rather than as a professional nurse, when these discursive positionings collided in the view of other health professionals, because knowing as a nurse was an integral part of how she functioned as a person. However, Jean's experience illuminates some of the tensions she found in positioning herself as the nurse family member for her mother, using insider knowledge of the health system as a nurse. Jean would have preferred to be her mother's daughter rather than her nurse. She said,

*I tended to put my professional responsibility first and as a daughter that's not what I would have chosen... the professional role overtook that.*

Jean found caring for her mother as a registered nurse more difficult than the other dying relatives she had been involved with before she was registered. Her story emphasised the tensions she experienced about her sense of professional responsibility and accountability for her mother's clinical care but at the same time spoke about her very strong opinions of death and dying and her belief that the aim was to do what the dying person wanted.

Jean's call to care, and her subjectivisation as a nurse family member, occurred in spite of these tensions. Despite concerns about the complexities of what she saw as a dual role, she resisted the pull of discursive dividing practices that demarcate professional and lay caring because she felt her mother needed better palliative care than what she had been receiving from professional services most of the time. Apart from Jean, there

was no hesitation in the participants' stories in responding to being called to care for family members. They spoke in very articulate ways that clearly situated them within caring discourse as a nurse in relation to their family members. In doing so they collapsed the categories of caring for and caring about (Ward-Griffin, 2004) to the point that the dividing practices that separate these categories became invisible and caring became a seamless construct that encompassed subjectivisation as a daughter, mother or wife that embraced their professional role as a nurse.

While the discursive practices that divide the self between professional and lay caring appeared in Jean's story, an ethical substance of political work (Cooper & Blair, 2002) within the discourse of caring seemed to close this gap. The mode of subjection for this political work seemed to be directed toward the struggle to ensure that their dying family member received appropriate and timely palliative care. Political work showed how the participants engaged in care of the self as care of others in an attempt to enact the freedom necessary to enable the best possible outcome for the dying person, the nurse family member and other relatives. Sarah explained this point by suggesting that because nurses have a certain foresight about death and dying they know what it means for someone to die at home. She cared for her relatives to enable the family to manage events rather than being managed by others. She saw being at home as a way of maintaining more control on the part of the family who have more power to articulate their own wishes inside the 'private' space of the family home, and thus the potential to create a better outcome for both the dying person and the rest of their family. Subjectivisation as the nurse family member within caring discourse also freed the participants to draw strength from their professional knowledge and experience. It produced a certain kind of strength and capacity to express their love and commitment to their family through being actively involved in accessing appropriate services, and undertaking the self-work necessary to deliver the best palliative care to their relative. This aspect of caring discourse will be further explored in Chapter Six in relation to negotiating boundaries between the private and public discourses that divide lay and professional caring and normalise professional conduct.

### *Family discourse*

This section explores how the participants negotiated relations of the self within family discourse, taking up family roles as daughters, wives or mothers. Family discourse can be identified as sets of statements that systematically order the landscape of care within families as the knowledge and practices that inform the constitution of them together with sets of roles and obligations. Normative understandings about what families ought to look like, and values about the sort of obligations that families have in the care of their dependent or ill members, articulate with related sets of discourses on gender, ability and freedom of choice (Blain, 1994). While in contemporary life, these discourses may be relatively fluid in constructing discursive practices as family roles, tensions remain in the relation between the self and others for both women and men, mainly between the choices and constraints that arise from positioning the self as a particular kind of gendered subject (Medved & Graham, 2006). As Lucas and Buzzanell (2006) suggest, the discourses that are used to talk about family life often hide assumptions about family roles and mute possible alternatives for how family members might take up and act certain roles. Medved and Graham argue that traditional values and beliefs about family roles normalise and perpetuate discursive dividing practices that separate roles and identities within dichotomies of public and private, masculinity and femininity, and rationality and emotionality. These roles and identities within families are formed at the intersections of these competing discourses and the dividing practices that they sustain (Ashcraft & Mumby, 2003).

Statements that make the role of families and women in particular, appear natural and desirable as first-line caregivers for their ill or frail members, at first glance appeal to a dominant discourse of the traditional family (Clark, 2007). However, in the second half of the 20<sup>th</sup> century, family discourse has become more fluid in allowing women to work to augment the family income as discourses of consumerism have constructed the desire for more material goods and increased living standards (Bowen & Finegan, 1969; Easterlin, 1987; Rankin, 1993). In 2001, female workforce participation rates in New Zealand varied from 76% to 79% for women aged 35 to 54, declining to approximately 60% for those aged 50 to 59 (Bryant, Jacobsen, Bell & Garret, 2004). While it has

become more acceptable for women to work as a way of augmenting the family income, to a large degree they still retain their role as the primary providers of emotional and nurturing work within families. This situates women with competing subjectivities as both productive earners and family nurturers, where their work outside the family is now normative, but also has the potential to be viewed as causing conflict and requiring sacrifice on the part of the family (Gilbert & Rader, 2004). It creates a complex, ambiguous and changing context for how women perceive their family obligations and participate in caring for others (McGrew, 1998).

Health policy has the potential to further complicate women's lives by calling on their competence in caring through a discourse of home care that constructs normative expectations about families meeting caring commitments to their ill members rather than 'abandoning' them to public health services (Clark, 2007). Home care situates end of life care within the family as its preferred model of care delivery. The neo-liberal discourse of choice, visible in the New Zealand Health Strategy (Minister of Health, 2000) and The New Zealand Palliative Care Strategy (Minister of Health, 2001), informs the idea of people being free to die at home with their families, and articulates with traditional family discourse making home care appear as the natural preference of families and ill people. While this tension between women's family and work roles will be further explored in Chapter six in terms of the choices women make about family caring and the affects of this caring on their lives, the point here is that the call to care originates within the family. It is reinforced by the expectation that care should only be undertaken outside the home when family caregiving resources are exhausted, or adequate health services are not available in a particular geographical location.

The conceptual topographies developed from the participants' storylines showed how these norms of reciprocity and obligation learned within the context of their family influenced their subjectivisation in caring discourse. Michelle, Sarah, Jean and Maree all spoke about wanting to be a nurse from the time they had been children; an aspiration that was influenced by family experiences and relationships as daughters and sisters. Hazel related how her experience of caring for her mother when she was a child influenced her decision to become a nurse. As the elder sister, Hazel often fulfilled

caregiving duties within the family during her mother's long periods of illness. She suggests that her decision to care for her parents when they both developed cancer-related illness in later life was informed by her religious values and sense of responsibility to her parents. Similarly, Jean's decision to become a nurse was influenced by her mother, who had aspired to be a nurse but was unable to fulfil this ambition beyond the probationary period of hospital training. She said that her mother was very proud of Jean's achievement, and as she put it, caring for her mother when she became ill in later life was an expectation that was clearly apparent.

*It was my mother's expectation... I felt that she wanted me to look after her... she wanted to be home... and she felt that because I was a nurse I would do that for her. I wanted to be a daughter to mum, and I guess that's something daughters do.... they nurse their relatives.*

The socialisation of women as nurturers within families creates a 'blueprint' to care, particularly when women have a prior experience of caregiving for other family members as children (McGrew, 1998). McGrew used grounded theory to explore the decision experience of ten caregiving daughters, aged 43 to 60 years in Florida, and to examine how these women negotiated the nature and level of their participation in caring for aged parents. She argues that the socialisation of women within psychological, biological and moral discourses about family roles and responsibilities normalises women as family caregivers. In this sense, the gender category of woman becomes synonymous with the idea of caregiving in family roles. It constructs an ethical substance of relational work where mode of subjection within the intimacy and connections of family make women visible as someone who can be called to care; the person on whom others are able to make a claim to meet the needs of ill or aged family members (Lashley et al., 1994). For example, Sarah and her husband were closest to their respective mothers and mothers-in-law in a geographical sense with most of their siblings living overseas or in the South Island. Her mother-in-law chose to come to Sarah, probably because she was a nurse. Her mother also lived in another house on the same property, so caring for her in Sarah's own home seemed like a natural extension of

their prior family relationship. Family values about dying also influenced, Sarah and the rest of her family in their decision to be involved in the care of dying family members. As she put it,

*I think birth and death should happen at home and it should happen around people that love you and want to care for you and not be in a strange place with strangers, strange routines, unfamiliar surroundings.... it should happen in familiar and loving conditions... so it was not a doubt for me.*

Sarah suggests that having a really good experience with her mother's death brought the family closer together. Her statement that dying ought to be situated within the family appeals to a moral discourse that situates caring as an important value within family relationships, and as a duty or obligation to others that, in the right circumstances, is likely to create a good outcome for the whole family.

For the participants in this research, the call to care for an ill family member constructs a mode of subjection as the struggle to meet perceived obligations. As a relational practice, caregiving is situated within these sets of rights and relationships within families and their inherent moral and practical obligations (McGrew, 1998; Sacks, 1967). Self-forming activities, in relation to this mode of subjection, become apparent as the work undertaken by the participants to meet family commitments and responsibilities. Sarah relates how in the first experience with her mother-in-law, she and her husband were very independent in caring for her where she suggests that in retrospect they should have been more open to help from others rather than trying to do it all as their own responsibility. *I actually put them first, always, sometimes probably at my own expense.* Sarah talks about how her concern for her siblings was also a focus during her mother's illness.

*It was like I'm watching mum and I'm caring for mum, but I'm also watching my siblings.... who had been quite capable of looking after themselves for the past fifty years... I was worrying about how they were doing as well... Even going for a walk down the road was always stressful because I would be thinking I wonder*

*what's going on at home.... I hope everything's OK even though there would be somebody here that was actually very capable.....*

Sarah's story about how she found it difficult to step outside the role and accept help from others while immersed in caring for family members shows how this mode of subjection to obligation dominated her thinking to the point that she extended a 'duty of care' to include other family members, whom as she suggests, were able to care for themselves.

Michelle spoke of a similar sense of obligation to her family, where she cared for multiple family members as well as her dying mother, but felt torn between her need to care for her own children and husband and her mother's family. She had left one of her preschool children in the care of her husband and took the younger one with her to her mother's house. For a period of six to seven weeks, she prioritised the care of her mother over that of her children. She found herself not only doing of all the clinical nursing care for her mother, but also running the house, doing the shopping and cooking for other family members who prior to her arrival, had been catering for themselves.

*I took over lots of roles.... like I was cooking for mum's boyfriend and my stepfather and my stepfather's always cooked for himself. I don't know why I started doing that.....*

This became hard going when her mother wanted someone to sit with her during the night. Michelle eventually took her one year old child back home to be cared for by her mother-in-law because she wasn't getting enough sleep, but this resulted in not seeing her children for periods of time as her husband tended not to visit because he didn't want to see her mother so ill. But while this was a difficult time for Michelle, she has a sense of accomplishment in having cared for her mother and extended family through this time. She said,

*..... I didn't think of what I was doing as being anything very special until I was reading through those sympathy cards and they all said you did a wonderful thing for your mum and I thought..... that is what people thought... and I just look*

*back at my life and I thought well this is why I became a district nurse... otherwise I wouldn't have had the confidence to do it... to nurse my mum.*

Michelle's storyline shows how this mode of subjection to obligation creates the potential to find meaning in the experience of caring for loved ones when they are most in need, and to achieve a sense of satisfaction in having the outcome of this care recognised by others (Chattoo & Ahmad, 2008).

The decision to engage in the care of a loved one, and choices about the extent of this involvement, involve complex responses to personal, situational and environmental factors both within and beyond the family (McGrew, 1998). Drawing on Berman's (1987) norm of reciprocity within families, McGrew suggests that a feeling of debt, duty and responsibility to others creates the need to care as a 'normal' and 'natural' response to the need of other family members for nurturing and physical and emotional support. She sees this reciprocity as an idea within moral discourse about caring for another as they would do for us, rather than as a debt owed to another in a reciprocal sense. As a mode of subjection within this moral discourse, obligation is informed by a sense of being attached to and identifying with the other. McGrew saw the predisposition to care as the first inclination for the women in her research.

Hazel, Jean, Sarah and Michelle clearly articulated this sense of obligation in talking about how they situated themselves as caregivers in relation to their dying parents or parents-in-law. However, while the call to care within the family exerts a strong pull on these women, they also positioned themselves both as nurses and women, with the capacity to resist, contest and transform how they cared as active social agents (Davies, 2003; Thompson, 2008). The subject positions they occupied as family members might have been historically constructed within dominant discourses about families, but as Anderson (2004) suggests the circumstances that arise in people's lives can inspire them to respond in ways that disrupt taken for granted normative expectations. Similarly, Chattoo and Ahmad (2008) suggest that even within the same family people may have



different knowledge, understanding and life experience and therefore interpret normative expectations in diverse ways.

In becoming subjectivised as family caregivers the participants in this research responded to normative expectations about their family obligations as women. However, their knowledge and experience as nurses gave them a variety of conceptual frameworks about human relations and family processes to understand what they were experiencing and the confidence to respond to these expectations in specific ways. By this I mean that in the context of this research, a mode of subjection to obligation in caring for a dying family member at home enabled them, in most circumstances, to negotiate the context of and process for this person's care because they knew it could be done in particular ways. Jean, Michelle, Hazel and Sarah all described the family home as a space where they could be themselves. Jean and Sarah's storylines related the idea of advocacy where they talked about keeping the family together within the family home as a space where they could do ordinary things, albeit in the extra-ordinary and life changing context of a family member's illness and dying. Jean explained how having her mother at home enabled them to do normal family type things together, and maintain her mother's own routine, rather than being in what she termed the more clinical environment of the hospice. She thought it was lovely that one of her nieces was able to get into bed with her grandmother. Sarah also spoke of having her own daughter involved in her grandmother's care, including care given after she had passed away. Holding this dying person within the space of the family home seemed to involve an active decision on the part of these nurse family members in order to take back the care of the dying person into the family where the participation of medical discourse and health care workers was mediated in this space by family.

The choice of home as a place for their family member to die created a sense of freedom for the participants to be themselves and maintain a degree of control over the events surrounding the illness and dying of a loved one. In this sense, family caregiving can be seen as political work; a liberating practice for both the caregiver and recipient of care

with the potential to enable expressions of the self in unique cultural and social modes of being that move beyond societal norms and expectations (Kessler, 2005). Michelle's story line shows how she resisted institutional care for her mother, preferring instead to respond to her mother's wish to die at home by constructing her own palliative care service for her, given that health care services were limited in the remote rural area where her mother lived. Michelle described how she drew on her own experience as a palliative care nurse and called on the expertise of other nurses who were colleagues or nurses that she contacted to seek support for the clinical decisions that she made. In doing so, Michelle transgressed discursive norms about her responsibility to her own children and her professional role by taking time out from them both.

Negotiating the shape and form of family relationships, especially with siblings was a struggle for some of the participants who were caring for dying parents. Nurse family members are bound up in relations of forces that individualise them in particular ways relative to other family members. They have 'insider' professional knowledge that marks them as different with particular capacities to know and intervene that other family members do not possess. Sarah's story shows how nurse sisters or sisters-in-law were able to work together amicably in caring for a parent.

*My sister ..... there was never any conflict of opinion or – I mean, it was run like a tight ship, you know, with two of us on it together. We turned, we bathed, we were making sure she was hydrated, we were making sure she was fed and there was just always something going on. It was really neat and I saw so many sides of her that I've never seen and vice versa. She's a great clinician, you know. She just comes in and she's so sort of practical and things I probably wouldn't even thought of. I'm probably more the spiritual nurse and I can see that she's – I was picking where she was at in her dying process, whereas my sister was worrying about the red spot on her hip.....*

While Sarah and her sister expressed themselves differently in caring for their mother they are positioned similarly in terms of the nursing knowledge and skills that inform their capabilities. Sarah's recollections of their conversations showed how they

discussed their thoughts and ideas about how they should proceed with aspects of care according to how each of them interpreted her health state. This capacity for negotiation represents an ethical substance of political work (Cooper & Blair, 2002) that involved them in open dialogue with one another in order to free the self and other to meet the moral end of caring for their mother. The idea of ‘running a tight ship’ also demonstrates the relational work undertaken together within a mode of subjection that strives for connection and the capacity to work together with a clear understanding of one another’s roles. Most importantly in this connection between nurse sisters, there seemed to be the ability to share, or at least to negotiate power in establishing relations of truth and self in caring for their parent, themselves and each other. Hazel and Jean experienced similar relationships with their nurse sisters-in-law, who sometimes assisted them or gave them time out from caring for their parents.

Both Hazel and Jean experienced what they termed ‘difficult’ relationships with their respective younger sisters who were not nurses, and their stories about the history of these relationships were remarkably similar. Jean spoke about how she found her family relationships were disrupted through caring for her mother as a nurse.

*I must admit I did feel isolated in the family group in the fact that I was the one with the knowledge and there was nobody else there up to the same level of the knowledge that I had and did feel isolated there.... my sister was unable to cope with some of the things that go along with death that she hadn’t seen before, expected, which is quite interesting because she stood right back from it – My sister and I lived not too far from mum and my sister would sort of duck off for a shower but not come back for hours and hours so – at one time we thought mum was going and couldn’t get hold of her to come and you know.... It did interfere with our relationship after mum died. I think there was a lot of anger between both of us.*

While Jean’s sister tended to withdraw from the family for periods of time, Hazel’s experience was different. In this case her sister resisted the professional authority and expertise that was apparent in Hazel’s ability to care for her mother to the point that she

felt it was best to leave the family and return to her work overseas before her mother had died. Hazel never knew what happened for her mother in the final days of her life but suspects that she was eventually admitted to hospital to die.

*My sister was causing so many problems .... I just left it to her. It was so sad .... because it was mum that suffered but my sister just couldn't handle me having the knowledge and expertise which she didn't have... my sister was .... the favourite and she could do all the farm work and all the stuff that ...was important ... for a daughter to be able to do ... but I'd had all this experience ..... and I just slotted to straight into it and knew exactly what was what .... which probably didn't make it easy for my sister.... yes that was my big learning curve..... and because I had been used to working with families with dying relatives I thought I knew it all didn't I? .... And then I realised that lots of stuff can be going on in families that the health professionals have no idea about and that for me was far worse than looking after mum... was trying to deal with my sister ....*

The younger sisters had stayed living close to their parents, caring for them and supporting them as they aged, while the elder sister had lived out the mother's aspiration to be a nurse and moved to live some distance away from the rest of the family, sometimes working overseas. In returning home to care for the parents when they became ill, the nurse sister usurped the family role of the younger sister by becoming the primary caregiver. The mode of subjection of obligation within family discourse was practised differently by the nurse sister as the nurse family member, because she was an expert in this caring. As the younger sister resisted the nurse family member's expertise and professional authority, she recruited the parents into her struggle to re-establish her own authority and former subjectivity as the one her parents depended upon. This contestation of family roles sought to re-establish the boundaries of relationships in relation to the normative framework (Butler, 2005) that sets boundaries for sibling behaviour and relationships in family discourse.

Leder (1991) identifies the potential for rivalry and disagreement in sibling relationships, which can manifest the relationships between sisters but these tensions tend to be cyclical, depending on the pressure of family circumstances. It is also important to note that disharmony within their relationship does not necessarily mean that sisters do not care for one another, but jealousy and competition are likely to surface emotional responses that test relationships (Neale, 2004). However, the capacities formed by the subjectivity of the nurse family member disturbed the relations of power that exist between siblings, in particular the ability to establish relations of truth to professional discourse in the care of a parent. Hazel shows how she exercised an ethical relation to the self in family discourse by absenting herself from her mother's care. She ceased to practice the subjectivity of nurse family member because in the end she believed her obligation to family discourse was more ethically served by her departure. As Kessler (2005) suggests, women's subjectivisation within family discourse should be understood as located within complex set of practices and relationships where "no single identity is sufficiently stable to have fixed meanings, whether positive or negative" (p. 5). She further states that it is important to de-essentialise gender as a specific category or identity for women to be able to perceive them as having other possible identities and motivations that call them to care within families. The political work of care practice creates the potential for families and caregivers to be seen as engaged in an active process of choosing to respond to family needs and commitments in unique and creative ways, albeit within the emotional resources that are available to family members. It provides an opportunity to conceive of such care practices as relational but not necessarily totally subject to the normative structure of family relationships.

*Discourse of expertise in knowing as a nurse*

As stated in the previous section, the call for nurses to care for their family members is informed by normative expectations about female roles in the family as well as well as relational factors that create an ethical substance of obligation. However, the relation to the self as a nurse positions nurse family members differently to other family caregivers because they have the ability to 'read' their loved one's health state using a nursing gaze (Sandelowski, 1998; Parker & Wiltshire, 1995). As a metaphor, the nursing gaze

signifies ways of knowing and understanding the physical, social and cultural worlds of health care (Lawler, 2003). It is a particular kind of clinical vision that affords the ability to interpret people, things and events in terms of what is healthy or pathological and to draw certain conclusions about a person's health state. Jean described how she carries out the surveillance of a client's physiological state using the nursing gaze in her usual working day.

*You walk in and one of the first things you do is look at them and you're just sort of mentally ticking away.... you're looking at them and assessing them while you're talking to them. I always touch them because you can pick up so much with touch....*

The nursing gaze is a way of looking and seeing; a mode of being and acting as a nurse. Parker and Wiltshire (1995) see the nursing gaze as similar to the medical gaze described by Foucault in that it relies on technical and scientific knowledge. It makes the patient visible as an object of discourse and a site of intervention, according to defined physiological classifications and practices. Nurses are socialised into this way of thinking and dealing with clinical situations through their professional education and experience (Ellefsen, Kim & Han, 2007). The nursing gaze is a key aspect of the nursing work that interpellates the nurse-as-family-member; it calls them out and subjectivises them as nurses so that they are drawn to interpret their families as objects of biomedical discourse. Subjectivity as the nurse family member comes into being through this relation to the self, as intellectual work (Cooper & Blair, 2002) within scientific discourse, which both constitutes the self as knowing and produces a particular kind of relation to the other as the object of that knowing (Foucault, 1984e).

Foucault (1980/1997) suggests that who one is emerges out of the self-work we do in relation to the problems we struggle with. He insists that our freedom to live our lives ethically lies in this ability to work on and be in command of oneself, and to integrate practices of the self into our practices with others in intelligent and socially just ways. The nursing gaze produced the capacity for the participants in this research to recognise and intervene in clinical situations, beyond the ability of other family members,

including the ill person. This expertise relative to the rest of their family was recognised by the nurses themselves and their families. It produced understandings that informed expectations about how the participants and other family members thought they ought to intervene and advocate for their parent, spouse or child using their ‘insider’ knowledge. For example, Jean’s mother wanted her present at appointments with doctors so she could use her clinical knowledge to interpret information that she was given about her illness. As Jean put it, she had the understanding to ask the right questions during consultations with doctors and later explain the meaning of certain information to her mother. Maree also showed how her persistence in pushing for a diagnosis was informed by her sense that something was seriously wrong with her daughter. This ability to understand and interpret clinical information for family members was an important element of the call to care for the participants in this research, as they struggled to help their loved ones come to terms with their life-threatening diagnosis and manage the physiological effects of it. Duke and Connor (2008) noted that in their study of senior nurses as patients, ‘insider’ knowledge was helpful in facilitating effective care and created a greater sense of safety for these nurses in vulnerable situations.

Sarah’s storyline about caring for her family members shows how her eye was constantly drawn to physiological indicators in monitoring their health state. She believed that having this knowledge was priceless in caring for a dying family member, because as she put it

*.... even if you don't have a great knowledge of the disease itself the fact that you have got that pathophysiology education there anyway...because you're watching it .... have your finger on every pulse.... you're so mindful of what's going on at that pathophysiological level.... its an unconscious but practical, wonderful tool .... doing that top to toe assessment every morning, every time you go into that room and you are second guessing every step of the way.*

Maree also related how she constantly monitored her daughter.

*I would walk into a room and immediately scan and I could tell by the look in her eyes or the colour of her skin or how tossed the sheets were or what her body language was or what was up in the drip bag – I'd add it all together. So you're assessing all the time. I would assess each time I looked at her.*

The nursing gaze illuminates the thinking and practices of the self that construct the ethical substance of intellectual work (Cooper & Blair, 2002) in response to the nurse family member's perception of their loved one's physiological vulnerability. As the participants' storylines show, intellectual work is a mode of subjection that involves watchfulness and clinical judgement as they struggled to understand and control clinical aspects of care. Self-forming activities brought nursing knowledge into the foreground of their thinking, where the nursing gaze was practised as concerned observation and careful interpretation (Norveldt, 1998). This reading of the nursing gaze draws on moral discourse about the purpose of nursing, as the ethical substance for intellectual work, where the careful nurse watches over the sick, protecting and nurturing those in need of care (Nightingale, 1859/1970). For nurse family members, there is "a complex moral-emotional relation of responsibility" where one's own life is bound up with that of another (Van Manen, 2002, p. 262). As relational work (Cooper & Blair, 2002) where the mode of subjection manifests as concern and worry in the struggle to care for another, this careful watchfulness is a technique of the self that enables nurse family members to grasp clinical situations as they problematise and critique their loved one's physiological state.

In describing her role in the care of her mother and mother-in-law, Sarah sees this way of thinking, doing and being as a nurse as an integral part of how she functions in her life. She spoke of how being able to think as a nurse gave her a sense of being in control of events and that, in caring for family members at home, it was impossible not to think as a nurse.

*It was just totally automatic and I was busy watching, assessing, predicting, doing all those things 24/7 and thinking, OK this is happening... this is probably*



*the outcome tomorrow. Do we need to act on this? Is this stuff that we can handle ourselves or do we need to get assistance... ...I'm constantly assessing and thinking and watching and making suggestions and it just doesn't ever go away.....its just there and its automatic... I often think we pick up things that other people miss....*

Sarah's storyline about thinking as a nurse shows how scientific discourse informs the nursing gaze as *savoir* (Parker & Wiltshire, 1995), or the kind of knowing that relies on the application of theoretical concepts to a clinical situation. Parker and Wiltshire insist that *savoir* is not necessarily a distant and totally objective gaze from *no where*. They argue that "it is a gaze from *some where*" (p. 165) in that it is understood within a specific context. Similarly, Titchen and McGinley (2004) describe propositional knowledge that allows nurses to predict certain outcomes based on theoretical models. The application of propositional knowledge requires situated knowledge that is drawn from the practitioner's experience and practice location as a rationale for making a knowledge claim; where 'knowing that' (Schon, 1983) has a relational aspect of knowing the person in its application. This is the practice knowledge that Parker and Wiltshire refer to as *connaissance* or the nursing look. Sarah's comment that she was thinking about whether they could manage certain aspects of care or not implies the use of judgement in this application of knowledge. In caring for her own mother, she had the added advantage of a nurse-sister's presence with her and she described how conversations between the two of them developed a kind of synergy that enhanced their clinical reasoning and nursing judgement.

Jean's storyline about the care of her mother also shows her thinking as a nurse. While her background in intensive care nursing had sharpened her assessment skills, personal knowledge of her mother was pivotal in understanding her clinical situation. She explained how bone metastases had resulted in a fracture of the neck of femur that required her mother to have a total hip joint replacement.

*She was admitted from an oncology outpatient appointment... she also had emphysema, ischaemic heart disease and peripheral vascular disease and she was*

*on the sub-acute list so they would get her ready for theatre and then cancel it and this went on for about four days. They kept her on IV fluids... but I couldn't get people to see that she was in fluid overload ... and then three days later they called us up and said that she was dying and I took one look at her and said, "Give her some frusemide, you know that's all it is, fluid overload" so they gave her the frusemide and half an hour later she's sitting up in bed absolutely fine. .... you just needed to look at her hands and face. You could see the fluid in her skin... built up in her face.... how swollen her fingers were.....her face was smooth and she's a seventy six year old lady.... I have very good skills in that area.... I mean I do it with everybody.... you see someone down the street and think," Oh Gosh, they've got ....", it's not something I can turn off.*

Jean explains the clinical reasoning she undertook in this moment, showing how she read her mother's body using a nursing gaze that brought together clinical knowledge with personal knowledge of how her mother usually looked. Her story illuminates the importance of particularity (Titchen & McGinley, 2004), or situated knowledge, as 'knowing the patient' and therefore being able to recognise the difference between the pathophysiology of fluid overload and clinical picture of a client who is dying. Jean reiterates Sarah's point about the nurse family member being able to pick up things that other health professionals might miss because they do not have intimate knowledge of the ill person. She also showed how the power of being able to speak in a discourse of pathophysiology with such authority facilitated appropriate interventions for her mother in a critical situation. These interventions in her mother's care illuminate the ethical substance of political work as the struggle for justice through resistance to domination (Cooper & Blair, 2002). The mode of subjection for political work draws her into simultaneous positionings as a nurse and daughter, where the self becomes a site of resistance that pushes back against the forces (Hofmeyer, 2006b) that would normally limit a family member's capacity to speak and constitute them as an observer. In positioning herself with a claim to the truth, Jean carves out a space to speak that identifies and positions the self as a nurse, and in doing so, creates the freedom to critique the diagnosis made by the ward staff and offer alternative interventions.

Michelle's storyline also highlights the political work of the nurse and the notion of the nursing scan in understanding what lies within her responsibility as a nurse. According to Parker and Wiltshire (1995), nurses understand the effect that an environment has on their ability to care for people. They are able to assess the look of a patient and their environment and know what help and support they may need to ensure their safety and comfort. Given that her mother was adamant about wanting to die at home in a remote rural location; Michelle used her knowledge as a palliative care nurse to set up the systems that would be needed for her mother in a location where there were minimal health care services available. From her own experience, she knew what kind of support her mother would require to die at home, constructing a palliative care service around her mother with herself as the primary nurse. She was the person who drove the care plan with support from the Palliative Care Clinical Nurse Specialist at the base hospital situated over four hours drive distant from her location. Michelle's call to care for her mother also had an ethical substance of political work (Cooper & Blair, 2002).

*You do it with your patients but I think you do it even more with your family... you can just try that bit harder or try something else or try a little bit more, but I guess I had this expectation that I wanted mum completely pain free. The hardest thing is .... the suffering and... thinking... I'm sort of responsible for this suffering..... I need to be able to do a better job than this.*

She had high expectations for her mother's palliative care and understood that when her mother required a syringe driver to administer medication, that she would need to move in with her to provide this care. The mode of subjection for her practice is the desire to relieve suffering. The self-forming activities she undertakes as she tries to solve the clinical problems that patients present with and to provide the best care possible involves asking critical questions about what can be done and seeking advice from other nurses and health professionals. While Michelle understood her own capacity to practice as an expert palliative care nurse, she had moments of doubt in her isolation with her mother where she wondered whether she was doing the right thing.

Sometimes nurse family members find themselves drawn into events with a sense of knowing too much about the clinical situation and immediately being able to predict the outcome, including the death of a loved one (Mills & Aubeeluck, 2006). In the face of such knowledge, they sometimes struggled to be a family member rather than a nurse. For example, Jean felt ambivalent about her role in her mother's care as she would have preferred to have had the opportunity to simply be her daughter. She describes her struggle with her sister's current illness where she has made a conscious decision to be a sister rather than a nurse but she explains how difficult it is to stop reading her sister's body and clinical situation as a nurse.

*She's been diagnosed with breast cancer.... so I've made a very definite decision that I'm her sister as she's going through this... I've intervened when she's asked but apart from that I've stood back.... having the knowledge that .... she's had three very large aggressive tumours right up against the breast wall... so she feels that she's got a good prognosis and I'm certainly not talking about anything other than that.*

Despite her best intentions to be a sister, Jean fails in this struggle to contain her relation to the self as a nurse. While she was adamant that she did not to be the nurse family member again, Jean shows how she cannot stop using this nursing gaze as a way of looking at the world. It is a way of reading her sister's clinical situation that calls her to intervene in spite of the desire to contain the nurse relation to the self.

*She's had a lot of surgery and infections and just about every single drain they stick in she has problems with.... so one day I went up there when she was in post-op and I sat there and just hand pumped the drain all day because she had developed this huge haematoma because the drains weren't working and they weren't checking.... so you do tend to fiddle a bit and she was very grateful that I did that for her as much as I was trying to step back.*

The nursing gaze constructs a particular way of seeing and speaking about something that enables the nurse family member to interpret clinical phenomena in the light of nursing knowledge (Parker & Wiltshire, 1995; Titchen & McGinley, 2004). The nurse

family member is called to work on herself as she becomes positioned in competing discourses of nursing and family where professional expertise in knowing as a nurse constantly disrupts any desire to contain the self as a family member.

### **Summary**

This chapter introduced the research participants within biographical portraits of their subjectivities as nurse family members. The call to care was the first landscape that appeared in the conceptual mapping of their stories about caring for a dying loved one. The complex and sometimes contradictory subjectivities that created a new relation to the self as the nurse family member are constructed within discourses of caring, family and expertise in knowing as a nurse. Care of the self and others was explained as an effect of the self-forming activities that the participants performed within these discourses as the ethical substance of intellectual, political and relational work that constitutes the subjectivity of the nurse family member. These nurse family members illustrate how the self is contested, negotiated and transformed (Yeatman, 1994) in response to shifting social and cultural forces (Miller, 1993). Caring discourse subjectivises nurse family members with an ethical substance of beneficence as the moral aim of nursing, where they undertake self-forming activities within a mode of subjection of duty and service that constructs the desire for them to engage in the palliative care of their loved one. While tensions between their lay and professional roles appeared in the participants' stories, an ethical substance of political work closed this gap as they worked to ensure that the best care possible was provided.

Family discourse calls the participants to care as a daughter, daughter-in-law, wife or mother within normative understandings about the obligations that families have in the care of their ill or dependent members. It constructs an ethical substance of relational work and a mode of subjection of obligation that makes female family members in particular, visible as someone who ought to meet the needs of other family members. The discourse of expertise in knowing as a nurse shows how the nursing gaze is a way of seeing that calls the participants to act as a nurse. It constructs an ethical substance of intellectual work as they are drawn to interpret their loved one as an object of

biomedical discourse. Nurse family members feel obliged to interpret information for their families and are expected to use their insider knowledge to watch over the ill person's clinical care.

In finding the limits of thinking and acting as either the nurse or family member, the participants in this research transgressed the space between the normative boundaries of these subjectivities, transforming the relation to the self by creating new discursive positionings in the space between them. The following chapter explores how the participants negotiate the self's relation to the self and others across normative boundaries that work to demarcate and illuminate the subjectivities of nurse family members. As Miller (1993) notes, we become what we need to be in order to practice an ethical life. Being called to act as the nurse family member within a community of care that is also one's family creates a unique responsibility. It requires a particular kind of sensitivity in knowing the self and the capacity to negotiate the relational spaces that constitute families and relationships with other health professionals.

## **Chapter 6**

### **Negotiating boundaries**

#### **Introduction**

This chapter explores how the participants negotiated the constitution and limits of their subjectivity as nurse family members in fulfilling their professional and family obligations. In giving an account of their nursing practice and self-work in the interstitial spaces between the self and other, new subjectivities are illuminated for them as nurse family members. These subjectivities are apparent in their accounts as a series of actions and ideas that reflect particular constructions of the self. The analysis in this chapter is informed by Foucault's concern with how people practice freedom to constitute the self in relation to the self and other and how this practice of one's freedom is affected by and affects others (Marshall, 2001, p. 83). This analysis of subjectivity continues the exploration of how the participants come to be who they are in relation to what they feel obliged to do in caring for a dying relative. It examines how they exercise their freedom to practice as nurse family members and constitute the self in ways that are contingent upon shifting social and cultural forces. As Foucault (1998) suggests, the process of subjectivisation in discourse engages the individual in struggles for truth, rights and intimacy in order to become a particular kind of ethical being. Through this process of subjectivisation, the individual is required to undertake self-work to position the self in relation to the other within discursive knowledge and practices, and in doing so determine their own status and legitimacy as a subject in that discourse.

The second storyline in the conceptual topography of 'Landscapes of care' becomes apparent as boundaries that are negotiated at the borders or margins of the participants' experiences and knowledge. Boundaries demarcate the 'normal' limits of subjectivity. An analysis of the constitution and operation of boundaries as a discursive practice shows how the subject becomes divided from the self and others in taking up and practising a particular kind of identity (Foucault, 1982/2003a). In conceptualising the

storyline in this chapter as negotiating boundaries, the analysis shows how the participants negotiated the constitution and limits of these new subjectivities in caring for a dying family member through relational, political and intellectual work as they positioned themselves within sometimes conflicting professional and family obligations. It identifies and explores the boundaries that define and delineate formal from informal care, professional from lay knowledge, professional and regulatory authority from delegated care, professional codes from personal values, and family obligations from work responsibilities. The analysis further examines the epistemological conditions that determine how relations of power establish and invest authority and the capacity to act in specific individuals (Rouse, 2005) and enable the transgression, containment or permeability of boundaries in particular circumstances.

### **Boundaries as discursive constructs**

Boundaries represent classifications and categories that create specific definitions about how people ought to act in relation to one another (Lamont & Molnar, 2002). These classifications and categories illuminate the form and limits of the discursive practices that define relationality (Emirbayer, 1997) as the means through which relationships between people are established, maintained and governed. The classification of similarities and differences within specific boundaries enables groups to set themselves apart from others by creating a collective identity that establishes superiority over others as expertise in knowing or practising some dimension of human activity (Hogg & Abrams, 1988) or some other attribute that represents the right to belong. In this sense, boundaries are both creative and destructive. On the one hand a boundary enables a space to be demarcated that signifies a particular kind of identity but at the same time it defines a line at its extremity that marks exclusion.

This collective identity involves a complex interplay of norms that provide the authority to establish and enforce difference, which are recognised by both insiders and outsiders (Jenkins, 1996). Norms simultaneously construct a collective identity and individualise the subject, classifying and ranking them in relation to their homogeneity (Butler, 2005; Foucault, 1975). Norms also create moral standpoints that set limits on what is



considered to be an acceptable range of behaviour or performance within specific boundaries. The relations of power between the self and other within the epistemological field of the discourse define degrees of normality for a collective identity, expressed in practice as normalising judgement (Hacking, 1990). Normalising judgement works through the moral code that calls the individual to account for themselves according to values that are held to be true by others in the social group to whom this individual belongs. However, Adorno (1983) argues that norms construct a false unity for moral standpoints that cover over the discontinuity that exists in moral codes. A compulsion to act according to norms that represent universal interests, but do not offer a useful ethical standpoint for the individual in a unique situation, brings these norms into conflict with morality.

Ethical deliberation involves critique of how the subject has come into being and attempts to live by a set of norms or moral code (Butler, 2005). As Butler suggests, even if the subject is produced by certain norms, he/she must find their own relation to morality; negotiating these norms in “a living and reflective way” (p. 10). This is Foucault’s (1984/1990) notion of reflexivity developed in the history of sexuality, where morality and values are created in relation to conscience and a sense of responsibility to the other. For Foucault, reflexivity emerges through this process of developing a critical relation to moral codes in taking them up as ethical substance for self-work. When situations arise where norms are not self-evident or no longer credible, the subject is required to undertake ethical self-work in relation to the code to establish how they ought to fulfil their obligations. All of the participants in this research described situations where boundaries between one category and another became apparent in relation to their own and others expectations about what constituted the limits of their subjectivity in specific situations. In caring for their own family members, the participants negotiated, transgressed and at times accommodated the boundaries between lay and professional knowledge, formal and informal care, professional authority and care delegated to families, professional codes and personal values and family obligations and work responsibilities.

### **Negotiating boundaries**

The storyline of negotiating boundaries shows how the participants experienced the limits of particular subjectivities as discursive dividing practices demarcating boundaries that divided the self from the self. For Foucault the self is not an object or substance. As Marshall (2002, p.91) puts it, the self is a conceptual form, where conceptualising the self involves

... a complex interplay of intellect, character and action. .... The singularity of the present in its games of truth and practices of power may either require a certain form of the self or present the opportunity to constitute one's subjectivity actively in a form of transfiguration of other forms of the self (p. 91).

In defining the limits of discursive practices available to the subject, boundaries bring a conceptualisation of the self into consciousness in a way that makes resistance to these limits apparent, and subjects them to critique. For Foucault, critique is a necessary element of freedom because it identifies and exposes forms of power that until the moment of experiencing a limit, remain manifestations of power that are not recognised as discursive effects but nevertheless work behind the scenes of our consciousness to curtail ways of thinking and acting (Olssen, 2006). Olssen (p. 245) notes that critique involves an ongoing questioning of limits as the means to reformulate the self's relation to normative codes that have the potential to call subjects into being as passive entities.

In this sense, critique aims to free us from the historically transitory constraints of contemporary consciousness as realized in and through discursive practices. Such constraints impose limitations which have become so intimately a part of the way that people experience their lives that they no longer experience these systems as limitations but embrace them as the very structure of normal and natural human behaviour.

Butler (2005) explains how rationalisation is subverted in desubjugation, in the moment the subject disengages from the power of the discourse by thinking outside it, and

transforms the relations of the self within it. Telling their stories in the research gave these participants the opportunity to think again about their experiences and to engage in this critique of the self by giving an account of their conduct as nurse family members. As Butler notes, giving an account of the self to another is a moral exercise where the ethical substance of subjectivity and the outcomes of self-work are held up for scrutiny in terms of their effects on others. In the following analyses of negotiating boundaries, the participants described situations where they engaged in the intellectual, political and relational self-work that was necessary to act in accordance with the ethical substance of their obligations as the nurse family member. Their stories show how they called themselves into being as subjects with an awareness of their own conduct in the light of family obligations as a daughter, wife or mother, and their professional responsibilities as a nurse.

#### *Professional and lay subjectivities*

In giving an account of their conduct, the participants showed how discursive dividing practices worked to enforce norms about who is authorised to speak in professional discourse and who is formally licensed to practice and direct health care. There were situations where the struggle to fulfil the ethical substance of their role as the nurse family member became apparent because they were classified within professional discourse as a lay person in the care of their relative, but were always/already capable of doing more. They also showed how they resisted the authority of professional discourse by refusing, challenging and limiting its authority in circumstances where accommodating it would have limited their freedom (Foucault 1984/1990) to meet a perceived need for care that they had recognised in their relative. For example, Michelle described the consultation with her mother's General Practitioner (GP) where she expected an initial plan to be developed to manage the symptoms of metastatic breast cancer that her mother was experiencing.

*.... she was going to meet him for the first time and wanted me to come.....I felt really sorry for this doctor.... he hadn't even received the notes and... This family [go] in there with expectations.... it really caught him off guard. With that initial*

*visit with the doctor he just prescribed some morphine elixir for her pain..... no anti-emetics, no information about how to increase the dose, nothing for constipation, and said, "Come back in a month". .... and I knew her pain ... within days she was going to need some tablets. I thought we could work out what she needed quite soon. I said, "Look I'll come back and see you before long". She was still relatively independent but ... the pain was her biggest concern then, getting this pain under control with the morphine.*

Michelle was present at the consultation with her mother in her role as a daughter, but with her expertise as a palliative care nurse, she like Jean was pulled beyond herself as the daughter by clinical knowledge that enabled her to interpret this situation. She knew that the approach the GP proposed, albeit with limited information about her mother's case, was insufficient to provide the level of care needed. During the consultation, Michelle had already realised that this was all he was going to prescribe initially and that, given the level of pain her mother was experiencing, the morphine elixir would not last a month. Her intellectual work in thinking critically about what the GP had offered and her ability to speak in professional discourse was derived from her experience of practising as a palliative care nurse. Her desire to seek the best care for her mother was an outcome of the political work she undertook in negotiating with him to prescribe MST and maxalon because she knew these medications were the minimum required to manage her mother's level of pain in the interim. Michelle's expectations for what she considered to be good palliative care for her mother were based on the experience of working in an interdisciplinary team in her own service.

*..... I felt the GP was out of his comfort zone really ..... there was a shock at some of the doses of medication ..... that you could actually give that much morphine without killing somebody ..... just things like that I think really surprised him because ..... I just felt really spoilt with our doctors, but I guess you had years to build up the rapport with them so.....when we look after patients we can go down to the doctors and wait outside their rooms and basically request whatever we thought our patients needed..... we have such good relationships with the GPs here and I missed that.*

In effect Michelle developed her own palliative care service around her mother in this isolated rural location, drawing on the social and professional resources from the health service that she worked in and from health professionals in the community some distance away where she lived with her own family. She also sought expert advice from the palliative care resource nurse at the base hospital, located several hundred kilometres distant from where her mother lived, about how to approach her mother's GP to ask for changes in treatment.

*I rang a few times and talked to the palliative care resource nurse in [the base hospital] from mum's place just to run things by her before I asked for different ..... I would say what do you suggest I talk to the doctor ..... you know..... how with mum's different symptoms and what do you think might work in the pump or what else do you think I could try..... I talked to her a lot ..... I rang my GP a couple of times when I felt like I wasn't getting the understanding I needed from mum's GP ..... and I even brought her home once and took her to my GP .....*

Michelle's knowledge about how the health system worked and accepted best practice in this clinical field informed her intervention in persuading the health professionals involved in her mother's care to provide more resources that they otherwise would have. She refused to be governed by the norms for professional relationships that situate the patient's daughter without a 'clinical' voice. As a discourse that defines and regulates who is eligible to speak with authority, professionalism creates assumptions about the use of specialist knowledge to intervene in human problems (Brien, 1998). The ontological distance between the knower and what is known, valued as a core epistemological condition for scientific knowledge (Duquette, 1990), becomes visible as objectivity in the discourse of professionalism. It is this boundary between 'objective distance' and 'subjective immersion' that Michelle carefully negotiates in constructing a palliative care service around her mother.

While professionalism has developed as the dominant discourse for health care practitioners, with medicine establishing normative responsibilities for occupations that aspire to be professional (Fagermoen, 1997), Shirley and Padgett (2004) note that the

discourse of professionalism functions differently for different groups. Practising as a health professional involves having the knowledge, expertise and the ability to enact professionalism as a mode of conduct or behaviour (Hodgson, 2005). The normative values that are produced through moral codes set out reference points, assigning positive or negative values to particular conduct, though the subject has certain degree of power in interpreting and enacting the moral code in the process of becoming subjectivised with professionalism as the ethical substance of the relation to the self (Dalglish, 1998). Professional codes of conduct articulate the norms that embody the profession's collective conscience, operating as a self-regulating mechanism for the profession and its members (Oliver & McGhee, 2005). However, nursing also involves relational work (Cooper & Blair, 2002), where meaning as an effect of knowledge is constantly negotiated and contested in the connections between the nurse, client and other health professionals. These connections are complex sites through which relationships are governed, where professional people work at managing their own conduct and that of others within the social and cultural conditions of practice (Owen & Powell, 2006).

Hazel's account of her practice with her parents shows how she was subjectivised as the expert palliative care nurse with international experience and this expertise was recognised by the health professionals she interacted with.

*I think I was probably in an unusual position because ... it was my job in London to have been caring for people in their own homes for nine hours every night and making these clinical judgments of what to do ... you know you get used to thinking ... outside the square as to how to cope and deal with the huge amount .... it was juggling whether I needed hospice advice .... Or whether it was a GP that I went to so it was my call in trying to suss ... who was the person to go [to], with what problem ... without upsetting the other... yes I mean you don't want to go to the doctor if the hospice nurse could deal with it ... you've got to work within their boundaries ...*

As Hazel suggests, being a nurse is part of who she is as a person where she negotiates with the families she cares for and the other health professionals who are involved in

that care. Her explanation of herself locates her subjectivity as a nurse within her thinking and actions in ways that reflect this construction of the self. She speaks in the professional discourse of nursing with authority as she identifies herself as an expert nurse to others; a nurse who is at the same time the family caregiver. As Hazel put it,

*We have that language and its just that kudos .. you just say I'm a trained nurse and I've been working in palliative care and to any other professional that says a huge amount ..., I suppose even if you're just said I'm a nurse it still says a lot doesn't it...*

On the one hand a boundary enables a space to be demarcated that signifies a particular kind of identity but at the same time it defines a line at its extremity that marks exclusion. The ability to articulate the language of nursing, positions the speaker with a certain kind of power in professional discourse, even when not primarily acting in a professional capacity. Jean's description of how she felt she had to intervene in her mother's care in a hospital ward, when she had been told her mother was dying was related in Chapter Five. Her actions represent a boundary transgression where she steps beyond the role of the daughter. In stating, *I felt I had to intervene because she wasn't getting the care she needed*; Jean was pulled beyond herself as the daughter (Salmond, 2008) by the intellectual work she had undertaken in recognising the pathophysiology of her mother's problem as fluid overload. In the same moment she was drawn to act for her mother as a daughter and a nurse in doing the political work necessary to bring this situation to the notice of the staff. Jean's story shows how the analysis of boundaries as discursive constructs that categorise people and make distinctions between them, in this case between a person who is acting in a formal professional role in health care and that of a relative, illuminates complex social processes that demarcate accepted roles for the daughter and nurse.

Jean's sense of compulsion to further intervene in her mother's care on this acute medical ward reflects an ethical substance of political work in her critique of the standard of care that was practised.

*..... they put her on a – it wasn't a CPAP – they brought something up from intensive care to and help because.... these terrible apnoeic episodes she was having and they actually connected it up back to front and so ... the air that was being pumped into her was actually very hot and they wouldn't turn it off and mum was just getting sicker and sicker - just so uncomfortable with it and so in the end I actually turned – as much as I didn't want to I went and turned it off and got somebody who – a more senior person who I felt could come in and .....they had connected it up back to front. I could see things weren't being done as they should be and so I felt I needed to step in.*

Jean acknowledged that both nursing and medical staff were relatively inexperienced and very busy on this ward and that they were not familiar with this equipment. In recognising these factors she defined boundaries and limits for the minimum level of care that would be provided for her mother. While she was not familiar with this particular item of equipment, she knew enough from her ICU background to see that it was being used incorrectly. Jean's intervention in turning the equipment off was a point that marked the limits of her tolerance, demonstrating her ability to use power to uphold a professional standard of care as an expression of her subjectivity as both a nurse and a family member. As she sought to protect her mother by confronting the mistakes made in using the equipment in discussions with staff, Jean practised an ethic of resistance that transgressed the discursive space (Cooper & Blair, 2002) usually afforded to a family member. This was a position that she reinforced through relational self-work by recruiting a nurse friend employed at the hospital to her cause, who as Jean put it, validated her concerns. She asked this nurse to review her mother's case notes and mediate on her behalf with the charge nurse of the ward about the standard of care given to her mother.

Like Jean, Hazel used her knowledge of how the health system works to establish the relations of power necessary to position the self with a critical voice about the care provided to her mother. While she had very effective relationships with many of the health professionals involved in her both her parents' care, she explained how she was



concerned to arrive home from London to find her mother's medical consultant had ordered a diagnostic test that involved a mediastinoscopy.

*I knew straight away that it wasn't going to change anything, that he was doing it for him not for mum because it wasn't going to change her treatment in one iota and he was being a naughty boy but it was too late ....mum wasn't prepared to flag it away since it had all been set up and everything ... anyway so she had it ... but I saw the blood results that came back and I mean her liver results were all very abnormal and he just shouldn't have done it. I had the experience to be able say ....is that going to change anything?*

Hazel situated herself with an ethical substance of political work (Cooper & Blair, 2002) in critiquing the consultant's decision to undertake this diagnostic test. She draws on professional discourse to both situate herself with a mode of subjection as resistance and to call attention to professional norms about the need to limit invasive or redundant interventions in palliative care. While Hazel, like Jean, marks one boundary, she simultaneously collapses the space between professional and lay subjectivities in speaking as the expert nurse about her mother's care and demarcates boundaries between best practice and what she considers to be the consultant's clinical interest. In expressing normative values about what constitutes ethical practice in this context, Hazel marks the boundary between about what is held to constitute reasonable grounds for intervention and what might be considered to be futile. For example, there is a moral claim situated in the discourse of virtue ethics, that diagnostic tests conducted on consenting patients might contribute to the body of knowledge about palliative care, and benefit other members of this clinical population. However, the potential for harm to these people because of their level of vulnerability is the central moral concern that defines the normative boundary between reasonable grounds and futility (Keely, 2008). While Hazel established her own relation to the ethical code, the consultant may have taken up a different positioning informed by his own relation to it and his beliefs about the value of clinical knowledge.

In another story about the idea of futility, Robyn spoke of her anguish about being unable to fulfil the ethical substance of political work in seeking to free her husband from the pain of undergoing a diagnostic test.

*Now he'd had ultrasounds and things so they knew exactly what the lymphoma was doing ... that is was blocking off his ureters and this was [the] terminal phase of his illness... they knew all that.. But they said they wanted him to go to Xray and I wish that my nurse part had been stronger then and said no ... ....it's an intellectual exercise ... it's not going to contribute to anything and I wasn't strong enough... my nurse bit knew that ... I felt that at the time... this is just insane. It was horrendous for him .... and I was behind the lead screen in the Xray department just sobbing and sobbing..... I guess they say that knowledge is power but I didn't think I had power and I think that's part of the way I trained ..... you know that things aren't right but you don't have the courage to do anything about it because the system will win in the end ... so I had knowledge but I didn't think it gave me power in that sense you know... I think it frightened me a lot...*

Robyn problematised this situation, establishing her relation to it as one that required resistance by speaking out as a self-forming activity, but her clinical voice is constrained by the perception that she does not have the power to speak. This story shows how subjectivisation as the nurse family member calls her to act as an ethical subject, but discursive relations of power within the hospital constrain and alter her capacity to intervene as she relates to herself as a target of institutional discipline (Rose, 1996a). Whether her concerns were justified or not, the desire to voice her opinion that this diagnostic test was inappropriate and have that argument accepted as valid is silenced within relations of power that Robyn has learned position nurses with a subordinate status in the hierarchy of the hospital (Ceci, 2003a). For Robyn, an ethic of resistance required the confidence to refuse to participate in events that were morally distressing. The ability to enter into struggles against forms of power and confront the moral issues at stake requires the resourceful use of power that has created the source of oppression (Cooper & Blair, 2002). Using this source of oppression for one's own advantage

necessitates calling attention to an ethical standpoint that others will recognise within professional discourse; in this case her husband's degree of vulnerability and the ethical obligation to avoid unnecessary harm.

Robyn's story about her husband shows how a capable and self respecting nurse, with a strong sense of her own agency, finds herself in circumstances that made her a target of discipline, constructing her as a silent, dutiful and docile subject (Ceci, 2003a; Rose, 1996a) against her will. Another story about caring for her husband at home shows how she created a thoughtful and careful response to a challenging situation. Robyn relates how her husband asked to her to help him die when he was in the final stage of his illness.

*It was the first time I cried in front of him and he just put his skinny little arm around my shoulders... and patted me you know..... He was at the stage then where I don't think he cared much what they did to him he just wanted it over. Like he'd deal with a sick ewe, you know... I mean the farm was what he did..... So he put his arm around me and just patted me and said, I want you to help me ... I want you to help me make it end..... There's no purpose anymore. .... I've said goodbye to the kids and I want you to help me ... and I couldn't do that. I thought I could do it .... but I couldn't do it ... it would have been so easy but I couldn't do it. I didn't realise what I actually felt about that at the time ... because he was a man of the land and it didn't fit with him... where it was going..... I felt just totally devastated because I wanted to help him.... And I wasn't able to .. and he so wanted it. I understood why. I just couldn't ....*

As Robyn reflected on this moment she identified tensions between her personal values about her obligation to her husband and her professional beliefs about nursing. The rationale she offered for choosing not to actively help her husband die illuminates the ethical substance of intellectual work (Cooper & Blair, 2002). She reasoned that the power of nursing provided the means to ease his dying, keeping him comfortable and safe through the use of expert knowledge and skills. Reflecting on her own values and those of her profession guided her belief that she could not actively help him die, even

though as she put it, she had “*enough morphine in the house to kill an elephant*”. In searching for understanding she constructs a politics of truth as the relation to the self that she can live with; the one that set limits on her actions and created the least ethical conflict in her mind. In positioning herself as a nurse, Robyn undertakes self-forming activities to construct a mode of subjection to professional discourse that satisfies her obligations as both nurse and wife. Her agency and creativity as a nurse was also apparent in the relational work she undertook with her nurse friends who had come to stay with the family. It is interesting to note that all of the participants in this research had nurse friends who provided informational, emotional or practical support for them, sometimes staying in the family home with the nurse family member when their relative was dying. In Robyn’s case, these nurses became her clinical mentors in her struggle to care for her husband and she relates how in the middle of the night, they talked to her husband about his power to create some control over what was happening to him.

*I had some good friends here then ... nurse friends, people that B. loved as well, three of them registered nurses and they were helping me with his care and supporting me .... and I told them what B. had asked me to do .... so they came out and spent a couple of hours talking in between B’s sort of dozing off and things ... and they told me that they had said to B. that he had the power to make it end faster ... and what he could do was to not eat and drink anymore, they said you can do that and it will be faster ... so from that point on B. told me he wasn’t going to drink anymore .... and I respected that ... I used to give him crushed ice just to keep his mouth moist and they also told him that he could say to the palliative care nurse that his pain was increasing so she would increase the morphine which was what he did .... ... I’m just so thankful they did that for B.... B. made the decision and he did tell the palliative care nurse that he had more pain .... And she did increase the morphine.*

As Foucault (1982/2003b) suggests, resistance involves refusing what we are in a given moment and reinventing ourselves anew through alternative forms of subjectivity. Through their collective knowledge and skill, these nurses offered Robyn’s husband a means of transforming his relation to the self, by redefining the extent and means of his

freedom to act. This example of collective action among nurses represents a social practice where care of the self involves caring with and for others, helping them to recreate themselves through alternative ways of knowing and acting. It situates values about what constitutes an ethical self within relations of friendship and obligation (Infinito, 2003) drawing on the collective knowledge and skills of a nursing community as intellectual self-work undertaken in collaboration with one another to solve problems. Relational self-work is the means through which they construct a mode of subjection as the struggle for intimacy and connection between members of a community (Lashley et al., 1994), where dialogue enables the limits of different ways of knowing to be explored and weighed for their value in a given situation (Cooper & Blair, 2002). The formation of ethical sensibilities requires the freedom to cultivate our own individuality as the means through which we can know and appreciate the self in relation to and with others (Clifford, 2001). Hofmeyr (2006a) believes that while the self's relation to the self involves individual self-work, it has the potential to create social change by practising freedom as both an ethical and political action through constant de-individualisation of normalising forces and re-invention of them in new ways. The participants in this research show how their knowledge and skills as nurses informed their discursive positionings in relation to other health professionals involved in the care of their relative. Their stories illuminate the ethical work undertaken in exercising modes of subjection as struggles for knowledge, freedom and community connections in the care of their loved one.

#### *Boundaries between formal and informal care*

As identified in Chapter Two, health care at home care and family support for people dying at home are central visions for The New Zealand Palliative Care Strategy (Minister of Health, 2001). The idea of home care is identified as a choice for families and communities, with family members positioned as active participants in the care of their loved ones. This vision of care is consistent with research in the United Kingdom that suggests most people would prefer to die at home (Higginson, 1998; Higginson & Sen-Gupta, 2000), as home is a place that may be consistent with family beliefs about dignity, comfort and control over events surrounding death (Brown & Colton, 2001).

The six participants in this research cared for a total of nine dying relatives at home, with Robyn's mother the only one who died in a rest home facility that contracted to offer palliative care in her region. These nurse family members identified their own home, or that of their parent, as a place where they felt an increased level of comfort and control over the care of their relative. Negotiating this space within the family home was an important aspect of self-work undertaken by the participants to create the freedom to care for their relative according to their own values in collaboration with other family members.

For example, Michelle cared for her mother in a remote rural setting because it was her mother's choice to be at home in her own environment. The palliative care service in this remote region relied on, what Michelle identified as, generalist health care professionals who were not particularly experienced in contemporary palliative care approaches. Caring for her mother at home enabled Michelle to establish a measure of control over the clinical care that her mother received. She described how she found herself in conflict with the palliative care nurse, who had become a good friend to her mother but gave advice that Michelle considered not to be best practice.

*I found it quite hard because I was giving mum advice over the phone about her pain relief. She had started on morphine and was still having pain and I'd suggest she increase her dose and she would say things like, "Oh no. C..... told me to stay at this dose for at least 3 more days. I just thought we would do it but mum respected this palliative care nurse.... and I think mum felt a bit in between really, not knowing who was right or what to do and ..... Her symptoms weren't in control and no one was really listening to her. But this nurse, I mean she was lovely and I think she provided a lot of emotional support, which was really good – it just frustrated me that we were coming from different angles sometimes and I just wanted mum to be pain free. I felt it was going to be difficult if there were too many people involved – perhaps and maybe that's why I decided to go it alone after that so there was one person calling the shots. I'd been district nursing for probably 6 years and by then had done palliative care ...so I was quite happy to just go it alone with the GP..... by then I was living with mum .....*

*it was just easier to ..... and not involve any other help especially as it wasn't necessary. I was there 24/7.*

While home palliative care relies on the presence of a family member to provide care, nurse family members change the dynamics of relationships that other nurses and health professionals have with the family. The ethical substance of Michelle's mode of subjection encompasses both intellectual and political work in caring discourse (Cooper & Blair, 2002). As she struggles to establish a relation to truth about what constitutes best practice for the care of her mother, like Jean, Michelle constructs limits on the level of competence she is willing to tolerate in her mother's care. She constructs a field of responsibility for herself, with clearly defined boundaries of authority demarcated by the physical space of her mother's home. Within these boundaries she undertakes the political work of advocating for her mother's right to what she considers to be the best care possible, limiting the access of some nurses and seeking support from those whom she considers to be clinical specialists. Some degree of evaluation of the practice of other nurses who came into the participant's homes, or that of a parent, was present in all their stories about caring for their relative. Hazel related her observations of the palliative care district nursing service involved in her father's care.

*I noted that there was quite a difference between mum and with dad but I don't know if (the hospice service) was going through a really bad patch with dad but the people who came to see me were not nearly as clued up as they were with mum. I didn't have nearly as much confidence in them in that I felt they were ... just managing palliative care by the book rather than by the individual person so if there was a problem with bowels well it was just if you know if haven't had gone in so many days then you have one laxon ... and if you have gone by the next day then you have two ... and it was all very impersonal and standard and not ... there was no give and take or discussion .... until you've actually had someone close to you die at home you have no idea what it means and how important it is.*

Though she had been working as a home palliative care nurse for a number of years in the United Kingdom, Hazel said she did not really understand the significance of caring for a relative at home for family members until she experienced it. The nursing staff in this service had changed in the three years since her mother had died, and in her evaluation, they were less expert than the previous group, and less in touch with the priorities that her family had about the care of her father. Drawing on her experience, Hazel identified some of the challenges of working with families in this context.

*It's difficult but I think anybody who is being looked after at home, there must be one or maybe two people who are in charge and they form the key worker or... when I used to go in and look after patients at home in London and you'd walk in the door at ten o'clock at night and there'd be this whole group of, or maybe just a couple, or maybe twenty people in the room and the first thing that you intuitively did was suss out who was actually the key person to deal with, who had their finger on the pulse, who knew what was going on and who felt comfortable with taking that lead role and it maybe a trained nurse or it be just ... it may be number five daughter but it was somebody who could take that role and responsibility and was who happy doing it*

The connections between health professionals and families are complex sites where meaning is constructed within the social and cultural conditions that inform the participants' values and beliefs (Owen & Powell, 2006). Hazel's storyline about her experiences with other nurses emphasises the relational aspect of negotiating care with the family as a priority. Relational work involves a mode of subjection to caring discourse that positions nurses with the capacity to call forth their own stories, acknowledging one's own relation to truth (Miehls & Moffat, 2000), in order to work in community (Lashley et al., 1994) with families. Understanding one's own relation to the self enables the recognition of historical circumstances and experiences that have created particular ways of thinking and acting in a professional role. As Miehls and Moffat suggest, with this appreciation of the self, we can better understand how to position ourselves with others in ways that respect their concerns. All of the participants gave examples of generous and very effective relationships with nursing and medical



staff, and some other health care and voluntary support workers in the palliative care services that worked with their families. Some of these people were already known to the participants in a professional capacity while others were strangers. For example, Robyn's knowledge of nursing enabled her to appreciate the hospice nurse's skill.

*The hospice nurse had all of those things, sensitivity and foresight and an immense kindness. She also had lots of skill you know, professional skills .... it's no good being the kindest and the most sensitive person in the world if you don't know what you are doing but she definitely knew what she was doing ... I could tell .... I guess that's the positive thing about my nursing knowledge. I knew that ....B. was safe in her care. I knew that without any doubt at all and I guess if I wasn't a nurse that's something I wouldn't have known for sure.....*

Maree spoke of her experience of having district nurses that she knew from her work at the local health centre come into her home. She appreciated already knowing these nurses as part of her professional community, but also recognised that working with a terminally ill child of someone that they knew professionally took an emotional toll on them.

*..... they were wonderful. I can't stress enough how great they were.....I knew them already. I mean when you are a practice nurse and district nurses you're working together all the time. I'd often see them at work every day so they knew me..... OK it was pretty horrific because I remember they use to visit me with dark glasses on because they didn't want to – they used to stop – they told me afterwards they used to stop down the end of the road and cry before they came and put their dark glasses on so that I wouldn't see. They used to find it so hard coming.*

Having a sense of community with these nurses gave Maree confidence in them because she had often heard her patients speak about their satisfaction with the service that they provided in her rural town. Sarah further elaborates on the idea of working in community in her description of the relationship between a hospice nurse and her family.

*We were really, really lucky. We had a hospice nurse who was very aligned to our philosophies....so it was very easy for us,... I think really she just stood back and let us do our thing and ..... she was just so supportive of our process. It was always done in a consultative basis. Any visit that she made with us was very equal and we would discuss options and look at what was going to be the best for a certain issue that we might have. She was very respectful of our opinion and we were very respectful of hers. She had a sixth sense of where we were at..... and where Mum was at. She seemed to have her finger on everybody's pulse at once. She was just one of those really special, special nurses that managed to sense it all, but at the same time managed to keep her distance. We wanted to, like, wrap her up into us because she was that sort of person, but she really managed to just be.*

Sarah identifies how this nurse was able to sense what the family needed through her connection with them. Through her immersion in the family situation, she made her approach to the care of this dying woman seamless with that of the family. As Sarah's story shows, however, this immersion succeeds in being professional through the clarity that this nurse established in her role with the family. While she was deeply connected with them, there are limits apparent about the extent and focus of her relationship with the family as she worked to oversee the care Sarah and her registered nurse sister gave to their mother. According to Sarah's account, this nurse negotiated her role with these sisters as a clinical mentor in the way that thoughtful experienced nurses do, encouraging, supporting and directing them where necessary in ways that respected them as nurse family members.

*I think sort of closer to the end she could see that we were so sucked into that vortex .... we'd lost any concept of time. We're forgetting to eat ourselves, we're forgetting to do all those sorts of things, that she just reminded us that we needed to look after ourselves, and she was amazing. And just the support and the praise and the encouragement of what we were doing was just gorgeous, and she was just right there with us the whole way.*

The discursive practices that define relationality (Emirbayer, 1997) are apparent in the role this hospice nurse established with Sarah's family, showing how relationships between health care professionals and families can be governed in creative and reflexive ways. It is a means of 'gazing with' (Georges & Benedict, 2008) the family that establishes this creativity, building capacity with others by working on the self's relation to the self. It is a pedagogical relationship that moves the other towards self-mastery; reflecting their own situation back to them and teaching them how to live well within it. The participants' descriptions of relational practice with palliative care nurses involved with their families offers examples of reflexive practice in negotiating boundaries between professional authority for care and the delegation of care to families. The following section explores examples of situations where the boundaries between formal and informal care were blurred as nurse family members take up nursing roles that subsume the professional authority for care.

*Professional authority and care delegated to families*

Nurse family members have the ability to trust their own judgement, critically analyse the practice of other nurses and health professionals and argue for particular approaches to care in ways that a lay carer could not do. They are positioned with knowledge and skills that extend beyond the usual level possessed by lay carers or other family members bringing added value to role of family caregiver because they are always capable of doing more than someone who is not a registered nurse. The call to care situates nurse family members with an ethical substance of relational work in caring discourse. Self-forming activities in relation to this ethical substance involve working on themselves to produce the best care possible for their ill or dying relative. With their insider professional knowledge, the participants in this research found their own relation to morality, transgressing the limits of lay caring to subsume aspects of professional authority for care, particularly when they believed that the care offered was not best practice in a given situation.

For example, Sarah's experience as an intensive care nurse enabled her to exercise clinical judgement and intervene in situations when the palliative care nurse was not present or delayed in visiting. She relates how she was able to

*.....communicate what I felt need to happen now... and I think it sped up a lot of processes... whereas I think ... discomfort would be prolonged for some people and that worries me a bit. I was grateful to have that experience because if I hadn't ..... and were just Joe Bloggs, it would have been really hard. I don't know that Joe Bloggs could have had her at home. I don't know how well that (the analgesia) would have been managed.*

Sarah shows how she took control where she thought it was necessary to manage clinical situations effectively. There were times, particularly with her mother-in-law when she intervened because she felt something could not wait, such as giving analgesia, or changing the syringe driver. However, Robyn spoke about choosing not to manage the syringe driver because she found the emotional impact of this aspect of her husband's care too difficult. Instead, she recruited nurse friends to help.

*... I mean I know how to set up a syringe driver ..... I've done it hundreds of times but couldn't do it for B. I had to get my RN friends to come and do it. I could administer the drugs I was required to but I couldn't set up the syringe driver... I was torn between the invasiveness of it when he was so ill ... that was hard, very hard. Such a simple thing.... I mean in the end ... I couldn't bear ... so we decided to do it. One of my friends helped me at night... you know he had two syringe drivers... staggering to the toilet and back again. She helped me ..... so I didn't have to deal with it.*

While Robyn spoke about the excellent relationship she had with the palliative care nurse in this situation, this nurse did not always respond to her calls for assistance. She believes this lack of response was related to the nurse's extremely heavy workload at that time and given that she knew Robyn was a registered nurse, may have given her calls less priority. As Robyn's story shows, she was resourceful enough to recruit help from elsewhere. Michelle also situated herself with the professional authority to care because she knew that she had the nursing knowledge and expertise to manage her mother's palliative care, even if in reality she was sometimes challenged by clinical situations that she encountered. In doing so, to some degree she limited the involvement of professional nursing services, so that these nurses were in contact with her by phone,

or came to the house to drop off supplies. As Michelle suggests, she initiated most of the contact she had with them.

*..... I don't think they ever called really .... I called them if I needed something  
..... they basically left me to it..... they didn't visit ... they'd drop things off  
..... but they didn't actually oversee anything.... I needed a new pump at one  
stage because mum's pump wasn't keeping good time so they dropped off  
another pump and would drop off syringes or whatever I needed ..... and say you  
know ... say how's it going but that was OK ..... that was just our  
understanding really that I could have what I wanted just ring them ... and they  
were good and I think you know it was awkward for them too..... nurses can feel  
a bit funny about coming in with ..... trying to care for someone who is already  
being cared for by a registered nurse and I think ..... I think it was easier for  
them to just you know ... I knew they were there if I needed anything ... they  
weren't palliative care nurses otherwise I .....may have asked their advice ..... I  
think they just assumed I had it organised..... just to ring if I had any problems  
.... All the medications, you know all the drugs.... I just organised with the  
GP..... ..*

If Michelle had not been an experienced palliative care nurse, it is likely that her mother would either have been placed in a hospice, or the palliative care service would have been much more involved in her day to day care at home. The participants' stories show how the level of care delegated to these nurse family members, or the level of care that they chose to undertake, was beyond that generally delegated to family members. It is also possible that, as Robyn suggested, in prioritising a busy workload, palliative care nurses might expect a nurse family member to cope where they might respond sooner to a request from a person who is not a nurse.

The guideline on delegation and direction (Nursing Council of New Zealand, 2008a) states, "The Council acknowledges the rights of consumers and their whanau to determine their own care and expects registered nurses to work in partnership with them when delegating and directing care" (p. 6). The delegation of nursing care is defined as

the transfer of responsibility for certain activities to another person, but the registered nurse remains accountable for the process and outcome of delegation. In an earlier statement, the Nursing Council of New Zealand (2000) defined professional authority for nursing care in situations where family members are involved in the care of a relative.

Where health service assistants are employed, or the client's family are assisting with the care of the client/patient/resident/woman, and the **registered nurse or midwife accepts responsibility for the supervision/and or delegation of that care**, criteria for direction and supervision apply and accountability for nursing processes and outcomes remains.

The Nursing Council's guideline on direction and delegation indicates that professional authority for nursing care would have remained with the palliative care nurse representing the service providing care to the family. This would include assessment and monitoring of the client's health state, providing direction, and monitoring and evaluating care (Nursing Council of New Zealand, 2008a). However, as identified in Chapter One, the Nursing Council held the view that Lesley Martin, who was convicted for attempted murder, was primarily acting in the role of a nurse, using nursing experience and skills to care for her terminally ill mother (Radio New Zealand, 2007). This view would indicate that registered nurses are accountable for their practice within the Registered Nurse Scope (Nursing Council of New Zealand, 2007), for caring activities undertaken with their families, where those activities make use of nursing experience and skills. Nurses are political entities using disciplinary power to practice with professional authority while at the same time being subject to the state authority of regulatory discourse (Thompson, 2008). The Health Professionals Competency Assurance (HPCA) Act, 2003, the Code of conduct for nurses (Nursing Council of New Zealand, 2008b), and the competencies for registered nurses (Nursing Council of New Zealand, 2007) represent discursive objects that govern the form and limits of nursing subjectivity. The governance of nursing subjectivity also involves self-work, where

nurses regulate their own conduct in ways that are consistent with norms for professional practice that are expressed in regulatory discourse.

The stories in this research show how the participants exercised a critical relation to professional subjectivity, taking up the professional authority to practice nursing for their own relative. At the same time, they remained mindful of the regulatory requirements for nursing practice. In doing so, they show how they constructed an ethical relation to the self in seeking the necessary guidance and support from expert nurses and medical staff when this support was not available from the palliative care service engaged in the care of their family. Michelle provided an example of seeking this mentorship from her own colleagues and a clinical specialist palliative care nurse at the base hospital, in recognition of her own professional isolation. Sarah's story about an effective relationship with a palliative care nurse shows how it might be possible to negotiate the concept of partnership identified in the guideline on direction and delegation (Nursing Council of New Zealand, 2008a). Partnership is a discursive concept that can be understood as practising strategies of power (Silverman & Bloor, 1990) where health professionals usually define the form and limits of a relationship. Sarah showed how, by being able to speak and act strategically (Kettunen, et al., 2001) in health care discourse, nurse family members are positioned with more power in this partnership and consequently more able to negotiate the conduct of the relationship (Cheek, 2003).

The analysis in this section shows how the subjectivity of nurse family member positioned the participants with a marginal professional status that involved the constitution of self with an ethical substance of intellectual, political and relational work (Cooper & Blair, 2002). In doing so, their stories show how they took up the professional authority necessary to fulfil this ethical substance, calling on nursing knowledge and skills to define the relations between self and others within complex negotiations of truth and power. The following section explores how the participants managed the relationships between family obligations and work responsibilities. Their accounts of themselves as women who had complex roles with multiple obligations to

negotiate, shows how the participants struggled to act as particular kinds of ethical beings in the relation to self (Foucault, 1998) in fulfilling their obligations to the self and others.

### **Negotiating subjectivities**

The participants' stories show how they negotiated the form and limits of the subjectivity of nurse family member in fulfilling their professional and family obligations. Negotiating boundaries between their professional responsibilities in paid employment and the obligation to care for their own relative created was challenging, particularly when their workplace was short staffed. Five of the six participants were practising as nurses in paid employment at the time they began caring for their relative. While they developed strategies to organise their work and family commitments to reduce the demands made on them, each of them reached a limit in balancing these commitments and sought varying lengths of time out from paid employment. The conceptualisation of home and work as separate realms of existence potentially subordinates the obligation to care for a relative, as a mode of subjection to family discourse, when similar obligation is felt towards one's work role. The normative separation of work and family constructs them as sites of tension where competing interests are played out (Barnett, 1994; Small & Riley, 1990). Feeling responsible for work commitments, and being called back to work when family obligations are a priority can create a sense of being torn between two worlds (Ross et al., 1994). While all of the employed participants in this research found their employers to be supportive of a period of absence from work, nurses are a scarce resource in health care settings. This meant that they were encouraged by their employers to return to work as soon as possible or, in Jean's case, there was a reluctance to allow any further leave for a period of time once she had returned to work.

Hazel was in the process of beginning a new position overseas when she realised her mother was dying, this position was kept open for her so she could return home to New Zealand to care for her mother. Three years later, when her father was terminally ill, she resigned from work to care for her father on a full time basis. Jean related how her employer was willing to grant her leave to care for her mother, which she took



intermittently as there were times when she went back to work for a few days to give herself time out from family caregiving. Maree also took periods of leave from work over the time her daughter was ill. Initially she took six months off and then went back to work part-time, until she was needed at home full time with her daughter in the palliative care stage. The practice where she worked had a relieving nurse who was able to increase her hours to compensate for Maree's absence until she returned to work in the same practice two months after her daughter died, which as she said was still too soon.

*I went back to work ..... probably before I was ready I think because the pressure was on because the girl who had filled in was getting desperate to cut her hours back. .... I can still remember that phone call saying when are you coming back to work and thinking oh God I don't ever want to go back there but probably needed someone to draw a boundary because for a decision to be made I guess.*

Robyn was working in a busy surgical ward in the last stages of her husband's illness, and while she took some leave from work to care for her husband, she felt compelled to return to work as soon as possible after his death to support her family.

*.... and it was a really busy, busy ward and ... they were ok with the time off but after... we had no money and we had a mortgage ... I couldn't lose the farm ... you know I had to keep the farm and that's what sustained him a lot of the time you know so I probably .... went back to work far too soon ... a week after his funeral because I felt I have to get back and earn some money and pay the bills.*

Similarly, Michelle took six weeks off work to move in with her mother in the end palliative care stage and returned to work a week after her mother's death. While she found her employer very supportive in allowing her to take sick leave, the district nursing service she worked in was very short staffed.

*There were four of us and if you ever had time off work through sick leave you had to call one of your colleagues to come in on their day off to work and so I know I felt very privileged to be given that time to nurse mum and when I went*

*over there I didn't realise I'd be there for 6 weeks so every week was a week extra – they'd keep ringing to see how mum was and I'd say, "Well she's still got another week, she might have another 2 weeks", and they were desperate for me to get back to work really – so, and I can appreciate why they couldn't give me any extra time..... It's not like a hospital where there's somebody on pool comes in and works.*

The complexities of working as a nurse in a busy health service, where registered nurses are a scarce resource, are apparent in these nurses' accounts of needing to return to work before they felt ready. In Robyn's case the need for an income to support her young family was the driving factor, but Michelle and Maree work in primary health care settings, as part of a small team where on call staff was not always available to replace them. This lack of readiness to return to work was a significant factor in how they were able to situate themselves as practitioners who had been changed through the experience of caring for their own relative.

Becoming subjectivised as the nurse family member transforms the self's relation to the self, in such a way that there is 'no return' to the former self (Butler, 2005), and previous ways of viewing the world. New knowledge about what it is like to journey with another person through the illness events and death establishes new relations of truth, and consequently a different relation to the self as a practitioner. In returning to work, Michelle, Robyn and Maree found themselves faced with new challenges that they had not experienced prior to caring for their own relative. All three of these participants lived and worked in small rural towns where families lived their lives intertwined with each other personally and professionally. Each of them returned to a familiar workplace having been changed by their experience. They could no longer take for granted the normative values about what counted for formally reliable ways of thinking and acting (Bonner, 2001) within professional discourse in their relationships with clients and families. Having been subjectivised as nurse family members, new knowledge drawn from the experience of caring for their own relatives transformed how they thought and acted as nurses. Families they encountered who were undergoing similar events where a person was dying of a cancer-related illness, called them back

into their own experience. Robyn recalled her feelings about working with these families.

*I remember ... particular patients ... I knew that I couldn't be there in a totally professional way for them because of what they made me remember and feel ... I remember a middle-aged bloke ... he wanted to write a diary ... he had known my husband.... and knew that he had died .... But he wanted to talk to me ....and he said you know you've been through this ... what can I do for my children? He asked me that and only asked me that because he knew ..... what had happened ... and I told him he could write a diary for his children because I was still journaling then and I said you know, do that ... and I think he did do that.*

Maree found her experience as a nurse family member gave her a deeper understanding of clients in her practice who were experiencing similar situations.

*I saw a patient recently that came in recently who needed something from the doctor.... whose husband is a terminal patient at the moment... and she was flustered and all wound up and I could just appreciate where she was at....it made me very grateful that I had been a nurse and didn't have to be on that side of the desk begging for someone to understand how I felt..... thinking I didn't have to do that because I could just ring [GP] and get put through straight away.....so its influenced my practice hugely.....*

While she did not speak of her daughter's death with clients in the practice, Maree's experience informed her assessment of their situations and her desire to intervene quickly for them where necessary. She also spoke of how she now focuses on assessing the whole family, particularly the primary caregiver for the ill person, consulting with them and enquiring about how they are managing. Maree explained how she is now more careful about discussing the meaning of illness experiences with families. As she put it,

*I mention words in the world they're living in so that they know I know where they are at.... what their world view is right now... and even in newly diagnosed*

*patients I'll often mention the shock we felt..... I don't mention ours..... I might say to them... I bet that knocked your socks off.....and they can see that you understand what happened to them last week.... how within one sentence their life changed totally and utterly....*

Similarly, Michelle found that her practice as a palliative care nurse had changed when she returned to work after her mother's death.

*I was a much better nurse afterwards ....listening to the families.... if they said they had a bad night I sat down and listened ..... I'd go round and visit and find out why, what could make it better. I think a big thing – probably the hardest thing I found is – coming back into practice was I felt like a lot of families needed a lot of emotional and probably spiritual support that as district nurses there's a limit to how much we can give.*

These accounts show how Michelle, Robyn and Maree were called to care for the patients and families they encountered in new ways. Becoming subjectivised as nurse family members transformed their previously held values about how nurses ought to be with others in their professional work. The ethical substance of relational work (Cooper & Blair, 2002) created a mode of subjection to caring discourse drawn from personal knowledge about what it is like to live through the experience of illness and dying with a relative. This mode of subjection positioned the self with a deeper sense of interest and concern for the vulnerability of the other. It moved these participants to 'gaze with' (Georges & Benedict, 2008) the ill person and their family with an intimacy and connection derived from shared understanding. Foucault (1982/2003b) explains this process of becoming subject to the self through new self knowledge as a pedagogical relationship. People learn to recognise themselves as new subjects through self-forming activities that make subjectivity the object of self-reflexive thought. Self-work involves reflecting on the limits that have previously been imposed on one's thinking and finding ways to move beyond these limits (Foucault, 2003c). This ability to think outside the former self, in response to new knowledge enables a new more ethical 'sculpting' of the self (Peters, 2005) that transforms the relation between the self and others. In making the

effects of one's actions on others an ethical concern, there is an increased awareness of how to intervene with families in ways that address their central worries and needs in caring for their dying relative.

However, this call to care for patients and families that was characterised with a greater degree of intimacy and connection was to have an impact on the ability of these participants to sustain their practice in palliative care. Each of them arrived at a point where they had to change something about their work situation to sustain themselves within their practice in the small rural towns where they lived and worked. Robyn found caring for patients diagnosed with cancer who came through her surgical ward difficult, particularly when she knew them.

*I was able to cope with older patients but people that were similar in age to my husband and .. some of the families had young children and I would feel for them, ... their wives and ... all of that was hard. So I didn't look after them, I was never their primary nurse ..... because I found it too hard somehow ....*

While Robyn coped by choosing not to look after these patients in her ward, Maree found that she had to leave the practice in her own town and travel to work in another place so she could re-establish boundaries between self and other in her professional role.

*The experience did affect my practice because I did have to leave and work somewhere else.... because different patients that I knew started to get cancer and I was cancered out .....and I got sick of seeing nice people dying.... so I had a bit of a blow out and just needed to distance myself..... and it was good to be anonymous again... to work in a practice where no one knew me... they didn't know my background..... when I am at work... there's a safety in that because the definition of your job gives you rules.... the boundaries are there already...*

Michelle found herself similarly positioned in her role as a palliative care district nurse. She felt that she was being judged by her manager for providing care that went beyond the boundaries of that which was offered by the service.

*I loved palliative care and I just felt – I felt that I would probably continue to do some palliative care in my life in my life time but not as a district nurse because I felt the limitations were huge and I know they are even if you join hospice. ....After I'd nursed mum I had a very special patient .... through her terminal weeks and we became very good friends and I visited probably three days a week anyway to do her pump and then I would just pop in on my day off and just sit with her and give her foot massages and she just really appreciated it and got something out of it. I found it very rewarding and got into trouble with my boss for visiting on a day off and I just found it frustrating and just thought we're friends now .....*

Eventually Michelle sought grief counselling through a private service because she recognised the need to work on herself to learn to live with the grief she had experiencing in her personal and work lives. She thought perhaps she ought to have had some counselling earlier than she did.

*I did later but not specifically for mum. I just had two miscarriages and I thought it was about time. But I've put that down to the whole - you know – perhaps if I'd had some counselling then maybe I wouldn't have had two miscarriages – who knows..... The best thing I ever did was to have grief counselling and I would recommend it to anybody .....*

While the discourse of professional boundaries marks a discursive dividing practice that potentially alienates the self from the self (Foucault, 1982/2003a), it also marks an important site for care of the self. The stories told by these participants about their call to care for patients and families in palliative care with a renewed concern for them illuminates the fine balance in negotiating personal and professional boundaries. They show how the search for wisdom and truth in knowing the self is a constant practice in governing the self as a moral agent (Foucault, 1984a). The struggle about maintaining an ethical relation to the self within professional discourse is played out in their stories shows how they worked on themselves to establish a new mode of subjection that encompassed their experience as a nurse family member. Care of the self involves both

being shaped by the discursive effects of normalisation and constraint and resistance to or refusal of discursive positionings that do not take account of the uniqueness of people and their situations (Hofmeyer, 2006b). The form and limits of the knowledge and practices that define relationality (Emirbayer, 1997) in nursing became visible through the process of creating themselves anew within professional discourse.

Establishing a new relation to the ethical code that defines and demarcates professional boundaries creates a mode of subjection to relational work that struggles for a deeper connection and intimacy (Cooper & Blair, 2002) with patients and families. In critiquing their former practice these participants simultaneously became ‘de-subjugated’ while remaking the self (Butler, 2002) in a new relation to professional discourse as they became aware of the limits of previously known ways of relating to clients and families as nurses. As Butler suggests, critique is a practice that makes us question the limits of certainty and troubles the knowledge that constitutes the normative boundaries for practice. At the same time critique is essential because, as she puts it, the “epistemological field in which one lives” (p. 5) is already in crisis in resisting normative expectations for conduct. Nurse family members experience a sense of alienation when the self is no longer able to be recognised with an ethical relation to the self in professional discourse, and attempts to re-establish subjectivity fail. Nurses make active choices about how to manage their family and work lives. Their exodus from the workforce has been shown to be linked to the impact of the emotional demands of practising as a nurse (Ceci & McIntyre, 2001; IOM, 1996; Simon et al., 2004; White, 1999). When these demands are coupled with the emotional self-work that is required to re-establish an ethical relation to the self in professional discourse on returning to work after caring for a dying relative, the potential for nurses to exit the workforce is increased. Three of the six participants in this research are no longer practising as nurses, though all of them expressed their beliefs about the importance of nursing as a profession. And yet, for some of them the demands of practising in their field became incompatible with their values about how to live their lives well.

## Summary

In giving an account of their conduct in caring for their own relative as the nurse family member, the participants showed how discursive dividing practices worked to enforce norms about who is authorised to speak in professional discourse and who is formally licensed to practice and direct health care. The discussion in this chapter has shown how the subjectivity of the nurse family member is constituted in the self's relation to the normative frameworks that classify and demarcate professional and lay roles in discourses on caring, family and professionalism. These classifications establish boundaries as the limits for subjectivity as the relation to normative frameworks, defining discursive subjects according to their homogeneity. The tensions between professional authority and care that is delegated to families by health professionals are analysed as an effect of the subjectivity of the nurse family member, who is positioned with knowledge and skills that extend beyond the usual capacities of lay carers or other family members. Returning to work creates further tensions as the nurse family member finds that there is no return to the subjectivity of the former self. Re-making the relation normative frameworks becomes a priority, forming new modes of subjection to professional discourse in order to practise care of the self as a nurse.

The following and final chapter reflects on limits and possibilities for nursing subjectivities in summarising the findings and recommendations for the research. The ideas surfaced from the discussion of these concepts are examined for their potential to conceptualise an ethical framework for care of the self as intellectual, political and relational work. The implications of the findings of the research for professional self-governance of individual nurses and nursing as a professional community are considered in relation to the discursive knowledge and practices that inform and regulate practice. Limitations of the research are offered as reflections on the positioning of it as a qualitative study that locates its findings within particular practice context and geographical location. These limitations are explored as points of departure for new opportunities for critical inquiry on the relationships between nurses, their families and the professional and regulatory discourses that construct normative frameworks for nursing practice.



## **Chapter 7**

### **Reflecting on limits and possibilities**

#### **Introduction**

This chapter reflects on limits and possibilities in summarising findings and recommendations for the research. I begin by reframing the conceptual positionings for the research using theoretical tools derived from Foucault's writing on the critical history of thought (1983/1998) and restating the aim of the research as a critique that questions the limits of the ways of knowing about how nurses are situated within and called to care for their families and communities. My reflections on the data analysis explore the limits and possibilities for positioning the self within the modes of subjection to discourses that constitute the subjectivity of the nurse family member. The ideas surfaced from the discussion of limits and possibilities are then examined for their potential contribution to theoretical frames for nursing practice as intellectual, political and relational work. Implications for professional governance are explored in considering how the findings of this research might inform the actions of individual nurses and the regulatory discourse and practices that guide nursing practice. Limitations of the research are explored as points of departure that present new opportunities for further research about the relationships between nurses, their families and the wider professional and regulatory contexts of nursing practice. The concluding remarks reflect on possibilities for conceptualising and practising critical nursing subjectivities.

#### **(Re) framing conceptual positionings for the research**

The aim of this research was to explore the experiences of registered nurses who had cared for their own relative with a cancer-related illness in palliative care. The focus for inquiry was to examine the discourses that construct nursing subjectivities and explore the conditions under which these subjectivities became apparent in the participants'

stories. The specific objectives for the research were to analyse how the participants became subjectivised as nurse family members through the multiple and sometimes contradictory positionings that emerged from accounts of their experiences. Through this analysis, the research explored the constitution of subjectivity in the relation between truth, power and the self that construct discursive categories of subjectivity for the nurse family member. Of particular interest was how situated knowledge appeared in the negotiation of boundaries between self, professional practice and others in caring for one's own relative as a nurse. As there is little research published on the experience and effects of caring for an ill or dying relative as a nurse family member, this exploration of nursing subjectivities is an important topic for nursing research because nurses are positioned with knowledge and skills that call them to care for their own families and communities. The conclusions for this research argue that negotiating this call to care as a nurse family member has implications for nurses, their families and the profession.

Curiosity evokes the idea of taking care of the self in relation to one's existence in the world (Foucault, 1984/1994). In the context of this research, the idea of curiosity has been concerned with how knowledge and practices that structure our social and professional worlds have come into being and how things could be ordered in different ways to create new ways of practising nursing subjectivities. Curiosity, and the resolve that is necessary to sustain critique of what we know and how we have come to know it, are capacities that offer the means to work beyond an uncritical reliance on moral codes (Luxon, 2008). As Luxon notes, these capacities are expressed as the ability to sustain an intellectual curiosity towards experiences that have suddenly become unfamiliar through experiencing the self as divided in discourse and resolving to explore the potential for different responses and outcomes. The coherence of moral codes that call the subject to establish a particular kind of relation to self in discourse becomes problematic when the subject finds the self divided and alienated from the self in moving beyond prior ways of knowing. The experience of finding possibilities for action limited by previously taken for granted values and beliefs provides an opportunity

to question what has previously been taken as self-evident in relation to the moral code. These limits define the moment of de-subjugation where the subject resists being governed, or chooses to be governed differently, within the confines of the discourse that they are called to inhabit (Butler, 2002).

In exploring the subjectivity of the nurse family member, this research sustains an intellectual curiosity towards what at first glance seems self-evident. It offers a critique that questions the limits of our ways of knowing about how nurses live within, and are called to care for their families and communities. Critique is used as the conceptual means through which the epistemological horizon is made visible as the limits of the authority of the discourse and its power to call the individual to account for themselves as a particular kind of subject (Butler, 2002). Butler argues that “one has already run up against a crisis in the epistemological field within which one lives” (p. 5) in experiencing the divided self in discourse. The critique of a normative framework as it is expressed in a moral code is already an expression of a capacity to think beyond it and is in itself an act of resistance to the mode of subjection that the code calls the subject to practice. Ethical self-governance, as mastery over the self, draws on normative frameworks in the sense that norms are starting points for reflection and self analysis. However, self-mastery is demonstrated in how one speaks, acts and writes about events and experiences in establishing an ethical relation to the self (Luxon, 2008). Offering an account of oneself, that explains how discursive resources were used to work on the self to establish a new relation to a normative framework, is an important aspect of reflecting on self-governance (Butler, 2005).

The relation to the self practises an ethical awareness in self-governance that enables the subject to differentiate and discriminate between alternative modes of subjection to discourse (Luxon, 2008). Rather than conceptualising the subject as a discursive object that calls on knowledge without necessarily engaging in the critique of its authority, a performative subjectivity involves learning through a critical relationship between the knowledge represented in moral codes and the self. This idea of subjectivity as performed situates nurse family members within their families as subjects who are capable of practising a nursing gaze as particular ways of seeing, speaking and acting.

Through this process of seeing, speaking and acting; in the space between the light and language of discourse (Kendall & Wickham, 1999), nurse family members simultaneously construct the self within multiple discourses of caring, professional practice and family. In answering *the call to care* for their own relative, the participants in this research crafted particular kinds of self that illuminated the normative boundaries of subjectivity within each of these discourses. As previously stated, subjectivity is to some degree constrained by the authority of normative frameworks that determine what is recognisable as a particular category of subject within a discourse. Normative frameworks establish certain qualifications for inclusion and exclusion, but this relation to a norm is always negotiated in the context of practising subjectivity (Butler, 2005). In other words, while inclusion as a particular kind of subject is always already established in discourse, the subject is to some degree self governing through the specific relation that they form to the moral code and take up its relation to truth. The risk for nurse family members is that they may not be recognisable as entirely one discursive category or another as neither entirely a nurse nor a family member.

For the participants in this research, giving an account of their experiences provided an opportunity to talk in depth about some ideas and feelings that they had not previously related to other people. The act of telling their stories engaged them with their experiences in new ways that made them reflect on how they had come to position themselves as nurse family members in caring for their relative. In accounting for their actions, they came to realise how significant knowing and practising as a nurse had been in influencing what they valued about themselves and others and how they made decisions in their lives. Caring for their own relative made them think more carefully about what it means to be a nurse and engage with others in professional and personal relationships. The *call to care* and *negotiating boundaries* were the two storylines that emerged in the landscape of care as modes of subjection to caring, family and professional discourse for the nurse family members who gave accounts of the self for this research. I have explained the ethical substance of these modes of subjection as intellectual, political and relational work (Cooper & Blair, 2002), through which these nurse family members worked on themselves to establish an ethical relation to the self.

These storylines illuminate the self-work undertaken to create the self as a practising subject in an active process of self formation in discourse.

### **Limits and possibilities in positioning the self**

In experiencing themselves at the margins of the normative construction of the subjectivities of both the nurse and family member, the limits and possibilities of knowing within these discourses become apparent. Care of the self as care for another was apparent in modes of subjection that established particular kinds of relation to the self that tested the limits of their subjectivisation in discourses of caring, professional practice and family. The first storyline conceptualised as *the call to care*, shows how the participants worked on themselves to establish an ethical relation to the self as nurse family members. The second storyline, *negotiating boundaries* examined the complexities involved in fulfilling their professional and family obligations while positioned in marginal and sometimes contested discursive locations.

#### *Positioning the self*

*The call to care* situates nurse family members with an ethical obligation to care for another, which is established as an ethical relation to the self in family discourse. Being called to care illustrates how subjectivity, formed as the self's relation to the self, is always established in relation to the other (Butler, 2005; Luxon, 2008). Both family and caring discourse rely on the concept of social normativity (Butler, 2005) where the subject is called to account for themselves in relation to norms about obligation and reciprocity. Subjecting oneself to the authority of a discourse is a reflexive process that informs and shapes how an encounter between the self and other plays out. Consenting to this subjection entails the recognition of particular discursive knowledge as convincing or compelling in a given context (Butler, 2002). *The call to care* relies on this belief in the authority of the moral code and the recognition of self as someone who has a moral obligation to care for others who are vulnerable or in need. It positions the nurse family member with a mode of subjection that has as its moral end the thoughtful care and comfort of another human being (Hultgren, 1994). It is relational practice that is lived out in community with others (Lashley et al., 1994), creating specific moral demands on people who exist in reciprocal relationships.

The subjectivity of the nurse family member is also informed by an ethical substance of obligation that situates the care of the other within one's own realm of responsibility as a duty owed to them. As a mode of subjection, this sense of obligation calls a family member to care as a nurse who has extraordinary knowledge and skills that other family members do not possess. This subjectivity creates a disposition towards others that is informed by the conceptual resources and clinical experience developed in practising as a nurse. It enables the nurse family member to see beyond ordinary or 'lay' interpretations of physiological and social phenomena and provides the capacity to challenge the limits of these discursive categories of professional and lay carer. While Foucault (1994) sees the 'un-making' of discursive categories as a practice of freedom that is necessary for an ethical relation to the self, nurse family members do not so much 'unmake' these categories as step across the gap between professional and family subjectivities. They fuse together the discursive divisions that have been conceptualised as caring for and caring about (Ward-Griffin, 2004) into a mode of subjection as obligation in caring discourse that calls them to exercise professional authority in practising as a nurse. The nurse family member transforms the self by problematising the relation to the normative framework in professional discourse, which has the effect of negotiating rather than 'un-making' their place in the order of the discourse.

*The call to care* is also situated in the context of health policy that promotes a community model of palliative care with families supported in caring for people to die in their own home, situating family members as active participants in that care (Minister of Health, 2001). This discourse of home care positions nurse family members as always capable of doing more for their own relatives, particularly in rural locations where expert palliative care services may not be readily available. Their presence creates complex arrangements of care as the nurse family member moves to fill gaps in services or extend the boundaries of care usually delegated to families. In doing so, they choose a different relation to the self, taking up the professional authority to practice as a mode of self-governance (Butler, 2002) that resists the limits of their subjection to both professional and family discourse. This resistance rearranges their relation to the order of these discourses and renegotiates the divisions between them (Healy, 2001),

positioning the nurse family member with a 'clinical voice' and an authoritative role in ensuring their relative receives the best care possible. However, these transformed subjectivities remain marginal positions in relation to the normative frameworks governing the inclusion and exclusion of categories of subjectivity in both professional and family discourse.

Nurse family members find the limits of this subjectivity when challenged by other health professionals and their own family members to become either one thing or the other; to act as the wife, daughter, mother or sister in relation to their ill relative. They risk being situated outside the discursive categories of either nurse or family member; categories for which there may be "no place within the given regime of truth" (Butler, 2002, p. 13). While the qualifications for inclusion and exclusion are always negotiated in the context of practising subjectivity, the failure to identify another brings to light a crisis in the norms governing recognition within a discourse (Butler, 2005). As Butler suggests, a discursive category or identity is always formed on the basis of what it rejects. The subjectivity of the nurse family member surfaces what has been excluded, situating the personal in the realm of professional discourse. It also illuminates the subjectivity of the nurse in ways that constructs professional authority as a power differential that threatens the order of family discourse.

### *The nursing gaze*

The nurse family member is also called to care by the nursing gaze (Sandelowski, 1998; Parker & Wiltshire, 1995) that is practised as concerned observation and careful interpretation (Norveldt, 1998) of their relative's health state. The nursing gaze is informed by the context of care, using situated knowledge that draws on propositional knowledge (Titchen & McGinley, 2004) from biomedical discourse but also has situated and relational aspects in knowing the person in its application. Nurse family members are able to 'read' the pathophysiology that classifies diagnostic categories and interpret such knowledge in the context of this person's life. This is a way of being and acting as a nurse that constantly draws them beyond the 'normal' role of a family member; making them subject to biomedical discourse in ways that produce the other as the

object of that knowing, even in moments when they would have preferred not to know (Mills & Aubeeluck, 2006). While this subjectivity potentially alienates them from themselves within family discourse, families, including the ill person, make demands on their nurse family members to mediate with other health professionals to establish the best possible conditions for care. The limits of their subjectivity become apparent in potentially constraining the ability to practice in this space between professional and family discourse. An ethical substance of intellectual work (Cooper & Blair, 2002) provides the means to negotiate these limits as the nurse family member seeks to understand and watch over their loved one's physiological vulnerability.

Exercising the professional authority to practise involves managing one's own conduct and that of others within the social context of health care (Owen & Powell, 2006). Nurse family members employ a critical gaze that constructs an ethical relation to the self as protecting the other from harm. While they are able to recognise good practice when they see it, they set limits for the minimum level of care to be provided to their relative, moderating the practice of other health professionals when it is not up to their standard. Exercising professional authority in this context appeals to the order of professional discourse, using the normative framework of professionalism to maintain standards of care while simultaneously renegotiating it in terms of their own authority to speak. While there may be times when nurse family members find themselves marginalised and silenced within the discursive relations of power that operate in health care systems, they also have the potential to use this power against those who would silence them. Critique of another's practice employs the power of professional discourse, calling others to account for themselves in relation to the moral code that values beneficence and the prevention of harm (Oliver & McGhee, 2005). More oblique strategies of power include recruiting nurse friends to obtain information about their relative's care from other nurses and mediate on their behalf with the management of a health service.

Nurse family members actively seek ideas and advice from other practitioners, whose knowledge and skills they respect, in order to sculpt their own practice into more creative and responsive forms that will harmonise with their relative's need for care. While they call others to account for the care they give, they also create the means to



ensure their own accountability by calling on the knowledge and skills of nurses and other health professionals to act as guides or mentors. In Foucault's (1982/2003a) writing, the use of a guide or counsellor involves a reflexive relationship, where the expertise of another person acts as a touchstone in clarifying the ethical relation to the self. Reflexivity creates the conditions for a 'widening' of the self by employing the critical gaze of another that is aimed at the self, in order to evaluate the congruence of one's actions in the context of their relationships with others (Luxon, 2008). However, as Simons (1995) suggests, acting outside, or challenging normative frameworks for conduct does not always fulfil the promise of liberty because challenging the order of a discourse is likely to reinforce the power of it. Reflexivity, informed by the guidance of another, creates an ethical site of assessment bringing to bear the judgement and practice wisdom of an intermediary to challenge the symmetry and harmony of the self's relation to the self and others. Accountability requires practitioners to engage reflexively with other points of view that oblige them to reassess their commitment to particular truths and transform their thinking about what might be possible, useful or responsible in a given context (Healy, 2001).

Effective relationships with nurses and other health professionals arise from their generosity and expertise, through their ability to be with the family and work through solutions to problems in ways that enhance their capacity for caring. Palliative care nursing is a field of practice where caring needs to be lived out in community (Lashley et al., 1994), where reflexive relationships are developed with families to negotiate the form and limits of lay and professional subjectivities. For palliative care nurses, the presence of a nurse family member complicates this relational aspect of establishing the form and limits for subjectivities in the palliative care because of the need to negotiate the shape, processes and responsibilities for care. Georges and Benedict's (2008) notion of the nursing gaze as 'gazing with' denotes a mode of subjection to caring discourse that works to establish empathy, connectedness and understanding as a way of being with families and making space for others to care. 'Gazing with' families requires a mode of subjection to caring discourse where nurses work on themselves to understand the effects on their practice on others. The ability to call forth one's own stories in

reflexive dialogue with the self (Miehls & Moffat, 2000) is an important aspect of the political work (Cooper & Blair, 2002) required for this mode of subjection to avoid marginalising others who also have an interest in the care of an ill person.

Families position their nurse family members with authority in calling on them to interpret medical diagnostic and treatment information and use their expertise to care for an ill relative and negotiate paths through health services (Laylan, 2006). The ethical substance of intellectual work that positions the nurse family member with a nursing gaze threatens the normative framework of family discourse, potentially disrupting family relationships. Family relationships are the outcome of the history of lives lived together, where subjectivities are a product of the choices and constraints of positioning the self as a particular kind of gendered subject (Medved & Graham, 2006). These relationships may be complex sites of struggle where relations of power are played out in positioning the self in relation to siblings, parents, children or other people who fit within the realm of the family. Relations of power constantly reconstruct and reposition family relationships, reworking their moral and material legacies (Finch & Mason, 1993) in the light of new experiences with one another. In the struggle to meet their obligations to the ill or dying person, families sometimes find themselves in conflict as each of its members strive to position themselves purposefully in the relation to self and one another. As Chattoo and Ahmad (2008) suggest, people within the same family may interpret their normative responsibilities to family discourse differently according to their own sense of worth and the resources they believe they bring to the family in the context of a relative's illness. However, assumptions about how family members might take up and act particular roles within the family potentially constrain other possible alternative subject positionings (Lucas & Buzzanell, 2006).

Sibling relationships, particularly those between nurse and non-nurse sisters may become sites of conflict when the nurse family member is seen to usurp the family role that has been formerly undertaken by another sister (Neale, 2004). Competition between sisters occurs when the relations of power within family discourse are disrupted by discursive practices that are external to it, marginalising the one who no longer has the

authority to speak or act because she does not have the conceptual resources of the other. The subject positioning of nurse family member transforms the nurse sister into another who may be unrecognisable within the normative framework (Butler, 2005) of family discourse that shapes encounters between siblings. Finding new directions for conduct requires a new relation to this normative framework to transform the conditions under which recognition becomes possible. The ethical substance of relational work (Cooper & Blair, 2002) in caring discourse is a mode of subjection that struggles to mediate the impact of power derived from the nurse family member's professional authority.

The idea of 'gazing with' (Georges & Benedict, 2008) locates the nurse family member inside more egalitarian politics (Yeatman, 1994) for family relationships, making space for other family members to care and according them respect for the resources that they bring to support the family. 'Gazing with' engages the nurse family member in a mode of self-governance that establishes a new relation to the self, with an endpoint that is not predefined by assumptions about the other. Instead this relation to the self problematises the past to create a different possible future, seeking a shared commitment to normative values that might bind family together in their joint obligations (Luxon, 2008). Sharing professional authority involves calling the self and others to account for their own assumptions, creating space for ideas to be surfaced and contested in the light of the challenges that face the family in the present, to create another kind of future for their relationships. While the limits and possibilities for subjectivisation in family discourse relies on the capacities that individual family members possess, the nurse family member may act as a channel through which others can be called to establish an ethical relation to the self and learn to situate themselves in new ways that utilise the resources they are able to contribute.

#### *The relation to self*

The experience of caring for a relative in palliative care transforms the subjectivity of the nurse family member beyond the limits of the former self, by 'unmaking' or 'remaking' one's relation to the normative framework within a discourse (Foucault,

1994). Questioning one's relation to available norms tests the limits of the normative framework, problematising the conditions that govern encounters between the self and other (Butler, 2005). This exercise of power over the self produces a complex interplay of provocation and resistance in response to being called to act within the bounds of social normativity that are expressed in the discursive regime of truth (Foucault, 1982/2003b). It reforms or bends the relations of power that constitute the subject's relation to truth, enlarging the limits of the self to make room for the other (Hofmeyr, 2006b). Foucault (1984/2003) sees this reordering of power over oneself as the means through which the subject regulates the effect of power over others, where the ethical imperative to care for the self becomes the means through which one cares for another. But this struggle to care for the other through care of the self creates "a transformation of self from which there is no return" (Butler, p. 28). As Butler suggests, the limits to the ability to exercise power over the self become apparent through the process of subjectivisation to discourse that has its origins outside the self. The subject is constantly called outside themselves by normative frameworks that establish specific modes of conduct as the right thing to do, but the 'remaking' of the self dislocates the prior relation to the self that previously conditioned this process. The normative criteria that once established a particular kind of self, and made that self recognisable to the self and others, can no longer be comprehended in quite the same way.

In returning to paid employment after the death of their relative, the nurse family member finds the relation to the self transformed and potentially unrecognisable within the normative frameworks that define the conduct of the nurse as a health professional. Normative values that were previously taken for granted as reliable frames to guide the conduct of the self in relation to others (Butler, 2005) within professional discourse fail to contain the self as the nurse is constantly called back into the subject position of nurse family member. This sense of being called back into the subjectivity of the nurse family member occurs with clients and families where a person is dying in circumstances that are similar to those the nurse experienced within her own family. While the nurse family member has new knowledge about caring for a family member in palliative care, this

knowledge is bound up with the emotional conditions that produced it (Jumaa, 2005). The view of another person's suffering that is similar to one's own challenges the limits of self containment within professional relationships. Containing the subjectivity of the professional self becomes a constant process of mediating one's own conduct through relational work (Cooper & Blair, 2002) in attempting to reform a new mode of subjection to the normative framework of professional discourse or 'remake' the relation to it. Reforming professional subjectivity involves coming to an understanding about who the self can be, and how encounters between the self and others might be conducted in relation to the discursive regimes of truth that order professional normativity (Butler, 2005). The call to care for others in a professional capacity relies on this ability to establish new modes of subjection that create intimacy and connection with clients and families but at the same to contain the potential to be called back into one's own experience.

Experiencing the self differently as a nurse in relation to others signals the need for a 're-sculpting' of the self as a different kind of subject of professional discourse, with a deeper understanding of what it means for families to care for a dying relative but at the same time knowing the potential for the self to be engulfed by the experience of the other. Caring for another through care of the self necessitates reflexive self-work to relearn how to both engage in and set limits for emotional investment with clients and families; to create fluid and purposeful professional relationships but at the same time avoid being constantly called back into one's own experience in ways that potentially disrupt the ability to function in the professional role. Self-forming activities require the nurse family member to negotiate modes of subjection to caring discourse as one who is able to empathise with the vulnerability and struggle of another but at the same time recognise that the other's emotional and ethical work in caring for their relative is separate from one's own. 'Re-sculpting' the self as a different kind of professional subject through relational work (Cooper & Blair, 2002) is arguably one of the most difficult challenges for nurses who have cared for their own relatives. It requires the

nurse family member to engage with the effects of their changed subjectivity in order to develop strategies for ethical self-governance in professional practice.

Maintaining curiosity about how the changed self engages in relationships with others in clinical practice, and exploring moments of dissonance when the self feels strange or different, are starting points in constructing a new relation to the self that encompasses rather than alienates former subjectivities. Curiosity requires one to be present with the self, attending to responses that are felt by experiencing the self differently, before paying attention to normative values about how one ought to act (Luxon, 2008). Situating the self with a mode of subjection to intellectual work guides the search for new ways of knowing, not to establish a finite truth but to examine how practising nursing might provide multiple possibilities for different kinds of professional relationships. Self-forming activities for intellectual work situate the self within a dialogic ethic, where problematisation and critique of events occurs in conversation with another, and through writing as a form of companionship with the self (Cooper & Blair, 2002). Speaking and writing about experiences are reflexive strategies that bring one's thinking into the gaze of the self and other for contemplation and critique (Butler, 2005), to make the self and one's actions into objects for ethical assessment. Reflexivity opens the subject up to the possibility of knowing something about what might have been lost from consciousness in positioning the self as a particular kind of subject in discourse, and with that knowledge, understand how the self could be governed differently (Foucault, 1984a).

While all of the historical conditions that are involved in creating the subject are never able to be made visible to the self, giving an account of the self enables something to be understood about the formation of subjectivity and its relation to ethical responsibility (Butler, 2005). As intellectual work (Cooper & Blair, 2002), reflexive strategies necessitate showing aspects of the self to the self and others in a process of writing and speaking that examines how one's thinking and account of oneself fits with normative frameworks. Writing and speaking also constitute political work because in addressing the self and another we put a discourse to work in terms of what we consider to be our

relation to its truth. Accounting for oneself is an act of power that illuminates the ethical substance of one's subjection to discourse and shows how discursive resources have been used to establish a particular kind of relation to a normative framework (Butler, 2005). The quality and soundness of the rationale for this relation is, as Butler puts it, made public as a social manifestation that enables recognition of the reconstituted self through a pedagogical relationship with another. This training of the self by the self, in relation to external points of reference, is also found in Foucault's (1994) notion of self writing where one's thoughts and ideas are mediated through reading and reflection about how to position the self in relation to others. As intellectual work, reading is a way of enlarging the mind in considering one's responses to the ideas and actions of others to find new modes of subjection to discourse that constitute an ethical relation to the self.

For the nurse family member, this cultivation of the self through reflexivity and self-care constitutes an ongoing struggle to reposition the self within in the discursive arrangements of nursing practice. Self-mastery is the aim of the intellectual, political and relational work (Cooper & Blair, 2002) that enables them to construct modes of subjection to professional discourse that encompass the altered self and free them to practice in ways that take account of the humanity of the self and others. The question of how to situate the self in ways that encompass the altered self lies in the ability to develop a relation with normative frameworks that constitute the discursive order of professionalism, not a return to the former self (Butler, 2005), but as a kind of return that enables self-mastery in professional work. Self-mastery in this sense involves coming to recognise the self in new ways and being able to establish new modes of subjection for relational work that enable the self to test the limits of the self (Foucault, 1994), but at the same time use strategies that contain and conserve the self. The following section explores the significance of intellectual, political and relational work as an ethical framework for practising self-governance in nursing.

### **Care of the self: An ethics for nursing practice**

The analysis in this research has been concerned with the constitution of subjectivity in the relations between truth, power and self that construct discursive categories as subject

positions for the nurse family member. It shows how the practice of ethical self-governance, creates an ethical sensibility that enables nurse family members to discriminate between alternative modes of subjection to discourse, and achieve self-mastery in establishing an ethical relation to the self (Luxon, 2008). Limits and possibilities in positioning the self in the call to care and negotiating boundaries between the self and other became apparent as modes of subjection to the ethical substance of intellectual, political and relational work (Cooper & Blair, 2002). The following discussion explores the relevance of Cooper and Blair's framing of Foucault's ethical work as conceptual positionings for practice knowledge. It situates knowledge for nursing within the normative ethic of social justice that Foucault (1984c) advocated as care of the self, not as a theoretical model for the emancipation of nursing and the clients and families who use its services, but rather as a way of conceptualising practices (Foucault, 1977b) that nurses might usefully employ to free themselves to act ethically in the relation to self and others.

### *Intellectual work*

The ethical substance of intellectual work is concerned with the practice of transforming the self's relation to the self through the discursive knowledge that is available to the subject (Cooper & Blair, 2002). This ethical substance is represented as the nursing gaze; as recognising and practising one's professional responsibility to effectively assess and interpret human functioning to perceive health or illness states, in order to know how best to intervene in the physical, social and cultural aspects of health and illness (Lawler, 2003). The mode of subjection to intellectual work involves creating the conditions for a 'widening of the self' through strategies of problematisation and critique of the discursive knowledge that one is called to take up and practice as one's own (Butler, 2002). The nurse family members in this research practised intellectual work, which was evident in their positioning as a knowledgeable and expert presence within their families.

Effective clinical vision is developed through self-forming activities that develop expert ways of knowing and practising as a nurse through reading and reflection on clinical



cases and the scientific, social and cultural discourses that inform nursing. Reflexivity is an essential element of the self-forming activities for intellectual work that enables a critical relation to the self in the constant ‘remaking’ (Foucault, 1994) or reassessment of one’s orientation to discursive knowledge in terms of its efficacy for guiding practice in a given clinical situation. The ‘remaking’ of the relation to the self is practised within a pedagogical relationship, ‘in community’ with the self and others, where nursing knowledge and practice are made available for appraisal and reconsideration in accounting for one’s actions (Butler, 2005). The normative framework for caring discourse calls the nurse to account for the quality and soundness of the intellectual work that informs nursing knowledge and its practice within specific client and family contexts. While the nursing gaze situates the moral end of intellectual work in caring discourse, personified as the careful nurse who watches over the sick and protects and nurtures those in need of care (Nightingale, 1859/1970), each nurse practises their own critical relation to it.

As previously stated, the nursing gaze locates the nurse’s clinical vision and its inherent discursive practices within a specific kind of relation to the self and other (Foucault, 2003b). In constructing one’s identity as a subject of professional discourse, the nurse is constituted as a knowledge worker; the kind of specific intellectual that Foucault (2003d) refers to, whose practice is located within the relations of power that construct and disseminate knowledge about others. As specific intellectuals, nurses have a normative relation to the principle of social justice that creates ethical responsibilities in mediating and channelling the effects of power in constituting others as subjects of discourse. The ethical substance of this responsibility involves maintaining a self consciousness (Blacker, 1988) about how the effects of the theory one puts into practice as a nurse might impact on the lives of others towards whom nursing work is directed. By this I mean that nurses should not define the relations of truth for clients and families but work with them to imagine how they might learn to live well within the context of their lives and the resources and capacities they possess.

Theory ought to be constructed and practised with those who are engaged in struggles with factors that limit their capacity to negotiate their lives to make explicit the sites where power is exercised to construct such limits (Simon, 1995). Blacker (1998) sees the mode of subjection for the specific intellectual as harmonisation, bringing one's actions into harmony with an area of professional influence through careful practices that make the self's relation to truth explicit. The power of nursing, as a community of specific intellectuals, lies in this ability to work with others to illuminate subjugated knowledge as alternative possibilities for new subjectivities that are inclusive of their concerns and interests. Nurses, individually and collectively have the power to transform themselves and their sites of practice in health care through a political will to action that practises power as the intellectual work of critique and problematisation.

#### *Political work*

Political work has the value of social justice as its moral end, which calls the subject to engage in a struggle for rights through resistance, contestation and negotiation of the normative limits that would otherwise marginalise and disenfranchise them (Cooper & Blair, 2002; O'Farrell, 2005; Yeatman, 1994). The exercise of agency and freedom relies on the creative interpretation and application of the normative frameworks that define the limits of discursive knowledge. Although the subject is not autonomous in that one can never be situated outside discourse, the ability to contest received discursive positions remains as the ability to think outside the social conditions that work to shape subjectivity (Bevir, 1999). The responsibility to shape the self within these social conditions, and all of the other forces that work to shape subjectivity, constructs the ethical imperative of care of the self and others as political action (Hofmeyr, 2006b), or as Foucault (1984d) described it, the practice of politics as ethics.

The nurse family members in this research established a mode of subjection to political work in struggling to create the conditions to care for their dying relatives at home as a response that was chosen as the mode of subjection to honour family obligations and commitments. While they were shaped by a call to care that positioned them as bearers of specific responsibilities within family discourse, these nurse family members show

how it is possible to use discursive resources to sculpt the self as a subject who is capable of practising with professional authority. Self-forming activities for nurse family members in this ethic of political work take the form of negotiating the professional authority to care for their own family member with other health professionals and their own families. The negotiation of professional authority to care involved both extending the limits of care that is usually delegated to family members by health professionals in palliative care, and setting limits on their degree of participation in care of their relative in order to sustain the self.

Power constructs a politics of the self that is visible in how nurses strive to alter the factors that condition their ability to practise in order to achieve better outcomes for those who are the recipients of their care. The self-forming activities for political work, like intellectual work, involve making statements that illuminate the struggle around a particular source of power, but mode of subjection for political work is concerned with the struggle for freedom for the self and others (Cooper & Blair, 2002). Consequently, self-forming activities are concerned with calling attention to how certain truth claims constrain potential action, by speaking out about them. Political work resists the authority of others by exposing and the limits that are expressed in statements about how one ought to act, setting the scene for a new struggle that refutes or renegotiates these limits. As such, political work is an important element of nursing practice. The negotiation of power is an integral part of the therapeutic relationship, which is “always a power relationship” (Silverman & Bloor, 1990, p. 5). However, the analysis in this research illustrates how it is possible to conduct oneself with others in ways that thoughtfully, if not always successfully, consider the choices that are available to shape the self as an ethical subject and create the conditions to enhance the other’s ability to care for the self. In this sense nurses become an instrument of power, negotiating the order of discourse and mediating its effects in conditioning relationships and actions.

Political work is concerned with sharing power ‘in community’, mindful of the effect of one’s actions on others. It has, as its moral end, the aim of freeing people and their

families to live well in situations of health and illness through pedagogical relationships that build capacity and choice with them. While Foucault (1984c) conceptualised the exercise of freedom as an individual undertaking, there is also the possibility of thinking about political work as collective action for 'care of ourselves' as a profession. Mindful of Foucault's warning that philosophy and politics should not be collapsed into the same conceptual space, collective action can be thought of as compilations of individual activities. Subjectivity positions the self as a node in networks of power and knowledge, which are broader than the self and external to it, so as Hofmeyr (2006b) suggests, the subject is enmeshed in conditions that create the self through relationships with others. As well, because one's actions have an effect on the actions of others, individual efforts have effects beyond the location in which they are practised. Individuals participate in collective action as situated inquirers who involve themselves in multiple and diverse communities of interest (Healy, 2001). Following Healy's argument, nurses are individuals who engage in dialogue with other's points of view as we contest and negotiate our own understandings and those of others. Political work as collective action might be conceptualised as a coalition of individuals that supports contestation and critique among its members, with a view to creating transformations in thinking that remain provisional and available for modification.

### *Relational work*

Nursing is a relational practice that is lived out in the encounters between nurses and those they care for. Relational work is concerned with harmonising the self in relation to others in order to achieve intimacy and connection with them. It has as its moral end an ethics that is expressed as concern with the effects of one's behaviour for the self and others (Cooper & Blair, 2002). This research shows how the participants engaged in relational work within a mode of subjection that engaged them in a struggle to meet the commitments and responsibilities of the call to care created as a moral obligation to care for another. This mode of subjection was expressed as the vision for the kind of care they wanted their relative to have in palliative care and working on themselves to establish effective relationships that would enable this outcome. Self-forming activities required the participants to negotiate boundaries between the self and others, in both

professional and family roles, in order to exercise the authority and capacity to care as the nurse family member. The analysis of their stories shows how nurses retain the capacity to transform their own subjectivity and practice an ethical sensibility in self-governance that discriminates between alternative modes of subjection to the normative frames that establish relations of truth within professional discourse.

Practising as a health professional involves taking up a mode of subjection to professional discourse in order to govern one's relation to the self and mediate the effects of one's actions on others. The social, cultural and professional boundaries between the self and others are points of sensitivity (Nedelsky, 1991) that are made visible when the limits of them are transgressed (Butler, 2005). It is precisely at these points of sensitivity that nurses should become curious about the effects of their actions on others and critique their own relation to normative frameworks. While establishing limits to contain the self are an important protective strategy for nurses and their clients, boundary work in nursing should be conceptualised as a space that is negotiated between the self and other in the context of practice. The normative framework for professional discourse constructs boundaries between self and others as a space for self-work where health professionals ought to take up the values of the profession as their own. However when emphasis is placed on boundaries as discursive constructs that create specific definitions about how people ought to act in relation to others (Lamont & Molnar, 2002), normalisation acts as an external force that regulates the self's relation to the self. An important aspect of self-governance as a nurse is this ability to exercise one's judgement in choosing an ethical relation to the self. The ethics oriented morality that Foucault developed as care of the self offers new possibilities to create the self as an ethical subject of professional discourse because it gives precedence to the subject's freedom and responsibility to establish their own ethical relation to normative frameworks (Dalglish, 1998).

Reflexivity offers useful strategies for ethical self-governance, as the means to achieve greater awareness the self's relation to normative frameworks, and the effects of one's actions on others in positioning the self as a particular kind of subject. It provides

conceptual tools that enable a critical engagement and ethical concern with how we find ourselves situated in events and interpret the behaviour of other people and ourselves (Coles, 1992). Being able to recognise the effects of one's actions on others creates the potential to think about how the normative framework for professional discourse sets limits that both inform and constrain us. Reflexivity involves a self conscious scrutiny of how the self engages with others (Chiseri-Strater, 1996), in order to create a more astute sensitivity towards the effects of that engagement. The word 'reflex' means to bend something back, so reflexivity has to do with the idea of bending feelings and thoughts back on oneself, making the self and our actions the object of inquiry (Bonner, 2001). As Bonner suggests, creating the self as the reference point to critique the effects of one's actions creates awareness about the relationships between what we know and how we know; where how we use knowledge can be understood as an effect of our past experiences and the frames of reference that we have used to interpret them.

In paying attention to the effects of the self in relation to others, critical self appraisal creates the freedom to transform ourselves into new kinds of discursive subjects through thinking and acting differently (Gardiner, 1996). Being able to listen to others and write reflexively about experiences provides the opportunity to think about how the history of our own engagement with others influences how we practice (Pillow, 2003). This cultivation of the self through reflexivity and self-care constitutes an ongoing struggle for nurses to constantly reposition the self within in the discursive arrangements of nursing practice. Self-mastery in relational work (Cooper & Blair, 2002) is concerned with establishing modes of subjection for relational work that test the limits of the self (Foucault, 1994), but at the same time contain and conserve the self. It enables nurses to practice in ways that take account of the ethical responsibilities that one has to the self and others and to enact the values they hold about themselves as ethical beings.

### **Implications for nursing**

Developing a deeper awareness of the complexity of the relation to the self and others for nurses involved in the care of their own relatives has been the central focus of inquiry for this research. The findings show how nurses are called to care to practice

nursing for one's own family with the kind of sensitivity that has as its moral end the thoughtful care and comfort of another human being (Hultgren, 1994). Nursing is practised, and the identity of the nurse is created, through relational work that is undertaken on the self in relation to the self and others, that entails specific modes of ethical engagement. These modes of ethical engagement create specific commitments and responsibilities that inform how nurses practice and live within their families and communities. Nurses are called to care because they are present within their families with knowledge and expertise that has the potential to make a difference to how a dying relative experiences palliative care.

In finding the self positioned as nurse family members, nurses need to thoughtfully choose how they situate themselves within their families and participate in the care of a relative. Foucault (1984c) values the role of the mentor as the person who can give honest feedback to the person who strives to create an ethical relation to the self. This is an important idea that both individual nurses, and the profession as a collective, ought to consider as a potential strategy to support nurse family members while they are engaged in the care of a relative and following their return to work. While nurse friends were a constant presence with the participants in this research, and helped to sustain the nurse family member in challenging situations, a formal relationship with a critical nurse friend provides a different kind of wisdom and support derived from experiencing a similar event. The profession might consider how such a strategy could be implemented through national and regional nursing networks.

Trust and a sense of confidence in the other's practice are important elements of the relationality (Emirbayer, 1997) that is necessary for nurses to assist one another to care for the self and others in creative and reflexive ways. Professional boundaries are an expression of this relationality, and provide the means through which relationships between nurses and their clients and colleagues are governed. Palliative care nurses are strategically positioned to assist nurse family members in living well within the complex role they take up within their families. A critical appreciation of the power relations that may exist in these relationships is important as the nurse family member endeavours to

meet their own obligations and manage their own concerns. The most effective relationships identified by the participants in this research were characterised by the palliative care nurse's ability to practice in ways that were attuned to the family's needs and concerns. These nurses understood the demands that family caregiving make on its members, and the nurse family member in particular. This relational work should also involve negotiation of the form and limits of professional authority for nursing care and providing a safety net for nurse family members as practitioners who are working in a marginal space. Nurse family members should also be aware of the extent of their professional and regulatory responsibilities for practice that is undertaken outside their role in paid employment

Negotiating boundaries between family and work roles is a constant challenge for nurses who have family responsibilities outside their work roles (Ward-Griffin, 2004). Nurses ought to be able to negotiate periods of absence from their work roles in paid employment, supported by employers who recognise that caring for one's own dying relative is an important commitment for them. However, there is currently no statutory requirement for paid family leave in New Zealand, apart from parental leave following the birth or adoption of a child. According to the Department of Labour (n.d.), paid sick leave, accumulated at the rate of five days per year, may be taken to care for a dependant relative, where a medical certificate attesting to the illness of this relative is supplied. As well, each employee has a minimum of four weeks annual leave per year. Unpaid leave, and changes to hours or days of employment is negotiated at the discretion of the employer. While nursing workforce shortages make demands on all staff, creating space for nurse family members to take leave may be an important factor in retaining them in the workforce. Creating the conditions for nurse family members to set their own priorities for care of the self may be an important factor in retaining them in the workforce. Nursing workforce statistics (New Zealand Health Information Service, 2004) show that most nurses who are currently practising in New Zealand are aged over forty and work full time and this age group encompasses women who are likely to be caring for dependent children and aging parents. While the population



sample in this research is too small to draw conclusions about the reasons why nurses leave the nursing workforce, the fact that three of the six participants in this research are no longer practising as nurses is a point of interest. And this is a point of interest that nursing ought to be concerned with in mediating the factors that influence its members to withdraw from practising and work collectively to care for its own.

Nurse family members return to work as people who have been transformed by their experience. Professional support, particularly when they are involved in the care of clients in similar situations, may help nurse family members to care for the transformed self in their professional role and avoid being called back into their own experience in ways that are beyond their capacity to manage. Given that nursing subjectivities are constructed in relation to people and families in need of nursing care, nurses need conceptual tools and mentorship that enable them to develop a critical relation to the normative frameworks that guide relational work (Cooper & Blair, 2002) in practice relationships. Care of the self is not sufficiently addressed as an aesthetic of care of the self in the documents that define and regulate nursing, including the Competencies for RN Scope of Practice (Nursing Council of New Zealand, 2007), the Code of Conduct for Nurses and Midwives (2001) and the NZNO (2001) Code of ethics. Boundaries are relational constructs (Nedelsky, 1991) that indicate points of sensitivity and vulnerability for the self and others in professional relationships. The ability to successfully negotiate a relation to the self in choosing between the various subject positions that are available is an important aspect of ethical self governance in professional discourse. Boundaries establish dividing practices within the normative framework for professionalism that classifies and demarcates what is held to be professional behaviour from that which is not. Nurses are required to undertake the self-work that is necessary to form their own relation to this normative framework within the context of their own practice and the specific relationships that they encounter.

Professionalism should be understood as the process of learning that the practitioner engages in throughout their professional life as part of a wider professional community. Conceptualising the normative framework for professional practice as a starting point

for the ethical relation the nurse ought to have with the self, where professional conduct is understood as the outcome of reflexive work that is undertaken on the self would better serve this aim. Nursing education could also consider how to teach ethics in nursing as providing the conceptual resources for a process of developing the professional self as care of the self and others. Developing the professional self through the relation one has with the self as a health practitioner, within a supportive and educative process that connects them to the collective wisdom of other nurses, might enable nursing students to negotiate their place in the professional world. Nursing students need to learn how to create an ethical relation to the self that will be constantly revised through their professional life according to their engagement in and learning from practice experience. The value of reflexivity and writing as transformative practices (Foucault, 1984c) that create the conditions for curiosity and critique should not be underestimated as tools for the development of the professional self.

Finally, health policy that identifies home care as a community model of palliative care, locates the responsibility for supporting people in need of palliative care within their own families, with family members as active participants in that care. Primary Health Care services are situated as an adjunct to this vision of care in partnership with the family (Minister of Health, 2000). While this idea of care for the community by the community locates palliative care within an ethics of choice, and creates the potential for innovative ways of working with families, it relies on the availability of at least one family member to act as a caregiver. The Ministry of Women's Affairs (2001) expressed the need for an analysis of the assumptions that health policy makes about the capacities and resources that families have to participate in such a model of care. In particular, the Ministry identified the need for a gender analysis of health policy that normalises women's roles as caregivers for other family members, albeit within an emancipatory discourse of choice. Nurses should be mindful of their power to influence the development of health policy as a profession that is intimately connected with families and concerned with their health and wellbeing as its moral end. The discussion in this section has offered analysis of the implications of the findings of this research for

nursing as a community of professional practitioners who are engaged with people and their families, often in situations of vulnerability. The following section explores the limitations of the research as points of departure that present possibilities for further research.

### **Limitations of the research as points of departure**

Limits are starting points, points of departure that illuminate new possibilities to explore issues that are of concern to nursing (Ceci, 2000). This research presents an analysis of the choices made by nurse family members in being called to care as something that nursing ought to be concerned with. It illuminates the limits and possibilities for action that became apparent through their subjection to the multiple and competing discourses of caring, professionalism and family, and examines the implications of the self-work they undertake for their relationship with the self and others. Some of the choices I have made in emphasising aspects of the participants' experiences and interpreting them within particular ethical and theoretical frames have had the effect of making certain knowledge visible while other aspects of their experience may remain unobserved in the analysis. As such, in presenting an analysis of participants' experiences that occurred within specific locations and contexts, it constitutes knowledge about nurse family members that is situated and partial; its legitimacy always derived from its context and methods of production. Further exploration of how nurses and nursing students form an ethical relation to the self, and develop ethical judgement about how to proceed in clinical practice, would be valuable in further developing the findings of this research.

The theoretical conduct of the research has been guided by conceptual tools that Michel Foucault (1926-1984) developed in his later writing and interviews. As a critical history of thought, Foucault's philosophy draws attention to the relation one ought to have with the self in attempting to live an ethical life. Secondary sources, as interpretations of aspects of Foucault's thinking, have also been used to inform the conceptual framework that has guided the research process. My interpretation of these theoretical sources as a methodology for the research is somewhat experimental, given that this later aspect of Foucault's work remains marginal in nursing discourse. In that sense, this research

constitutes a point of departure on a journey to find new epistemologies to inform different kinds of knowledge. Foucault (1984/1994) valued curiosity as the ability to question what appears self-evident in the world and believed creativity was derived through the capacity to free oneself from truths that dominate one's thinking and choices about how to conduct oneself in the world (Foucault, 1984a). Using Foucault's methods has enabled me to be concerned with the relations of truth and power that construct nursing subjectivities, and to practise his concepts of curiosity and critique as intellectual work in the development of new knowledge for nursing about these subjectivities. Further research might help to refine the use of these concepts to develop new research methodologies for nursing. Judgement about the validity of my interpretations of Foucault's methods and the extent to which the findings of this research create relevant practice knowledge for nursing must remain with the reader.

As stated earlier, this research is a situated and partial interpretation of aspects of the nurse family members' subjectivities. Further elements of the situatedness of this research include the small number of participants who volunteered for the research, who each had their own story to tell for their own reasons. I found them to be deeply reflective women who were aware of their own capacities to act ethically in the interests of their dying relative. They self-selected into the research in order to inform other nurses about both the challenges and compensations of their experiences. The fact that only women were participants of this research excludes the perspective of men as nurse family members whose experience will be informed by different discourses that create specific kinds of gendered subjectivity. The cultural implications of caring for one's own relative as a nurse have only considered Pakeha perspectives, which is only one cultural aspect in a nursing workforce that has multiple other perspectives. In particular, the research does not encompass the experiences of Maori nurses who may be uniquely situated within their <sup>4</sup>whanau or family's need for care when their relatives become ill, given that social normativity is informed by cultural values about obligation and reciprocity (Butler, 2005; Chattoo & Ahmad, 2008). The findings of this research may

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<sup>4</sup> Whanau is a Maori word that is usually translated as meaning extended family

not be consistent with the values and beliefs of other cultures. However further research that considers broader cultural perspectives in New Zealand/Aotearoa may be useful in showing how culture influences the relation to the self and others as a nurse.

### **Concluding statement**

The central focus of inquiry for this research has been concerned with creating awareness of how nursing subjectivities are formed as a relation to the self in discourse. The contribution that this research makes to the body of knowledge for nursing is to illuminate the complexity and challenges of living well within one's own family and community as a nurse who strives to maintain an ethical relation to the self and others. The theoretical framework and methodological approach to the research interprets Foucault's critical history of thought as an ethical project for nursing. This ethical project is concerned with the forms and limits of knowledge that is available to nurses and to consider how they come to form a specific kind of relation to the knowledge that guides their practice. It is also concerned with how nurses put knowledge into practice in making assumptions about what they can do and what they can be as nurses. While these questions are destabilising in that they take away our certainty in knowing how to proceed when we meet the limits of our knowledge, they expose how power constrains our thinking and, with that understanding, free us to create the conditions to practice differently.

## **Appendix 1: Participant Information Sheet**

**Title of research study:** Negotiating boundaries: The Registered Nurse caring for her own family member in palliative care.

**Researcher:** Patricia McClunie-Trust

### **Invitation**

Thank you for responding to my advertisement for this research study. I am a doctoral student in the Graduate School of Nursing and Midwifery at Victoria University of Wellington. The report for this research will be published as a doctoral thesis.

### **What is the purpose of this research?**

This research will explore the stories of women registered nurses who have cared for their own family member who is receiving palliative care for a cancer-related illness at home and/or in hospital. The stories told by participants will be analysed to show how these registered nurses gave meaning to particular situations and managed relationships with the ill person, family members and other health professionals involved in palliative care.

It will examine how registered nurses caring for their own family member in palliative care, managed the connections and boundaries between family caregiving and their professional practice. This research will create knowledge about the complexities and challenges of caregiving with a family member.

### **How are people chosen to be part of the study?**

Participants in this research will be women who are registered as nurses in New Zealand, who have been involved in caring for a person, who is defined by them as a family member, and with whom they were involved in a relationship as a family caregiver, where this person required palliative care at home and/or in hospital in New Zealand. Participants will preferably be recruited from the central North Island area.

### **What happens in the study?**

The researcher will conduct interviews where the research participants will be invited to tell their story about caring for their own family member in palliative care. Each participant will be interviewed for approximately one hour, up to five times in the course of the research over a period of approximately 12 weeks. The interviews with participants will be audio-taped, transcribed and returned to the participants before each subsequent interview to allow participants to check the accuracy of data and to give their consent to the use of it. Participants will be interviewed in a location and at a time of their choice. Interviews will be spaced at a minimum of two weeks apart to enable transcription of audio-tapes and receipt of the transcript from the researcher.

### **What are the benefits of participating in the study?**

The information collected from the interviews with the research participants will create knowledge about an under researched aspect of nurses' lives by exploring the connections between professional nursing work and the caregiving in palliative care that has been undertaken by the research participants within their families. It will explore an issue that has implications for the professional and private lives of registered nurses, relating to their professional practice, and employment as nurses.

### **Are there any risks to participating in the study?**

Participation in this research will involve registered nurses sharing experiences that are likely to have been significant life events. As a registered nurse you will have substantial knowledge of emotional self-care however you may find that discussing events surrounding the illness and death of a family member evokes feelings of discomfort.

The researcher will minimise this potential discomfort by:

- suggesting that you discuss your involvement in the research with your family to assess any possible implications for them or your relationships with them.
- suggesting that you seek the support of a critical friend, support person or chaplain to discuss any feelings that arise as memories are surfaced.
- contacting you one week after each interview to discuss your reflections on the previous week's interview

- supporting you in gaining access to a counsellor in your area, if this support is requested by you.

You will have the right to withdraw yourself and your data from this study at any time, without being disadvantaged in any way, up to the completion of the data analysis phase of the research process. If you do withdraw from the study, all your personal information will be destroyed or returned to you.

### **How will my privacy be protected?**

All names and places will be removed from the transcribed data to make sure that your privacy is maintained. Participants will be asked to choose a fictitious name (pseudonym) that will be used in the research transcripts, notes or reports. Your interview tape will be erased or returned to you (at your request) at the completion of the research. Any printed research material or notes will be stored in a locked cabinet and destroyed after a period of 10 years.

### **What are the costs to me as a research participant?**

Your time would be the only cost to you. The research interviews will be conducted at a place and time that is convenient to you.

### **Opportunity to receive feedback on the results of the research**

Copies of the interview transcripts will be returned to you and changes will be made to the content of them if this is requested by you. You may also request a copy of the doctoral thesis.

### **Publication of research findings**

The findings of this research will be written up as a doctoral thesis, which will be deposited in the library and the Graduate School of Nursing and Midwifery at the Victoria University of Wellington. The research will be published in nursing journals and presented at conferences. It will also inform the researcher's teaching in undergraduate and postgraduate clinical nursing programmes.



**Participant concerns**

If you have any concerns about this research, please contact the research supervisors

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**How do I join the study as a research participant?**

If after having read this sheet and carefully considered the potential implications of being involved with it, and if you think you would like to participate, please contact me on 021 267 8967 or email me with a contact phone number at [Patricia.McClunie-Trust@wintec.ac.nz](mailto:Patricia.McClunie-Trust@wintec.ac.nz)

This research was approved by the Victoria University of Wellington Human Ethics Committee on 2<sup>nd</sup> August 2005, Ethics Application No. 77/2005

## Appendix 2: Participant Consent Form

**Title of research study:** Negotiating boundaries: The Registered Nurse caring for her own family member in palliative care.

**Researcher:** Patricia McClunie-Trust

Tick box to indicate

consent

○ I have read and understood the information provided about this research study.	<input type="checkbox"/>
○ I have had the opportunity to ask questions and have them answered.	<input type="checkbox"/>
○ I understand that the research interviews will be audio-taped and transcribed.	<input type="checkbox"/>
○ I understand that I may withdraw myself and/or any information that I have provided for this research study at any time prior to the completion of data collection without being disadvantaged in any way. If I withdraw from the research, I understand that all information I have contributed on the tapes and printed transcripts, or parts of this information will be removed and returned to me on my request.	<input type="checkbox"/>
○ I am aware that ethical approval for this research has been gained from <u>(name of Human Ethics Committee)</u> and that research supervision will be given by the Graduate School of Nursing and Midwifery at Victoria University of Wellington.	<input type="checkbox"/>
○ I give my consent to participate in this research study	<input type="checkbox"/>
○ I would like to receive a copy of the final research report on completion of the study	<input type="checkbox"/>

Participant signature: \_\_\_\_\_

Date: \_\_\_\_\_

Participant's name:

Researcher: Patricia McClunie-Trust, Student, Graduate School of Nursing and Midwifery, PO Box 600, Wellington. Email: [nupam@wintec.ac.nz](mailto:nupam@wintec.ac.nz)

This research was approved by the Victoria University of Wellington Human Ethics Committee on 2<sup>nd</sup> August 2005, Ethics Application No. 77/2005

## References

- AARN (2005). *Professional boundaries for registered nurse: Guidelines for the nurse-client relationship*. Edmonton: Alberta Association of Registered Nurses.
- Adorno, T. (1983). *Prisms. Studies in contemporary German thought*. (Trans. S.W. NicholSEN & S. Weber). Cambridge, MA: MIT Press.
- Agger, B. (1992). *Cultural studies as critical theory*. Washington, DC: Falmer Press.
- Alcoff, L. (1988). Cultural feminism versus post-structuralism: The identity crisis in feminist theory. *Journal of Women in Culture and Society*, 13(3), 406-436.
- Allen, A. (2003). Foucault and enlightenment: A critical reappraisal. *Constellations*, 10(2), 180-198.
- Allen, D. (2001). Nursing and sociology: An uneasy marriage? *Sociology of Health and Illness*, 23(3), 386-396.
- Allen, D., & Hardin, P. (2001). Discourse analysis and the epidemiology of meaning. *Nursing Philosophy*, 2, 163-176.
- Anderson, J. (2004). The conundrums of binary categories: Critical inquiry through the lens of postcolonial feminist humanism. *CJNR* 36(4), 11-16.
- Andrews, H., & Roy, C. (1986). *Essentials of the Roy Adaptation Model*. London: Appleton-Century Crofts.
- Ashcraft, K., & Mumby, D. (2003). *Reworking gender: A feminist communicology of organization*. Thousand Oaks: Sage.
- Barnett, R. (1994). Home-to-work spillover revisited: A study of full time employed women in dual-earner couples. *Journal of Marriage and the Family*, 56, 647-656.
- Barrett, E. (2006). Materialising pedagogies. Working papers in art and design, 4. Retrieved December 12<sup>th</sup>, 2008 from <http://www.herts.ac.uk/artdes/research/papers/wpades/vol4/ebfull.html>
- Bashford, A. (1993). Frances Gillam Holden and the Children's Hospital Dispute, 1887: Women's sphere, feminism and nursing. *Women's History Review*, 2(3), 319-330.
- Bauman, Z. (1992). *Intimations of postmodernity*. London: Routledge.

- Benoit, C., & Heitlinger, A. (1998). Women's health care work in comparative perspective: Canada, Sweden and Czechoslovakia/Czech Republic as case examples. *Social Science & Medicine*, 47, 1101-1111.
- Berman, H. (1987). Adult children and their parents: Irredeemable obligation and irreplaceable loss. *Gerontological Social Work with Families*, 10, 21-34.
- Besley, A. C. (2005). Self denial of self mastery? Foucault's genealogy of the confessional self. *British Journal of Guidance and Counselling*, 33(3), 365-382.
- Best, S., & Kellner, D. (1991). *Postmodern theory: Critical interrogations*. New York: The Guilford Press.
- Bevir, M. (1999). Foucault and critique. Deploying agency against autonomy. *Political Theory*, 27(1), 65-84.
- Blacker, D. (1998). Intellectuals at work and in power: toward a Foucaultian research ethic. In T.S. Popkewitz & M. Brennan (Eds.). *Foucault's challenge: discourse, knowledge and power in education* (pp. 348-367). New York: Teachers College Columbia.
- Blain, J. (1994). Discourses of agency and domestic labor: Family discourse and gendered practice in dual earner families. *Journal of Family Issues*, 15, 515-549.
- Bonner, K. (2001). Reflexivity and interpretive sociology: The case of analysis and the problem of nihilism. *Human Studies*, 24, 267-292.
- Boutain, D. (2005). Social justice as a framework for professional nursing. *Journal of Nursing Education*, 44(9), 404-408.
- Bowan, W., & Finegan, T. (1969). *The economics of labour force participation*. Princeton: Princeton University Press.
- Bowling, A., & Cartwright, A. (1982). *Life after death: A study of the elderly widowed*. London: Tavistock Publications.
- Brien, A. (1998). Professional ethics and the culture of trust. *Journal of Business Ethics*, 17, 391-409.
- Brockelsby, J., & Cummings, S. (1996). Foucault plays Habermas: An alternative philosophical underpinning for critical systems thinking. *Journal of the Operational Research Society*, 57, 741-754.
- Brody, E. (1990). *Women in the middle: Their parent care years*. New York: Springer.

- Brown, M., & Colton, T. (2001). Dying epistemologies. An analysis of home death and its critique. *Environmental Planning*, 33, 799-821.
- Brownlee, K. (1996). The ethics of non-sexual dual relationships: a dilemma for the rural mental health professional. *Community Mental Health Journal*, 32, 497-503.
- Bryant, J., Jacobsen, V., Bell, M., & Garret, D. (2004). Labour force participation and GDP in New Zealand. *New Zealand Treasury working paper 04/07*. Retrieved February 2<sup>nd</sup>, 2009 from <http://www.treasury.govt.nz/publications/research-policy/wp/2004/04-07/twp04-07v2.pdf>
- Butler, J. (1990). *Gender trouble: Feminism and the subversion of identity*. New York: Routledge.
- Butler, J. (2002). What is critique? An essay on Foucault's virtue. In D. Ingram (Ed.). *The political: readings in continental philosophy*. London: Basil Blackwell. Retrieved October 10<sup>th</sup>, 2008 from <http://www.law.berkeley.edu/centers/kadish/what%20is%20critique%20J%20Butler.pdf>
- Butler, J. (2005). *Giving an account of oneself*. New York: Fordham University Press.
- Caputo, J. (1987). *Radical hermeneutics: repetition, deconstruction and the hermeneutic project*. Bloomington: Indiana University Press.
- Carolan, M. (2005). The conspicuous body: Capitalism, consumerism, class and consumption. *Worldviews*, 9, 82-111.
- Carolan, M., Andrews, G., & Hodnet, E. (2006). Writing place: A comparison of nursing research and health geography. *Nursing Inquiry*, 13(3), 203-219.
- Carper, B. (1978). Fundamental patterns of knowing in nursing. *ANS I*, 13-23.
- Ceci, C (2000). Not innocent: Relationships between knowers and knowledge. *Canadian Journal of Nursing Research* 32(2), 57-73.
- Ceci, C. (2003a). *Analysing and reflecting upon limits. A Foucault influenced study of some recent events of concern to nursing*. A thesis submitted to the Faculty of Graduate Studies in partial fulfilment of the requirements for the degree of Doctor of Philosophy. Faculty of Nursing. Calgary, Alberta.
- Ceci, C. (2003b). Midnight reckonings: On a question of knowledge and nursing. *Nursing Philosophy*, 4, 61-76.

- Ceci, C. (2004). Nursing, knowledge and power: A case study. *Social Science and Medicine*, 59, 1879-1889.
- Ceci, C. (2006a). Impoverishment of practice: Analysis of effects of economic discourses in home care case management practice. *Nursing Leadership*, 19 (1), 56-68.
- Ceci, C. & McIntyre, M. (2001). A 'quiet' crisis in health care: Developing our capacity to hear. *Nursing Philosophy*, 2, 122-130.
- Chattoo, S., & Ahmad, W. (2008). The moral economy of selfhood and caring: Negotiating boundaries of personal care as embodied moral practice. *Sociology of Health & Illness*, 30(4), 550-564.
- Cheek, J. (2000). *Postmodern and poststructural approaches to nursing research*. Thousand Oaks: Sage.
- Cheek, J. (2003). Negotiated social space: A relook at partnership in contemporary health care. *Primary Health Care Research and Development*, 4, 119-127.
- Chiseri-Strater, E. (1996). Turning in upon ourselves: positionality, subjectivity, and reflexivity in case study and ethnographic research. In P. Mortnesen & G. Kirsch (Eds.). *Ethics and responsibility in qualitative studies of literacy* (pp. 115-133). Urbana: NCTE.
- Clark, D., Neale, B., & Heather, P. (1995). Contracting for palliative care. *Soc. Sci. Med.*, 40(9), 1193-1202.
- Clark, P. (2007). Understanding aging and disability perspectives on home care: Uncovering facts and values in public-policy narratives and discourse. *Canadian Journal on Aging*, 26 (suppl 1), 47-62.
- Clifford, M. (2001). *Political genealogy after Foucault*. New York: Routledge.
- Cody, W., & Mitchell, G. (2002). Nursing knowledge and human science revisited: Practical and political considerations. *Nursing Science Quarterly*, 15(1), 4-13.
- Coles, R. (1992). Communicative action and dialogical ethics: Habermas and Foucault. *Polity*, 25, 583-591.
- Colege and Association of Registered Nurses of Alberta. (2005). *Professional Boundaries for Registered Nurses: Guidelines for the Nurse-Client Relationship*. Retrieved March 30<sup>th</sup>, 2008 from [www.nurses.ab.ca/Carna-admin/Uploads/Professional%20Boundaries%20Guidelines.pdf](http://www.nurses.ab.ca/Carna-admin/Uploads/Professional%20Boundaries%20Guidelines.pdf)

- Cooper, M., & Blair, C. (2002). Foucault's ethics. *Qualitative Inquiry*, 8, 511-531.
- Cordoba, J.-R. (2006). Using Foucault to analyse ethics in the practice of problem structuring methods. *Journal of the Operational Research Society*, 57, 1027-1034.
- Cosimo, S., Pistilluci, G., Ferretti, G., Cicchetti, A., Leggio, M., Silvestris, N., Moro, C., Mandala, M., Curigilano, G., Battigaglia, B. DiChio, G., Cirignotta, S., & D'Aprile, M. (2003). Palliative home care and cost savings: encouraging results from Italy. *The New Zealand Medical Journal* 116 (1170). Retrieved June 17<sup>th</sup>, 2008 from <http://www.nzma.org.nz/journal/116-1170/370/>
- Craig, D. (2003). Re-territorialising health: Inclusive partnerships, joined up governance and common accountability platforms in Thirdway New Zealand. *Policy and Politics*, 31, 335-352.
- Cronqvist, A., Theorell, T., Burns, T., & Lutzen, K. (2004). Caring about – caring for: Moral obligations and work responsibilities in intensive care nursing. *Nursing Ethics*, 11(1), 63-76.
- Crowe, M. (2000). The nurse-patient relationship: A consideration of its discursive context. *Journal of Advanced Nursing*, 31(4), 962-967.
- Crowe, M. (2005). Discourse analysis: Towards an understanding of its place in nursing. *Journal of Advanced Nursing*, 51(1), 55-63.
- Dalglish, B. (1998). Foucault's genealogy of an anti-theory of the normative ethical subject. Paper presented at the 4<sup>th</sup> Annual Qualitative Methods Conference: "Histories of the present" 3 & 4 September. Johannesburg, South Africa. Retrieved March 18<sup>th</sup>, 2008 from <http://www.criticalmethods.org/historie>
- Danaher, G., Schirato, T., & Webb, J. (2000). *Understanding Foucault*. St. Leonards, NSW: Allen & Unwin.
- Davidson, A. (1986). Archaeology, genealogy, ethics. In D. Hoy (Ed.). *Foucault: a critical reader* (pp. 221-233). Oxford: Blackwell.
- Davidson, A. (1998). Introductory remarks to Pierre Hadot. In A. Davidson (Ed.). *Foucault and his interlocutors* (pp. 195-202). Chicago: University of Chicago Press.
- Davies, B. (1992). Women's subjectivity and feminist stories. In C. Ellis & M. Flaherty (Eds.). *Research on lived experience* (pp. 53-76). Newbury Park: Sage.

- Davies, C. (1995). *Gender and the professional predicament in nursing*. Buckingham: Open University Press.
- Davies, K. (2003). The body and doing gender: The relations between doctors and nurses in hospital work. *Sociology of Health and Illness*, 25(7), 720-742.
- Deleuze, G. (1988). *Foucault*. London: The Althone Press.
- Department of Labour. (n.d.). *Holidays and other leave: a guide for employees*. Retrieved 2<sup>nd</sup> February, 2010 from <http://www.ers.dol.govt.nz/publications/pdfs/holidays.pdf>
- Dreyfus, H. & Rabinow, P. (1982). *Michel Foucault: beyond structuralism and hermeneutics* (2<sup>nd</sup> ed.). Chicago: University of Chicago Press.
- Drought, T., & Koenig, B. (2002). "Choice" in end-of-life decision making: Researching fact or fiction? *The Gerontologist* 42, (Special Issue III), 114-128.
- Duke, J., & Connor, M. (2008). Senior nurses as patients: Narratives of special and meagre care. *Contemporary Nurse*, 31(1), 32- 43.
- Duquette, D. (1990). Kant, Hegel and the possibility of speculative logic. In G. Giovanni (Ed.). *Essays on Hegel's logic* (pp. 1-16). New York: SUNY.
- Dyck, I. (2005). Feminist geography, the 'everyday', and local-global relations: Hidden spaces of place making. *The Canadian Geographer*, 49(3), 233-243.
- Dzurec, L. (1989). The necessity for and evolution of multiple paradigms for nursing research: A poststructuralist perspective. *Advances in Nursing Science*, 11(4), 69-77.
- Easterlin, R. (1987). *Birth and fortune: The impact of numbers on personal welfare* (2<sup>nd</sup> ed.). New York: Basic Books.
- Edwards, J., & Rothbard, N. (2000). Mechanisms linking work and family: Clarifying the relationship between work and family constructs. *The Academy of Management Review*, 2 (1), 178-199.
- Eichler, M. (1988). *Families in Canada*. Toronto: Gage.
- Ellefsen, B., Kim, H., & Han, K. (2007). Nursing gaze as a framework for nursing practice: A study from acute care settings in Korea, Norway and the USA. *Scandinavian Journal of Caring Science*, 21, 98-105.



- Ellis, C. (2005). *Final negotiations: A story of love, loss, and chronic illness*. Philadelphia: Temple University Press.
- Emirbayer, M. (1997). Manifesto for relational sociology. *American Journal of Sociology*, 103(2), 281-318.
- Euswas, P., & Chick, N. (1999). On caring and being cared for. In I. Madjar & J. Walton (Eds.). *Nursing and the experience of illness: Phenomenology in practice* (pp. 170-188). St Leonards, NSW: Allen & Unwin.
- Fagermoen, M. (1997). Professional identity: Values embedded in meaningful nursing practice. *Journal of Advanced Nursing*, 25, 434-441.
- Finch, J., & Mason, J. (1993). *Negotiating family responsibilities*. London: Routledge.
- Flaming, D. (2004). Nursing theories as ontologies. *Nursing Philosophy*, 5, 224-229.
- Flaming, D. (2006). The ethics of Foucault and Ricoeur: An underrepresented discussion in nursing. *Nursing Inquiry*, 13(3), 220-227.
- Fook, J. (2000). Deconstructing and reconstructing professional expertise. In B. Fawcett, B. Featherstone, J. Fook & A. Rossiter (Eds.). *Practice and research in social work: Postmodern feminist perspectives* (pp. 109-119). London: Routledge.
- Forssen, A., Carlstedt, G., & Mortberg, C. (2005). Compulsive sensitivity – a consequence of caring: A qualitative investigation into women carer's difficulty in limiting their labours. *Health Care for Women International*, 26, 652-671.
- Foucault, M. (1963/2003). A preface to transgression. In P. Rabinow & M. Rose (Eds.). *The essential Foucault: Selections from essential works of Foucault, 1954-1984* (pp. 442-457). New York: The New Press.
- Foucault, M. (1966/1970). *The order of things: An archaeology of the human sciences*. (Tr. A. M. Sheridan Smith). London: Tavistock.
- Foucault, M. (1969/2003). What is an author? In P. Rabinow & M. Rose (Eds.). *The essential Foucault: Selections from essential works of Foucault, 1954-1984* (pp. 377-391). New York: The New Press.
- Foucault, M. (1970). Orders of discourse. *Social Science Information*, 10(2), 7-22.
- Foucault, M. (1973). *The birth of the clinic: An archaeology of medical perception*. (Trans. A.M. Sheridan Smith). London: Tavistock.

- Foucault, M. (1975). *Discipline and punish: the birth of the prison* (Trans. A.M. Sheridan Smith). Harmondsworth: Penguin.
- Foucault, M. (1977a). Nietzsche, genealogy, history. In D. Bouchard (Ed.). *Language, counter memory, practice. Selected essays and interviews by Michel Foucault* (pp. 139-164). Ithaca: Cornell University Press.
- Foucault, M. (1977b). Intellectuals and power (Trans. D. Bouchard & S. Simon). In D. Bouchard (Ed.). *Language, counter-memory, practice. Selected essays and interviews*. (pp. 205-217). Oxford: Basil Blackwell.
- Foucault, M. (1977/1980). Christianity and confession. In S. Lotringer & L. Hochroth (Eds.). *Michel Foucault: The politics of truth* (pp. 199-236). New York: Semiotext.
- Foucault, M. (1980a). Two lectures (Trans. C. Gordon, L. Marshall, J. Mepham & K. Soper). In C. Gordon (Ed.). *Michel Foucault: Power/knowledge. Selected interviews and other writings 1972-1977* (pp. 78-108). Brighton: The Harvester Press.
- Foucault, M. (1980b). Power and strategies (Trans. C. Gordon, L. Marshall, J. Mepham & K. Soper). In C. Gordon (Ed.). *Michel Foucault: power/knowledge. Selected interviews and other writings 1972-1977* (pp. 134-145). Brighton: The Harvester Press.
- Foucault, M. (1980/1997). Introduction. In P. Rabinow (Ed.). *Ethics, subjectivity and truth. The essential works of Michel Foucault 1954-1984*. Volume one (pp. xix). Harmondsworth: Penguin.
- Foucault, M. (1980/2000). Interview with Michel Foucault (Trans. R. Hurley & others). In J.D Faubion (Ed.). *Power* (pp. 239-297). New York: The New Press.
- Foucault, M. (1981/1988). The political technology of individuals. In L.H. Martin, H. Gutman & P.H. Hutton (Eds.). *Technologies of the self: a seminar with Michel Foucault*. (pp. 143-162). Amherst: The University of Massachusetts Press.
- Foucault, M. (1981/2003). So it is important to think? In P. Rabinow & N. Rose (Eds.). *The essential Foucault. Selections from the essential works of Foucault 1954-1984* (pp. 170-173). New York: The New Press.
- Foucault, M. (1982/2003a). Technologies of the self. In P. Rabinow & N. Rose (Eds.). *The essential Foucault. Selections from the essential works of Foucault 1954-1984* (pp. 145-169). New York: The New Press.

- Foucault, M. (1982/2003b). The subject and power. In P. Rabinow & N. Rose (Eds.). *The essential Foucault. Selections from the essential works of Foucault 1954-1984* (pp. 126-144). New York: The New Press.
- Foucault, M. (1983/1998). Structuralism and Poststructuralism. In J. Faubian (Ed.). *Aesthetics, method and epistemology. Essential works of Foucault 1954-1984 Volume 2* (pp. 431-458). New York: The New Press.
- Foucault, M. (1984a). On the genealogy of ethics: An overview of work in progress. In P. Rabinow (Ed.). *The Foucault reader* (pp. 340-372). New York: Pantheon Books.
- Foucault, M. (1984b). Politics and ethics: an interview. An interview with P. Rabinow. In P. Rabinow (Eds.). *The Foucault reader: an introduction to Foucault's thought* (pp. 584-590). New York: Penguin Books.
- Foucault, M. (1984c). The ethic of care for the self as a practice of freedom. An interview with Michel Foucault on January 20<sup>th</sup> 1984. (Trans. J.D. Gauthier). In J. Bernauer & D. Rasmussen (Eds.). *The Final Foucault* (pp. 1-20). Cambridge: MIT Press.
- Foucault, M. (1984d). The concern for truth. In L. Kritzman (Ed.). *Michel Foucault: Politics, philosophy, culture* (pp. 259-267). London: Routledge.
- Foucault, M. (1984e). The ethics of the concern for self as a practice of freedom. In P. Rabinow (Ed.). *Michel Foucault: ethics, subjectivity, truth* (pp. 281-301). New York: The New Press.
- Foucault, M. (1984/1990). *The care of the self: The history of sexuality, Volume III*. New York: Vintage.
- Foucault, M. (1984/1992). *The use of pleasure. The history of sexuality, volume II*. (Trans. R. Hurley). Harmondsworth: Penguin.
- Foucault, M. (1984/1994). The masked philosopher. In P. Rabinow (Ed.). *Ethics, subjectivity and truth* (pp. 321-328). New York: The New Press.
- Foucault, M. (1984/2003). The ethics of the concern of the self. In P. Rabinow & N. Rose (Eds.). *The essential Foucault. Selections from the essential works of Foucault 1954-1984* (pp. 25-42). New York: The New Press.
- Foucault, M. (1988). Truth, power, self: an interview with Michel Foucault October 25, 1982. R. Martin Interviewer. In L.H. Martin, H. Gutman & P.H. Hutton (Eds.). *Technologies of the self: A seminar with Michel Foucault* (pp. 9-15). Amherst: The University of Massachusetts Press.

- Foucault, M. (1994). Self writing (Trans. R. Hurley). In P. Rabinow (Ed.). *Ethics: Subjectivity and truth* (pp. 207-222). New York: The New York Press.
- Foucault, M. (1998). Foucault (Maurice Florence). In J. Faubian (Ed.). *Aesthetics, method and epistemology. Essential works of Foucault 1954-1984 Volume 2* (pp.459-463). New York: The New Press.
- Foucault, M. (2003a). The birth of social medicine. In P. Rabinow & N. Rose (Eds.). *The essential Foucault. Selections from the essential works of Foucault 1954-1984* (pp. 319-337). New York: The New Press.
- Foucault, M. (2003b). The politics of health in the eighteenth century. In P. Rabinow & N. Rose (Eds.). *The essential Foucault. Selections from the essential works of Foucault 1954-1984* ( pp. 338-350). New York: The New Press.
- Foucault, M. (2003c). What is enlightenment? In P. Rabinow & N. Rose (Eds.). *The essential Foucault. Selections from the essential works of Foucault 1954-1984*(pp. 43-57). New York: The New Press.
- Foucault, M. (2003d). Truth and power. In P. Rabinow & N. Rose. (Eds.). *The essential Foucault. Selected works of Foucault, 1954-1984*. New York: The New Press.
- Fox, N. (1993). *Postmodernism, sociology and health*. Buckingham: Open University Press.
- Frank, A. (1991). For a sociology of the body. In M. Featherstone, M. Hepworth & B. Turner (Eds.). *The body, social processes and cultural theory* (pp. 216-228). London: Sage.
- Frank, A. (1998). Stories of illness as care of the self: a Foucauldian dialogue. *Health*, 2(3), 329–348.
- Frederick, J., & Fast, J. (1999). Eldercare in Canada: Who does how much? *Canadian Social Trends*, 54, 26-30.
- Friere, P., & Macedo, D. (1987). *Literacy: reading the word and the world*. Westport: Bergin & Garvey.
- Frow, J. (1997). *Time and commodity culture*. Oxford: Oxford University Press.
- Gadow, S. (1995). Narrative and exploration: Towards a poetics of knowledge in nursing. *Nursing Inquiry*, 2, 211-214.
- Gadow, S. (1999). Relational narrative: The postmodern turn in nursing ethics. *Scholarly Inquiry for Nursing Practice*, 13(1), 57-70.

- Gardiner, M. (1996). Foucault, ethics and dialogue. *History of Human Sciences*, 9, 27-46.
- Gattuso, S., & Bevin, C. (2000). Mother, daughter, patient, nurse: Women's emotional work in aged care. *Journal of Advanced Nursing*, 31(4), 892-899.
- Georges, J. (2003). An emerging discourse. Toward epistemic diversity in nursing. *Advances in Nursing Science*, 26(1), 44-52.
- Georges, J. (2005). Linking nursing theory and practice: A critical feminist approach. *Advances in Nursing Science*, 28(1), 50-57.
- Georges, J., & Benedict, S. (2008). Nursing gaze of the Eastern Front in World War Two: A feminist narrative analysis. *Advances in Nursing Science*, 31(2), 139-152.
- Gerson, J., & Peiss, K. (2004). Boundaries, negotiation, consciousness: reconceptualising gender relations. In M. Kimmel & A. Aronson (Eds.). *The gendered society reader* (2<sup>nd</sup> ed., pp. 114-126). New York: Oxford University Press.
- Giddings, L. (2005). Health disparities, social justice, and the culture of nursing. *Nursing Research*, 5 (5), 304-312.
- Gilbert, L., & Rader, J. (2004). Current perspectives in women's adult roles: Work, family and life. In R. Unger (Ed.). *Handbook of psychology and gender* (pp. 156-159). New York: John Wiley & Sons.
- Gilbert, T. (1995). Nursing: Empowerment and the problem of power. *Journal of Advanced Nursing*, 21(5), 865-871.
- Gilligan, C. (1982). *In a different voice*. Cambridge, MA: Harvard University Press.
- Gilmour, J. (2001). *On the margins: nurses and the intermittent care of people with dementia – a discourse analysis*. A thesis presented in fulfilment of the requirements for the Degree of Doctor of Philosophy in Nursing at Massey University, Palmerston North.
- Glazer, N. (1990). The home as a workshop: women as amateur nurses and medical care providers. *Gender and Society*, 4(4), 479-499.
- Gordon, S. (2002). Thinking like a nurse: You have to be a nurse to do it. *Nursing Inquiry*, 9, 57-61.

- Gordon, C. (1991). Governmental rationality: An introduction. In G. Burchell, C. Gordon & P. Miller (Eds.). *The Foucault effect: studies in governmentality* (pp. 1-51 ). London: Harvester Wheatsheaf.
- Gould, D., & Fontenla, M. (2006). Commitment to nursing: Results of a qualitative interview study. *Journal of Nursing Management*, 14, 213-221.
- Graham, L., & Slee, R. (2005). Inclusion? Paper Presented at *Australian Association for Research in Education Annual Conference*, Sydney, 27<sup>th</sup> November to 1<sup>st</sup> December.
- Green, R., Gregory, R., & Mason, R. (2006). Professional distance and social work: Stretching the elastic. *Australian Social Work*, 59(4), 449-461.
- Grzywacz, J., Frone, M., Brewer, C., & Kovner, C. (2006). Quantifying work-family conflict among registered nurses. *Research in Nursing and Health*, 29, 414-426.
- Hacking, I. (1986). The archaeology of Foucault. In D. Hoy (Ed.). *Foucault: A critical reader* (pp. 27-40). Oxford: Blackwell.
- Hacking, I. (1990). *The taming of chance*. Cambridge: Cambridge University Press.
- Harper, D. (2003). Developing a critically reflexive position using discourse analysis. In L. Finlay & B. Gough (Eds.). *Doing reflexivity: A critical guide for qualitative researchers in health and social science* (pp. 114-136). Oxford: Blackwell.
- Healy, P. (2001). A 'limit attitude': Foucault, autonomy, critique. *History of the Human Sciences*, 14(1), 49-68.
- Heaton, J. (1999). The gaze and visibility of the carer: A Foucauldian analysis of the discourse of informal care. *Sociology of Health and Illness*, 21(6), 759-777.
- Heikkinen, S., Silvonen, J., & Simola, H. (1999). Technologies of truth: Peeling Foucault's triangular onion. *Discourse: Studies in the Cultural Politics of Education*, 20(1), 141-157.
- Higginson, I. (1999). Which cancer patients die at home? District data for North West Region. *Fact Sheet No. 31*. London: Hospice Information Service.
- Higginson, I., & Sen-Gupta, G. (2000). Place of care in advanced cancer: A qualitative systematic literature review of patient preferences. *Journal of Palliative Medicine*, 3, 287-300.

- Higgs, J., & Titchen, A. (2000). Knowledge and reasoning. In J. Higgs & M. Jones (Eds.). *Clinical reasoning in the health professions* (2<sup>nd</sup> ed., pp. 23-32). Oxford: Butterworth Heinemann.
- Hodgson, D. (2005). "Putting on a professional performance": Performativity, subversion and project management. *Organization*, 12(1), 51-68.
- Hoffman, R., & Mitchell, A. (1998). Caregiver burden: Historical developments. *Nursing Forum*, 33(4), 5-11.
- Hofmeyr, B. (2006a). The power not to be (what we are): The politics and ethics of self creation in Foucault. *Journal of Moral Philosophy*, 3, 215-230.
- Hofmeyr, A.B. (2006b). The meta-physics of Foucault's ethics: Succeeding where Levinas fails. *South African Journal of Philosophy*, 25(2), 113-125.
- Hogg, M., & Abrams, D. (1988). *Social identification*. London: Routledge.
- Hook, D. (2005). Genealogy, discourse, 'effective history': Foucault and the work of critique. *Qualitative Research in Psychology*, 2, 3-31.
- Hoy, D. (1991). Foucault: Modern or postmodern? In J. Arac (Ed.). *After Foucault. Humanistic knowledge, postmodern challenges* (pp. 12-41). New Brunswick: Rutgers University Press.
- Huijer, M. (1999). The aesthetics of existence in the work of Michel Foucault. *Philosophy and Social Criticism*, 25(2), 61-85.
- Hultgren, F. (1994). Being called to care – or- caring being called to be: Do we have a new question? In M. E. Lashley (Ed.). *Being called to care* (pp. 179-188). New York: State University of New York Press.
- Hurliman, H. (2004). *The experiences of nurses providing care to parents or in-laws*. Thesis submitted to the Faculty of the School of Nursing in partial fulfilment of the requirements for the degree of Master of Nursing Science. University of Anchorage. Alaska.
- Infinito, J. (2003). Ethical self-formation: A look at the later Foucault. *Educational Theory*, 53(2), 155-171.
- IOM . (1996). Committee on the adequacy of staffing in hospitals and nursing homes. Division of home care service, Institute of Medicine. In G.Wunderlich, F. Sloan, C. Davis (Eds.). *Nursing staff in hospitals and nursing homes: Is it adequate?* (pp. 169-188). Washington: National Academy Press.

- Jenkins, R. (1996). *Social identity*. London: Routledge.
- Jumaa, M. (2005). Leadership for emotional intelligence. In M. Jasper & M. Jumaa (Eds.). *Health care leadership* (pp. 159-176). Oxford: Blackwell Publishing.
- Keddy, B., Gregor, F., Foster, S., & Denney, D. (1999). Theorizing about nurses' work lives: The personal and professional aftermath of living with healthcare 'reform'. *Nursing Inquiry*, 6, 58-64.
- Keely, P.W. (2008). Improving the evidence base in palliative medicine: A moral imperative. *Journal of Medical Ethics*, 34(10), 757-760.
- Kelsey, J. (1995). *The New Zealand experiment: A world model for structural adjustment*. Wellington: Bridget Williams Books.
- Kendall, G., & Wickham, G. (1999). *Using Foucault's methods*. London: Age Publications.
- Kemshall, H. (2000). Conflicting knowledges on risk: The case of risk knowledge in the probation service. *Health, Risk & Society*, 2(2), 143-158.
- Kessler, T. (2005). Transgressive caregiving. *Florida State University Law Review*, 33(1), 1-87.
- Kettunen, T., Poskiparta, M., Liimatainen, L., Sjogren, A., & Karhila, P. (2001). Taciturn patients in health counselling at hospital: Passive recipients or active participators? *Qualitative Health Research*, 11, 399-422.
- Killien, M. (2004). Nurses' health: Work and family influences. *The Nursing Clinics of North America*, 39, 19-35.
- Kvale, S. (1996). Themes of postmodernity. In W. Anderson (Ed.). *The Fontana post-modernism reader* (pp. 18-25). London: Fontana Press.
- Labott, S., & Johnson, T. (2004). Psychological and social risks of behavioural research. *Ethics and Human Research*, 26(3), 11-15.
- Lamb, A. (1995). Freedom, the self and ethical practice according to Foucault. *International Philosophical Quarterly*, 35, 440-467.
- Lamont, M., & Molnar, V. (2002). The study of boundaries in the social sciences. *Annual Review of Sociology*, 28, 167-195.
- Lather, P. (1993). Fertile obsession: Validity after poststructuralism. *The Sociological Quarterly*, 34(4), 673-693.



- Lashley, M. E., Neal, M., & Slunt, E. (1994). Keeping the call alive. In M. E. Lashley (Ed.). *Being called to care* (pp. 189 -210). New York: State University of New York Press.
- Lawler, J. (1991). *Behind the screens: Somology and the problem of the body*. Melbourne: Churchill Livingstone.
- Lawler, M. (2003). Gazing anew: The shift from a clinical gaze to an ethnographic lens. *American Journal of Occupational Therapy*, 57, 29-39.
- Laylan, J. (2006). Role of the nurse family member when a loved one is hospitalised. Paper presented at *The 17<sup>th</sup> International Nursing Research Congress Focusing on Evidence-Based Practice* (19-22 July). Retrieved May 10<sup>th</sup>, 2008 from [http://stti.confex.com/stti/congrs06/techprogram/paper\\_29825.htm](http://stti.confex.com/stti/congrs06/techprogram/paper_29825.htm)
- Leder, J. (1991). *Brothers and sisters: How they shape our lives*. New York: St Martin's Press.
- Leight, S. (2002). Starry night: Using story to inform aesthetic knowing in women's health nursing. *Journal of Advanced Nursing*, 37, 108-114.
- Liaschenko, J. (1998). The shift from the closed to the open body – ramifications for nursing testimony. In S. Edwards (Ed.). *Philosophical issues in nursing* (pp. 9-30). Hampshire: Macmillan Press Ltd.
- Lucas, K., & Buzzanell, P. (2006). Employees 'without' families: Discourses of family as an external constraint to work-life balance. In L. Turner & R. West (Eds.). *The family communication source book* (pp. 335-352). Thousand Oaks: Sage.
- Luxon, N. (2008). Ethics and subjectivity: Practices of self-governance in the late lectures of Michel Foucault. *Political Theory*, 36 (3), 377-402.
- Mackay, H. (2007). 'Do not ask me to remain the same': Foucault and the professional identity of occupational therapists. *Australian Occupational Therapy Journal*, 54, 95-102.
- Marshall, J.D. (2002). On what we may hope: Richard Rorty on Dewey and Foucault. In M.A. Peters & M.J. Ghireldelli (Eds.). *Richard Rorty: Education, philosophy and politics* (pp.79-100). Lanham, MD: Rowman & Littlefield Publishers.
- Marshall, J. (2001). A critical theory of the self: Wittgenstein, Nietzsche, Foucault. *Studies in Philosophy and Education*, 20, 75-91.

- Martsolf, D. (2002). Codependency, boundaries and professional nurses caring. Understanding similarities and differences in nursing practice. *Orthopaedic Nursing*, 21(6), 61-67.
- May, C. (1992). Nursing work, nurses' knowledge, and the subjectification of the patient. *Sociology of Health and Illness*, 14(4), 472-487.
- McCance, T., McKenna & Boore, J. (1997). Caring: dealing with a difficult concept. *International Journal of Nursing Studies*, 34, 241-248.
- McClunie-Trust, P. (2000). *Body boundaries and discursive practices in life threatening illness: narratives of the self*. Thesis presented in fulfilment of the requirements for the Degree of Master of Nursing. Victoria University of Wellington.
- McCosker, H., & Gerber, R. (2001). Undertaking sensitive research: issues and strategies for meeting the safety needs of all participants. *Forum: Qualitative Social Research*, 2(1). Retrieved May 22<sup>nd</sup>, 2007 from <http://qualitative-research.net/fqs/fqs-eng.htm>
- McGrew, K. (1998). Daughters' caregiving decisions: From an impulse to a balancing point of care. *Journal of Women and Aging*, 10(2), 49-65.
- McLaughlin, J. (2003). Risky professional boundaries: articulations of the personal self by antenatal screening professionals. *Journal of Organization and Health Management*, 17 (4), 264-279.
- McWhorter, L. (1999). *Bodies and pleasures: Foucault and the politics of sexual normalization*. Bloomington: Indiana University Press.
- Meadmore, D., Hatcher, C., & McWilliam, E. (2000). Getting tense about genealogy. *Qualitative Studies in Education*, 13(5), 463-476.
- Medved, C., & Graham, E. (2006). Communicating contradictions: (re) dialectical tensions through work, family and balance socialisation messages. In L. Turner & R. West (Eds.). *The family communication source book* (pp. 353-372). Thousand Oaks: Sage.
- Mellow, M. (2005). The work of rural professionals: Doing the gemeinschaft-gesellschaft gavotte. *Rural Sociology*, 70(1), 50-69.
- Mennino, S., Rubin, B., & Brayfield, A. (2005). Home-to-job and job-to-home spillover: The impact of company policies and workplace culture. *The Sociological Quarterly*, 46, 107-135.

- Miehls, D., & Moffat, K. (2000). Constructing social work identity based on the reflexive self. *British Journal of Social Work*, 30, 339-348.
- Miller, J. (1993). *The passion of Michel Foucault*. New York: Simon & Schuster.
- Miller, R. (1981). Successful urban-to-rural professional role transition. *Community Mental Health Journal*, 17, 143-152.
- Mills, J., & Aubeeluck, A. (2006). Nurses' experiences of caring for their own family members. *British Journal of Nursing*, 15(3), 160-165.
- Minister of Health. (2000). *The New Zealand Health Strategy*. Wellington: Ministry of Health.
- Minister of Health. (2001). *The New Zealand Palliative Care Strategy*. Wellington: Ministry of Health.
- Ministry of Health. (2003). *Palliative Care: Report of the Palliative Care Expert Working Group to the Cancer Control Steering Group*. Wellington: Ministry of Health.
- Ministry of Women's Affairs. (2001). *Using gender analysis to improve the quality of policy advice*. Wellington: Ministry of Women's Affairs.
- Moffat, K., & Miehls, D. (1999). Development of student identity: Evolution from neutrality to subjectivity. *Journal of Teaching in Social Work*, 19, 65-76.
- Monahan, D., & Hopkins, K. (2002). Nurses, long-term care, and eldercare: Impact on work performance. *Nursing Economics*, 20(6), 266-291.
- Morrissey, M. (1997). Extending the theory of awareness contexts by examining the ethical issues faced by nurses in terminal care. *Nursing Ethics*, 4(5), 370-379.
- Morse, J. (1996). Nursing scholarship: Sense and sensibility. *Nursing Inquiry*, 3, 74-82.
- Morse, J., Solberg, S., Neander, W., Bottoroff, J., & Johnson, J. (1990). Concepts of caring and caring as a concept. *Advances in Nursing Science*, 13, 1-14.
- Munhall, A. (1995). Nursing research: What difference does it make? *Journal of Advanced Nursing*, 21(3), 576-583.
- Nehamas, A. (1986). What an author is. *The Journal of Philosophy*, 83(11), 685-691.
- Neale, J. (2004). *No friend like a sister: exploring the relationships between sisters*. Wellington: Victoria University Press.

- Nedelsky, J. (1991). Law, boundaries and the bounded self. In R. Post (Ed.), *Law and the order of culture* (pp. 162-190). Berkeley: University of California Press.
- Nelson, S. (1999). Entering the professional domain, the making of the modern nurse in 17th Century France. *Nursing History Review*, 7, 171–188.
- Nelson, S. (2001). From salvation to civics: Services to the sick in nursing discourse. *Social Science & Medicine*, 53, 1217-1225.
- New Zealand Health Information Service. (2004). *New Zealand health workforce statistics 2004: Nurses and midwives*. Retrieved March 7<sup>th</sup>, 2006 from <http://www.nzhis.govt.nz/stats/nursestats.html>
- Nightingale, F. (1859/1970). *Notes on nursing: What it is and what it is not*. London: Duckworth.
- Norveldt, P. (1998). Sensitive judgment: An inquiry into the foundation of nursing ethics. *Nursing Ethics*, 5, 385-392.
- Nurses' Association of New Brunswick. (2002). Position statement: delegation of nursing acts to family members. Retrieved March 1<sup>st</sup>, 2008 from [http://www.nanb.nb.ca/pdf\\_e/Publications/Position\\_Statements/POSITION\\_STATEMENTS\\_pdf/DELEGATION\\_OF\\_NURSING\\_ACTS\\_TO\\_FAMILY\\_MEMBERS\\_E.pdf](http://www.nanb.nb.ca/pdf_e/Publications/Position_Statements/POSITION_STATEMENTS_pdf/DELEGATION_OF_NURSING_ACTS_TO_FAMILY_MEMBERS_E.pdf)
- Nurses Board of Victoria. (2007) *Professional Boundaries for Registered Nurses in Victoria*. Retrieved March 30<sup>th</sup>, 2008 from <http://www.nbv.org.au/media/43308/professional%20boundary%20guidelines.pdf>
- Nursing Board of Tasmania. (2005). *Professional Boundaries standards for nurses in Tasmania*. Retrieved March 3<sup>rd</sup>, 2008 from [www.nursingboardtas.org.au/.../\\$File/Professional%20Boundaries%20Standard%20%20web%20version.pdf](http://www.nursingboardtas.org.au/.../$File/Professional%20Boundaries%20Standard%20%20web%20version.pdf)
- Nursing Council of New Zealand. (2000). *February 2000 Newsletter*. Retrieved November 8<sup>th</sup>, 2009 from <http://www.nursingcouncil.org.nz/feb00.html#4>
- Nursing Council of New Zealand. (2001). *Code of conduct for nurses and midwives*. Retrieved March 3<sup>rd</sup>, 2008 from <http://www.nursingcouncil.org.nz/codeofconduct.pdf>
- Nursing Council of New Zealand. (2007). *Competencies for registered nurses*. Wellington: Nursing Council of New Zealand.

- Nursing Council of New Zealand. (2008a). *Guideline: Direction and delegation*. Wellington: Nursing Council of New Zealand.
- Nursing Council of New Zealand. (2008b). *Code of conduct for nurses*. Wellington: Nursing Council of New Zealand.
- Nurses and Midwives Board, New South Wales. (1999). *Guidelines for registered nurses and enrolled nurses regarding the boundaries of professional practice*. Retrieved June 7<sup>th</sup>, 2005 from [www.nmb.nsw.gov.au/Boundaries-of-Professional-Practice/default.aspx](http://www.nmb.nsw.gov.au/Boundaries-of-Professional-Practice/default.aspx)
- NZNO. (2001). *Code of ethics*. Wellington: NZNO.
- NZNO. (2007). High Court reverses Tribunal decision in Lesley Martin case. *Kai Tiaki*, 13(8), 33.
- Oakley, J. (1992). *Morality and the emotions*. London: Routledge.
- O'Farrell, C. (2005). *Michel Foucault*. London: Sage.
- Oliver, P., & McGhee, P. (2005). In search of professional identity. A descriptive study of New Zealand "Professional" Bodies' codes of ethics. *Research Paper Series 16-2005*, Faculty of Business, Auckland University of Technology.
- Olssen, M. (2006). Foucault and the imperatives of education: Critique and self creation in a non-foundational world. *Studies in Philosophy and Education*, 25, 245-271.
- Osmond, J. (2005). The knowledge spectrum: A framework for teaching knowledge and its use in social work practice. *British Journal of Social Work*, 35, 881-900.
- Owen, T., & Powell, J. (2006). "Trust", professional power and social theory. Lessons from a post-Foucauldian framework. *International Journal of Sociology and Social Policy*, 26 (3/4), 110-120.
- Parker, J., & Wiltshire, J. (1995). The handover: Three modes of nursing practice knowledge. In G. Gray & R. Pratt (Eds.). *Scholarship in the discipline of nursing* (pp. 151-168). Melbourne: Churchill Livingstone.
- Paternelj-Taylor, C. (2002). Professional boundaries: A matter of therapeutic integrity. *Journal of Psychosocial Nursing and Mental Health Services*, 40(4), 22-20.
- Penfold, P. (1998). *Sexual abuse by health professionals*. Toronto: University of Toronto Press.

- Peters, M. (2005). Foucault, counseling and the ethics of existence. *British Journal of Guidance and Counselling*, 33(3), 383-396.
- Pickard, S., Jacobs, S., & Kirk, S. (2003). Challenging professional roles: Lay carers' involvement in health care in the community. *Social Policy and Administration*, 37(1), 82-96.
- Pillow, W. (2003). Confession, catharsis or cure? Rethinking the uses of reflexivity as methodological power in qualitative research. *International Journal of Qualitative Studies in Education*, 16(2), 175-196.
- Porter, S. (1997). The degradation of the academic dogma. *Journal of Advanced Nursing*, 25, 655-656.
- Poster, M. (1993). Foucault and the problem of self constitution. In J. Caputo & M. Yount (Eds.). *Foucault and the critique of institutions* (pp. 63-80). University Park: Pennsylvania State University Press.
- Powers, P. (1996). Discourse analysis as a methodology for nursing inquiry. *Nursing Inquiry*, 3, 207-217.
- Prince, R., Kearns, R., & Craig, D. (2006). Governmentality, discourse and space in the New Zealand health care system, 1991-2003. *Health and Place*, 12, 253-266.
- Radio New Zealand. (2007, 28<sup>th</sup> February). *Lesley Martin struck off nursing register*. Lesley Martin and Marion Clark with Geoff Robinson.
- Rankin, K. (1993). The New Zealand workforce: 1950-2000. *New Zealand Journal of Industrial Relations*, 18(2), 214-235.
- Read, T. (2003). *A process of relinquishing: Daughters caring for dying elderly parents*. A thesis submitted in partial fulfilment of the requirements for the Degree of Master of Nursing in the Graduate Academic Unit of Nursing. The University of New Brunswick.
- Read, T., & Wuest, J. (2007). Daughters caring for dying parents: A process of relinquishing. *Qualitative Health Research*, 17, 932-944.
- Reineck, C., & Furino, A. (2005). Nursing career fulfillment: Statistics and statements from registered nurses. *Nursing Economics*, 23(1), 25-31.
- Reverby, S. (1987). *Ordered to care: The dilemma of American nursing, 1850-1945*. New York: Cambridge University Press.

- Reverby, S. (1989). The caring dilemma: Womanhood and nursing in historical perspective. In P. Brown (Ed.). *Perspectives in medical sociology* (pp. 470-484). Prospect Heights: Waveland Press.
- Rolfe, G. (2000). Writing ourselves: Creating knowledge in a postmodern world. In G. Rolfe (Ed.). *Research, truth, authority: postmodern perspectives on nursing* (pp. 109-123). Basingstoke: Macmillan Press Ltd.
- Rosenfeld, P. (2007). Workplace practices for retaining older hospital nurses: Implications from a study of nurses with eldercare responsibilities. *Policy, Politics and Nursing Practice*, 8, 120-129.
- Rose, N. (1996a). Authority and the genealogy of subjectivity. In P. Heelas, S. Lash & P. Morris (Eds.). *Detraditionalization: Critical reflections on authority and identity* (pp. 294-327). London: Blackwell Publishing.
- Rose, N. (1996b). Identity, genealogy, history. In S. Hall & P. DuGay (Eds.). *Questions of cultural identity* (pp. 128-159). Thousand Oaks, CA: Sage.
- Ross, M., Rideout, E., & Carson, M. (1996). Nurse's work: Balancing personal and professional caregiving careers. *Canadian Journal of Nursing Research*, 26(4), 90-111.
- Rouse, J. (2005). *Power/knowledge*. Arts and Humanities Division 1 Faculty Publications. Retrieved July 14<sup>th</sup>, 2009 from <http://wescholar.weslyan.edu/div1facpubs/34>
- Runté, M., & Mills, A. (2002). *The discourse of family-work conflict: a critique*. Retrieved June 17<sup>th</sup>, 2008 from <http://luxor.acadiau.ca/library/ASAC/v23/231103.pdf>
- Rutman, D. (1996). Caregiving as women's work: Women's experiences of powerfulness and powerlessness as caregivers. *Qualitative Health Research*, 6(1), 90-111.
- Sacks, H. (1967). The search for help: No one to turn to. In J. Schneidman (Ed.). *Essays in self destruction* (pp. 203-223). New York: Science House.
- Salmond, S. (2006). A grounded theory study of nurse family members' experiences during the critical illness of a loved one. *The 17th International Nursing Research Congress Focusing on Evidence-Based Practice (19-22 July)*. Retrieved April 17<sup>th</sup>, 2008 from [http://stti.confex.com/stti/congrs06/techprogram/paper\\_27662.htm](http://stti.confex.com/stti/congrs06/techprogram/paper_27662.htm)

- Sandelowski, M. (1998). Looking to care or caring to look? Technology and the rise of spectacular nursing. *Holistic Nursing Practice*, 12(4), 1-11.
- Schon, D. (1983). *The reflective practitioner: How professionals think in action*. London: Temple Smith.
- Scott, L., Hwang, W., & Rogers, A. (2006). The impact of multiple care giving roles on fatigue, stress, and work performance among hospital staff nurses. *The Journal of Nursing Administration*, 36(2), 86-95.
- Scott, P.A. (2000). Emotion, moral perception, and nursing practice. *Nursing Philosophy*, 1, 123-133.
- Sheets, V. (2001). Professional boundaries: Staying in the lines. *Dimensions in Critical Care Nursing*, 20(5), 36-40.
- Shirley, J., & Padgett, S. (2004). Professionalism and discourse: But wait, there's more! *The American Journal of Bioethics*, 4(2), 35-38.
- Silverman, D., & Bloor, M. (1990). Patient-centred medicine: Some sociological observations on its constitution, penetration and cultural assonance. *Advances in Medical Sociology*, 1, 3-25.
- Simon, M., Kummerling, A., & Hasselhorn, H. (2004). Work-home conflict in the European nursing profession. *International Journal of Occupational and Environmental Health*, 10, 384-391.
- Simons, J. (1995). *Foucault and the political*. London: Routledge.
- Skeggs, B. (1997). *Formations of class and gender: Becoming respectable*. London: Sage.
- Small, S., & Riley, D. (1990). Toward a multidimensional assessment of work spillover into family life. *Journal of Marriage and the Family*, 52, 51-56.
- Starr, P. (1982). *The social transformation of American medicine. The rise of a sovereign profession and the making of a vast industry*. Cambridge: Basic Books.
- Street, A. (1997). Thinking about nursing futures. *Nursing Inquiry*, 4(2), 79.
- Stevens, J., & Crouch, M. (1998). 'Care' – the guiding principle of nursing? In H. Keleher & F. McInnerney (Eds.). *Nursing matters: Critical sociological perspectives* (pp. 157-168). Marrickville: Harcourt Brace & Company.



- St. Pierre, E. A. (2001). Coming to theory: Finding Foucault and Deleuze. In K. Weiler (Ed.). *Feminist engagements: Reading, resisting and revisioning male theorists in education and cultural studies* (pp. 141-163). New York: Routledge.
- Tarnas, R. (1991). *The passion of the Western mind: Understanding the ideas that have shaped our world view*. New York: Ballantine Books.
- Taylor, D. (2003). Practicing politics with Foucault and Kant: Toward a critical life. *Philosophy & Social Criticism*, 29(3), 259-280.
- The Dominion Post. (2004). *Accused 'too close' to dying mother*. Retrieved Wednesday, December 13, 2006 from the Australia/New Zealand Reference Centre Data Base.  
<http://web.ebscohost.com/ehost/delivery?vid=53&hid+102&sid+90e05eab-e849-4b6e-b058-821d7f456141%40sessionmgr104>
- Titchen, A., & McGinley, M. (2004). Blending self-knowledge and professional knowledge in person centred care. In J. Higgs, B. Richardson & M. A. Dahlgren (Eds.). *Developing practice knowledge for health professionals* (pp. 107-126). Edinburgh: Butterworth Heinemann.
- Thompson, L. (2008). The role of nursing in governmentality, biopower and population health: *Family health nursing. Health & Place*, 14, 76–84.
- Van Manen, M. (2002). Care as worry, or “Don’t worry, be happy”. *Qualitative Health Research*, 12, 262-278.
- Vermont State Board of Nursing. (2003). Nurses functioning in positions other than that for which they are licensed. Position statement. Downloaded 07/04/2008 from <http://vtprofessionals.org/opr1/nurses/forms/nursingopinions.pdf>
- Veyne, P. (1997). Foucault revolutionizes history. In A. Davidson (Ed.). *Foucault and his interlocutors* (pp.146-182). Chicago: University of Chicago Press.
- Victoria University of Wellington. (2007). *Human Ethics Policy*. Wellington: Victoria University of Wellington.
- Wanhalla, A. (2007). To ‘better the breed of men’: Women and eugenics in New Zealand, 1900-1935. *Women’s History Review*, 16(2), 163-182.
- Ward-Griffin, C. (2004). Nurses as caregivers of elderly relatives: Negotiating personal and professional boundaries. *CJNR*, 36(1), 92-114.

- Ward-Griffin, C., Brown, J., Vandervoort, A., McNair, S. & Dashnay, I. (2005). Double Duty caregiving: Women in the health professions. *Canadian Journal on Aging*, 24(4), 379-394.
- Ward-Griffin, C., & Marshall, V. (2003). Reconceptualising the relationship between public' and 'private' eldercare. *Journal of Aging Studies*, 17, 189-208.
- Watson, J. (1988). *Nursing: human science and human care: A theory of nursing*. New York: National League for Nursing Press.
- Weedon, C. (1987). *Feminist practice and poststructuralist theory*. Oxford: Basil Blackwell.
- Wepa, D. (2005). Culture and ethnicity: What is the question? In D. Wepa (Ed.). *Cultural safety in Aotearoa New Zealand* (pp. 30-38). Auckland: Pearson.
- Wharton, A. (1991). Structure and agency in Socialist-Feminist theory. *Gender & Society*, 5(3), 373-389.
- Wilkinson, J. (2007). *The New Zealand nurse practitioner polemic: A discourse analysis*. A thesis presented in fulfilment of the requirements of Doctor of Philosophy in Nursing. Massey University, Wellington.
- White, J. (1999). Changing labour process and the nursing crisis in Canadian hospitals. In P. Armstrong & M. Connelly (Eds.). *Feminism, political economy and the state* (pp. 57-90). Toronto: Canadian Scholars' Press.
- World Health Organisation Regional Office for Europe. (1989). *Palliative Cancer Care Statement based on the recommendations of a WHO consultation*. Geneva: WHO.
- WHO. (2004). *Health and human rights*. Retrieved January 20<sup>th</sup>, 2009, from <http://www.who.int/hhr/en/>
- Will, C.I. (2001). Knowledge in nursing: Contemplating life experience. *CJNR*, 33(3), 107-116.
- Woolf, V. (1978). *A writer's diary*. Bungay: Triad, Granada.
- Wuest, J. (1998). Setting boundaries: A strategy for precarious ordering of women's caring demands. *Research in Nursing and Health*, 21, 39-49.
- Wuest, J. (2000). Repatterning care: Women's proactive management of family caregiving demands. *Health Care for Women International*, 21, 393-411.

Yeatman, A. (1994). Feminism and power. *Women's Studies Journal*, 10(1), 79-100.

Zander, P. (2007). Ways of knowing in nursing: The historical evolution of a concept. *The Journal of Theory Construction and Testing*, 11(1), 7-11.

Zubrzycki, J. (2003). *The construction of personal and professional boundaries in Australian social work: A qualitative exploration of the self in practice*. A thesis submitted to the School of Social Work and Social Policy for the degree of Doctor of Philosophy. Curtin University of Technology.