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ON THE MARGINS:
NURSES AND THE INTERMITTENT CARE OF
PEOPLE WITH DEMENTIA – A DISCOURSE
ANALYSIS

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requirements for the degree of

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Jean Alison Gilmour

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ABSTRACT

The purpose of this research has been to explore the representations and practices of nurses in the context of intermittent care for people with dementia, and to situate their accounts within the wider discourses of dementia care. Discourse, as explicated by Michel Foucault, is the body of knowledge, and the related disciplinary practices, that can be considered to be *the truth* at a particular time, shaping what is possible to be said, and with the associated power to exclude what cannot be said. In the first section of the thesis it is argued that the concept of dementia is not the description of some pre-determined biological phenomenon but a powerful disciplinary construction informed by a specific historical and cultural perspective, a construction that has major policy implications and ramifications for the representations of dementing illnesses in disciplines such as nursing.

Section two of the thesis shifts from the disciplinary representations of dementia produced in published texts, to the representations and everyday practices of the nurses and families who participated in this study. While all the nurses' texts represented the care of the person with dementia as problematic, at times, in the institutional setting, there was considerable diversity apparent in nurses' discursive positionings, and in the associated practices and inscriptions of the person with dementia. The organisational context emerged as a major factor influencing those discursive choices and practices. One research site provided particularly successful respite care as judged by family caregivers' expressions of confidence in the service. The dominant nursing discourse in this site framed the hospital as home-like and the relationship with patients as being family-like. The permeability of social and geographic boundaries at this research site signaled inclusion for family and patients in contrast to the more traditional boundaries demarcating social and physical spaces evident in the other sites.

This study highlights the institutional bases of powerful discourses such as biomedicine as well as the existence of alternative discourses. The marginal discourse of care as being family and home-like may lack the authority of biomedical and formal nursing discourses, situated as it were outside the academy, but space is provided in this representation to produce a social environment, and nursing practices, that encourage a sense of relationship

and social inclusion for people with dementia and their family caregivers. Dementia has proved to be a fruitful area of study in that the current dominance of biomedical knowledge in nursing literature can be challenged as being marginal to nursing concerns. The subsequent discussion of how nurses have suppressed the knowledge and interests of people with dementia and, indeed, the knowledge of nurses themselves, provides a productive starting point for wider discussion about issues of power/knowledge in nursing representations generally.

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CHAPTER ONE

Locating the Study

What is philosophy today - philosophical activity, I mean - if it is not the critical work that thought brings to bear on itself? In what does it consist, if not in the endeavor to know how and to what extent it might be possible to think differently, instead of legitimating what is already known? (Foucault, 1990, p. 9)

These words written by Michel Foucault resonate with my belief that there is a need to read against the grain of the established doctrine surrounding the care of people with dementia and to critically re-view how we, as nurses, talk and practise in this area. Dementia is currently the most acceptable term for referring to people who have progressive loss of cognitive function. Medically, dementia describes symptoms such as memory loss, disorientation, loss of intellectual ability and judgment. The most common illnesses causing these symptoms are Alzheimer's Disease and cerebral vascular disease (multi-infarct dementia).

My intellectual and emotional engagement with the issues engendered in this area of practice has been driven by my experiences in the 1980s working as the charge nurse of a hospital intermittent and continuing care ward. The aim of intermittent care¹ services is to allow the family caregiver some respite from caregiving. Caring for people with dementia

¹ Intermittent care for the purpose of this research, is defined as regular, pre-planned hospital care for people who are very substantially disabled. I have adopted the term *intermittent care* to represent in-patient hospital respite care as this is the name used in the research sites and in other areas of New Zealand (Sainsbury, Collins, Duff, Harrison, Haydon & Wilkinson, 1997). However, in the literature discussing respite care the terminology is varied and includes terms such as in-patient respite, in-hospital respite and residential respite care.

involves increasing supervision for safety reasons as their condition deteriorates, changes in relationships, and assistance with activities of daily living. Intermittent care is part of a continuum of services aimed at supporting family caregiving. Other services include community nursing care and alternative respite services such as sitter services and adult day care, as well as support from field workers, social workers and carers' support groups. In hindsight, I consider that I was ill prepared for working in this area, although at the time I had considerable and varied nursing experience and substantial post registration nursing education. As my knowledge and experience increased in this setting, so did my appreciation of the complexity of developing constructive relationships with both the person being cared for and the caregiver. Furthermore, the impact of institutional routines and environments on the quality of life of the person receiving care emerged as a highly problematic factor.

The people I cared for were profoundly disabled by the time they were eligible for hospital respite care services, and all were in the late stages of a dementing illness. They had varying degrees of memory loss; some were unable to recognise close family members, while others knew the significant people in their lives and seemed to have some familiarity with the institutional setting on re-admissions. But all the patients experienced some degree of disorientation and, at times, mobile people left the ward seeking their home and relatives. Other disorientated behaviours included wandering from cubicle to cubicle, frenetically packing and unpacking belongings, and occasionally reacting angrily to offers of assistance. These people required considerable nursing support for activities of daily living such as washing, going to the toilet, dressing and eating. Their requirements for help were highly individual and, as a result of difficulties with communication, considerable knowledge was required about their abilities as well as needs. Verbal communication was always impaired and, generally, conversations were frustratingly unintelligible to the listener. Attempts to provide care were sometimes actively resisted as people were at times unable to recognise the need for assistance, or even that they were in a hospital ward being cared for by nurses.

At the time I was concerned about the obvious distress of some of the people who were being cared for, lost and anxious in the strange ward environment of the hospital. However, I intellectually justified their situation as necessary in order that family caregivers could have some respite. My assumption was that the continuance of home caregiving was a desirable outcome that mitigated, to some degree, the misery of the present experience. It was quite evident, from nursing the people in the unit, that the unrelenting and demanding nature of the physical care required to sustain life, in conjunction with the supervision often needed to ensure safety, as well emotional support, was unsustainable for the family without outside support. Yet the problem with this comfortable intellectualisation was that many families expressed distress and feelings of ambivalence and guilt at taking some respite from caregiving at the cost of the happiness of their relative. My positioning was uncomfortable. As a nurse, I was faced with an ongoing challenge to provide nursing care to people unwillingly relocated from home to hospital, as well as allay family members' concerns so they could actually take advantage of the respite time and have a break from the labour of caring.

My response, as I grappled with these complex issues, was to attempt to adapt the social and physical environment to the needs of all the people living in the ward, including both permanent residents and intermittent care patients. The rationale behind this attempt to create a flexible and pleasant living environment was that if the patients in the ward were happy and contented then family caregivers would also feel confident about using the respite service. My thoughts at this time were recorded in a journal article.

Nurses need to see their role in continuing care as a crucial one, which sets up and maintains an environment that is health-orientated and health-creative. All the participants in the ward - residents, family and staff - should work as a community with all the human relationships that entails. (Gilmour, 1989, p. 29)

In hindsight, the injunction that the ward should work as a community has somewhat dictatorial overtones. However, the underlying sentiment, that a continuing and intermittent care ward was a place where people had the right to be involved in everyday life in contrast to the very circumscribed existence endured in traditional hospital wards where the environment and care is driven by immediate and urgent medical exigencies, still permeates

my thinking today. I also believe this ideal, while seemingly simple and self evident, is difficult to achieve in hospital, an institution fundamentally set up to serve the interests of medicine. Transforming hospital wards into residential settings requires different ways of thinking about the care of people who are very disabled and living in a collective setting.

I have been employed as a nursing lecturer since I left the continuing and intermittent care ward in 1989, but the contradictions and challenges of nursing people with intermittent care have captured my attention in an enduring manner. Ongoing involvement in the local Alzheimer's Society, and the subsequent alliances with family caregivers in political and educational activities designed to improve services and care, have also kept me engaged in this area of nursing practice. Through these working relationships I have developed a deep respect for the investment made by many families in providing emotionally and physically sustaining care to their relatives over many years. My growing awareness of the contribution and commitment made by families in caring for their relatives has fueled my interest in exploring quality of care issues in the intermittent care context.

My review of the literature at the beginning of this project revealed that little was known about nurses' concerns and practices within the intermittent care context. The knowledge base informing the provision of intermittent care services is limited, the most significant gap being, in my opinion, the lack of research interest in the quality of formal care provided during the intermittent care admission. I believe that research exploring ways in which intermittent care could be improved in terms of the experience of the person requiring care in order to enable families to relinquish care confidently and take full advantage of respite opportunities, is critical in order to inform a currently neglected area of nursing practice.

The field of inquiry

Research inquiry is shaped by the intersection of the epistemological concerns directing the questions asked, the methods used for data collection, the analytic approach and the relationship between the researcher and the researched. Choosing the research approach to explore nursing practices in the context of caring for people with dementia was, in

retrospect, a critical exercise as the ramifications of using particular research methodologies only became apparent as the research proceeded.

Initially, for this research project, I used a grounded theory approach which is informed by the sociological perspective of symbolic interactionism and focuses on the processes of human interactions. Social events, in symbolic interactionism are conceptualised as happening in steps, each succeeding step creating new possibilities and new conditions for negotiation. This viewpoint suggests the notion of contingency in that nothing is fully determined, which contrasts with the view that culture or social structure shape people's options (Becker & McCall, 1990). My aim at this time was to develop a detailed description and theoretical interpretation of the experience of nursing and family caregiving within the context of institutional intermittent care of people with dementia. However, using grounded theory proved to be a frustrating exercise in my research context. I developed a description of intermittent care processes with little space to critique the broader social forces that play a role in creating and constraining nursing practices. Furthermore, I found the detailed articulation of grounded theory method by Strauss (1987) and Strauss and Corbin (1990) stifled exploration and experimentation with ideas as I tried to apply techniques such as *axial coding* and *conditional matrixes* to unruly data. As the research proceeded I increasingly agreed with Barthes' (1977) comment that there was "no surer way to kill a piece of research and send it to join the great waste of abandoned projects than Method" (p. 201).

In addition to finding the analytic processes of grounded theory constraining, I also grappled with the difficulties in conveying a representation of people with dementia in such a way that acknowledged their central, yet paradoxically voiceless, role in intermittent care. There is criticism that the literature relating to dementing illness tends to highlight either the progress made by medical research or to emphasise caregiver experience, with the consequent marginalisation of the person with the dementia (Kitwood, 1993), and I wanted to avoid either of those positions. In addition, as a nurse caring for people with dementia, I could not help but come up against disciplinary and institutional boundaries circumscribing my practice. These boundaries were formed by the dominance of medical representations of

dementia and the associated allocation of sparse organisational resources to support the care of people not amenable to medical cure. These constraints directed my attention to the nature of knowledge and the ensuing power relationships in the field of dementia care and to theoretical perspectives that could assist my analysis.

The work of Kitwood (1989; 1990; 1993), Gubrium (1986; 1987), Lyman (1993) and Robertson (1991) also provided impetus in shifting my focus from grounded theory to a more critical viewpoint. For these writers, the term dementia is not the description of some pre-determined biological phenomena, but a construction informed by a specific historical and cultural perspective with particular social implications. This encounter with the critique of the construction of knowledge around dementia, coupled with research findings that demanded further exploration, prompted a radical rethink of my research. Eventually I abandoned grounded theory and the beginnings of a descriptive model of intermittent care for a critical discourse analysis approach using the ideas of Michel Foucault.

My shift from symbolic interactionism to using some of Foucault's ideas as a *toolkit*, as he puts it (Foucault, 1980c), has resulted in a considerably different study from my original venture. The emphasis created through a grounded theory analysis was on the generation of a local theory to explain the social interactions of my participants, families and nurses. Using Foucault's ideas has involved a conceptual shift and a widening of the field of interest. From this theoretical positioning participants' experiences provide a key point of access to the discourses of dementia care. The individuals in the study - nurses, families and most importantly people with dementia - are envisaged as being positioned within these discourses, their accounts and behaviours informed by the knowledge currently accepted as being authoritative. This theoretical move has entailed abandonment of a particular form of qualitative research that, as Crowe (1998) argues, is based on an ideological position that maintains that "reality can be apprehended by capturing the individual's point of view (subjectivity) and that qualitative researchers can directly represent this lived experience in language" (p. 340). The adoption of a poststructuralist approach, in which I locate Foucault's work, entails a reading of knowledge as being imbued with power, and that subjectivity is seen as constituted through discourse, a cultural construction rather than

natural given (Crowe, 1998). It also needs to be clearly stated from the outset that this study makes limited claims, located as it is within Anglo-American disciplinary discourses about nursing and dementia, and represents one facet only of a complex phenomenon.

Outlining the study

Part one of this thesis, *Mapping the Field*, surveys several fields of knowledge which intersect and overlap at various points. Chapter two sets the theoretical scene, discussing the work of Michel Foucault that I have found especially pertinent for the purposes of this study. The concept of discourse is the core theoretical concept underpinning my analysis of nursing practice in the context of intermittent care for people with dementia. Discourse, as explicated by Foucault, is the body of knowledge and the related disciplinary practices that can be considered to be *the truth* at a particular time, shaping what is possible to be said, and with the associated power to exclude what cannot be said. Along with discourse and knowledge, power relations are another important and enduring thread in Foucauldian analysis, constituted through discourse, and always permeated with the possibility of resistance to dominant views, as well as the possibility of new counter discourses creating new knowledges and truths. The concept of genealogy has also been pivotable in forcing me to read nursing and biomedical texts in a more critical manner through the disruption of my ingrained assumptions about what is truth in this field. Genealogy is a term used by Foucault (1980a) to describe a method of analysis that combines scholarly, historical knowledge with local memories in order to allow “us to establish a historical knowledge of the struggles and to make use of this knowledge tactically today” (p. 83). I have found Foucault’s ideas to be illuminating and catalytic, but it is also important to acknowledge the absences in his work. I have focused on the feminist critique of Foucault’s work in order to foreground the lack of connection between gender, power and knowledge in his theorising. Finally, the theoretical approach underlying the research design, discourse analysis, is described drawing predominately on the work of Parker (1992).

The focus of the thesis then shifts to the discourses informing nurses’ practice in the context of dementia care. In chapter three the changing definitions of the medical category of dementia are traced and the circularity of medical discussion in this context highlighted,

along with the counter-discourses claiming dementia is not a pre-determined biological truth, but rather a historically and culturally specific social construction. The appropriation of biomedical knowledge in nursing texts is critiqued in terms of the suppression of the debates, contradictions and uncertainties apparent in medical literature. The paradoxical positioning of the person with dementia in this literature is also foregrounded, central as the object of inquiry but marginal in terms of voice. In chapter four the major themes evident in contemporary nursing literature are discussed, along with currently advocated nursing practices, and caregiving dilemmas. Relations of power between people with dementia and their caregivers are highlighted in my reading of nursing texts.

Chapter five provides an overview of the development of intermittent care in the last three decades and the developing body of research-based knowledge focusing on respite care services is reviewed. My discussion focuses on the central contradiction of intermittent care, namely that, despite the articulated purpose of intermittent care being to reduce caregiver burden, the actual outcome of using the service for some family members can be added stress. Another significant issue explored in my discussion is the negligible interest in researching the care actually provided by nursing and other health care workers working in respite services.

Part two of the thesis, *Representing Practice*, shifts from the disciplinary representations of dementia produced in published texts, to the representations and everyday micro-practices of nurses and families who participated in this study. Chapter six introduces the second part of the thesis with a methodological account of the production and analysis of the nurses' and families' texts. Fifteen registered or enrolled nurses working in four intermittent care services participated in the research along with nine family caregivers² using the intermittent care sites. Detailed descriptions of the four research sites are presented, with particular note of the differences and similarities between the organisations with regard to the physical environment and the social organisation of nursing work. I then discuss the processes used to collect the texts used as the basis for my discourse analysis, namely

² A family caregiver in this study is defined as a person (family or friend) who identifies her or himself as having the primary responsibility for the care of the person with dementia.

interviews, field notes and documentation, along with the techniques used to analyse these texts and the ethical issues that needed to be addressed as part of the study.

Considerable heterogeneity characterises nurses' accounts of intermittent care. While all the nurses' texts represented the care of the person with dementia as problematic in the institutional setting, there was considerable diversity apparent in nurses' discursive positionings, and the associated practices and inscriptions. In chapter seven these dominant discursive positionings are discussed along with the possible implications for the person with dementia and their families. The organisational context emerged as a major factor influencing discursive choices and practices.

Chapter eight concentrates on the family caregivers' accounts of using intermittent care services. The variability of families' texts is foregrounded in terms of their feelings about intermittent care and the differing degrees of care relinquishment during the stay of their relative in hospital. Family caregiver relationships with nurses and the interrelated impact of intermittent care on the person with dementia emerge as important factors in the family caregivers' degree of satisfaction with the service.

In chapter nine the analytic focus is an alternative representation of care emerging predominantly in one site. In this discursive location the nurses spoke of the hospital as a home and the relationship with patients as being family like. The associated micro-practices were significantly different from the other sites. Also, very significantly, this was the only organisation in this study where all the family caregivers expressed a high degree of satisfaction with the intermittent care service and were able to take full advantage of the respite period. The various implications of discursively transforming the hospital into a home-like setting are explored in this chapter along with the organisational attributes supporting this representation of care.

The discussion in chapter ten, the final chapter, has several focal points. Firstly, I discuss the implications of this study for nursing practice and education. I revisit the position, outlined in chapters three and four, that nursing representations of dementia are dominated

unnecessarily by medical discourse. An alternative account is produced, positioning an account by a person with dementia centrally in the text, in an attempt to think differently about nursing relationships and care in this context. In the discussion on the implications for practice in intermittent care I focus on the power/knowledge relationships inherent in nurse-family relationships and the role of the organisational context in enabling or, alternatively, constraining nursing practices. The next part of the chapter focuses on the issues that emerged through the process of adopting a Foucauldian approach to discourse analysis. Finally, the limitations to this study are reported, along with suggestions for further research in this area.

PART I

Mapping the Field

CHAPTER TWO

The Theoretical Terrain

Introduction

The work of Michel Foucault provides a useful vantage point from which to review and critique the construction of dementing illnesses and ensuing nursing practices. In this chapter, I will discuss Foucault's work in relation to the theoretical ideas of structuralism and poststructuralism, along with the aspects of Foucault's work that have been particularly useful in informing this study. Due to the wide ranging and mutable nature of Foucault's theoretical concerns, I have not attempted to provide a comprehensive overview of his work in the following discussion of the epistemological basis of this research. Rather, I have focused on the key theoretical ideas that have informed this study. These areas of discussion include the role of discourse in the construction of knowledge, the relationship between power and knowledge, the genealogical approach as a method of analysis, and the representation of the body as an inscribed surface and object of power. In this section I will also foreground the feminist critique of the absences in Foucault's work in such areas as the lack of connection between gender, power and knowledge. Discussion then focuses on how his work has been used to explore nursing issues. The final section of this chapter moves on to a description of the approach to discourse analysis used in this study.

The theoretical foundations of the study

Foucault's ideas are catalytic, problematising practices that might otherwise be unquestioned. Prado (1995) describes Foucault as a "a strong poet - a thinker who

redefines himself or herself in new terms, who invents new metaphors, and so creates a new vocabulary for the rest of us” (p. 49). Foucault sought to expand the limits of knowledge in the human sciences, through his “histories of the present” (Sawicki, 1991, p. 101), in the quest to understand how we have come to think as we do today in order to think differently in the future. His work is characterised by a fluidity that denies easy categorising and description, located as he was at the margins of the disciplines of philosophy and history. Over time, his concerns shifted from his initial interest in the development of the discourses of the human sciences, the study of which he called archaeology, to a new focus on a method of analysis called genealogy where the relationship between power and knowledge was explored, and finally to an interest in the issues of subjectivity and how we construct our sense of self.

Foucault also resisted positioning within the broad theoretical movements of structuralism (Foucault, 1994), poststructuralism and postmodernism (Foucault 1983a). However, his work is positioned within poststructuralist thought by Anglo-American academic commentators (Poster, 1989). Poststructuralism needs to be understood in relationship to earlier structuralist theorising. Structuralist writers shared an approach to the analysis of language that began with the work of Saussure, who argued that meaning is conveyed in an arbitrary relationship between the signified or the meaning, and the signifier or the spoken or written form of the sign. According to Dant (1991), meaning, to Saussure, did not exist before the development of the system of relationships that comprises a particular language. Saussure’s conception of language was as a collective social endeavor in order to realise shared meanings rather than as meaning being vested in the individual speaking. Dant argues that French theorists, such as Lévi-Strauss, took up Saussure’s idea of language as an autonomous structure as a template in the search for underlying explanatory structures for social phenomena.

Structuralist ideas, as with any other theoretical approach, have explanatory limitations and have been criticised for the lack of emphasis on human agency and power relationships, for the implications of one underlying structure which is an essentialist notion, and for the ahistorical nature of the structures (Dant, 1991). While Foucault was categorised as structuralist by some commentators in the 1960s, he distanced himself emphatically from this theoretical approach in 1970.

In France, certain half-witted ‘commentators’ persist in labeling me a ‘structuralist.’ I have been unable to get it into their tiny minds that I have used none of the methods, concepts, or key terms that characterise structural analysis. (Foucault, 1994, p. xiv)

Sheridan (1990) suggests that Foucault was erroneously positioned in a structuralist mode because of his rejection of causation in historical accounts, and also the philosophy of the subject. All of Foucault’s work has been the exploration of historical change rather than arresting historical processes in structures and Sheridan believes that Foucault’s work could be seen as antistructuralist rather than structuralist. Poststructuralist thought addresses the criticisms of structuralism. While language remains central, poststructuralism links language with subjectivity, social organisation and power (Richardson, 1994; Weedon, 1987). According to Poster (1989) the work of the philosopher Nietzsche makes an important contribution to this theoretical position with the idea that “truth is not a transcendent unity”(p. 15), thus creating the possibility that there are multiple truths continually reinterpreted in the light of opposing ideas. Knowledge is, therefore, always partial and context-specific. Nietzsche’s connection between truth and power is also adopted, truth being communicated in discourses which are forms of power in their capacity to shape practices.

Poststructuralist challenges to mainstream social theories encompass three areas (Barrett, 1992). Firstly, theory based on materialistic claims is challenged, as is the idea of a consciousness being dependent on a material world.

The conventional view used to be that ‘things’ exist in the material and natural world; that their material or natural characteristics are what determines or constitutes them; and that they have a perfectly clear meaning, *outside* of how they are represented. Representation, in this view, is a process of secondary importance, which enters into the field only after things have been fully formed and their meaning constituted. But since the ‘cultural’ turn in the human and social sciences, meaning is thought to be *produced* – constructed – rather than simply ‘found’. Consequently, in what has come to be called a ‘social constructionist approach’, representation is conceived as entering the very constitution of things. (Hall, 1997a, p. 5)

Foucault (1972a) took the position that language is constitutive, arguing that discourses systematically formed the objects spoken about in contrast to the notion that language reflects some pre-existing material reality.

Secondly, poststructuralists challenge the search for causality in human phenomena (Barrett, 1992). Instead, theorists, such as Foucault, foreground the historical specificity of particular knowledges and practices, drawing attention to “the way representational practices operate in concrete historical situations, in actual practice” (Hall, 1997a, p. 6). Foucault used a specific form of historical analysis, termed genealogy, to theorise about the nexus between power and knowledge. He aimed to surface the discontinuities and contradictions that characterise transformative historical events, rather than attempting to find the original illusive moment that is supposed to hold the power to explain why things are (Miller, 1994).

Finally, the idea that language is an unproblematic and transparent vehicle for the expression of thought is critiqued from a poststructuralist viewpoint (Barrett, 1992). For Foucault, “the central question was ‘What can be said’ ” (Barrett, 1992, p. 203), emphasising the power of discourse in creating epistemological frameworks for what can be said, when and by whom. This conceptualisation of discourse underpins my exploration of the construction of dementia and the implications of the associated discursive practices for people with dementia, their families and nurses.

Discourse

In common usage, discourse refers to speech between people. However, for Foucault, discourse refers to bodies of knowledge (such as the disciplinary knowledge of medicine or sociology for instance) and the related disciplinary practices that control or create options and behaviours (McHoul & Grace, 1993). Discourses are represented within dominant modes of knowledge and thereby inform practices in ways that position people differently as social beings in terms of power. Discourses are permeated with power; power to inform and form, to dictate what is said and by whom, and they are imbued with the power leading to acceptance of what comes to be seen as *a truth* in a historically and culturally specific context.

Disciplines such as nursing and medicine are founded on distinctive conventions as to what are the appropriate objects of study and how to study them. Practices exist within these disciplines to regulate what can be said. “To speak ‘within the true’ of a particular discipline is to speak within a complex web of inclusions and exclusions” (Barrett, 1992, p. 212). As a consequence of a particular positioning within a discourse, other modes of knowledge can be prohibited or alternately marginalised, or suppressed; leaving some things unspoken in certain places, times or by particular people operating from that discursive location. Knowledge can also be rejected. Foucault (1988b) uses the division between reason and folly as an example of how the voices of the *mad* are ignored, excluded from mainstream everyday discourse. The opposition between true and false provides yet another system for rejection. What is accepted as truth changes over time, but always the *will to truth* survives, supported by a range of institutional practices controlling the production and circulation of the knowledges accepted at a particular time as authoritative (Foucault, 1972b).

Said (1988) suggests that Foucault’s work breaks away from the notions held by humanistic and modernist social sciences of a culture and society deriving from individual heroic endeavor, to the idea that social life and work is a collective enterprise shaped by discursive forces. The task emerging from this stance is

... to circumvent or break down the ideological biases that prevent us from saying that what enables a doctor to practice medicine or a historian to write history is not mainly a set of individual gifts, but an ability to follow rules that are taken for granted as an unconscious *a priori* by all professionals. More than anyone before him Foucault specified rules for those rules, and even more impressively, he showed how over long periods of time the rules became epistemological enforcers of what (as well as how) people thought, lived, and spoke. (Said, 1988, p. 10)

Discursive structures define what can be spoken of as truth. The principles of exclusion in relation to the discourses pertaining to dementia illustrate this well. In this context the voices of family caregivers and health professionals are documented and acknowledged, while the knowledge of the object of inquiry, the person with dementia, is marginalised, excluded from dominant discourses.

I have used Foucault's (1991b) criteria for delineating the existence of individual discourses as my guidelines in discourse identification. He suggests that while there are the familiar criteria for recognising the existence of separate discourses, such as the language used and the choice of topics, there are other more "enigmatic" (Foucault, 1991b, p. 54) criteria that define discourses such as psychiatry or medicine. His first criterion is that of formation, whereby rules can be identified guiding the formulation of the objects of the discourse. Discourses are more than signs indicating particular representations or content, they are also practices that form the objects spoken about. The rules dictating the formation of legitimate objects are the requirements within a discursive practice for particular forms of knowledge relationships in order that certain concepts or strategies may be legitimately used (Foucault, 1972a).

Discursive formulations are not frozen in time and the second criterion, transformation, focuses on the ability to define the conditions that existed at the time of discourse formation, what modifications could be made within the discourse and when transformations could occur that required new rules of formulation (Foucault, 1991b). Foucault emphasises the different types of transformation of discourses, exploring difference and deviation characterised by three levels of analysis. The first level is the detection of changes within a discursive formation that affect the objects of inquiry, concepts and theoretical alternatives. Discursive formations are the next level of analysis with changes to the boundaries of knowledge, the positions and role of the speaking subject, the functioning of language and the localisation and circulation of the discourses explored. Finally, the third type of change affects several discursive formations and includes changes in order of importance or power, and displacements by one discourse by another.

The third of Foucault's criteria, correlation, refers to the relationship of an individual discourse, such as medicine, with other types of discourse, such as biology or politics, and the positioning of the discourse within the broader context of institutions and the economic and political milieu (Foucault, 1991b). These criteria reflect what Foucault (1991b, p. 55) calls the

...*episteme* of a period, not the sum of its knowledge, nor the general style of its research, but the divergence, the distances, the oppositions, the differences, the relations of its multiple scientific discourses: the *episteme* is not *a sort of grand underlying theory*, it is a space of *dispersion*, it is an *open and doubtless indefinitely describable field of relationships*.

The term *episteme* is used to emphasise differences, discontinuities and change both in and between discourses, rather than a notion of unity and continuity (Ramazanoglu, 1993). Discourse from this approach is explored not from the point of view of the individuals who are speaking, or indeed the content spoken, but rather examines the discursive rules that determine the value and applicability of what is spoken.

My reading of Foucault's theorising about discourse underpins this research project. Nursing texts are embedded in biomedical constructions of dementing illnesses, representations which constitute certain sorts of subjectivities, allow for particular subject positionings for people with dementia and caregivers, and suppress knowledge from marginalised groups while legitimating other forms of knowledge. In chapters three and four the discursive field of nursing knowledge, in the context of caring for people with dementia, is examined in terms of the correlation between nursing and medicine, and the implications for nursing representations of care and for ensuing practices.

Power/knowledge

Foucault foregrounds the relationship of power with discourse, a catalytic connection that has generated a fertile field of inquiry. Knowledge is inextricably bound up within power and creates the effects of power. Each society has its

...*régime of truth*...the types of discourse which it accepts and makes function as true; the mechanisms and instances which enable one to distinguish true and false statements, the means by which each is sanctioned; the techniques and procedures accorded value in the acquisition of truth; the status of those who are charged with saying what counts as true. (Foucault, 1980b, p. 131)

Power, for Foucault, is constituted through discourse, a departure from a traditional juridico-discursive model of power where power is conceptualised as being possessed by individuals and classes (Sawicki, 1991). From the juridico-discursive viewpoint, power flows hierarchically from a central source such as the state and is essentially repressive, enabling the

prohibition or sanctioning of particular actions. In contrast, Foucault argues that power is exercised rather than possessed, is productive rather than primarily repressive, and furthermore emerges from below.

Power must be [*sic*] analysed as something which circulates, or rather as something which only functions in the form of a chain. It is never localised here or there, never in anybody's hands, never appropriated as a commodity or piece of wealth. Power is employed and exercised through a net-like organisation. And not only do individuals circulate between its threads; they are always in the position of simultaneously undergoing and exercising this power. They are not only its inert or consenting target; they are also the elements of its articulation. In other words, individuals are the vehicles of power, not its points of application. (Foucault, 1980a, p. 98)

Turner (1997) argues that Foucault's view of power challenged the theoretical ideas of Marxists such as Althusser and the conceptualisation of power as a macro-structure embedded in the state, existing to support a capitalistic society and practised through institutions such as the law and the church. In contrast, Turner (1997) suggests, the view of power as a relationship which operated at a local level and was embodied in day-to-day practices means that "the attempt to seize the state through political action would not destroy power, because power is rather like a colour dye diffused through the entire social structure" (p. xii). This conception of power leads to an interest in local, micro-practices of power as well as the rather more impersonal power of the state, and focuses on the productive role of discourse in creating and maintaining dominant forms of power (Diamond & Quinby, 1988).

Foucault (1983b) states his goal has not been to analyse power as a particular phenomenon but rather to develop "a history of the different modes by which, in our culture, human beings have been made subjects" (p. 221). To be a subject is to be both subject to others through being controlled or dependent, and to oneself and personal identity through conscience and self-knowledge. This is a critical differentiation from the notion of the self-made and creative subject of modernity, autonomous and sovereign.

If there is one approach I do reject, however, it is that (one might call it, broadly speaking the phenomenological approach) which gives absolute priority to the observing subject, which attributes a constituent role to an act, which places its own point of view at the origin of all history - which, in short, leads to a transcendental consciousness. It seems to me that the historical analysis of

scientific discourse should, in the last resort, be subject, not to a theory of the knowing subject, but rather to a theory of discursive practice. (Foucault, 1994, p. xiv)

Lupton (1995) explains subjectivity as being a sense of self, socially constructed through social interactions, that are also discursively inscribed, and as being acquired rather than a pre-ordained product of birth. The constitution of subjectivities is through language and discourse interrelated with embodied sensual experiences and unconscious drives. Subjectivity is also fragmented and fluid, dependent on the context and “there are numerous, often contradictory ways in which individuals fashion subjectivities” (Lupton, 1995, p. 7). But choices of subjectivities are constrained by the operation of power, the effect of power being that “certain bodies, certain gestures, certain discourses, certain desires, come to be identified and constituted as individuals” (Foucault, 1980a, p. 98). Power relations are, in Foucault’s work, differentiated from relations of force or violence where there is no choice and where possibilities are curtailed.

A relationship of violence acts on a body or upon things; it forces, it bends, it breaks upon the wheel, it destroys, or it closes the door on all possibilities. Its opposite pole can only be passivity, and if it comes up against any resistance it has no other option but to try to minimize it. On the other hand a power relationship can only be articulated on the basis of two elements which are each indispensable if it is really to be a power relationship: “the other” (the one over whom power is exercised) be thoroughly recognized and maintained to the very end as a person who acts; and that, faced with a relationship of power, a whole field of responses, reactions, results, and possible inventions may open up. (Foucault, 1983b, p. 220)

This clear differentiation between relationships of power, where people both consent to be acted upon and also to exercise power, and relationships of force, where there are no free choices, is important in the context of relationships between nurses and people with dementia where relationships of both power and force co-exist.

Foucault maintained that modern configurations of power/knowledge were first developed in disciplinary institutions such as hospitals, schools and prisons in the late eighteenth century as a consequence of the necessity of managing large groups of people, a problem that would later also become the concern of modern governments. Disciplinary power derived from

particular practices, namely hierarchical observation, normalising judgement and the examination (Foucault, 1995).

Hierarchical observation implies visibility from above, a form of power to know the other, or at least the actions of an other, and requires a mechanism to create a coercive effect on those observed. Foucault (1995) argued that by the end of the eighteenth century structures were no longer built to be simply seen or in order to survey external spaces, but rather so as to “permit an internal, articulated and detailed control – to render visible those who are inside it; in more general terms, an architecture that would operate to transform individuals: to act on those it shelters, to provide a hold on their conduct” (p. 172). The military camp, designed so all ranks had their particular place, predictable and visible, was the first step in the design of modern hospitals and schools as “a mechanism for training” (Foucault, 1995, p. 172) which allowed for better observation. Hierarchical observation further evolved as the need for continuous supervision of labour in factories was created in the industrial setting and a specialised supervisory workforce developed. The hospital was also built in such a form as to allow effective observation of patients and therefore treatment. It was “no longer simply the roof under which penury and imminent death took shelter; it was, in its very materiality, a therapeutic operator” (Foucault, 1995, p. 172).

Normalising judgement, as a disciplinary practice, requires the comparison of individual actions with others in relation to a particular rule to be followed (Foucault, 1995). The ability and value of individuals is measured in order to achieve a stipulated conformity, defined on the basis of good and bad and ranked between positive and negative poles. Through this comparative technique a class of abnormality is created, along with penalties for the deviations from what is judged as normality, in order to correct or reduce the gaps and deficits in behaviour or performance. The subjects of this disciplinary practice are judged as *good* or *bad*, rather than the act itself.

Through this micro-economy of a perpetual penalty operates a differentiation that is not one of acts, but of individuals themselves, of their nature, their potentialities, their level or their value. By assessing acts with precision, discipline judges individuals ‘in truth’; the penalty that it implements is integrated into the cycle of knowledge of individuals. (Foucault, 1995, p. 181)

The most ritualised of all the disciplinary techniques, the examination, is defined by Foucault (1995) as a normalising gaze, the combination of an observing hierarchy and a normalising judgement; “a surveillance that makes it possible to qualify, to classify and to punish” (p. 184). The reorganisation of the hospital as an “examining apparatus” (Foucault, 1995, p. 185) in the eighteenth century enabled almost constant observation of the patient. Power relations shifted as the doctors, previously irregular visitors but now members of staff, relegated religious staff to a subordinate role and the status of the hospital shifted from the poorhouse to a place of training and knowledge development. Along with surveillance, documentation is an integral component of the examination, the individual constituted as an object who can be described in writing in terms of his or her abilities. Furthermore, the disciplinary writing techniques that accompanied the practice of examination created the possibility of developing a system that could describe and compare groups of people, and calculate gaps between individuals, as well as their distribution in particular populations. The examined individual is made a *case*, an object “for a branch of knowledge and a hold for a branch of power” (Foucault, 1995, p. 191). As objects of knowledge, individuals are described, measured and judged, while in terms of power they are classified and corrected, or excluded.

The envisaging of power as being linked with knowledge, and as being simultaneously productive and constraining in the constitution of subjects, provides a useful method of analysis by which to explore the type of subjectivities produced by the disciplinary knowledge and practices of nursing. Moreover, the practices associated with disciplinary power resonate with nursing practices of observation and assessment deployed in the care, and at times control, of people with dementia, and suggest certain kinds of power relationships. These practices are contradictory in that they can be interpreted as both benign and caring in ensuring individual safety, as well as controlling and as curtailing human rights. The implications of these practices are discussed later in this thesis.

Genealogy as resistance

Historical research is central to Foucault’s radical philosophy. In his early work he explored the history of the development of new knowledge within the sciences of life, language and economics. However, this was not conventional history, a linear progressive narrative focused on discovering causal events. Foucault conceived of the past in terms of discontinuity and rupture with ensuing transformations in knowledge influenced by French historians of science

such as Gaston Bachelard, a student of poetry and modern physics. The creative role of the scientist was stressed in this view of scientific discovery, rather than the notion of a slow accumulation of immutable truths (Miller, 1994). History is conceptualised as being the power struggles between different interests, not just in relation to the domination of one group over another but also in the values that permit particular hierarchies (Foucault, 1991a).

Genealogy, for Foucault, describes a method of analysis in tracing the history of a particular event. The term arises from Nietzsche's description of morals as being the product of historical descent rather than some immutable form that has always existed. The search for the origins of some essential site of truth is rejected in a genealogical approach. Rather, the researcher searches for the "accidents, the minute deviations...reversals...errors, the false appraisals, and the faulty calculations that give birth to these things that continue to exist and have value for us" (Foucault, 1991a, p. 81). The exceptions and accidents that shape the emergence of events are emphasised in a genealogical approach in order to disrupt notions of some grand design and continuity in historical progression. The familiar is defamiliarised in order to emphasise how the past is different from the present and to refuse to sanction the present (Harootunian, 1988). This is a rather different undertaking from the efforts of traditional histories to " 'memorize' the *monuments* of the past" (Foucault, 1972a, p. 7).

Genealogies challenge conventional views and surface marginised knowledge or, as Foucault terms it, *subjugated knowledges*, referring to knowledges and experiences not qualifying as being worthy of note in traditional academic accounts.

These unqualified, even directly disqualified knowledges (such as that of the psychiatric patient, of the ill person, of the nurse, of the doctor - parallel and marginal as they are to the knowledge of medicine - that of the delinquent etc.), and which involve what I would call a popular knowledge (*le savoir des gens*) though it is far from being a general commonsense knowledge, but is on the contrary a particular, local, regional knowledge. (Foucault, 1990, p. 82)

Power produces resistance through counter discourses that produce different and new knowledges and truths, thus leading to new power relations, different discursive opportunities and different subjectivities. People, for Foucault, are social selves,

historically variable, constituted as subjects of discourse, but also contributing, knowingly or unknowingly, to the process of becoming a particular kind of subject (Ramazanoglu, 1993). Discourse provides the point of resistance to dominant forms of power relations through counter or reverse discourses revealing and undermining those forms of power (Foucault, 1990).

Genealogy as resistance involves using history to give voice to the marginal and submerged voices which lie “a little beneath history”- the voices of the mad, the delinquent, the abnormal, the disempowered. It locates many discontinuous and regional struggles against power both in the past and present. These voices are the sources of resistance, the creative subjects of history. (Sawicki, 1991, p. 28)

Using a genealogical approach in this reading of nursing and medical texts has directed my attention firstly to the incidents marking shifts and challenges to the knowledge accepted as authoritative, and secondly to emphasising the absent voices, the marginalised knowledges in nursing and medical discourses, namely the people with dementia and the nursing practitioners actively providing care. These accounts reflect struggles, conflicts between the qualified and disqualified knowledges. Nursing knowledge formally presented in the published literature often mimics medical discourses, and indeed, in the case of dementia, draws heavily of the scientific discourse of medicine. Yet, nursing knowledge developed from practitioners’ experiences bear a close relationship with Foucault’s notion of subjugated knowledges, as different from and invisible in the accounts positioned as authoritative as the experiences of people with dementia themselves.

The “body” as text

The body is a central concern in nursing. Nurses work in a professional capacity caring for the physical bodies of comparative strangers during times of illness and disability in a socially sanctioned and unique relationship. Nurses also grapple with their own embodied experiences as predominantly women within health care institutions where their experiences are influenced by medical and managerial discourses as well as caregiving concerns. For Foucault, the body is the object of power, a text read by others, an

...inscribed surface of events (traced by language and dissolved by ideas), the locus of a dissociated self (adapting the illusion of a substantial unity), and a volume in perpetual disintegration. Genealogy, as an analysis of descent, is thus situated within the articulation of the body and history. Its task is to expose a body totally imprinted by history and the process of history's destruction of the body. (Foucault, 1991a, p. 83)

Foucault presents the viewpoint that the body is not totally natural and preordained but rather is discursively produced and reproduced through social practices. Grosz (1995) contrasts Foucault's *inscriptive* approach to the *lived body* approach of psychoanalysis and phenomenology. In the inscriptive approach the body is conceived as a surface on which values, morals and social laws are inscribed, and where each *body* participates in different ways in this process of inscription, the body inherently social and public, whereas, with the lived body approach, the internal experience is the point of interest. But the body has no intrinsic truth if truth is, as Foucault maintains, a historical category dependant on particular contexts and produced by discourses. Rather, the discursively produced body is the point where the operation of power can be observed, normalised through the supervision and surveillance practices of modern disciplinary regimes, "the field on which the play of powers, knowledges, and resistances is worked out" (Grosz, 1994, p. 146).

The inscription of power on the discursive body is defined by Foucault (1990) as biopower and as having two forms, which Fox (1993) describes as the "micro-politics of bodily regulation and the macro-politics of surveillance of populations" (p. 28). The first form focuses on the control of the body through knowledge of the individual in terms of abilities, expressions, behaviour and location and the disciplinary practices located within institutions such as hospitals, schools and prisons and in the micro-level everyday activities and interactions. The second form of biopower incorporates the regulatory power governing populations through state intervention with populations the object of study (Sawicki, 1991).

In medicine, biopower is illustrated by a particular technology of power, the *gaze*, the act of seeing, of perceiving an object in order to describe and know that object (Foucault, 1975). The language of medical description, the product of the speaking eye, encapsulates a particular medical world, unintelligible to the uninitiated.

Description, in clinical medicine, does not mean placing the hidden or the invisible within reach of those who have no direct access to them; what it means is to give speech to that which everyone sees without seeing - a speech that can be understood only by those initiated into true speech. (Foucault, 1975, p. 115)

For instance, the use of specialised medical language restricts knowledge to those that can understand it by virtue of disciplinary preparation. Medical power over the body is also illustrated at the macro-level by the creation of the institution of the hospital. All extraneous variables such as the home environment, family, friends and usual activities are excluded. The hospital provides the ideal laboratory setting where the causes of symptoms can be isolated and the effects of treatment monitored. Furthermore, there is opportunity for twenty-four hour surveillance by that extension of the doctor's gaze, the nurse. The principles of the *panopticon*, a prison designed by Bentham enabling total surveillance of the prisoner by unseen observers, can readily be transposed to hospital design, the patient constantly exposed, "the object of information, never a subject in communication" (Foucault, 1995, p. 200).

However, while conceptualising the body as discursively inscribed provides a space for analysing the effects of practices ensuing from authoritative constructions, interpretations and possibilities for transformation are, of necessity, limited in the case of dementing illnesses by biological constraints. As Lupton (1995, p. 5) states:

Throughout the lifespan the body is taken up and transformed by social relations, but within certain limits imposed by biology. There is, therefore, a symbiotic relationship between the body and society which defies determinism of either a biological or social constructionist nature.

People with dementia have biological changes that affect them in profound and dramatic ways, changing forever their abilities, relationships and life expectations. While the impact of the underlying disease is socially constructed, described and interpreted through language and shaped by social practices, there is co-existing an all pervasive and unalterable physical reality of suffering and decline.

The feminist critique

A considerable amount of secondary literature has been generated from Foucault's work and his problematising of previously unchallenged interpretations of particular knowledges and discursive practices. There is also a significant body of work expressing reservations about aspects of Foucault's writing. Space and time preclude a substantial review of the extensive commentary on Foucault's work, so I have decided to focus on the feminist critique of the absences in his work. The correlation between gender and power cannot be neglected in the field of nursing and medicine, and there is a need to address some of the absences in Foucault's work if a fuller analysis of nursing practices and the ensuing power implications is to emerge.

Feminist writing is characterised by both an advocacy of the ideas of Foucault which are believed to be valuable in advancing the feminist critique of current power relations, and an ambivalence about, and criticisms of, assumptions and absences apparent in his work. Points of commonality and convergence between Foucault and feminism are to be found. For example, as Diamond and Quinby (1988) note, there is the identification of the body as the focus of the enactment of power, leading to an interest in local, personal operations of power as well as the rather more impersonal power of the state. Both approaches also focus on the productive role of discourse in creating and maintaining dominant forms of power. However, feminist writers also critique the lack of acknowledgment in Foucault's discussions of the gender dimensions of power (Diamond & Quinby, 1988; Martin, 1988; Morris, 1988).

One of the major vehicles of the feminist critique of Western humanism involves the issue of authority and processes of authorization. Foucault might have given new status to discourse, but he fails to take into account the relations between masculinist authority and language, discourse, and reason. Language, feminists claim, is never gender-free. (Diamond & Quinby, 1988, p. xv)

A major difficulty for feminists using Foucault's work is his unabashed assumption of a sexually neutral body and, by extension, sexually neutral *bodies* of knowledge. This strange blindness to gender differences is difficult to accept in Foucault's work, given his interest in marginalised knowledges, voices and alternative discourses and his use of sexuality to demonstrate normalising practices. This conspicuous lack of connection between gender, power and knowledge may well be explained by what could be interpreted as a passionless

approach of focusing on how discourses and practices create certain effects rather than on the effects themselves. However, to those women who are silenced and excluded from dominant discourses, Foucault can be interpreted as yet another male oppressor.

Foucault's theorising about power is also critiqued. Harstock (1990) presents a cogent argument questioning the utility of Foucault's theorising about power for women. She believes that Foucault writes from the position of someone who is in a dominant position, despite his sympathy for subjugated people, and that unequal relationships of power become invisible in Foucault's work. She supports Said's (1986) view that "Foucault's imagination of power is largely *with* rather than *against* it" (p. 152), an imagining of what you would do if you had power rather than envisaging a new order or thinking outside any forms of power presently existing, a position emphasising resistance rather than transformation. Harstock argues that women need to go beyond resistance and transform power relationships by reconstituting women as the subjects and makers of history not just as the objects of history. Marginalised knowledges in this vision are repositioned as primary and central rather than disruptive and subjugated.

McNay (1994) also criticises Foucault's analysis of power as being one sided, as coming from the perspective of those doing the controlling rather than from the point of view of those subject to that power. Consequently, the effectiveness of disciplinary control is overestimated, neglecting the diverse everyday micro-practices that resist imposed domination and normalising forces. Fraser (1989) equally has difficulties with Foucault's positioning, or perhaps more accurately, his lack of declaration as to his intent, his political commitment and the practical application of his work in providing an alternative political vision.

However, these criticisms can be countered by the argument that Foucault has enabled new readings of discourse, power and history. His work makes an important contribution to critical perspectives through opening up new spaces for feminist's questions that have been marginalised in other theoretical approaches (Diamond & Quinby, 1988; Fraser, 1989; Martin, 1988). I agree that Foucault has not highlighted women's experiences but I do not believe that using Foucault's work as a theoretical lens precludes women's concerns. Rather, women's experiences, as subjugated knowledges, can be surfaced using a genealogical approach. Furthermore, Foucault's conceptions of the body have ready theoretical

applicability and the potential to provide alternative and provocative interpretations of nursing practices in the context of caring for people with dementia.

Foucault and nursing

Foucault's work has only recently been used to explore nursing issues. A series of articles by Julianne Cheek, a sociologist and Trudy Rudge, a nurse (Cheek & Rudge; 1993, 1994a, 1994b; 1994c; 1994d; 1994e), exposed a wide nursing audience to the use of Foucault's concepts in nursing and health care settings. Cheek and Rudge (1993, 1994a, 1994b) applied the notion of discourse and the linkages between power and knowledge to health care. These authors suggest that medical and scientific discourses are dominant in the Australian health system, limiting the discourses and power of other health care workers as well as effacing the experiences of patients. Foucault's metaphor of the panopticon is also used to illustrate the disciplinary techniques of examination and surveillance in health care (Cheek & Rudge, 1994a). The use of these disciplinary techniques includes the use of the nursing process as a technique of examination for categorising what is normal and what is judged as abnormal, and the use of nursing uniforms to increase nursing visibility. The mammography is used as an example of health screening to illustrate surveillance mechanisms.

Contentious aspects of Foucault's work are also examined in nursing literature. Sam Porter (Cheek & Porter, 1997; Porter, 1996) appears to be the most strident critic writing in nursing literature. Porter, writing in a co-authored article with Cheek (who writes from a position advocating the utility of Foucault's work in the health care context), argues that Foucault takes a relativist stance in his rejection of criteria with which to judge the value of different knowledge claims. Porter argues that this position results in a lack of direction or grounding for alternative forms of knowledge.

Here we can see clearly the dilemma involved in adopting a Foucauldian analysis in nursing. While it can be used effectively to criticise the dominant discursive regime, it cannot be used to support an alternative, in that it repudiates the possibility of loosening the tie between knowledge and power. (Cheek & Porter, 1997, p. 113)

Porter suggests that modernist theoretical positions are preferable in allowing for both critique and positive action towards redressing unequal power relationships in human societies (Cheek & Porter, 1997). This comment surfaces a fundamental division between modernist thought whereby individuals are conceived, potentially anyway, as free creators of meaning, and poststructuralist thought where language is attributed with the power to construct individual subjectivity and meaning (Heslop, 1997).

Cheek and Rudge (1994b), while acknowledging the claim that Foucault's work does not suggest possible political strategies enabling empowerment and emancipation, note that Foucault does not make any pretence at developing grand and totalising theory. Instead, these authors suggest that Foucault's identification of the nexus between power and knowledge embedded in dominant discourses allows for the discovery and development of strategic sites of resistance. These debates about the utility of Foucault's work in nursing and health care, as in other arenas, will not dissipate in the foreseeable future. However, as Cheek and Porter (1997) suggest, criticism and identification of the limitations of Foucault's theorising do not negate the value of certain insights but that it is important to acknowledge the complexity of the ideas presented, and the range of positions that can be adopted.

Foucault's work has been used to inform nursing research in a variety of ways. Some nurse researchers have used a discourse analysis approach to analyse nurses' documentation in patient records in a range of settings including intensive care (Henderson, 1994), a rehabilitation setting (Cheek & Rudge, 1994c; 1994d) and an acute care ward (Heartfield, 1996). Common findings were that the patient was silenced, their subjective experience invisible in nurses' accounts as they were discursively reduced to body parts. Paradoxically though, while a nursing discourse may ignore the patient's subjective world, nursing caring work was also absent with institutional and medical discourses paramount in nurses' accounts. In another study, Cheek and Gibson (1996) used published literature as text for a discourse analysis on medication administration. Once again, the discursive frameworks of science and, in this case law, were found to dominate nursing writing, while the clinical nursing perspective was absent. The nurse in these texts is " 'objectified' as the instrument (technology) of the ritual's application" (Cheek & Gibson, 1996, p. 86), with normalising judgement and surveillance ensuring conformity to medication rituals.

May's (1995) reading of the interviews of nurses caring for terminally ill patients was informed by Foucault's concepts of power and surveillance. The nurses caring for dying patients constituted them as active and speaking subjects. These accounts represented patients very differently from the texts discussed in the previous paragraph based on nurses' written documentation. A prominent aspect of nurses' work in this context was encouraging patients to talk about their feelings about dying, a practice of surveillance conducted through talk as well as observation.

Respondents' accounts are organized around such talk – through which the patient is revealed in depth – being seen to be an entirely legitimate activity that most patients will wish to do and find helpful. While talk is stressed in nurse's accounts, it is important to note that surveillance of the patient's social and emotional conditions involves visual indications of behaviour as well as verbal exchanges. Nurses 'know' the patient by how they 'look' as well as by what they say. (May, 1995, p. 557)

Paradoxically, in light of the findings voiced by other nurse researchers that the patient was silenced (Cheek & Rudge, 1994c; 1994d; Heartfield, 1996; Henderson, 1994), the problematic patient in the terminal care context is the silent one who does not wish to be *known*, and remains opaque to the nurse's therapeutic gaze (May, 1995)

Ethnographic studies exploring nursing practice have been informed by Foucault's work (Street, 1992; Wicks, 1995). Foucault's view that power relations are synonymous with resistance is explored by Wicks (1995) who focused on nurses' practices of resistance in relation to biomedical discourses in a general medical and surgical ward. Wicks suggested that three areas of nursing work; namely pain relief, wound healing and the care of dying patients, were examples of healing discourses that are marginal and at times oppositional to the medical domain. She believes these aspects of nursing work provide a space for nursing autonomy and for alternative nursing practices, but their practice is dependent on factors such as individual drive and institutional support.

Street (1992) adopted a critical ethnographic approach exploring clinical nursing practice. Her research is partly informed by Foucault's work on power relations (she also takes an overtly emancipatory stance underpinned by Habermas' work on emancipatory knowledge and action). The concept of surveillance, a key practice for Foucault in

creating objects of power, is used by Street to illuminate aspects of nursing practice. For instance, Street discusses how uniforms allow for instant identification in terms of role and responsibilities and reflect particular types of power relations. Interestingly, uniforms also create the potential for invisibility as individual nurses become subsumed in the generic entity of *nurse*, individual characteristics unnoticed, except when needed for a specific purpose. Foucault's conceptualisation of power/knowledge is also used by Street, but she critiques his work in terms of neglecting the gender dimensions of knowledge and power, and so having limited application in relation to nursing practice. Street suggests that nurses find satisfaction in nurturant relationships and "that nurturance/knowledge is also a powerful orientation capable of leading to enlightenment, empowerment, and emancipation" (Street, 1992, p. 262). Street's development of a nurturance/knowledge construct is challenged by Powers (1996), who interprets the nurturance theme as a marginalised nursing discourse that could provide alternative subject positions. This interpretation seems to negate Street's criticism of the limitations of Foucault's theorising about power/knowledge in a nursing context.

New Zealand studies by McLauchlan (1997) and Papps and Olssen (1997) focus on midwifery and childbirth using Foucault's work. Midwifery in New Zealand is a distinct and separate discipline from nursing¹ but these studies provide useful examples of how Foucault's ideas can be used to provide valuable insights on the dynamics of power and discourse from a closely allied disciplinary perspective. The medicalisation of childbirth and the resultant changes in midwifery positioning in terms of power relations, resonates with my interest in the medical discourse about dementia and the ensuing implications for the range of subject positions available within this discourse for the person with dementia, and the people providing support.

The findings of the various research projects discussed in this section raise questions about the puzzling contradictions and frustrating constraints of every day nursing practice. Foucault did not claim to have ultimate answers but rather exposed comfortable assumptions about the nature of the social world to the hard light of challenge and

¹ The Nurses Amendment Act of 1990 enabled autonomous midwifery practice and the development of a direct entry education programme without a requirement for a previous nursing registration.

critique.

It's true that certain people...are not likely to find advice or instructions in my books that tell them 'what is to be done'. But my project is precisely to bring it about that they 'no longer know what to do', so that the acts, gestures, discourse which up until then had seemed to go without saying become problematic, difficult, dangerous. (Foucault, 1991c, p. 84)

Nursing authors drawing upon Foucault's work (Cheek & Gibson, 1996; Cheek & Rudge, 1994b; Cheek, & Rudge, 1994d; Heartfield, 1996) are careful to leave the reader with the suggestions that rather than having no alternative but to accept dominant discourses, these can be resisted and disrupted rather than unquestionably accepted and that there are a range of subject positions that can be adopted along with possibilities for alternative actions. That "there are no relations of power without resistances...like power, resistance is multiple" (Foucault, 1980c, p. 142).

The approach to discourse analysis used in this study

Discourse analysis is a study of the texts in which discourses are realised and in any form where meaning is conveyed. Texts include what we say and write but, as importantly, they also include any image that can be interpreted such as signs, codes and architecture (Parker, 1992). There are diverse approaches to discourse analysis, ranging from conversation analysis where every nuance of speech is examined, to broader inquiry into how discourses form and are informed by social knowledge and practices.

McHoul and Grace (1993) divide the non-critical approaches to discourse analysis into two groups, formal and empirical. The formal approach studies discourse as text, linguistic methods of analysis used to explore the social functions of language. The attempts by this approach to establish foundational rules of linguistic function is critiqued by McHoul and Grace as being a mechanical endeavor with a very narrow field of interest. Empirical approaches to discourse analysis have a sociological orientation wherein discourse is considered to be human conversations and the goal of analysis is identifying the "*commonsense knowledges* which ultimately inform conversational rules and procedures" (McHoul & Grace, 1993, p. 29) through analysing how conversations are structured.

Hall (1997a) suggests that there are two main divisions to social constructionist² approaches to the study of meaning in language. The first is the *semiotic* approach, the study of signs in culture derived from the work of Saussure. The second approach, called *discursive*, is concerned with the role of discourse in culture and is the approach that underpins this study. Hall (1997a, p. 6) argues that while both approaches are constructionist, there are important differences in these approaches.

The *semiotic* approach is concerned with the *how* of representation, with how language produces meaning – what has been called its ‘poetics’; whereas the *discursive* approach is more concerned with the *effects and consequences* of representation – its ‘politics’.

The approach adopted for this research fits with what Fairclough (1995) and McHoul and Grace (1993) call a critical approach to discourse analysis. In this approach the intention is to examine the effects of particular discourses in creating the context in which social practices are conceived and enacted, aiming to “make clear social determinations and effects of discourse which are characteristically opaque to participants” (Fairclough 1995, p. 28). Foucault contributes a view of discourse that is in relation to knowledge rather than purely language. The relationship between disciplines as bodies of knowledge and disciplinary practices as historically situated forms of social control, are highlighted in his work. Discourse is more than what is said and written, and analysis must include ideas, practices and power relationships as well as “the conceptual and social conditions that made it possible for the discourse to come to exist in the first place, the assumptions of the discourse, and the effects of the discourse in the social world” (Powers, 1996, p. 207).

The processes of discourse analysis have not been codified and indeed this would seem antithetical to the methodology. There is no recipe or set of principles for analysis but rather an underlying theoretical position which highlights the “constructive and functional dimensions of discourse, coupled with the reader’s skill in identifying significant patterns of consistency and variation” (Potter & Wetherell, 1987, p. 169). In

² A theoretical approach that maintains that meaning is *produced* through language and representation. While a material world irrefutably exists, it is the language used to represent ideas about the material world that actually conveys meaning (Hall, 1997b).

this study, Foucault's (1977, p. 138) questions have been of pivotable importance in directing attention to the functions and the power effects of discourses in the research texts.

“What are the modes of existence of this discourse?”

“Where does it come from; how is it circulated; who controls it?”

“What placements are determined for possible subjects?”

I have also drawn upon Parker's (1992) description of discourse analysis, which is informed by his reading of Foucault, for the strategies I used to read the research texts, using the analytic ideas that I felt were relevant to my study, and capable of yielding productive results. Parker's work highlights the relationships between discourse and power. Discourse involves the operation of power, and this relationship is traced through the important analytic technique of searching for the internal contradictions within a discourse as well as absences or silences. For instance, the experiences of people with dementia are generally not discussed in published nursing texts, an absence that can be usefully explored in terms of power relationships between nurses and the person requiring nursing care.

Discourses are also interrelated with other discourses so any discourse study must entail an analysis of several related discourses. Discourses do not stand alone but refer to other discourses. “Discourses embed, entail and presuppose other discourses to the extent that the contradictions *within* a discourse open up questions about what other discourses are at work” (Parker, 1992, p. 13). Identifying contradictions between different descriptions of a particular phenomenon is a useful analytic tool enabling an understanding of the interrelationship between different discourses within texts. This aspect of discourse analysis is consistent with Potter and Wetherell's (1994) concerns with rhetorical organisation and variability. According to these authors, attention to variation focuses analytic attention on differences within and between texts and opens up questions about the operation of constructive processes in the production and deployment of discourses. The focus on rhetorical organisation in discourse analysis draws attention away from description to questions of how particular discourses are designed to compete with alternative discourses. This particular aspect of discourse analysis is also linked with variability as differences between versions draw attention to rhetorical organisation.

Another aspect requiring consideration in discourse analysis is the recognition that discourses are dynamic, moderated and informed by influences from other discourses, and through internal reflection and critique. Analysis must account for the location of discourses in time and history, “for the objects they refer to are objects constituted in the past by the discourse or related discourses” (Parker, 1992, p. 16).

In addition, discourse analysis is also explicitly concerned with the power effects of discourses. Discourses support institutions with discursive practices arising from discourses reproducing the institution. Therefore, analysis must be concerned with identifying the institutions supported by particular discourses, and those institutions that are challenged or subverted by particular discourses. Discourses also reproduce power relations and individual subjects gain or lose by the use of the discourse employed. Ensuing tasks for the analytic process include showing the connection between discourses supporting oppression and showing how dominant groups construct the past to justify the present and prevent the recording of subjugated discourses (Parker, 1992).

Finally, it is important to foreground the notion that discourse analysis is not a neutral enterprise merely describing what is, as though there is an immutable material reality, waiting patiently to be discovered. As Strickland (1994, p. 265) cogently argues:

In contrast to the misleading and unattainable ideal of transcendent reason and a view from nowhere, feminists have argued that all knowledge is situated and limited by its positioning; that it reflects our social experience, our understanding of our interests and our values; that objectivity seen in terms of political and personal disengagement and value-neutrality is neither possible nor desirable.

This study, then, is an inevitably incomplete and partial representation of nursing practices. In this respect, it is no different from all representations of any phenomena under investigation, all of which are the product of a particular time and location. My analysis is confined to texts that are recorded in some way, many everyday conversations and practices passing unnoticed and undocumented while others are foregrounded. My own sensitivity to new images and ideas is bounded by my positioning within the dominant discourses of nursing, and by particular values and assumptions about caring for people with dementia. Furthermore, the ideas, assumptions, historical influences and

power relationships informing any discourse can only be partially revealed. As Opie (1993, pp. 1-2) states:

The creation of text is not a neutral action. It consistently involves choices about audience, language, density of analysis, the positioning of theory in the text, and epistemological issues – what is included and excluded? What is foreground, what is marginalised? Whose voices dominate? What constitutes a valid generalisation? What questions concentrate attention not just on writing as a descriptive and analytic process but also on the accompanying embedded processes of suppression and expansion?

The critical self-awareness of my production of a text as being shaped by particular discursive positionings is referred to as reflexivity. The purpose of engaging in reflexive practice, ongoing critical self-interrogation, as I write this text is to unpack, at least in part, the assumptions and personal experiences that shape my questions and inscriptive practices, in order to highlight the context-specific and partial nature of this research, one story among many.

Summary

In this chapter I have discussed my interpretation of Foucault's work in relation to the aspects that have been useful in advancing my analysis of the circulating discourses that create particular inscriptions and subject positions for nurses, families and people with dementia. Of particular importance is the theoretical position that all knowledge claims are socially constructed and, as such, some types of knowledge will be foregrounded while other types of knowledge will be suppressed in any discursive formulation. Discursive rules shift over time in terms of what can be studied within a discursive formulation, and how that object can be studied and represented. Foucault's historical method of analysis, genealogy, emphasises the accidents and the power interests that characterise these discursive shifts, an approach that challenges the assumptions, and the taken-for-granted truth claims underpinning present day discourses and practices. The connection between knowledge and power is another important theme throughout Foucault's work. Power relationships shape what is written in and, correspondingly, what is written out of discursive formulations, and dictate the range of subject positions that can be adopted within a discourse. Discourse is bound up with power, producing and maintaining the dominant forms of power. This maintenance and exercise of power is

enacted through every day micro-practices as well as disciplinary techniques of power located within institutions. The body is the point where power is enacted, produced discursively and reproduced through social practices.

The next chapter marks the beginning of my engagement with the texts of dementia care and a focus on the discourses that inform nursing work, in the context of caring for people with dementia.

CHAPTER THREE

The Construction of the Dementing Body

Introduction

A central aspect of Foucauldian inquiry is tracing the history of particular events in a manner that emphasises the deviations and contradictions inherent in knowledge development. My intent in this chapter is to disrupt any notions that the term dementia is an immutable concept reflecting an empirical and static reality, and to argue that current knowledge about dementing illnesses is the product of a distinctive biomedical¹ disciplinary perspective. Nursing practices in the context of caring for people with dementia are embedded in this biomedical knowledge, knowledge that is contested by critical writers challenging medical *facts* as products of a particular culture and history with intended and unintended social consequences (Gubrium, 1986, 1987; Kitwood, 1993; Robertson, 1991).

This chapter will firstly focus on the shifting definitions of dementia over time with a particular emphasis on Alzheimer's disease.² I will discuss the debates as to why certain pathological changes were labeled as a new disease, Alzheimer's disease, when

¹ Biomedicine is the term used for the medical approach developed as a consequence of the major shifts in world-view associated with Enlightenment thought. The human body in this paradigm is constructed in material terms and diseases are attributed to biological causes. The methods of inquiry accepted as valid in the biomedical approach, those of observation and experimentation, are perceived of as being able to "*control* nature and *intervene* to correct the ailments that seemed to cut life short" (Samson, 1999, p. 3).

² There are many illnesses that give rise to the symptoms and signs of dementia, with varying pathological effects, treatments and progression, but I will focus on Alzheimer's disease as the most prevalent causation of dementia and the most problematic in terms of debate and changing definitions.

manifested in people below the age of sixty-five, in the early part of the twentieth century. The circularity of medical discussion in this context is highlighted in the reconstitution of Alzheimer's disease with senile dementia in the 1970s. The second section discusses classifications of Alzheimer's disease, diagnostic issues, and an overview of current biomedical research interests. The third section explores the tensions and contradictions in the way medical knowledge is used as the basis for nurses' understandings of dementing illnesses. In particular, the positioning of biomedical knowledge in nursing texts will be critiqued along with how epidemiological research is represented in these texts. The contradictions inherent in the use of stage models to describe the progression of Alzheimer's disease will also be foregrounded. I use critical commentaries about the social construction of dementia emerging from varying disciplinary backgrounds such as sociology, psychology and health policy to draw attention to the absences and lack of critique in nursing discussion. The final section of the chapter highlights the absence of the knowledge and experiences of people with dementing illnesses in nursing and biomedical discourse.

Creating the concept of dementia

The term dementia has been related to psychosocial incompetence in recorded history since at least classical times, but the symptoms and explanations of dementia have changed throughout history (Berrios, 1994). References to age-related dementia can be traced from about 500 B.C. when Plato, among others, debated issues in relation to social competency. Dementia was written about in medical texts by the first century A.D. with Galen listing dementia as a disease of old age (Fox, 1989), but the term was not commonly used in Europe until the end of the seventeenth century. The concept of dementia informing present day understanding was recognisable in the sixteenth and seventeenth century. Willis, writing in 1684 (cited in Berrios, 1987, p. 831), described familiar causes of dementia:

Some at first crafty and ingenious become by degrees dull, and at length foolish by the mere declining of age without any great errors of living...sometimes great strokes or bruising of the head specially such as happen from a fall from high place...frequent drunkenness and surfeiting...almost by the same reason the frequent use of opiates very much troubles the sharpness of the mind.

By the end of the seventeenth century the framework of polarities used to describe mental disorders affecting cognition; congenital or acquired, temporary or permanent, alone or with other symptoms and age related, shaped eighteenth century nosographies. In the medical entries in the French Encyclopaedia (Diderot & Alembert, 1754 cited in Berrios, 1994) dementia or *démence* was differentiated from mania and delirium, was believed to affect the cognitive ability in individuals of any age, could be chronic or irreversible, and was related to brain changes. The existence of non-cognitive as well as cognitive symptoms, such as delusions and hallucinations and behaviour problems, also contributed to the diagnosis. In a legal context, dementia was associated with psychosocial incompetence and the inability to manage personal affairs (Berrios, 1987).

A shift in medical knowledge occurred around the end of the eighteenth century. Previously, according to Sheridan (1990), the language of medicine took a classificatory form with diseases being ordered according to taxonomic families, genera and different species and “their semi-autonomous existences seemed to have more to do with one another than with the body that gave them temporary shelter” (p. 39). The era of modernity in the discipline of medicine was ushered in with a shift in discourse that privileged the “anatomy-clinical gaze” (Foucault, 1975, p. 146). The effects of disease upon the body were exposed to sight through the pathological techniques of the autopsy and in doing so, a new language of description emerged.

For twenty years, from morning to night, you have taken notes at patient’s bedsides on afflictions of the heart, the lungs, and the gastric viscera, and all is confusion for you in the symptoms which, refusing to yield up their meaning, offer you a succession of incoherent phenomena. Open up a few corpses: you will dissipate at once the darkness that observation alone could not dissipate. (Bichat, 1801, cited in Foucault, 1975, p. 146)

By the middle of the nineteenth century nosologies described specific diseases that left traces of visible evidence in body tissue. Initially, brain changes associated with mental disorders could only be described in gross anatomical terms involving such aspects as weight, colour and consistency. These descriptions were limited by problems with preservation and staining techniques. In the mid-nineteenth century macroscopic changes in brain tissue such as cortical atrophy, enlarged ventricles and the softening of brain

tissue were associated with senile dementia. After the 1880s new staining techniques were developed enabling the identification of microscopic changes including cellular death, plaques, and neurofibrils (Berrios, 1990b).

Alzheimer's 'discovery'

In 1906 Alzheimer described neurofibrillary changes as well as senile plaques (at the time called miliary foci) in the brain of a fifty-one year old woman with an unusual clinical history that included progressive memory loss as well as delusions and hallucinations. This description was made possible by the use of a new silver based stain that enabled visualisation of axons. This case, published in 1907, eventually led to the naming of a particular constellation of pathological features as Alzheimer's disease in 1910 by Kraepelin, one of the most prominent psychiatrists of the time and the director of Alzheimer's Munich laboratory.

The autopsy reveals according to Alzheimer's description, changes that represent the most serious form of senile dementia...the "Drusen" were numerous and almost one third of the cortical cells had died off. In their place instead we found peculiar deeply stained fibrillary bundles that were closely packed to one another, and seemed to be remnants of degenerated cell bodies....The clinical interpretation of this Alzheimer's disease is still confused. Whilst the anatomical findings suggest we are dealing with a particularly serious form of senile dementia, the fact that this disease sometimes starts already around the age of 40 does not allow this supposition. In such cases we should at least assume a "senium praecox" if not a more or less age-independent unique disease process. (Kraepelin, 1910, cited in Berrios, 1994, p. 33)

So how did Alzheimer's findings indicate a new disease? Berrios (1990b) suggests that Alzheimer's motivation in this case with the constellation of clinical features, later labeled as Alzheimer's disease, is unclear. Alzheimer's 1907 paper has a title that can be read as either suggesting that the pathological changes may be *peculiar* as in marking out one unusual case, or *characteristic* as in describing a disease or group. Alzheimer himself didn't think his findings indicated a new disease. He described a form of dementia where there was progressive cognitive impairment, delusions and hallucinations in people below the age of sixty-five who had brain changes including atrophy, plaques, neurofibrillary tangles and arteriosclerotic changes. These changes had previously been described. The

major point of interest appears to be the correlation of pathological lesions with the symptoms of dementing illness in people under the age of sixty-five. However, Alzheimer was not the first person to identify dementia in younger people as Griesinger had described the condition in 1845 (Thomas & Isaac, 1987).

Amaducci, Rocca, and Schoenberg (1986) believe the separation of Alzheimer's disease from senile dementia was at least partially precipitated by rivalry between the Munich laboratory and Fischer's³ institution which was the German Psychiatric Clinic directed by Pick in Prague. The division avoided problems as to whether Alzheimer or Fischer should name the condition, characterised by both neurofibrillary changes as well as senile plaques. Certainly, Kraepelin had very limited information on which to base his conclusions about a presenile form of dementia with only eight published descriptions of which at least two were described twice. However, Berrios (1990b) argues that there is no evidence to support Amaducci, Rocca, and Schoenberg's (1986) claim.

Another possible explanation for the naming of Alzheimer's disease also has political rather than pathological evidence supporting the distinction made between two groups of people, separated by age, but with identical pathological changes. In the early part of nineteenth century Kraepelin, who supported an organic basis for mental disorders, was pre-eminent in the discipline of psychiatry due to the production of a definitive text defining and classifying psychiatric illness (Torack, 1979). However, Freud was becoming increasingly influential at this time with the directly opposing view that psychological factors were responsible for mental illnesses. The pathological changes associated with Alzheimer's disease were, according to Torack (1979), useful in supporting Kraepelin's position on the organic causation of mental disease. Berrios (1990b) challenges Torack's explanation, arguing that the connection between organic changes and mental disorders was widely accepted before Kraepelin's naming of Alzheimer's disease with the established connection between syphilis and general paresis of the insane, and that Kraepelin did not need Alzheimer's disease to prove the connection between organic changes and mental diseases. But, Thomas and Isaac (1987)

³ The scientist who extensively described senile plaques, one of the pathological features of Alzheimer's disease.

also make a connection to Freud and suggest that Freud's career was in the ascendancy in the early 1900s while Kraepelin's clinic was producing little of significance. They suggest that Alzheimer's work was important in enabling some response to critics of the clinic's poor productivity.

Given the current debate about the importance of Alzheimer's contribution to new knowledge in relation to dementing illnesses, it remains unclear as to Kraepelin's motives in presenting a new disease.

Kraepelin for reasons of his own, which historical work has so far not fathomed, decided to present it as a new disease. As with all hurried creations, it was left with unclear boundaries. The unwillingness of its discoverer, and the inability of its sponsor, to carry out the required clinicopathological research left the disease adrift. (Berrios, 1990b, p. 363)

As the preceding discussion has demonstrated, the construction of Alzheimer's disease was by no means inevitable, but more a chance juxtaposition of a particular constellation of pathological findings with Kraepelin's positioning as a foremost psychiatrist of the time ensuring acceptance of this disease within the medical community. The meticulous work of Berrios (1987, 1990a, 1990b, 1994) in tracing the changing definitions of dementia challenges contemporary practitioners' assumptions that there was an objective entity just waiting to be discovered. As Berrios (1990b, p. 355) argues:

...patients wear their illnesses in the most personal of ways; clinicians take as 'given' ongoing textbook definitions which they regard as a reflection of some Platonic entity. Consequently, they see themselves more as clinical cartographers than as challengers of the putative immutability of disease. (Berrios, 1990b, p. 355)

Rather than cataloguers of species, clinicians may well be creators of meaning and form. From this perspective there is no final description of disease, but rather temporary boundaries surrounding clustered symptoms and pathological signs, defined by ongoing scientific shifts in knowledge and the decisions made by the *experts* in a political and contested field.

The politics of naming: Disease versus ageing

The question of whether Alzheimer's disease is due to ageing or to a pathological process is still debated. By the middle of the nineteenth century old age was separated on a medical basis from other age groups, the medical position being that rather than diseases affecting all people similarly, diseases affected people in differing ways according to age. Old age was associated with inevitable deterioration and "the clinical characterisation of the entire stage of senescence began to be viewed as a medical problem" (Fox, 1989, p. 61). This collapse of ageing and disease was marked from the middle of the nineteenth century and "the view almost came to be accepted that old age was a form of disease, and that it was not possible to distinguish the normal from the pathological" (Berrios, 1990a, p. 203). The term *senile*, now paired with dementia in old age, shifted in meaning from being a term that simply referred to old age in the 1600s, to meaning weakness in the 1800s, and to a pathological state in the nineteenth century (Katz, 1997). The increasing interest in the ageing process as an appropriate object for medical and psychiatric concern in recent history is influenced by several factors. Firstly there are increasing numbers of people age sixty-five and over in relation to the overall population. Secondly, dominant representations construct ageing as a pathological process. Thirdly, there are fears of unsustainable economic costs for health care services caring for an increasingly growing group of older and dependant people.

Huppert (1994), a psychologist, suggests that the fundamental challenge of dementia is in establishing what the relationship is between dementia and normal ageing. There is strong support for ageing processes being associated with dementia as the incidence rises with age and a continuum between normal ageing and dementia exists with memory loss ranging from benign senescent forgetfulness to almost total memory loss with blurred boundaries between disease and normal physiological changes. Performance on memory tests becomes increasingly diverse in older age as performance is influenced by varying levels of health and fitness. Because of these variations there are difficulties in making clear distinctions between the normal and abnormal (Huppert & Brayne, 1994). In older age, there is also a lack of definitive pathological boundaries as the markers of dementia; brain atrophy, plaques and neurofibrillary tangles, also exist in the brains of older people without dementia. The sheer numbers of pathological lesions become the significant

factor with symptoms becoming evident when the pathological changes accumulate over a certain threshold (Beach, 1987). Huppert (1994) proposes, in recognition of these ambiguities in attempting to define and differentiate between dementia and normal ageing, moving from a medical model that is based on a dichotomy between dementia and cognitive normality, to a continuity model based on research that indicates that “most of the variables associated with dementia fall along a continuum with normal ageing” (p. xiv).

However, there is much to gain by positioning Alzheimer’s disease in a medical framework as a disease rather than as an ageing process (Beach, 1987). By positioning Alzheimer’s disease within a medical model the funding for research and health services is legitimatised by a disease diagnosis. The critical importance of naming, in terms of enabling access and control over the resources vital to underpinning scientific inquiry first surfaced in the debate around the construction of Alzheimer’s disease in the early 1900s and re-emerged in the re-linking of Alzheimer’s disease with senile dementia in the 1970s.

According to Fox (1989), the emergence of dementia from a little used disease category in the 1970s to being attributed as the fourth leading cause of death in the United States resulted from a series of identifiable events. Dementia was ignored for substantial periods in the twentieth century, not withstanding early research discoveries around the 1900s. This is a surprising gap given the now intense research interest in this area. Even as late as 1982, a paper reviewing the epidemiology of common neurological disorders in old age did not include dementia (Evans & Caird, 1982). Lishman (1994, p. 44) provides some explanation for the lack of interest in dementing illnesses.

They were a no-man’s land, falling between neurology, psychiatry and the barely conceived discipline of geriatrics. In clinical terms they offered little of interest to the diagnostician or therapist. Research workers certainly found more hopeful openings than attempts to reverse a process of aging.

The initial event that eventually led to the reconceptualisation of Alzheimer’s disease as a major health issue was the increasing research interest in Alzheimer’s disease made possible with new technology, the advent of the electron and light microscope. As in

Alzheimer's time, technological developments contributed to an increasing interest in organic brain changes. British and American researchers found similar organic changes in people with dementia over the age of sixty-five to those of younger people in the late 1960s and early 1970s. A neurologist and researcher, Dr Robert Katzman, suggested in the early 1970s that dementia would be the fourth leading cause of death in the United States if the deaths that previously had been attributed to the consequences of dementing illness, such as pneumonia, were actually linked to the dementing illness. He also suggested that Alzheimer's disease and senile dementia were the same disease. Linking Alzheimer's disease with senile dementia served two purposes.

By suggesting an identity between senile dementia and Alzheimer's disease, Katzman was able to increase by many times the number of potential cases of Alzheimer's disease in the general population. This suggestion also challenged the assumption of inevitable cognitive decline associated with growing old. "Senility" became tied to a specific disease (i.e. Alzheimer's disease) and was disassociated from the commonly held belief that growing old itself caused dementia. These projections formed the catalyst both for subsequent efforts to define the disease as a major social and health problem, and to mobilise resources to address the defined problem. (Fox, 1989, p. 73)

Kraepelin could hardly have foreseen the interest and debates in his construction of a disease as a consequence of a juxtaposition between demographic trends forecasting exponential rises in incidence of Alzheimer's disease, linked with consequential concerns about the cost of care for people with dementia. Kraepelin might also have been intrigued with the reconstitution of Alzheimer's disease with senile dementia, his splitting related to age, unsustainable over time, for reasons other than purely medical.

Coinciding with the new conceptualisation of Alzheimer's disease, the American National Institute of Aging (NIA), established to promote research on aging, was interested in identifying Alzheimer's disease as an important research focus. The first director was Robert Butler, a psychiatrist, who urged the formation of a voluntary organisation to advocate for Alzheimer's disease research funding with the American Congress. Katzman once again performed a pivotal role in 1979 with the establishment of the Alzheimer's Disease Society, later named the Alzheimer's Disease and Related Disorders Association (ADRDA). Robert Butler encouraged local groups started by relatives of people with dementia to organise into a national organisation, a goal that

would be helpful in supporting his own bid to focus on Alzheimer's disease as a major research area for the NIA (Fox, 1989). From the outset two agendas emerged, the research interests of the medical community and the concerns of family in terms of support. ADRLA was established as an effective advocacy organisation by the early 1980s. The discovery of neurochemical changes was an important research development adding to the weight of evidence supporting a neurological disease, and this gave increased leverage for research funding which grew from four million dollars in NIA funding in 1976 to eighty million in 1989 (Fox, 1989).

Alzheimer's disease is used by Robertson (1991) as an example of how health policy is shaped by particular constructions of life phenomena. The new construction of a disease rather than ageing to explain particular phenomena enabled the capture of substantial health research funding, and the development of a research and health care infrastructure. The role of physicians expanded with the diagnosis assuming greater importance in order to exclude treatable causes of disease. However, according to Robertson (1991, p. 146), this reconceptualisation of a particular issue in older age created certain opportunities whilst ignoring other factors.

Constituting the "problems" of old age in terms of individual pathology leads to individualistic solutions. National policies, which might address more fundamental structural factors, are ignored in favour of policy interventions aimed at the individual level, often in the form of local, fragmented, often stop-gap service measures.

Robertson (1991) argues that the differentiation between normal ageing and the memory loss and disorientation associated with dementia has encouraged the development of a range of specialised health care services in a domain that was previously of private concern. This is a benign interpretation of the benefits of the medical construction of dementia. She also presents an alternative interpretation in that the medical focus on individual pathology and intervention has removed the incentive to develop generic national policies aimed at collective support for the changes associated with ageing.

In New Zealand the development of day care services is an example of the local fragmented service provision critiqued by Robertson. Historically, day relief for family

caregivers has been developed on an ad hoc basis, initiated by collectives of family caregivers and interested health professionals belonging to local Alzheimer's Societies. Government policy has been noninterventionist, limited to providing a strictly rationed subsidy, resulting in an uneven provision of day care nationally. This policy has resulted in a concentration on assessment and treatment services with caregiver respite becoming marginal to the health service's core business of treatment and cure. Day care in particular, is outside the formal health support provided for people with dementia, an interesting aberration given the necessity for ongoing relief from caregiving.

In conclusion, the changes in the conceptualisation of dementia and of Alzheimer's disease in the nineteenth century draw attention to the power of defining organic changes as pathological and therefore ultimately amenable to treatment, provided sufficient resources are devoted to finding a cure. But, as Lishman (1994, p. 52) states:

In the last analysis, of course, the distinction between 'aging process' and 'disease' may melt away - an artificial dichotomy drawn from older concepts. And there will be no need for a return to nihilism if we are obliged to reformulate the problem of Alzheimer's dementia in this fashion. Neurobiology may now have reached the stature when we can tackle head-on the nature of the aging processes within the brain, and the factors - genetic and environmental - which accelerate or retard it. We may no longer have the need of the shelter of a formal disease model to provide an impetus to scientific effort.

Contemporary biomedical knowledge

There are two widely used classifications systems used for diseases, the *International Classification of Diseases* published by the World Health Organisation, the latest edition published in 1992 and called *ICD-10* (the tenth edition), and the *Diagnostic and Statistical Manual of Mental Disorders*, the latest edition published in 1994 and called the *DSM-IV* (the fourth edition). The following discussion is based upon the definitions provided by the writers of *DSM-IV* (American Psychiatric Association, 1994), the most specific and comprehensive classification system for mental disorders.

The systematic classification of mental disorders in the United States began with the inclusion of a category-*idiocy/insanity* in the 1840 census, prompted by the need for

statistical information. In the 1880 census, seven mental health categories were identified, including dementia. The World Health Organisation included mental disorders in the sixth edition of the *ICD* published after the Second World War and the American Psychiatric Association developed the first edition of the *Diagnostic and Statistical Manual: Mental Disorders (DSM-I)* in 1952 (American Psychiatric Association, 1994). Classification of mental illnesses is a difficult exercise given the fine nuances involved in attempting to fit subjective and highly individual mental processes into a categorisation system that can differentiate between different conditions, and indeed between health and illness. This classification system must also be able to be used objectively by a diverse range of health practitioners, and be universally applied taking account of individual differences such as culture, age, gender and education. The writers of the *DSM-IV* are aware of the issues involved in developing categories of mental disorders based on specific criteria. They suggest that:

A categorical approach to classification works best when all members of a diagnostic class are homogeneous, when there are clear boundaries between classes, and when the different classes are mutually exclusive. (American Psychiatric Association, 1994, p. xxii)

The limitations of a categorical approach in the area of mental illnesses is acknowledged because of the heterogeneity of clinical presentations of mental disorders, and the lack of clear separation between mental *disorders*, or from a state of mental *order*. Certainly, dementing illnesses are not easily categorised, are highly variable in manifestation, and not easily distinguishable from each other (Arendt & Jones, 1992). Yet, even though the attempt to classify mental disorders seems seriously flawed, given the above limitations, the developed classifications have a disciplinary and political significance that expands far beyond the scientific quest to develop specific criteria by which to demarcate diseases. The criteria for defining mental disorders, set by the working parties contributing to the *DSM-IV*, shape ongoing disciplinary development and health care funding. Articles submitted to the major American psychiatric journals must meet the classification system of the *DSM*. Health care funding provided by insurance companies in the United States also follows a schedule using *DSM* coding (Hacking, 1995). Given this weighting of the *DSM-IV* in medical discourse it is prudent to give careful attention to the positioning of dementia in the manual and to explore current definitions of dementia in some depth.

Dementia is positioned with delirium, amnesiac and other cognitive disorders, all grouped in common as having disturbances in cognition or memory. Previously in the *DSM-III-R* these disorders were placed in a section called *Organic Mental Syndromes and Disorders*, a distinction now no longer made on the grounds that other mental disorders can have biological foundations. The dementias are listed in accordance with the possible aetiology into twelve categories which include: Dementia of the Alzheimer's Type, Vascular Dementia, Dementia due to Other Medical Conditions such as Parkinson's Disease and Huntington's Disease among others, Substance-Induced Persisting Dementia, Dementia due to Multiple Aetiologies and Dementia Not Otherwise Specified (American Psychiatric Association, 1994).

Dementia of the Alzheimer's Type is the first dementing illness specifically discussed in the manual, a pre-eminence warranted by prevalence rates. According to current medical knowledge, Alzheimer's disease is characterised by a gradual onset with initial memory deficits and later development of aphasia, apraxia and agnosia. The course of the disease is generally over eight to ten years with continuing cognitive decline, measurable on assessment instruments such as the Mini-Mental State Exam, and the development of motor and gait disturbances in the later stages leading to profound disability. The age of onset is categorised as *early onset* when the age of onset is sixty-five years or younger, and *late onset*, if age of onset is after sixty-five years. Alzheimer's disease is also separated in four coded subtypes: *With Delirium*, *With Delusions*, *With Depressed Mood* and *Uncomplicated*. Alzheimer's disease is diagnosed by a process of exclusion of all other aetiologies for the dementia. The prevalence of this disease is increased in people with Down's Syndrome, people with a history of head trauma, and in relatives of people who develop early onset Alzheimer's disease, possibly inherited as a dominant trait linked to chromosomes twenty-one, fourteen and nineteen. Alzheimer's disease is slightly more common in females. Laboratory findings in Alzheimer's disease include brain atrophy in the majority of people, and wider cortical sulci and larger ventricles than normally associated with ageing. Microscopic changes include senile plaques, neurofibrillary tangles, loss of neurones, granulovascular degeneration, astrocytic gliosis and amyloid angiopathy (American Psychiatric Association, 1994).

Diagnostic criteria

The critical diagnostic criteria for dementia in the *DSM-IV* include

...the development of multiple cognitive deficits that include memory impairment and at least one of the following cognitive disturbances: aphasia, apraxia, agnosia, or a disturbance in executive functioning. The cognitive deficits must be sufficiently severe to cause impairment in occupational or social functioning and must represent a decline from a previous higher level of functioning. (American Psychiatric Association, 1994, p. 134)

Assessments of memory, aphasia (language deterioration), apraxia (impaired motor function ability despite intact motor ability), agnosia (loss of ability to identify objects) and disturbances in executive functioning (as demonstrated in problems related to abstract thought and the management of complex behaviour), are part of the diagnostic repertoire. Diagnostic tests can include computed tomography (CT) or magnetic resonance imaging (MRI) to test for cerebral atrophy, brain lesions, and vascular disease, and functional imaging such as positron-emission tomography (PET) can show cerebral changes. The age of onset depends on aetiology, but risk increases with age with increasing prevalence over the age of eighty-five years. The definition of dementia in the *DSM-IV* is linked to cognitive deficits with no predictions about prognosis in terms of progression and irreversibility (American Psychiatric Association, 1994).

Dementia may be progressive, static, or remitting. The reversibility of a dementia is a function of the underlying pathology and of the availability and timely application of effective treatment. (American Psychiatric Association, 1994, p. 137)

Berrios (1987, 1990a) critiques the contemporary emphasis in the definition of dementia by cognitive deficits. The current diagnostic criteria focusing on the objectively observable and measurable symptoms of dementing illnesses create what Berrios (1990a) calls the *cognitive paradigm* of dementia. The development of this cognitive paradigm of dementia occurred in the nineteenth century at a time when the intellect was a dominant factor in defining madness and intellectual weakness and linked with theories of evolution. The narrowing of the clinical boundaries of dementia began in the 1860s with a focus on the senile and arteriosclerotic dementias. By the 1890s the growing reliability of histological techniques had resulted in the separation of depressive pseudodementia

from senile dementia, and a new definition that focused on intellectual functions. This shift in classification led to an emphasis on the study of memory as the one cognitive function that could be measured and so “supported by an adequate technology of measurement, mnemonic deficits were to become, *de facto*, if not *de jure*, the central feature of dementia” (Berrios, 1990a, p. 197).

Berrios (1987) suggests that contemporary medical knowledge about dementia is based on this cognitive perspective, emphasising assessment of memory functions and intellect while neglecting the emotional and sensory manifestations of dementia. The cognitive model of dementia was predominantly useful in developing measurement tools that enable correlations with brain cell pathology in the intermediate stages of dementia. There are, however, limitations in this quite restrictive model. In the early stages of dementia, the more evident symptoms might well be behavioural and personality changes rather than measurable cognitive changes. In the later stages of dementia, people might well not be able to be accessed using conventional instruments, although behavioural signs might well be evident. Current definitions of dementia are associated with inaccurate diagnoses, both falsely positive and negative. The limitations of the dominant cognitive viewpoint account for some of these diagnostic difficulties. Berrios (1990a) argues that accurate diagnosis as well as the capacity to compare signs and symptoms in order to judge disease severity, are the underpinnings of research into the causation and effects of dementing diseases, and are dependent on clear accurate definitions of dementia and reliable and valid assessment instruments.

The very blurry boundaries between what is medically judged to be normal functioning, in contrast to abnormal functioning, is also raised in the context of cross-cultural research about dementing illnesses. While dementia does seem to be a recognisable entity in all populations, there are wide variations in the reported incidence between different population groups (Pollitt, 1996). Pollitt suggests that these findings are inconclusive because of major issues with cultural differences in the definition of dementia and the lack of culturally specific assessment methods.

Alzheimer's disease and biomedical research

Current biomedical research focuses on a wide range of potential causes for Alzheimer's disease, an indicator of numerous factors that could contribute to diminished cognitive abilities over a lifetime. Genetic studies focus on families with familial Alzheimer's disease who have genetic mutations of chromosomes fourteen and twenty-one. A gene on chromosome nineteen, responsible for the production of apolipoprotein E (ApoE) a cholesterol-transporting protein, may be associated with late-onset Alzheimer's disease (Corder et al., 1993). Inheriting certain forms of the ApoE gene may be a risk factor for Alzheimer's disease, and this has possible implications for the use of ApoE as a screening agent (Advisory Panel on Alzheimer's Disease, 1995; Khachaturian, 1998).

Protein studies form another research focus. Senile plaques, one of the characteristic markers of Alzheimer's disease, are mainly composed of beta-amyloid protein, but the question as to whether the protein causes or results from Alzheimer's disease is still unanswered. There is interest in the possibility of early intervention to prevent beta-amyloid accumulation as well as a search for proteins which might process beta-amyloid and the amyloid precursor protein. Studies of amyloid damage are also of interest because there appear to be commonalities between several dementias, with indications that different causes for dementing illnesses, such as infections and genetic factors, can result in similar end-stage brain changes. Research studies of neurofibrillary tangles have also been productive, revealing that the excessive accumulation of phosphate groups in the brain protein of tau seems to lead to degeneration of nerve cells and the formation of neurofibrillary tangles (Advisory Panel on Alzheimer's Disease, 1995).

There is also interest in the role of inflammatory or autoimmune responses in late-onset dementias. Toxins or viruses may trigger an inflammatory reaction that destroys brain cells. Studies of the possible association of anti-inflammatory drugs with Alzheimer's disease are being undertaken (Breitner et al., 1994) and changes to neurotransmitters have also raised hopes of identifying drugs that will prevent damage to neurotransmitters and brain cells. Other areas of research interest include the study of deoxyribonucleic acid (DNA) and the damage caused by calcium, free radicals, environmental toxins, the possibility of latent viral infection in some people with dementia, and the role of poor

nutrition and brain damage (Advisory Panel on Alzheimer's Disease, 1995). Epidemiological studies are also making substantial contributions to the search for the aetiology of Alzheimer's disease. For instance, there is a suggestion that post-menopausal women taking oestrogen appear to have a delayed or reduced incidence of Alzheimer's disease (National Institute of Aging & National Institutes of Health, 1999; Paganini-Hill & Henderson, 1994) although Brenner et al. (1994) did not demonstrate a relationship.

Pharmacological developments are proceeding on several fronts in response to the growing understanding of the multiple factors contributing to the neuronal damage associated with Alzheimer's disease. Two cholinesterase inhibitor drugs, tacrine and donepezil, have been developed in response to the identification of the acetylcholine deficit associated with Alzheimer's disease. However, whilst there is some agreement that these drugs do result in some short-term improvement in symptoms (Gauthier, 1999; Mayeux & Sano, 1999; Small, 1998), their contribution is very limited as tacrine is associated with liver toxicity and donepezil has a minimal impact on the improvement of quality of life and functional ability (Pryse-Phillips, 1999). There are also ongoing clinical trials of other treatments aimed at improving cognitive function including oestrogen, anti-inflammatory agents, antioxidants such as vitamin E, and ginkgo biloba, but as yet there is no conclusive evidence of significant clinical benefit (Small et al., 1997).

While there is increasing understanding of the factors contributing to loss of neuron function in relation to Alzheimer's disease, there is still no indication from reading the latest biomedical literature that any definitive answers as to a cure are close to emerging (Small, 1998). Rather, there is the impression that investigation is increasingly minutely focused at cellular and biochemical level while, simultaneously, there is an acknowledgement of the heterogeneity of the many manifestations of Alzheimer's disease and the multiplicity of factors that contribute to neuronal change. Khachaturian, writing in 1985, highlighted the uncertainty surrounding Alzheimer's disease in terms of causation and the difficulties in pathological discrimination with early ageing and diagnostic difficulties. In 1998, however, Khachaturian seemed to be even more tentative than in 1985 as he stressed that Alzheimer's disease is a heterogeneous disorder and that the time of onset may be as much as twenty to forty years before the first symptoms are

evident. He cites findings from the longitudinal Nun Study⁴ (Snowden et al., 1996) suggesting that poor linguistic ability in early life is a predictor of the later development of Alzheimer's disease.

As evidence accumulates in support of the notion that AD has a long presymptomatic course, it becomes imperative to develop and refine all possible technologies for its early detection. At present, even the best available interventions are at a therapeutic disadvantage. Often, when a therapeutic regimen is initiated, it may be a case of too little, too late; at that stage of the disease, the destruction of the neural infrastructure is so extensive and progressing so rapidly that the duration of therapeutic benefits is substantially abbreviated. (Khachaturian, 1998, p. 27S).

The appropriation of biomedical knowledge in nursing representations of dementia

I have examined shifts in the definition of Alzheimer's disease in the preceding section in order to emphasise the political as well as scientific forces shaping knowledge development. It is clear that positioning Alzheimer's disease within a pathological, and therefore medical paradigm, has enabled the creation of a large research infrastructure to pursue treatments and a cure. However, I have also suggested that, while research in this area is flourishing in terms of the multiple avenues being explored, there has been little progress in the quest to develop effective interventions to treat or ameliorate symptoms. A major issue is then surfaced in relation to the construction of nursing texts. Biomedical knowledge makes a very limited contribution to the actual care of people with dementia. But nursing knowledge and concerns are routinely situated after detailed descriptions of pathological changes and current medical research findings in nursing undergraduate and specialist texts such as Ebersole and Hess (1998), Frisch and Frisch (1998), and Stuart and Laraia (1998). Nursing discussion is grounded on biomedical discourse, with the subsequent relegation of the personal and political dimensions of dementing illnesses to, at best, a highly marginalised positioning.

In this section I discuss the implications of the positioning and dominance of biomedical explanations of dementing illnesses in nursing discourse. I argue that medical knowledge is presented as authoritative and unproblematic in that its lacunae are persistently

⁴ Participants are members of a religious order.

suppressed, the debates, contradictions and uncertainties that permeate current biomedical constructions of the dementing body excluded from nursing literature.⁵ I also examine the uncritical appropriation of epidemiological research in nursing texts in order to create dramatic but dangerous representations of dementing illnesses. Finally, I focus on the contradictions inherent in the use of stages to describe the progression of Alzheimer's disease in nursing texts, despite the presence of a leitmotif stressing diversity in the individual manifestation of Alzheimer's disease in this literature.

The positioning of biomedical knowledge in nursing texts

Knowledge of the biological processes that create the symptoms and signs of dementing illnesses is promoted as being the basis of informed dementia care in nursing literature (Delieu & Keady, 1996b). The positioning and substantial discussion of the aetiology and pathologies of dementing illnesses in nursing texts support this view. Certainly, knowledge about the biological processes of dementing illnesses is an important requirement for the development of skilled and appropriate care. Delieu and Keady (1996a & 1996b), for example, note that the subcortical area of the brain is not affected to any extent by the development of neuritic plaques and neurofibrillary tangles, and therefore emotional responses are largely intact.

An illustration of the function of the subcortical area is provided by the great emotional outburst often displayed by people with late stage AD when mention is made of the death of their parents and/ or spouse (the so-called catastrophic reaction). This is usually momentary as the full impact of the memory is relived and then almost immediately lost again. (Delieu & Keady, 1996b, p. 216-217)

Explanations of biological processes in this extract are integrated with discernible behaviours and experiences. This knowledge has an immediate practical application to nursing practice as it can readily be appreciated that, for instance, the techniques of reality orientation⁶ are not just futile but also cruel in the forcing of a gratuitous reliving of a traumatic event in the context of substantial memory loss.

⁵ The exclusion of the debates and contradictions within biomedical discourse from nursing literature is not confined to the field of dementing illnesses. For instance, Carryer (1997) notes that the contradictory research findings linking obesity with health risks are not discussed in nursing literature.

⁶ A communication approach that aims to orientate a person to the present reality discussed in chapter four.

However, the emphasis on pathology in nursing descriptions of dementia has problematic dimensions with the consistent location of nursing knowledge and concerns subsequent to detailed descriptions of contemporary medical knowledge. This may be a useful format when discussing a disease such as diabetes where the pathology, aetiology and medical treatment of the disorder have a direct bearing on nursing interventions. But nursing texts focusing on caring for people with Alzheimer's disease provide no such medically generated guidelines. Current biomedical knowledge can offer only tentative possibilities rather than definitive answers. So while Johnson and Johnson (1995) and Miller (1995) provide particularly detailed accounts of the biological changes associated with Alzheimer's disease as well as theories about aetiology, these authors conclude that:

At present, the etiology of DAT is unknown, research continues, and specific treatment is unavailable. (Johnson & Johnson, 1995, p. 496)

And

No one theory can explain the cause of AD, and studies are pointing toward multiple, sometimes interacting, causative factors. (Miller, 1995, p. 468)

Nursing accounts of dementing illnesses reflect the distinction that psychiatry makes between organic and functional mental disorders. Dementing illnesses with visible pathology are classified as organic disorders. However, this classification can be problematic, according to Busfield (1986), as diagnosis and treatment can focus on the physical with little interest in social and psychological factors. As a consequence, the social, psychological, and environmental factors that can either enhance or mediate disability are minimised. Densely written descriptions of cellular, protein and neurotransmitter changes, while useful in providing an explanation for aberrant behaviour, provide little guidance for nurses attempting to interpret behaviour and to develop responsive and effective caregiving practices. In fact, it could be argued that the desire to locate nursing practice as a discipline associated with a more powerful disciplinary structure has resulted in the appropriation of biomedical knowledge at the expense of marginalising the nursing knowledge and the concerns of many practitioners who, in their everyday work, must respond to, and interact with the person with a dementing illness. Furthermore, the person whose existence has originated the discourse becomes a marginal figure, reduced to aberrant neurons and dysfunctional behaviour.

Kitwood's (1989, 1990, 1993, 1997) work provides an alternative view of Alzheimer's disease, highlighting the psychological factors that may contribute to the manifestations of Alzheimer's disease with his promotion of an "interpersonal psychology" (Kitwood, 1993, p. 155), so shifting the focus away from the pathological concerns of medicine and on to sustaining and supporting the person with dementia. Kitwood argues that medical science has reached an impasse with the search for a cure for dementia. While there are small incremental developments in knowledge at a cellular and chemical level, medical treatments have no more impact than a temporary slowing or amelioration of the underlying disease. He critiques the medical dominance of knowledge about dementia, pointing out the many anomalies (such as those I have discussed earlier in the chapter) within the medical discourse about Alzheimer's disease. He discusses how the diagnosis of Alzheimer's disease is hardly a certain science. Some people appear to have Alzheimer's disease but lack the characteristic neuropathy on post-mortem. Furthermore, the medical emphasis on the organic causation of dementia allows for no consideration of the possible contribution of stress and other psychological factors. Based on psychobiological studies, Kitwood's research suggests that stressful life events could precipitate the initial dementing behaviour in some instances. He also maintains that a marked deterioration in mental abilities can be associated with sudden life changes such as hospitalisation. For instance, the idea that Alzheimer's disease is inevitably progressive is challenged by evidence that cessation in deterioration and even some degree of "rementing" or recovery of powers that were lost" (Kitwood, 1993, p. 150), has been noted in stable and enriched living environments (Kitwood, 1993, Kitwood & Bredin, 1992).

Kitwood's ideas have been critiqued in nursing literature. Adams (1996) challenges the research methods used by Kitwood to develop the psychobiographies used as the basis for his ideas about the role critical life events and wider societal forces play in the development of dementing illnesses. These accounts have been developed from interviews with family members, and are based on an underlying, but contestable, assumption that these caregivers have provided an account that would be congruent with the person with dementia's account. Furthermore, Adam makes the point that only one biography has been published and that, in seventeen out of the forty-four family

caregivers interviewed, no life event was identified as a precipitant of a dementing illness. Woodrow (1998b) has also critiqued the applicability of Kitwood's ideas in nursing practice from a resource perspective. He argues that to implement these ideas would require intensive staffing, ranging from a ratio of one nurse to four patients, to one to two, if the people requiring care were highly dependent. This author comments that "like other health care professionals nurses often face a stark choice between developing professional values for the benefit of each individual, or following potentially cheaper and less humane behaviouristic models" (Woodrow, 1998, p. 1331).

However, I believe that nurses could usefully adopt Kitwood's critique of the construction of knowledge around dementing illnesses. The current limited contribution of medical knowledge to nursing discourse provides the space to construct accounts of Alzheimer's disease within the discipline of nursing that are very different from current representations. Medical knowledge could be repositioned as complementary rather than dominant in nursing accounts with the experiences of people with dementia, and with the concerns of nurses and families taking central place. Such accounts would be invaluable in informing and shaping practitioners' everyday practices in the privileging of the needs and desires of people with dementia and their families, rather than primarily attending to the microscopically focused accounts of pathological deficiency.

"Apocalyptic demography"

The prominent citation of varying prevalence rates for dementing illnesses in nursing texts draws attention to another problematic representational issue. There is agreement that the prevalence of dementing illnesses increases with age but the statistics quoted for over eighty-five years of age varies considerably in nursing literature. For instance, Davies (1991) cites a fifteen percent prevalence rate; Birchenall and Streight (1993) twenty percent; Miller (1995) twenty-five percent; Stockton and Burke (1997) and Johnson and Johnson (1995) forty-seven point two percent. A wider reading of medical literature reveals that the methodological issues affecting the reliability of the epidemiological studies are not surfaced in nursing texts. Larson (1993) comments on the range of prevalence rates reported in epidemiological studies, and attributes the wide variance to factors such as a lack of common definitions and methods, and the problems of distinguishing dementia from the changes due to ageing. For instance, the commonly

cited prevalence of forty-seven point two percent in over eighty-five year old people is derived from a study by Evans et al. (1989) that has been critiqued by Larson (1989) as possibly over-diagnosing dementia in the research population because of research design issues in the linkage of cognitive impairments with social and occupational functioning, and the lack of histological confirmation of a dementing illness.

Despite the above examples of critique in relation to the validity of some of the commonly cited prevalence rates of dementing illnesses, the most dramatic prevalence statistics continue to be used in professional literature. One explanation for this practice is that the prevalence of dementing illnesses is a critical component of the argument portraying dementia as a major health issue, with high health care costs requiring increased health service and research funding. This selective use of prevalence statistics for dementing illnesses is not confined to nursing writers. The following quote is from a report to the American Congress from the Advisory Panel on Alzheimer's Disease, a group of mainly health professionals formed to advise the United States Department of Health and Human Services and the Congress on the priorities for Alzheimer's disease research.

There now is reasonable agreement that the prevalence of dementia doubles with every 5-year increase in the age of subjects between 65 and 85 years old and appears to be present in more than 40 percent of people aged 85 and older. (Advisory Panel on Alzheimer's Disease, 1995, p.25)

The panel members cited two sources, Larson, Kukull, and Katzman (1992) and Larson (1993), as support for the above statement, but a close reading of these articles provides little evidence to back the panel's claim that forty percent or more of people aged eighty-five and older have dementia. Both Larson et al. (1992), and Larson (1993) comment on the very wide range of prevalence rates from twelve point six to forty-seven point two percent reported in various epidemiological studies for over eighty-five year old people. Larson (1993) discussed the results from a Swedish study (Skoog, Nilsson, Palmertz, Andreasson, & Svanborg, 1993) which investigated the causes and severity of dementia in a group of over eight-five year old people. The prevalence rate of dementia in this group of four hundred and ninety-four people was twenty-nine point eight percent. Larson et al. (1992) reviewed key studies estimating prevalence rates and concluded that

the reported prevalence of twelve point six percent in over eighty-five year old people in a study by Kokmen, Beard, Offord, and Kurland (1989) marked the lowest estimate of prevalence, while the study by Evans et al. (1989) of forty-seven point two percent marks the highest estimate in studies carried out in the United States.

The Advisory Panel on Alzheimer's Disease (1995) use of Larson, Kukull, and Katzman's (1992) and Larson's (1993) articles to support claims of the prevalence of dementing illnesses as being over forty percent of people over eighty-five is even more puzzling given that Larson was a member of this panel. Furthermore this claim is perpetuated in 1999 in the American National Institute of Aging and the National Institutes of Health's progress report on Alzheimer's diseases. An unsupported statement is made that "some studies show that nearly half of all people age 85 and older have some form of dementia" (National Institute of Aging & National Institutes of Health, 1999, p. 3). This problematic and biased use of research findings de-stabilises the notion that biomedical discourse represents one factual and immutable reality based on systemic investigation according to scientific principles. It emphasises the ongoing practices and power in disciplinary constructions of knowledge and, as demonstrated by the above use of equivocal statistical information, the selective use of research findings to present representations that serve particular purposes. As Shildrick (1997, p. 10) argues:

...once 'real' material entities as well as linguistic concepts are understood to be discursive constructions, then the practices of medicine and health care must necessarily be seen in a different light. It is not just that the concepts around the body, such as notions of health and disease, able-bodies and disabled, and so on become problematic, but that biomedicine may be concerned as much with constituting the body as with restoring it.

The emotive rhetoric employed in literature about dementia has subtle but influential effects on the representation of people with dementing illnesses when they are described as a current and future social problem in terms of cost and care. The depictions of dementing illness, and particularly Alzheimer's disease, as constituting a future epidemic is a particularly well used but inaccurate rhetorical device

With the increases in life expectancy and the number of baby boomers who will be reaching senior citizen status, the incidence of Alzheimer's may reach epidemic proportions in the 21st century. It is estimated that the disease now costs Americans \$80 billion per year. (Birchennall & Steight, 1993, p. 253)

.....

With the global population ageing "we have an imminent worldwide epidemic", warned Edward Truschke, president of the Alzheimer's Association. "If we don't find a cure... more than 22 million people will have this disease in 25 years". (Neergaard, 2000, p. 7)

Epidemics are defined in epidemiological terms as when the number of cases of a disease increase "greatly over the expected or normal levels" (Torrence, 1997, p. 44). The term epidemic conjures up frightening visions which suggest the "potential for sudden, exponential spread, for societal disorder, the need for harsh and decisive measures to be taken to keep the disease in check" (Lupton, 1995, p. 65). Indeed, the numbers of people with dementing illnesses will increase in the future due to a combination of factors such as increasing longevity, and the ageing of the significantly large generation of people born after the Second World War. This increase in cases of dementing illnesses is expected and the use of the term epidemic, while certainly attracting attention, is hardly warranted on epidemiological grounds.

Binny and Swan (1991) suggest that the development of the industry around Alzheimer's disease is a product of capitalism, where the needs of elderly people are transformed into commodities suitable for capital investment. The use of worst possible case statistical scenarios, in language that evokes images of future crisis in the construction of Alzheimer's disease, is a strategy for generating capital investment in research and health services. However, a construction of an illness is created that defines ageing as a problem, where interventions are individually focused, and where the medical quest for a cure is paramount, with the associated heavy investment in funding, possibly to the detriment of other ageing issues.

The biomedicalization of mental health problems has diverted a majority of attention and funds to biomedical Alzheimer's disease research...and sapped resources from service provision and non-Alzheimer's problems. (Binney & Swan, 1991, p. 176)

Robertson (1991) aptly calls the predictions of a greatly increasing demand on society as a result of increasing numbers of ageing people, “apocalyptic demography” (p. 135). She argues that ageing is constructed as a problem, associated with decline, interpreted from a medical perspective as essentially individual and pathological, to be treated with the aim of seeking a cure.

The implications of using dramatic statistics need to be surfaced in the nursing literature. As a result of giving such weight to biomedical constructions of dementia, nursing texts create a picture of biomedical certainty. They, therefore, suppress the considerable methodological problems underpinning such representations of dementing illnesses. Bleak biomedical predictions of an unsustainable future may be useful in the quest for more research funding but it is possible that the current needs of people with dementia could be compromised by a funding emphasis on biomedical research. Undoubtedly, health professionals are well meaning in their agenda of raising public and other health professionals’ awareness of dementing illnesses in order to improve care, but their strategies may well have unintended future consequences in the creation of ominous scenarios. As Foucault (1983c) argues, it is not that “everything is bad, but that everything is dangerous” (p. 231). For instance, the following quote could be read from a eugenics perspective, a perspective that was in vogue just fifty years ago in Nazi Germany, where euthanasia was seen as appropriate for the good of the greater society.

The impact of AD and other dementing disorders now is well recognised. The toll is exacted not only from patients and their families, but also from the general population. The cost imposed on our society by these dementias now is estimated to be 100 billion dollars a year. This terrible drain in society and associated costs will continue to increase as the population ages. The panel reemphasizes the unique advantages of a *scientific solution* [italics added] to reduce the oppressive financial and human burden imposed by AD and other dementias. (Advisory Panel on Alzheimer’s Disease, 1995, p. 27)

Stages of Alzheimer’s disease

Nursing texts often adopt a stage model to describe the progression of Alzheimer’s disease. Stage models are generally used in medicine to describe pathological changes, such as the clinical staging classification of Hodgkin’s disease (Xistris & Hogan, 1988) where lymph node involvement is used to indicate disease progression. The use of stages

to describe the progression of a chronic illness by functional loss appears to be unique to Alzheimer's disease. It is justified by reasons such as enabling planning for future care-giving needs, measuring of the effectiveness of experimental interventions, and creating criteria for eligibility for specific services (Mace, 1987).

The initial three stage description of Alzheimer's disease by Sjogren in 1952 (Mace, 1987) marks the progression of the disease through the first stage of initial memory loss; the second stage of impairment of language, motor ability and object recognition; and the terminal third stage distinguished by incontinence, immobility and loss of language. A later, more detailed stage model was developed by Reisberg, Ferris, De Leon, and Crook (1982) who described the progression of Alzheimer's disease by functional manifestations grouped in seven stages. The subtle transition from normality to being categorised as abnormal are highlighted in this model, in which the *diagnosis* for the first stage of Alzheimer's disease is that of a *normal adult* where no memory loss is apparent, and the second stage, where there is some evidence of forgetfulness, is diagnosed as *normal older adult*. While presumably the authors did not intend to classify all adult human beings in one of these stages of Alzheimer's disease, their classificatory work allows for such a reading and points to the ultimate medicalisation of the whole ageing population. The following subsequent five stages in this model are marked by decreasing ability to carry out activities of daily living. This inability is initially apparent in individuals' gradual loss of the complex skills required to manage in social and employment settings, and it progresses to a complete loss of ability to carry out normal activities of daily living by stage seven.

Nursing texts have not uniformly adopted one particular stage model. Instead, they reflect the variation apparent in other literature. For example, Johnson and Johnson (1995) and Needham (1993) refer to three stages; Birchenall and Streight, (1993) and Eliopoulos (1997) to four stages; and Davies (1991) and Miller (1995) to seven stages. This variation indicates a contradiction, in both the medical and nursing literatures, in the representation of Alzheimer's disease as having a predictable progression, especially as these same nursing texts also comment on individual variability in the course of the disease.

The rate at which the patient progresses from stage to stage is highly individualized. (Birchenall & Streight, 1993, p. 254)

Studies emphasize that there is very wide individual variability in the rate of progression. (Miller, 1995, p. 472)

.....

There is no “typical” person with dementia. (Johnson & Johnson, 1995, p.493)

Gubrium (1986 & 1987) has explored this contradiction in the social construction of Alzheimer’s disease, drawing attention to how it is simultaneously portrayed as having a predictable developmental progress as well as being described as diverse in individual manifestations.

The content analysis of disease literature and the field data indicate that, while Alzheimer’s is developmentally represented, at the same time, it is admittedly idiosyncratic and without “rhyme or reason”. As far as timing is concerned, although there is, say, progressive decline in the patient’s cognition that can be described as stage-like and finally terminal, it is also said that there is remarkable variation. (Gubrium, 1987, p. 10)

Gubrium (1987) argues that this elaborate development of stages to describe the course of Alzheimer’s disease perform an ameliorative function, in that they attempt to create the impression of order and predictability, at least from the caregivers’ perspective. In contrast, when the stresses created by the disease are foregrounded, the highly individualised nature of the effects of Alzheimer’s disease, and the unpredictability of the expression of the illness on the human body, are emphasised. There are, however, alternative discursive strategies for discussing the progression of Alzheimer’s disease. Stockton and Burke (1997) foreground the heterogeneity of dementing illnesses, as well as variations in progression and effects of biological changes from individual to individual, in their account. They therefore avoid the use of a predictive and normative model of the progression of Alzheimer’s disease while still providing a description of the range of effects, and the progression of dementing illnesses.

Is there any-body there? The experience of the person with dementia

In the previous section I have drawn attention to problematic aspects of textual representations of dementing illnesses in nursing literature. Nurse authors’ uncritical

appropriation of biomedical literature has resulted in the exclusion of the debates that permeate this field of knowledge, the simultaneous reification of the dominance of the biomedical discourse in this area of health care, and the presentation of a highly contestable epistemological certainty.

In this section of the chapter I attend to a further area of knowledge suppressed by biomedical representations, that of the experiences of people with dementia. Since the late 1980s there has been growing comment about the general omission of the experiences of people with dementia in the body of research about dementia care (Acton, Mayhew, Hopkins, & Yauk, 1999; Clarke, 1999a; Cotrell & Schulz, 1993; Foley, 1992; Froggett, 1988; Goldsmith, 1996; Keady & Nolan, 1995a, 1995b, 1997; Kitwood, 1993; Silverman & McAllister, 1995). Keady (1994, p. 1098) used Ronald Reagan's press announcement about his experience of the early stages of Alzheimer's to highlight the absence of the experience of the person with dementia in nursing texts.

A major challenge for nursing and dementia care in the next decade is not only to listen to the voices of early sufferers, but also to overcome our own fears, respond to the views of others and create a dynamic base to practice.

The experience of family caregivers features prominently in nursing literature (see for example Bonnel, 1996; Clarke, 1999b; Le Navenec & Vonhof, 1996; Kelley, Swanson, Maas, & Tripp-Riemer, 1999; McCarty, 1996; Suwa-Kobayashi, Yuasa, & Noguchi, 1995; Wuest, Ericson, & Stern, 1994). However, the needs of the person with dementia can become subsumed within the communicable experiences, knowledge and needs of caregivers. The current emphasis on the experiences and needs of family caregivers is further illustrated by recently published priorities for dementia research in New Zealand where it is suggested that "projects about service provision and stress levels in carers should be regarded with equal importance to those in other areas of medicine that have a higher public profile" (Sainsbury et al., 1997, p. 40). No mention is made of the interpretations, experiences and strategies of people with dementia in the thirteen research priorities in this document. The interests of caregivers appear to be the major focus in dementia care, in contrast to other areas of disability and chronic illness where the perspective of the person being cared for is central to all discussion.

There are several explanations for the exclusion of the knowledge of people with dementia in professional discourses. First, it is argued that the interest in family caregiving in the last three decades and, in particular, the burdensome aspects of care, has shifted the focus of research studies away from the person with dementia, marginalising them, albeit unintentionally (Froggett, 1988; Kitwood, 1993). Second, there is an assumption that the diagnosis of a dementing illness is synonymous with a lack of insight into the impact of dementia on the meaning and experiences of life (Goldsmith, 1996). The third possible explanation is that the ethical aspects of conducting research are challenging in terms of informed consent and communication issues (Cotrell & Schulz, 1993; Froggett, 1988). Finally, Kitwood (1993, p. 154-155) argues that the exclusion of the dementing person can be partially attributed to issues of power and control by professional groups such as psychiatrists, but the invisibility of the person with dementia is also attributed to anxiety, a discourse being created by health professionals that

...systematically defends its participants from psychological threat; and practices develop which are in harmony with the discourse. In the cases of dementia the threats principally concern dependency, frailty, loneliness, abandonment, madness, dying and death. In this general area lie some of the darkest fears that confront the human race. It is not surprising that an apparently coherent cluster of discourses has developed around dementia, in such a way as not to engage with these things at all.

Communicating the experiences of people with dementia may seem an impossible dream. Communication barriers are an inescapable reality that creates and shapes nursing practices in caring for people with dementia. Yet the ability to communicate is not automatically lost with the first organic changes within the brain. As early as 1986, Cohen and Eisdorfer argued that people with dementia had a significant contribution to make to the knowledge about dementing illness and included their reflections in a book written for family caregivers. Two later individual accounts by people with Alzheimer's disease, Robert Davis (1989) and Diana McGowin (1994) also challenged the notion that they have no insight into their condition. The desire for inclusion and support resonates through these accounts. At the time of her diagnosis of Alzheimer's disease McGowin (1994, p. 66) wrote:

What I wanted, no, what I needed, was someone to assure me that no matter what my future held, they would stand beside me, fight my battles with me. Or if need be, for me. I wanted assurance from someone that I would not be abandoned to shrivel away. They would give me encouragement, love, moral support, and if necessary, take care of me.

John Thomas (cited in Cohen & Eisdorfer, 1986, p. 21), who also had Alzheimer's disease wrote in his journal:

I am hungry for the life that is being taken away from me. I am a human being. I still exist. I have a family. I hunger for friendship, happiness, and the touch of a loved hand. What I ask for is that what is left of my life shall have some meaning. Give me something to die for! Help me be strong and free until my self no longer exists.

These texts provide essential knowledge for the development of appropriate professional support as well as informing other people with dementing illnesses and their families. Their stories challenge comfortable assumptions that research seeking the perceptions of people with dementia is intellectually unproductive or ethically dubious. The small amount of published work in this area provides valuable insights into the stresses for people who are living with memory loss. For instance, health professionals need to be aware of the profound impact of a diagnosis of a dementing illness on the person's self-identity. In Burgener and Dickerson-Putman's (1999) study people with a recent diagnosis of dementia used words such as *stupid* or *forgetful* after diagnosis when describing themselves, rather than referring to their previous or present roles and their personal current abilities. McGowin (1994) wrote, "I could not bring myself to confide in my children. Intellectually, I knew my condition was not cause for shame, yet emotionally I felt ashamed. I was losing my intelligence, losing my memory, and my directional system was really shot to hades" (p. 65). Consequent failure or mistakes in everyday activities or in assessment processes after diagnosis have much more severe consequences associated with the imposition of more limits on every day activities. Davis (1989) wrote: "I live with the imminent dread that one mistake in my daily life will mean another freedom will be taken from me. Each freedom taken places me in a smaller playpen with a tighter ritual to maintain myself" (p. 91). Issues about how much the person is told about their health or assessment processes have also been raised. "I wanted to have more say and information on what was happening to me. I felt a little used to tell

you the truth” (Person with a recent diagnosis of dementia, cited in Keady & Bender, 1998, p. 141).

As I have discussed earlier in this chapter memory loss is constructed as the critical feature of dementing illnesses (Berrios, 1990a). Initially, recent memories and immediate recall are the most compromised. There are also increasing problems with transferring new information into more long-term memory and the use of reminder cues, according to Welsh-Bohmer and Morgenlander (1999), do not substantially compensate for memory deficits. However health professionals need to be aware of how people compensate for memory loss so as to avoid undermining coping strategies. In Keady and Nolan’s (1995a, 1995b) research, people in the very early stage of dementing illness actively worked to adapt to memory loss by using memory aids and taking up cognitively demanding exercises such as crosswords. Some people covered up memory lapses by taking notes or by withdrawing from socially stressful occasions. These strategies were associated with a sense of personal achievement. However, they have reported that maintaining an image of normality progressively became more difficult and exhausting. The eventual disclosure of problems to other family members was associated with a relief in dropping any pretence of normality but also surfaced fears about future prospects. All participants in this study believed that establishing and maintaining a daily routine was essential for adaptation to memory loss. Little professional help was available for these people in the early stages of a dementing illness but they would have appreciated someone outside of their immediate social circle to talk to about their feelings.

There is evidence of an increasing nursing interest in the experience of people with dementia in the last four years, reflected in the research by Acton et al. (1999) and Burgener and Dickerson-Putman (1999). One nurse researcher in particular has, alone or as a co-author, published several research studies exploring the experiences of people with dementia. Although these publications are based on one set of data, eleven interviews of ten people in the early stages of dementing illnesses (Keady, 1997; Keady & Bender, 1998; Keady & Gilliard, 1999; Keady & Nolan, 1995a,b; Keady, Nolan, & Gilliard, 1995), this work makes a valuable contribution to developing a greater understanding of the coping strategies of people in the early stages of dementing illness.

It should be noted, however, that the number of publications is not indicative of an extensive group of participants.

In general, research in this area is minimal and at a beginning stage. Some studies are very small in scale, with several based on four or less participants with dementing illnesses (Froggatt, 1988; Foley, 1992; Proctor, 1998). In other studies, while the purpose of the work is ostensibly to communicate that people with dementia have worthwhile knowledge to contribute, their voice is subsumed in discussion about broader societal concerns. For instance, although Froggatt (1988) interviewed three women with early Alzheimer's disease, their views are presented very briefly in a discussion predominantly focused on broader philosophical and ethical concerns. Similarly, Foley (1992) presented a case presentation of one man who had Alzheimer's disease for five years but the article concentrated on the ethical debate about insight and dementing illnesses. In the preface to Goldsmith's (1996) study, Marshall (1996) writes that the study was predicated and funded on the claim that "in order to improve services for people with dementia and to make them more responsible to their individual wishes, it is necessary first to accept that people with dementia have a voice that is worth listening to, second to facilitate the use of it and third to hear it" (p. ix). Somewhat incongruously, however, while Goldsmith refers to six in-depth interviews with people with dementia and twelve less formal interviews, the voices of these people are not foregrounded in his discussion. Rather, the text focuses on the care providers' and caregivers' views about communication, along with the ideas that emerged from the author's extensive literature review. While the positioning of people with dementia is commented on in terms of lack of voice and power, paradoxically, dominant representations of the person with dementia as the voiceless other are also simultaneously reified.

Compounding this lacuna in knowledge is the absence of accounts of the phenomenon of experiencing cognitive changes and memory loss from groups ascribing to diverse worldviews. Their knowledge is excluded, by virtue of being unsought, from the formally circulated disciplinary discourses. These knowledge gaps draw attention to the culturally specific nature of the concept of dementia, a construct of allopathic medicine developed from European and Anglo-American epistemological worldviews. Major gaps in knowledge about different cultural representations of the experience of memory loss and

cognitive changes are not confined to the discipline of medicine. Marshall (1997) comments in the introduction to a multi-disciplinary text on the *state of the art* of dementia care that the British authors contributing to the book neglect cultural aspects of care. Discussion about the influence of cultural factors in relation to dementing illnesses is also minimally addressed in nursing literature. Garratt and Hamilton-Smith's (1995) text is exceptional in exploring how cultural background can shape individual responses to a dementing illness. Practice examples are used throughout the book to illustrate differences in behaviour and responses from people with dementia from a number of ethnic communities.

Unsurprisingly, given the general absence of cultural perspectives in English language literature, an extensive search of New Zealand literature also indicates that there is little published in relation to Māori representations and issues in relation to dementing illnesses.⁷ The national guidelines for the support and management of people with dementia does include a short section titled *Cultural Issues in the Support and Management of Māori with Dementia* (Sainsbury et al., 1997, p. 38-39). This document, however, highlights the significant representational issues, of which the authors appear unaware of, that are involved in conveying diverse cultural perspectives. For instance, the title of the section is firmly positioned within biomedical discourse with the inclusion of the word *management* and the ensuing connotations of control and supervision. The authors commence the discussion with the following statement:

⁷ The absence of Māori cultural perspectives in relation to dementia can also be explained by marked inequalities in health status between Māori people and those of European descent and significant differences in life expectancies. This issue is highlighted by the differences in categorisation of old age in the Ministry of Health report on "The Health and Wellbeing of Older People and Kaumātua: The Public Health Issues" (Ministry of Health, 1997). In this document non-Māori are categorised as older people aged sixty-five or older for the reasons that this age is an international benchmark and the age of entitlement for a retirement income in New Zealand. But an exception is made for Māori and the term *kaumātua* or older adult is used to refer to Māori aged fifty-five years or over. The rationale for this is that Māori currently still have a shorter life expectancy (seven years less for Māori born in 1996 compared to the total population [Statistics New Zealand, 1998b]), and age-related disabilities are encountered at a younger age than among New Zealanders of European descent. Interestingly, this rationale is not translated into eligibility for a retirement income at a younger age than non-Māori. Currently ninety-five percent of older people (the age group in which dementing illnesses are most common) in New Zealand are of European descent (Statistics New Zealand, 1998a) although Māori were fifteen point one percent of the total population in 1996 (Statistics New Zealand, 1998b). The higher prevalence of dementing illnesses in non-Māori populations, as compared to Maori, could well be interpreted, in terms of power relations, as an indicator of unequal access to the social-economic resources influencing overall life expectancy, given that the risks of developing a dementing illness rise substantially with advanced ageing.

Among people with traditional Māori values, there is a high level of tolerance for the changes in the behaviour of their older person or kaumātua. A person who is dementing will maintain their mana (status) if they still perform well-learned functions of tikanga Māori. In such situations behaviour changes and difficulties with short-term memory or adapting to new or unusual situations, may be seen as less problematic, and the whānau may delay seeking help. (Sainsbury et al., 1997, p. 38)

This particular representation has overtones of romanticism in implying the existence of enduring, static, cultural traditions. Durie (1998) challenges the notion that there is some generic Māori reality and stresses that “Māori live in diverse cultural worlds. There is no one reality nor is there any longer a single definition that will encompass the range of Māori lifestyles” (p. 215). Chater (1996) cautions about the tendency to develop homogenised accounts that mask diverse representations and positions within particular groups, and argues that “homogeneity lends itself to essentialism, which represents ‘the community’ as sealed, static, integrated, and enduring” (p. 81). This statement, stressing the partiality of all accounts and the heterogeneous nature of peoples’ experiences, is applicable to the overall representational issues in developing accounts of the experiences of people with dementing illnesses. However, while noting the limitations of all representations, it can be argued that the accounts of people with dementia have certainly as much validity as biomedical knowledge and family contributions in terms of developing nursing care, and could be incorporated into nursing texts. After all, as Kitwood (1993) suggests, understanding the experience of dementia - the loss in mental capacity, the capacity to form meaningful actions and the loss of agency to act upon the world - is critical in developing new interpretations of dementia that could potentially widen the limits of present day interventions.

Summary

This discussion has focused on the biomedical account of dementia disease as well as the contemporary debates challenging that representation. I argued that dementia is not the description of some pre-determined biological phenomenon but a powerful disciplinary construction informed by a specific historical and cultural perspective, a construction that has major policy implications and ramifications for the representations of dementing illnesses in disciplines such as nursing. Disciplinary constructions of knowledge can never

offer a full account of the phenomena under investigation. But, current nursing accounts actively suppress limitations in biomedical knowledge, while at the same time asserting the authority and validity of knowledge developed within medicine. Moreover, these accounts also suppress the knowledge of those currently marginalised in dominant discourses, the objects of study themselves, the people with dementia. Nurses' texts could be rewritten in such a manner as to foreground the current absences in conventional representations by including the diverse knowledge circulating in the field, rather than just a small part of that knowledge. Exploring how dementia has been socially constructed, and the consequences of that construction, is an important step in the critique and development of nursing practices. Ultimately this exploration can create possibilities for developing new representations of both the people with dementia, and of nursing care.

CHAPTER FOUR

Re-viewing Nursing Literature

Introduction

In the previous chapter I argued that nursing knowledge is substantially informed by the biomedical construction of the concept of dementia. However, the nursing literature specialising in dementia care also surfaces the issues of nursing practice, a quite separate sphere from that of medicine. In this chapter the major themes evident in nursing literature are discussed, as well as nursing practices and caregiving dilemmas in the context of caring for people with dementia. Given the extensive writing in this field, the literature reviewed in this chapter is by no means exhaustive. Texts have been selected as being representative of particular areas of interest, or as illustrating contradictions, gaps and shifts in a nursing discourse.

The discussion in this chapter will firstly be concerned with nurses' representation of particular behaviours of people with dementia as being problematic. My discussion foregrounds the tensions between the person with dementia's contradictory positioning as an adult with the associated rights of autonomy in Western society in conjunction with the need, at times, for protection from self harm. Foucault's theorising about relations of power and force provides a useful analytic approach to tease out the implications of nurses' representations and practices in this context. The next section focuses on the practice of assessment. Assessment can be interpreted as a technique of disciplinary power similar in intent and implications as the disciplinary technique of the examination discussed in chapter two. The third section of this chapter compares and contrasts the varying approaches to communication discussed in the nursing literature. I foreground the shift in nursing discourse from controlling forms of communication to

acceptance of the validity of communication attempts by the person with dementia. The next section focuses on the discussion about nursing relationships with people who have a dementing illness. Finally, some of the visual images used to represent people with dementia in the literature are discussed in order to emphasise the partial nature of all representations.

The representation of behaviour as problematic

Numerous nursing texts construct certain behaviours associated with dementia as problematic and unpredictable (recent examples include Beck & Vogelpohl, 1999; Maxfield, Lewis, & Cannon, 1996; Vollen, 1996; Wilkinson, 1999). The behaviours of the person with dementia that are represented as caregiving problems are labeled as *difficult* (Knapp & Shaid, 1991), *disruptive* (Nelson, 1995) and *aggressive* or *assaultive* (Beck, Robinson, & Baldwin, 1992; Wilkinson, 1999). These behaviours are defined as having the potential to impact on the safety of the person with dementia and other people, to be socially unacceptable and stressful, and frustrating or frightening to the person exhibiting them and other people (Beck & Shue, 1994). These descriptive terms also implicitly suggest agency, that the person with dementia intentionally and purposefully challenges nurses' actions.

These descriptions of the behaviours of the person with dementia give the impression of an unpredictable and unruly body in contrast with modern conceptualisations of the subject. Lupton (1995) suggests that the modern era privileges a certain kind of subjectivity, one that is distinguished by beliefs that appearance and behaviour are reflective of disposition, an interest in the personal conduct of oneself and others socially, and an emphasis on individualism and independence from others. The "civilized body is controlled, rationalized and individualized, subject to the conscious restraint of impulses, bodily processes, urges and desires" (Lupton, 1995, p. 8). Dementing illnesses impact on the individual subject's abilities to produce the public body deemed appropriate in this particular time. In contrast to the ideal of the *civilized body*, people with dementia are not always able to control and inhibit body functions, and urges and desires may well be spontaneously expressed rather than suppressed.

The nursing literature identifies a number of techniques to manage the behaviours of people with dementia. Behavioural strategies include calming activities, consistent

routines, and positive social interaction. Other approaches include environmental modifications, group programs that include exercise to music, social interaction such as touch, and psycho-social activities such as pet therapy and the use of stimulus objects such as toys (Beck & Shue, 1994). These strategies for managing disruptive behaviour focus on intervention at the individual level and, in particular, attempt to increase social interaction and diversion. However, behaviours constructed as nursing problems are still attributed to disease processes and labeled as agitation, wandering and aggression rather than other possibilities such as anxiety, fear and frustration. McGregor and Bell (1993, p. 30) note that:

The experience of most people with dementia is one of unremitting and unrelenting failure. This is especially true for those living in long-term care within a mixed group of people who are intellectually intact but physically frail. Those who have dementia can rarely compete with other residents in daily living skills without appearing clumsy, stupid and undignified.

Representing people with dementia as acting in ways that mean they become problems to be managed, rather than those actions being indicative of psychological needs that require attention can limit nursing interventions to controlling responses. For instance, research exploring current interventions for disruptive behaviour emphasised surveillance in recognising and documenting behaviour and the development of context specific interventions as well developing good communication processes between team members (Bair, Toth, Johnson, Rosenberg, & Hurdle, 1999). Organisational issues that influence the ability of nurses to adapt to individual needs, such as inflexible hospital routines, functional institutional environments, minimal education in the requirements of people with dementia, and a heavy nursing workload, were not addressed from this perspective focusing on the patients with individual behavioural problems.

Furthermore, the existence of relations of force between nurses and people with dementia in the exertion of techniques to control and curtail the behaviours of people with dementia that are deemed problematic by nurses, emerges in the discussion in nursing literature on the use of restraints. There is a significant amount of writing over the last decade arguing against the use of chemical and physical restraints (see for example Blakeslee, Goldman, Papougenis, & Torell, 1991; Brower, 1991; Evans & Strumpf, 1990; Evans, 1993; Gold, 1992; Matthiesen, Lamb, McCann, Hollinger-Smith,

& Walton, 1996; McHutchion & Morse, 1989; Middleton, Keene, Johnson, Elkins, & Lee, 1999; Sullivan-Marx, 1995). Yet the ongoing nature of this discussion and the findings of studies such as Retsas (1997), where twenty-six percent of nursing home residents had been restrained, suggest the ongoing use of restraints regardless of the arguments against their validity. As Sullivan-Marx (1996, p. 7) states:

Nurses' concerns for safety and control of behaviour form a foundation of belief for restraint use that stands in contrast to the efficacy and ethical arguments against such use.

However, the discursive construction of certain behaviours as problems to be managed, and which, by association, constructs the person with dementia as an object subject to techniques of control, is being challenged. For instance, Gibson (1997) and Potts, Richie, and Kaas (1996) discriminate between patients' aggressive behaviours and their resistance to care. Gibson (1997) states that, generally, there is no distinction in the nursing literature between acts motivated by aggression and acts motivated by resistance. She argues that this is a significant omission in that aggression has offensive connotations. The intention is to inflict harm, as distinct from resistance which is a defensive intention motivated by the intent to avoid harm. Gibson suggests that resistance occurs in long-term care when there are conflicts of expectations, in terms of what nurses want to achieve and what the individual person is willing to permit. It also occurs as a reaction to change. Environmental stimuli and social interactions can be misinterpreted by the person as threats because of the cognitive changes resulting from her/his dementing illness. Notions of autonomy underpin interventions when behaviour is represented as resistance. This conceptualisation encourages nurses to address tensions in relationships and environmental factors influencing behaviour rather than exclusively focusing on preventing the overt behaviours.

Potts et al. (1996) also link reactive and unwanted behaviour to overwhelming environmental stimuli. Shifting the way nurses talk about their dementing patients acknowledging this perspective positions people with dementia very differently. An interpretation of their behavior as meaningful requires an active, rather than reactive, nursing response and adaptation of the environment and of nursing actions. For example, Potts et al. (1996) state that "when encountering resistance to dressing and grooming, an initial intervention is to prioritize and determine what is really important.

Often this may mean that the nurse's perception of what the patient should wear is unrealistic and must be modified" (p.14). Nursing representations that inscribe people with dementia as people who at times resist nurses implies a relationship of power, both parties having some choices, possibilities and a degree of agency.

Some North American researchers are also suggesting moving from the "prevalent view of dementia-related behaviors as 'disruptive' or 'disturbing' to a perspective that conceptualizes these behaviors as potentially understandable needs that, if responded to appropriately, will enhance quality of life" (Kolanowski, 1999, p.7). The *Need-Driven Compromised Behaviour Model*, developed in the context of managing wandering behaviour (Algase, 1999b), problematic vocalizations (Beck & Vogelpohl, 1999) and passive behaviours (Colling, 1999), illustrates this change in representation. In this model, issues such as staff mix and stability and the ward ambience are positioned as issues that influence the expression of particular behaviours. For example, Beck and Vogelpohl (1999) address the organisational contribution to the production of what they term "need-driven dementia-compromised behavior" (p.17). They cite research findings suggesting a correlation between staffing by predominantly unregulated caregivers and higher levels of these behaviours, as a consequence of inadequate preparation for the work, as well as inconsistent care resulting from high staff turnover.

Advocates for the development of specialised care units (Grant, Pothoff, Ryden, & Kane, 1998; Teresi, Grant, Holmes, & Ory, 1998; Weaverdych, Whittle, & Delaski-Smith, 1998) also surface the structural issues that govern choices in nursing practice: staffing levels, skill mix, educational investment, and specialised environments. The concept of special care units has evolved in the belief that environmental factors are a critical component in enhancing functional abilities of people with dementia. A special care unit is characterised by admitting only people with cognitive impairment, particularly Alzheimer's Disease, the special selection and preparation of staff, a specially designed physical environment, an activity programme developed to meet the needs of the resident group, and the encouragement of family involvement (Mass, Swanson, Specht, & Buckwater, 1994). The promotion of especially designed and resourced living environments for people with dementia begins to address the organisational issues that govern and restrict nursing options. Rather than nurses attempting to mediate the effects of inappropriate living environments, institutions are

adapted to the needs of the person with dementia, with the aim of decreasing the incidence of behaviours currently problematic for caregivers and impacting on the nature and quality of care provided.

An Australian nursing text (Garratt & Hamilton-Smith, 1995) also presents a strong challenge to dominant discursive constructions of dementia care in nursing literature. In this text the authors discuss disturbing behaviour within a broader context of human responses to stress. They define the behaviours of people with dementia as normal, as predictable and understandably human reactions, given the losses and demands experienced.

In attempts to maintain balance and a sense of being in control the older person with dementia will often use coping strategies that seem totally out of context and are perceived by caregivers to be bizarre. In reality the behaviours exhibited are probably appropriate stress-release mechanisms that reinforce the preservation of self in a world that is confusing and often culturally inappropriate. (Garratt & Hamilton-Smith, 1995, p. 42)

Garratt and Hamilton-Smith (1995) argue that behaviours interpreted by caregivers as difficult are created by social and environmental factors, and that change and adaptation to the needs of the person with dementia will reduce unwanted behaviours. A model of care, the *Enhanced Lifestyle Through Optimal Stimulus* (ELTOS), presented by these authors, is aimed at a general improvement in the lifestyle of people with dementia living in residential care. The underlying foundations of the model are teamwork with agreement and cooperation between staff as to the caregiving approach, and strategies for effective communication with the resident. Critical elements of care in this model are validating the reality of the feelings of the person with dementia, lowering stress in the physical and social environment, and providing positive stimuli such as aspects of family life or former work skills that have been retained. Significantly, these authors also address the structural issues impinging on practice in their detailed discussion on the managerial environment supporting care emphasising the development and management of staff as the most important factors in improving care.

Assessment: A disciplinary practice

The practice of assessment is promoted in nursing texts as the basis for the development of care that acknowledges individual needs (Potter, 1997). The underlying assumptions informing nursing discussion are that the practice of assessment is a neutral and value-free technique and that there is a universally experienced human reality that can be objectively described. These assumptions are embedded in the principles of inquiry informing empirical sciences as the following description of assessment demonstrates.

The first step of the nursing process, assessment, begins with the nurse applying knowledge and experience to collect data about a client. Just as the astronomer uses knowledge of the galaxies to explore through a telescope, the nurse applies knowledge of science and the discipline of nursing to explore and discover clients' unique and personal health care problems. (Potter, 1997, p. 108)

This widely circulated student text demonstrates how much mainstream nursing literature has positioned itself uncritically with the scientific construction of the world. In such texts, the techniques of nursing assessment are aligned with the hard, academically reputable techniques of the physical sciences, assuming that there is a world *out there* (and implicitly a truth about the person under surveillance) waiting to be *discovered*.

The practice of assessment of the person with dementia is extended to areas other than that of care plan development. The specialist nursing literature of dementia care represent assessment as being important in providing base line information to judge the extent of disability in order to aid in appropriate nursing home placement (Dolamore et al., 1994), and as a useful tool for the monitoring of disruptive behaviour (Algase, 1999a, Cohen-Mansfield, 1999). The development of standardised tools are advocated in nursing literature (see for instance Gerdner and Buckwalter's [1994] evaluation of five instruments used to measure degrees of agitation). This framework for assessment encourages nurses to judge function and behaviour on scales that claim to distinguish *normal* from *abnormal*, measured by tested and validated *instruments*. So, on one hand, the notion of individualised care is promoted as a central tenet in contemporary nursing ideology. Yet, on the other hand, standardised frameworks and questions inevitably

create constraining and generalising categories that people must fit according to preordained criteria.

The practice of the examination as proposed by Foucault (1995) resonates with the nursing practice of assessment. Assessment, especially in a context where the capacity for verbal communication is limited by disease, requires hierarchical observation. It depends on the notion of the professional (here nurse's) gaze and requires the noting and recording the actions of the person with dementia. Yurick, Burgio, and Paton's (1995) article reifies this objective and reductionist construction of assessment in their discussion about the use of computer technology to record disruptive behaviour and the context in which it occurs. The disciplinary practice of normalising judgement also looms large in the assessment process. Normality is placed in a binary opposition to abnormality in the process of judging/assessing the person as being demented, or as not being demented; as being able to function independently, or as not able to function independently; as being disruptive, or as not disruptive. If the person does not *pass* certain criteria they are deemed to have failed the examination and are consigned, probably forever, to the category of abnormality (in the terms of the assessment criteria). Ultimately, the person with dementia in the hospital setting is written as a *case*; described briefly (given the time constraints that limit assessment processes), compared to a wider pre-determined population in terms of intellectual and physical functioning, and judged in terms of her/his degree of docility and capacity for independence.

Critiques of the value and effect of assessment processes are almost entirely absent in the nursing literature. There is little recognition that, although assessment is certainly an information-gathering exercise, the process is informed by the assumptions made by nurses about the abilities of people with dementia, about family members' contributions to care, and by what the nurse considers to be legitimate nursing concerns. These assumptions shape the questions asked and the assessment outcomes. Keady and Nolan (1994a) do, however, challenge the uncritical acceptance of the value of any assessment. These authors argue that the use of assessment tools could potentially have a stigmatising effect, especially given the difficulties in diagnosing dementing illnesses. They advocate for family caregivers' involvement in assessment, so they can report the abilities of the person being cared for and describe changes over time. The difficulties of obtaining informed consent for assessments and interventions from the person with

dementia are also raised, as “the individual concerned may refuse to see their behavioural, social and/or cognitive deficits as ‘a problem’ ” (Keady & Nolan, 1994a, p. 107). There is a resonance in this statement with the Foucauldian viewpoint of resistance as being always possible within the networks of power. The person being assessed in this context refuses to construct their selfhood in terms of pathology and decline, and as a problem. The difficulty here is reconciling that person’s perception with the possibly very different representation from the family’s perspective.

Another problematic aspect of the nursing discourse on assessment is the dominant emphasis on observable aspects of care, such as the measuring and monitoring the behaviour of people with dementia and the assessment of their abilities and disabilities. This representation draws attention to the absence of discussion of ways of including the subjective worlds of people with dementia in the assessment process. For example, Marzinski (1991) has noted that there had been little attention paid to the needs of elderly confused people in the area of pain assessment, despite chronic pain being a significant issue for older people. Although people with dementia may not be able to readily indicate they are in pain, they will inevitably experience pain as do all other humans. While in the last decade there has been more attention to the considerable complexities in identifying and treating pain in this area of practice (Feldt, Warne, & Ryden, 1998; Galloway & Turner, 1999; Hurley, Volicer, Hanrahan, Houde, & Volicer, 1992; Parke, 1992), this discussion is still not evident in mainstream nursing texts. For instance, one major nursing gerontological text (Ebersole & Hess, 1998) does not refer to pain as an important aspect of assessment in the chapter discussing dementing illnesses (McDougall & Ebersole, 1998), focusing instead on the areas of cognitive assessment and the assessment of functional ability. It is disappointing to note that the discussion about pain which, to some extent, begins to acknowledge the person with dementia as an experiencing human being, has yet to be surfaced in the major nursing texts used in nursing education.

Communication approaches

Discussion about communication,¹ while generally a prominent theme in nursing literature, is particularly conspicuous in texts about caring for people with dementia. This professional focus reflects a major concern for nursing practitioners in terms of everyday interactions with people who have dementia. Productive social relationships depend on meaningful verbal and non-verbal communication. However, people with dementia gradually lose the ability to communicate linguistically as the disease progresses. Their vocabulary becomes increasingly sparse and they cease recognising once familiar people and places. People with dementia continually have to renegotiate their worlds without the benefit of the shared meanings and interpretations with other humans that are normally taken for granted. Research studies highlight the impact of dementing illnesses on human interaction noting that people with dementia who were inpatient in medical and psychiatric units spent a large portion of the day in solitary activities (Armstrong-Ester & Browne, 1986; Armstrong-Ester, Browne, & McAfee, 1994).

There are marked differences between the various communication approaches discussed in nursing literature. General communication guidelines are aimed at improving compliance with activities of daily living. These guidelines are instrumental in nature, aimed at improving the clarity of everyday information-giving between nurses and patients to obtain cooperation in the activities of daily living. Advice includes using simple one statement sentences, repeating information, providing multiple auditory, visual and tactile cues, modeling behaviour and providing limited choices (Birchenall & Streight, 1993; McDougall & Ebersole, 1998).

Reality orientation, validation therapy, and resolution therapy go beyond the goals of functional communication strategies and have overt goals of improving quality of life or cognitive functioning. Reality orientation is aimed at orientating a confused person to the present reality (Holden & Woods, 1982). Reality orientation involves the inclusion of orientating information in everyday conversation and in the environment, as well as specially conducted group work. Validation therapy is a method developed by Naomi

¹ The concept of communication is defined in nursing literature as the “ongoing, dynamic series of events that involve the transmission of information or feelings from sender to receiver” (Potter & Perry, 1997, p. 1479).

Feil in the 1960s for communicating with people who have been diagnosed with a dementing illnesses. Feil (1993) states validation is underpinned by attitudes of respect and empathy and the caregiver's acceptance that all behaviour has a reason. Jones (1985, p. 21), in one of the first references to validation therapy in nursing literature, stated that this approach aimed to help very old and disorientated people to

...achieve their own goals of living, to ease their stress, to resolve their life's unresolved conflicts and business, to restore self-worth and to prevent further disorientation by communicating with them in whatever time or location is real to them.

Bleathman and Morton (1988) note that Feil developed validation therapy in reaction to reality orientation, maintaining that disorientated older people did not need to be orientated to function and participate in everyday life. Resolution therapy is a another approach advocated in relation to people with dementia (Goudie & Stokes, 1989). This is a one-to-one counseling approach employed during everyday social interaction and aimed at resolving present concerns.

These approaches have been criticised by a number of writers. Resolution therapy requires advanced counseling skills. This means that it is an inaccessible approach for most staff working in residential care settings (Woodrow, 1998a). Reality orientation, while popular in the 1980s, is time and energy intensive, with little proven benefit when a person has significant memory loss. The inappropriate adoption of this approach also creates the possibility of frustrating interactions where irreversibly confused people are constantly and futilely confronted with reminders of their disorientation. Although validation therapy is currently a popular approach, Kelly (1995) has argued that persisting with "ineffective or inadequate fad therapies ultimately may be at the expense of the very individuals we seek to assist" (p. 43). He attributes the popularity of validation therapy to strong commercial marketing and the lack of other positive options in caring for people with dementia.

Both validation therapy and reality orientation have also been critiqued for their lack of supportive research findings (Kelly, 1995; Mieson, 1992; Pulsford, 1997; Woodrow, 1998a). But some allowance must also be made for the inherent difficulty in designing a valid research project to evaluate effective communication in relation to dementia, an

area of complex human relationships involving subtle and multiple influences. Validation therapy, in particular, marks a shift in discourse away from health professionals controlling communication, to accepting the attempts to communicate by the person with dementia, in a context where these attempts are not dismissed as inappropriate and confused. As Crisp (1995a, 1995b; 1999) suggests, while people with Alzheimer's disease tell stories that may confuse past and present and mix truth with fantasy, they serve a useful purpose for the teller. She maintains that story telling creates opportunities for interaction with others, reaffirms personal identity and restores a sense of personal agency and power if the listener acts in a supportive way.

By telling a story, one is not only reaching out and making contact with another person, as one does in any face-to-face exchange however brief, one is also inviting that person to participate in a longer-term interaction, and one involving - if we play our role of listener properly - a relationship in which the balance of power and agency is on the side of the storyteller. For to be the storyteller is to take on a culturally valued status, and to be assumed to have something to offer to the person(s) to whom the story is being told. (Crisp, 1995a, p. 138)

Reality orientation and validation therapy have been positioned within a psychosocial model of care as therapeutic interventions which are designed to improve the social and psychological wellbeing of people with dementia (Adams, 1998; Clarke, 1999). However, there are significant institutional issues that limit the utility of these sophisticated communication approaches. Productive and affirming communication between caregivers and people with dementia requires considerable time as well as knowledge of the different principles underpinning the communication strategies. Institutional constraints, such as inadequate numbers of staff and lack of preparation for caring for people with dementia, shape and constrain practice possibilities. The dissonance between desirable communication practices as circulated in nursing texts, and the actual organisational conditions that govern nursing practices, are seldom addressed in the nursing literature.

Nurse-patient relationships

Tensions must inevitably occur in social interactions between people with dementing illnesses and nurses given communication difficulties, lack of reciprocity in interactions, and resistance to caregiving at times. In addition, there is the impact of dominant

western discourses of ageing, which represent old age as a time of deterioration and decay, on the attitudes of individual nurses working with older people (Koch & Webb, 1996; Lookinland & Anson, 1995; McMinn, 1996; Reed & Clarke, 1999). A degree of ambivalence in caregiving relationships is indicated by the research interest in nurses' attitudes towards people with dementing illnesses. Various factors such as institutional environments, management and education, have been found to influence nurses' satisfaction with caregiving (Alfredson & Annerstedt, 1994; Gilloran, McKinley, McGrew, McKee, & Robertson, 1994; Kuremyr, Kihlgran, Norberg, Astrom, & Karlsson, 1994). A particularly difficult practice issue for nurses highlighted in this literature is in finding personal meaning in caregiving (Kuremyr et al., 1994).

The nurse-patient relationship has preoccupied Anglo-American nurse scholars for decades since Peplau's (1988) pioneering work in the 1950s envisaging this interaction as a therapeutic,² interpersonal process. Since this early work American nurse theorists have produced varied and esoteric depictions of nurse patient encounters in their attempts to develop metanarratives of nursing (see for example Neuman, 1995; Orem, 1991; Parse, 1981; Peplau, 1988; Watson, 1998). There has also been a substantial research interest in nurse-patient relationships (for example Christensen 1990; May, 1990, 1991; Morse, 1991; Morse, Havens, & Wilson, 1997; Muetzel, 1988; Taylor, 1994; Williams & Irurita, 1998). But there has been relatively little interest in exploring nurses' relationships with people who have a dementing illness apart from the work of Scandinavian nurse researchers (Berg, Hallberg, & Norberg, 1998; Häggström & Norberg, 1996; Häggström, Jansson, & Norberg, 1998; Norberg & Asplund, 1990; Rundqvist & Sverinsson, 1999). It is of interest that in some of these accounts caring for people with dementia is represented by the participants as being maternal and family like in nature (Häggström & Norberg, 1996; Rundqvist & Sverinsson, 1999).

The carer's attitudes towards the inhabitants of the ward and each other were based on respect as in a functioning family. Their ambition was interpreted as an attempt to create an atmosphere that functioned not only as an institution, but as an incubator for human lives, which had become dependent on others for their survival and the preservation of their human dignity throughout their physical existence. (Häggström & Norberg, 1996, p. 431)

² A therapeutic nurse-patient relationship, as defined by Stuart and Laraia (1998), involves mutuality as both parties learn from the encounter, the nurse contributing personal and clinical knowledge in working with the client to support her/his adaptation to the stresses being experienced as a consequence of health changes.

This link between nursing and maternal type care does not feature in the mainstream Anglo-American literature exploring nurse-patient relationships. One exception is a study by Street (1992) which found that nurses in the study, working in acute care settings, found satisfaction in relationships they described as nurturing. The Scandinavian studies highlight the possibility that practitioners may well represent nursing, in situations where the medical and technological contribution is very limited, as being predominantly emotional in nature and talk about long term close relationships with patients using familial terms.

Visual representations of people with dementia

The visual representations in nursing literature of people with dementia also reflect nurses' concerns. Illustration 4.1 was used to illustrate the cover of a special issue of the *Journal of Gerontological Nursing* (February, 1999) focusing on Alzheimer's disease. This illustration conveyed, for me, impressions of sadness and isolation through the use of black and brown tones and through the person's facial expression. The texture of the illustration also contributed to the affective tone with its impression of a fragmented, disrupted surface reminiscent of aged skin or parchment. The illustration of an elderly man (illustration 4.2), positioned prominently with an article about disruptive behaviour in another edition of the same journal (*Journal of Gerontological Nursing* [January, 1999], illustration reproduced on the cover & p.8), provides an interesting contrast. The elderly man depicted in the illustration is painted in florid red tones. His arms are upraised and he is frowning. He is obviously elderly and is positioned as a patient in an institution with the use of such cues as pajamas and the corridor handrail in the background. My interpretation of this illustration is that the man is angry and his hand is raised to fend off other people. He appears to be snarling with his half open mouth and exposed lower teeth. This is an alienating and dramatic representation of the person with dementia far removed from the notions of subjectivity associated with the *civilised* body.

Kitwood (1997) produces very different representations of people with dementia from the two previously discussed illustrations. His images, in common with the illustrations from the nursing journal, are produced in reaction to concerns about the person with dementia's ability to communicate and to interact. But he chooses, both visually and



Illustration 4.1 Cover illustration for the February 1999 edition of the *Journal of Gerontological Nursing*. Cover photo by Richard Robinson/Image Bank, Swanstock Collection. Used with permission from the publisher.

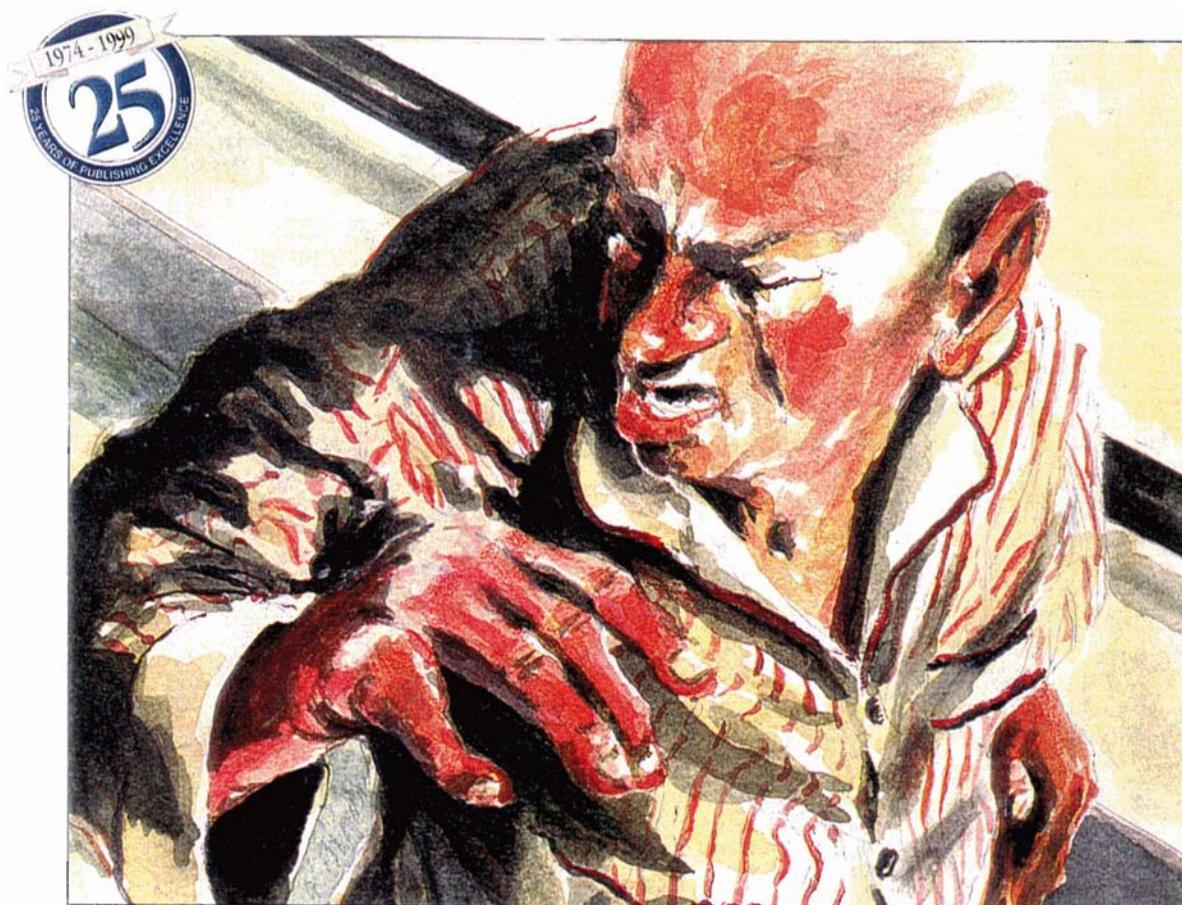


Illustration 4.2 Cover illustration for the January 1999 edition of the Journal of Gerontological Nursing. Used with permission from the publisher.



Darnall Dementia Group, Sheffield. Photograph: Paul Schatzberger



Well-being in dementia

Having dementia does not, in itself, entail a loss of personhood. These pictures all show people with a high level of well-being, despite the presence of cognitive impairment

The Grange Day Unit,
Sunderland. Photograph:
Sue Benson

Illustration 4.3

Photographs used with permission from the publisher. From Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. [p. 12]. Buckingham: Open University Press.

linguistically, to foreground the humanness of the person with dementia and the possibilities for human connection. The photos in his text, taken in specialised dementia care units, consistently portray the person being cared for in the company of others and often involved in domestic or recreational activities (see illustration 4.3).

The contrast between the images from the *Journal of Gerontological Nursing* with Kitwood's representation of people with dementia draws attention to the power of different discursive representations in terms of shaping possibilities. Kitwood's choice of images suggest that loss of contact with other humans is not a fully inevitable and pathological consequence of dementing illnesses, but rather that retaining contact is dependant on the actions of those people in continuing close contact with the person with dementia. This representation is positioned within a psychosocial approach to care and representations of the person with dementia as an experiencing human being with emotional and social needs. In contrast the illustrations from the *Journal of Gerontological Nursing* foreground problematic aspects of dementing illnesses from a nursing perspective. Neither of these discursive framings of people with dementia are false, but they are both partial and seek different ends. The dramatic representations of people with dementia in nursing literature stress the significance of particular caregiving issues in an attention grabbing but bleak manner. These representations of older people with dementia in nursing literature are firmly embedded in dominant western discourses of ageing which represent old age as a time of deterioration and decay (Reed & Clarke, 1999). Nurse readers are confronted with the stark images in an attempt, I suggest, to generate interest and action in this area of practice. In contrast, Kitwood's representation is rather more romanticised with his presentation of well-dressed smiling people enjoying the moment. In this depiction, the problems of everyday practice that are emphasised in nursing journal illustrations are suppressed, and the abilities of people with dementia highlighted in the context of supportive caregiving.

Summary

In this review of nursing literature my intention has been to highlight problematic aspects of nurses' representations of people with dementia. However, as previously discussed, there are challenges to the conventional representations of dementia in nursing literature, and changes are evident in nursing practice. In the discussion about

the management of problem behaviour, nursing responses are commonly aimed at controlling behaviour through individual interventions. However, the broader issue of organisational constraints, on both the lifestyle of people with dementia and nursing responses, is also articulated, and more recently published literature suggests that difficult behaviours of people with dementia are precipitated by social and environmental stresses. This discursive shift has important ramifications in terms of the development of relations of power (rather than those of force) between people with dementia and their caregivers. People with dementia are inscribed with a degree of agency from this perspective, as human beings who respond in understandable ways rather than as being portrayed as a problematic object to be contained. Appropriate responses in this conceptualisation of care include acknowledging the feelings of the person being cared for, and adapting the institutional environment to their needs.

Assessment practices are generally uncritically advocated in nursing literature as having a variety of useful functions. The disciplinary practices that Foucault describes of hierarchical observation and normalising judgement have ready applicability in this nursing context and serve to destabilise the notion that assessment is a neutral and value free exercise. The minimal discussion warning of possible stigmatising effects of assessment processes for people with dementia, and the neglect to attend to such issues as the experience of pain draws attention to the problematic aspects of assessment practices.

Communication emerges as a therapy in nursing literature in a context where medical science is powerless to provide curative or palliative assistance. A range of communication options, all based on quite different premises, can be used by nurses caring for people with dementia. In particular, validation therapy signals an important shift from health professionals controlling communication to acceptance that communication efforts of the person with dementia has validity and value. However, I have also noted that adequate institutional support for nurses in terms of education and the time allocated for care is a fundamental determinant in terms of the style of communication used by nurses.

I have also discussed how nurse researchers have explored nurse-patient relationships in the context of caring for people with dementia. In the Anglo-American nursing

literature there has been little research interest in nurse-patient relationships in this context of care. This gap in research-based knowledge may well become a fertile area of inquiry in the future. It is evident from the literature that nurses' relationships with people with dementia have problematic dimensions. Nurses' attitudes to caregiving are shaped by the dominant representations of ageing in circulation in Western societies. In addition, nurses can have difficulty in finding meaning and work satisfaction in caring for people who are unable to respond and reciprocate in an overt manner.

Attention has also been drawn to the contrasting visual images of people with dementia appearing in nursing and other health professional texts. These representations, like all representations, are partial and produced for particular purposes. Possibilities for practice are created through their deployment, just as other aspects of living with a dementing illness or particular caregiving exigencies are suppressed.

CHAPTER FIVE

Respite Care Literature: Rhetoric, Realities and Omissions

Introduction

In this chapter I provide an overview of the respite care¹ literature in order to locate the following analysis of family caregiver and nurse texts in a wider discursive context. In particular I draw attention to how prevailing economic and community care discourses have constructed the family caregiver as the object of concern and inquiry for research and policy interest in this area, with the subsequent disqualification of the concerns and issues of health care workers providing the substitute care in respite services. Initially, the discussion focuses on the comparatively recent development of respite services for older people and their caregivers over the last few decades, and the factors that have contributed to the legitimisation of the provision of respite care services in health care. These factors include the promotion of community care policies that shift the location of caregiving from institutions to the family with, consequently, the work of caregiving often provided by one family member, and the findings of studies demonstrating that family caregivers caring for chronically ill family members may themselves experience ill health.

¹ Respite care is defined as the temporary physical, emotional or social care of a dependent person in order to provide relief from caregiving to the primary care provider (Miller, 1991; Weber & Schneider, 1993). Respite care is divided into two categories, *informal* or *formal*. Informal respite care is provided by family and friends. Formal respite services are provided by organisations and can be divided into three types: respite within the person's home, adult day care, and overnight or short-term admission for residential care.

The discussion then moves to a review of the respite care literature. Researchers have concentrated on two areas: (i) caregivers' perceptions of respite care services and the effect of respite on their burden and stress levels; and (ii) the effect of using respite care services on delaying the transition of dependent people requiring care from home to long term institutional care. These research interests have reflected the prevailing dominant model of respite care services where caregivers are seen as the clients of services. The explicit aim of policy underpinning the provision of respite care services is to improve caregivers' quality of life with, it could be argued, an implicit economic agenda of reducing the use of long term institutional care. However, research findings expose major discrepancies between the aims of respite care, and the actual outcomes of using these services, with the family caregiver burden actually being increased in some instances. I also remark on the by now predictable lacunae in the body of research knowledge about respite care services, that is, the absence of attention to those placed in respite care settings about the factors bearing on quality care. Instead, the impact of respite care is measured either by judging the functional abilities of those admitted to respite care before and after admission, or by using crude measures of mortality and morbidity.

Finally, I highlight the negligible research interest in the quality of formal care provided in respite care services. Nurses' knowledge and concerns, in common with the person requiring care, are suppressed in the literature discussing respite care despite the persistent concerns expressed by family caregivers about quality of care issues and the impact of respite care on the health and wellbeing of their relatives.

Community care policies and respite care

The development of formal respite care services began in the 1960s when respite services were provided in Europe for the caregivers of developmentally disabled people (Weber & Schneider, 1993). Discussion about the need for respite for caregivers of older people first appeared in professional literature in the seventies with the emergence of adult day services (Toner, 1993). This recent interest in the provision of respite care services coincides with the development of community care policies for people with long-term care needs and the emphasis in these policies on the family as the site of caregiving. The shifts in community

care policies, and the ensuing implications for family caregivers, have been discussed extensively (see for example Dalley [1996], McBeath and Webb [1997], and Opie [1992a]). The following account is a brief outline only of the broader sociopolitical context shaping the adoption of particular discourses informing community care policies, and the consequences for family caregivers which have led to the development of caregiver support services such as respite care.

Care in/by the community

The concept of community care was originally advocated in the 1960s in Western nations in response to critiques of institutional care by writers such as Goffman (1968) and as a reaction to “scandals and revelations about appalling conditions in long-stay institutions” (Dalley, 1996, p. 3). New Zealand research reflected the wider critique of institutional care. One study carried out in the 1970s found that forty-three percent of residents of private residential homes (out of a total number of the one thousand and seventy-nine residents surveyed in private rest homes) were in unsatisfactory accommodation with inadequate staffing and inappropriate facilities (Salmond, 1976). Community care policies at this time were developed in order to improve the living standards of people requiring long-term care through the provision of small residential units linked into local communities. Resources from the large institutions were to be transferred to the new types of care provision (Dalley, 1996).

However, over the last two decades, there has been a discursive shift from the emphasis of care *in* the community to care *by* the community and, in particular, to care by the families and friends of disabled people (Jack, 1987). This shift in emphasis from collective to individual responsibility is evident in Koopman-Boyden’s (1988) definition of community care as being the “help and support given to individuals, including children, people with disabilities and elderly people in non-institutional settings. Such care may be provided by familial, informal or formal helpers, or by a combination of all three” (p. 638).

This transformation in the discourse about community care was based in part on the belief that there would be a reduction in health care expenditure through shifting the costs of

caring from institutional care to families and to less expensive community care programmes. In New Zealand, as in other Western countries, this interest in reducing costs has been driven by concerns about escalating demands on health services as a consequence of an increasing older population, the expense of residential care, and increasing government pressure for financial accountability as an integral part of policy development (Koopman-Boyden, 1988). This move from collective forms of care to care as predominantly a responsibility of the family members has been linked to the adoption of *New Right* economic policies by various Western governments (McBeath & Webb, 1997; Opie, 1992a). New Right policies are informed by neo-liberal economic theory, which is based on the beliefs that the right of the individual and freedom of choice is paramount, that there must be a free market and competition, that the state role is limited and that there is the necessity for fiscal restraint (Crowe, 1997). Current notions of community care reflect these values, and McBeath and Webb (1997) suggest the concept has become embedded in a “discursive matrix - of individualism, familialism, voluntarism, managerialism and market accountability” (p. 37).

The premise that community care costs significantly less than institutional care has been challenged (see, for example, Bowie and Shirley [1994], Glendinning [1992], Rimmer, [1983] and Opie [1992a]). The significant costs of caring for caregivers are suppressed when the cost of community care policies is calculated purely in terms of public expenditure. Family expenses include direct costs such as home alterations, extra heating needs, laundry and equipment; and indirect costs in terms of less leisure time, changes in personal relationships and constraints on paid employment (National Health Committee, 1998). A recent New Zealand study comparing the cost of care for people with disabilities in the home to resthome care, found caring for a person at home was more expensive than originally expected (Belgrave & Brown, 1997). The formal cost of caring for people in rest homes averaged five hundred and eight dollars a week while formal care in the community averaged three hundred and fifty-three dollars per week. The quantifiable costs of informal care for family and friends was also identified for both groups and found to be sixty-seven dollars per week in the rest home and one hundred and thirty dollars at home. Belgrave and

Brown (1997, p. iv) found there was little difference in measurable costs between rest home and community care but marked qualitative differences in that

...carers in the home suffered considerably more non-financial costs, such as stress and social isolation. The drudgery of providing day-to-day care was significant, but it was the ongoing, inescapable responsibility for care all day every day which was the real burden of care.

The family as site of care

An underlying premise of community care policies, that the family has a moral duty to care for dependant relatives and there should be minimum state intervention (Dalley, 1996) has also been contested. In New Zealand, at least eighty percent of people with dementia live in the community (Sainsbury et al., 1997) where care is frequently assumed predominantly by one family member (Opie, 1992a; Richmond, Baskett, Bonita, & Melding, 1995). Opie (1992a, p. 190) argues that:

A clear distinction needs to be made between the site of informal caring (family) and the family member doing the caring. Defining caring as performed within the 'the family' suppresses the fact that the actual work is generally performed by one member, and it cannot be assumed that other family members will be available or willing to support the carer.

Support within families can be restricted for many reasons such as widely geographically dispersed family members, the health of available caregivers, limited numbers of relatives on whom to call upon for help, and the quality of the relationships between family members (Opie, 1992a). There has been considerable research interest in the possible physical and mental health consequences for family members caring for chronically ill people (Fengler & Goodrich, 1979; Shanas, 1979), and evidence suggests that the work of caregiving, unequally borne within the family, can impact on the health of caregivers. In a study by Sanford (1975), over half of the fifty caregivers of older people interviewed attributed their feelings of anxiety and depression to caregiving. In other studies, caregivers of people with dementia showed higher rates of psychological stress (Anthony-Bergstone, Gatz, & Zarit, 1988; Brodaty & Hadzi-Pavlovic, 1990), and fatigue (Teel & Press, 1999), than non-caregivers. Rabins (1993) also found that, in contrast to matched non-caregivers, caregivers

showed higher rates of physical fatigue, as well as a greater use of antidepressants and medical services. A New Zealand study (Richmond & Moor, 1997) explored the impact of case management as an intervention in terms of the quality of life of older people remaining at home and their carers as compared to a control group admitted to long term institutional care. They found that the morale of the homecare caregivers, as compared to families whose relative was in residential care, was lower and their stress levels were higher.

Feminist writers have also contributed to the critique of community care by drawing attention to the position of woman as caregivers (Dalley, 1996; Finch & Groves, 1983; Graham, 1993; Wilson, 1982). Initially, Dalley (1996, p. 12) states that it was assumed "in a rather uncritical fashion, that the overwhelming majority of carers were women" generally middle aged, balancing the competing demands of child care, supporting elderly relatives and the need for paid employment. Subsequent studies challenged this assumption to some degree, in the findings that family caregivers were more a diverse group than formally thought. For instance, in New Zealand, Jack's (1987) study of one hundred and twenty one family caregivers found that one third of the caregivers were men while in Opie's (1992a) research ten of the twenty-eight caregivers caring for relatives with dementia were male. In contrast, Belgrave and Brown's (1997) study found that eighty percent of the sixty-five family caregivers were women. So while it appears that men do contribute more to the direct caregiving of dependent people than was originally thought, it is also evident that women are more likely to become carers than men. It is also significant that women generally provide the more onerous personal aspects of caregiving such as bathing, lifting and feeding the person (Dalley, 1996). The provision of these aspects of care, which require ongoing personal contact, disadvantage women in comparison to men in terms of opportunities for career development and accumulation of personal wealth, and also restrict access to pleasurable social activities.

Given the juxtaposition of the rhetoric about community care with its assumptions about how responsibility for care is shared collectively and the actual reality of caregiving as essentially a solitary occupation, it is not surprising that there has been an increasing interest from health professionals and family caregivers in support services, such as respite

care services. Care for dependent people is shifting from a discussion based on an either/or dichotomy of home or hospital care, to the notion of integrated care drawing on different sites of caring, home and hospital, and formal and informal services (Belgrave & Brown; 1997). Recent research and policy documents about caring for dependent people in New Zealand stress the need to provide respite care services to support family caregivers (Belgrave & Brown, 1997; National Health Committee, 1998; Sainsbury et al., 1997). However, these recommendations promoting the need for flexible and appropriate respite care services are not always solely made for altruistic reasons such as improving family caregivers' quality of life as the following statement by the National Health Committee (1998, p. 9) illustrates:

If carers didn't give their services for nothing, caring for people with disabilities would cost taxpayers a great deal more than it already does. So it's vital we look at **what services carers need** to allow them to keep on doing their unpaid work which might be a lifelong commitment.

The economic imperative is still a major factor driving the current interest in support services for family caregivers, just as interest in reducing the cost of care in eighties underpinned the shift of the site of care from the hospital to the family. The simultaneously interconnected, but, at times, competing discursive elements circulating around community care policies, one foregrounding quality of life issues, the other emphasizing fiscal restraint, surface again in the following discussion of the different agendas apparent in the considerable research interest in respite care services.

Using respite care services

The major assumption underpinning respite care provision is that caring for a dependent person is stressful because of ongoing and unremitting caregiving responsibilities, and that temporary relief from those responsibilities will reduce stress (Toner, 1993). The findings of several research studies support this position. Respite care was the leading service need reported by the family caregivers of older people in studies by Baldwin (1990), Caserta, Lund, Wright, and Redburn (1987), and Wallace (1990). Levin, Moriarty, and Gorbach (1993) reported that over half of the two hundred and eighty-seven elderly people with

dementia who participated in their research were never left alone in the house. Respite care services were valued by the caregivers in this study because of the opportunity to have some free time and relax, go on holiday and re-establish relationships with friends and family. Once used, the respite care services were rarely discontinued. Homer and Gilleard (1994) found that the majority of caregivers using hospital intermittent care felt respite was worthwhile (seventy-four out of seventy-seven), and most of those wanted more respite care. In another study of caregivers of people with predominantly physical disabilities using intermittent care, there was a significant improvement in caregiver mental health (Caradoc-Davies & Harvey, 1993). With reference to caring for people with Alzheimer's disease, Larkin and Hopcroft (1993) and Adler, Ott, Jelinski, Mortimer, and Christensen (1993) found that anxiety and depression were significantly reduced during the intermittent care period.

However, while some evidence suggests that respite care services provide important and necessary support for family caregivers, caregivers also express significant concerns about using the service. Using respite care services will not automatically reduce stress and, unsurprisingly, the quality of the care provided to the person requiring care during the respite period is an extremely important factor in terms of whether using a respite service is a positive or negative experience for caregivers. Caregivers in Twigg and Atkin's (1994) study described using respite services as a distressing experience because of concerns about the quality of care, poor facilities and the impact on their relative of other more disturbed people using the service. The caregivers of elderly people in Worcester and Hedrick's (1997) study reported that the process of using respite services was more stressful than beneficial because of the organisation required before the respite experience, their anxiety about what was happening the relative was in care, and because of difficulties after the respite period. Similarly, Graham (1989) reported that the burden scores of eight out of fifteen caregivers using day care respite increased.

Opie (1992a), in her study of the family caregiving of confused older people, highlighted both the conflict expressed by caregivers and the paradoxes underlying the organisation of respite care services. The caregivers in her study expressed relief at the respite from the

otherwise constant pressure of caregiving, but they also had to contend with feelings of loneliness and guilt as well as considerable disruption to their usual life style. Opie argued that there are several paradoxical areas inherent in the organisation of respite care services if it is accepted that (i) respite care services exist to provide relief to care caregivers by the provision of “quality, temporary alternative care”(p. 178), that (ii) service provision is at least in part based on a recognition of the value of caregivers’ work, and that (iii) the sharing of information between informal and formal caregivers is important for appropriate care. The first paradox identified by Opie is that, while the aim of the respite care service may be to provide relief to carers, the assessment process used to judge the degree of need for respite is focused on the degree of dementia, rather than the degree of stress and fatigue experienced by the caregiver. Secondly, Opie found that many of the caregivers in her study felt that they did not have opportunity to provide what they felt was necessary information about their relative on admission to the service and, furthermore, that there was no staff interest in discussing the person’s care during family visits. Opie (1992a) argued that this “lack of consultation underlined the lack of recognition of the value of carer’s work, symbolically rendering them of little significance to the formal system of care” (p.179). Finally, Opie noted that the local health organisation appeared to actively discourage the use of respite care by the inadequate provision of respite care beds so some caregivers were unable to plan holidays in advance and by providing, from the caregivers’ viewpoint, poor quality of care. Several caregivers in hers study talked about

...the way periods in respite care de-skilled their relatives and how loss of skills (mobility and weightbearing) then affected the caregivers’ ability to continue to offer home care. Two caregivers defined their relatives’ reduction in the ability to weightbear and walk following respite care placement as the result of the staff reduction on the wards. Staff on duty were now too rushed to encourage patients to walk. (Opie, 1992a, p. 180)

McNally, Ben-Shlomo, and Newman (1999), in an extensive review of twenty-nine studies covering all types of respite services, highlight the diverse research findings to date in relation to the effect of respite care on family caregivers’ wellbeing. They suggest that some of the differences in caregivers’ experiences may be explained by the type of respite care service utilised. The findings of the studies they reviewed indicated that intermittent

care was more effective in improving caregivers' psychological wellbeing and relieving stress than home respite care, probably due to the complete break from caregiving. Strang and Haughey (1999) also reported that the caregivers in their study did not associate adult day care programmes with respite, perceiving those services as enabling them to have some time to do household work. However, in contrast, another study (Netto, 1998) focused on the preferences of caregivers from minority ethnic groups in Scotland and found that, firstly, none of the forty-five participants had heard of the residential respite service and, secondly, seven-one per cent of them were not interested in using it. The reasons given included the probable angry response of the person being cared for, and other issues associated with language and culturally specific dietary requirements. The findings of this study suggested that home respite services might well be the preferred option for this group of caregivers. A study by Larkin and Hopcroft (1993) also draws attention to another possible reason for varied research findings with their differentiation between the experiences of first time users and other caregivers who had been on the programme for a longer period. The first time users, in particular, remarked upon their feelings of conflict and guilt about using the service, which might well have impacted on their ability to make full use of the respite time.

Another one of the assumptions underpinning the development of respite care services is that they may delay or avoid long term care placement if carer stress is alleviated, so reducing the financial cost of care to the government (Lawton, Brody, & Saperstein, 1989). A study by Lawton et al. (1989) examined the effectiveness of respite care in delaying institutionalisation for people with Alzheimer's disease. In a randomised experimental control group design with six hundred and forty-two caregiver participants, half the families were offered a range of formal respite care services including institutional care. The families in this study with respite services cared for their relatives with dementia for longer (twenty-two days) than the control group. These authors argued that the extended time frame for caring at home was significant and stressed the satisfaction of the caregivers with respite care services. However, there was presumably little difference in the formal costs of caring for the two groups of people in the research given additional access by the experimental group to formal respite services. Kosloski and Montgomery (1995), in a study of one hundred and eighty-one caregiving dyads who were offered various forms of respite

care, also found that respite as an intervention could prevent or decrease the possibility of long-term care. In this study, an increased use of respite care was associated with decreased long-term care placement, even after control for such factors as age, level of disability and Alzheimer's disease.

Other literature suggests that the relationship between respite services and the reduction of the use of long term institutional care is inconclusive, and the severity of the illness rather than the need for respite precipitates long term institutional care (U.S. Congress, 1987). Alternative care, while providing temporary respite to families, cannot address the underlying problems related to the demanding, complex and time-consuming nature of care in the context of profound disability. It is therefore interesting to note that, contrary to the assumption that respite care will delay placement in institutional care, one study of ninety-nine caregivers using an intermittent care service found that the reported possibility of institutionalisation increased as often as decreased (Scharlach & Frenzel, 1986). These findings indicate that intermittent care services may serve a transition role between home and continuing care, but only for some families. The following quote from a wife caring for a husband with Alzheimer's disease, interviewed in Opie's (1992a, p. 1) research highlights the ongoing tensions between the feelings of obligation and love and the actual demanding, and at time unpleasant, realities of caregiving.

Wife: Day care centers have been set up and I think possibly that one could go on for a longer period, you know. It is preferable that they do stay in their own home. Well, let's face it, it is preferable that anyone stay in their own home, and I think, um, all the support groups and all that keep you hanging in there, but...this peeing all over the place is - you know - not nice, and you say, 'Why me, why me?'...half of me says, 'Right, put them into a rest home environment or some environment and get out'.

Anne Opie: And the other half?

Wife: Go through what I did.

AO: But how can you reconcile those two?

Wife: Well you can't can you? One contradicts the other completely.

There is some debate as to whether intermittent care serves the best interests of the people actually being cared for. Twigg and Atkin (1994) argue that respite care focuses on the caregiver as the client, a model of care that "may in some cases be pursued at the expense

of the cared-for person, at least in the short term” (p. 14). Adams (1996) supports this position, suggesting that when the main aim of day centres and short-term beds is to help the caregiver, there is a danger of marginalisation of the person with dementia with his or her interests being subsumed within the interests of the caregiver.

A number of studies have focused on the effects of intermittent care on the people using the service in order to establish whether or not there are any benefits or consequences for those people. Nolan and Grant (1992) interviewed elderly users of respite beds and found that six out of thirty participants felt abandoned and the majority, at best, tolerated the service. The people in this study who found respite care a positive experience developed significant relationships with staff, were socially adept, were good conversationalists, and believed that the visit would be of some benefit to them. In contrast, the people who felt abandoned did not believe that their caregiver required a break, and were likely to resist admission and refuse to participate in ward activities. These people were most likely to be described by carers as “manipulative, domineering and unappreciative” (Nolan & Grant, 1992, p. 221), indicating that family relationships were already strained.

Several studies explore the impact of intermittent care on people with dementia in terms of their ability to perform various activities of daily living. In one study of the effects of intermittent care on thirty-seven people with Alzheimer’s disease, the more severely functionally disabled participants showed some improvement in relation to activities of daily living during the two week admission, but the functionally more able people declined in performance (Seltzer et al., 1988). In Homer and Gilleard’s (1994) study of in-patient respite care, while the majority of people admitted improved in general functioning, the improvement for people with dementia was not as marked. Adler et al. (1993) found that people with Alzheimer’s disease were more dependent in activities of daily living following time in a respite care facility. These authors suggested these findings could be accounted for by disease progression. Larkin and Hopcroft (1993) also suggest that in-hospital respite care can be associated with risks for the person with Alzheimer’s disease, with eight of the twenty-three clients in their study experiencing a negative health event in hospital such as a fall or developing pneumonia. On a more positive note, Burdz, Eaton, and Bond (1988)

found that caregivers reported improvements in the behaviour of people with dementia after intermittent care. Another positive finding, from Munro-Ashman's (1989) study of a geriatric unit of a general hospital, was that one-third of the people using the intermittent care service benefited from the treatment of previously undiagnosed illnesses and/or changes in medication.

There has also been interest in whether or not hospital respite care is associated with increased mortality in older people. Rai, Bielawska, Murphy, and Wright (1986) described a mortality rate of twenty-two percent of people using overnight respite care services, and so advocated respite within the home rather than hospital admission. However, other studies found that mortality rates in respite care are not significantly higher than at home (Seeley & Campbell, 1989; Howarth et al., 1990).

The research findings about the impact of respite care on the people using the service are far from conclusive. But what is significant, in terms of the focus of this study, is that none of these research studies have expressly addressed the role of nurses in ameliorating, or alternately exacerbating, the impact of institutional care on people with dementia, and how this role in the production of quality care is strongly influenced by organisational practices.

On the margins: Nursing and intermittent care

The minimal interest in the nursing contribution to respite care services such as intermittent care is surprising given the central positioning of nurses with regard to care provision, and the well-documented family caregivers' concerns about the quality of care provided. Care in respite services is extremely complex as nurses have to provide necessary nursing care to a reluctant and possibly angry person who has been unwillingly relocated from home to hospital, as well as try and allay family members' concerns, and mediate between long-term and temporary residents' needs. In an early article, Ellis and Wilson (1983) discussed the difficulties in the provision of respite care from a nursing perspective, noting that nursing staff had trouble coping with respite patients who did not want to be in the unit, and that the least successful referrals were patients with Alzheimer's disease who became anxious as the caregiver left, or wandered away from the ward. Homer and Gilleard's (1994) study is a notable exception in the respite literature in recognising, albeit in a very

brief aside, that nursing care may be a factor in respite care outcomes for people using the service.

The patients themselves more often than not show signs of improved functioning. Although patients were not routinely seen by therapists during their stay, nursing care was individualised on the respite wards, and this style of nursing has been shown to foster greater physical independence. (p. 275-276)

Lyman's (1993) ethnographic study of staff experiences working in eight Californian Alzheimer's day care centres makes a significant contribution to the development of a nursing perspective in this otherwise almost totally neglected aspect of respite care. Lyman found that staff members experienced work-related stress in the day care centres as a result of the demanding nature of the caregiving, their lack of control over the working conditions, and a perception that social support was lacking. The resultant stress management strategies adopted by staff members created power relationships in caregiving that amplified the losses resulting from the disabilities associated with dementing illnesses. She argued that dementia care is a "reciprocal, stressful relationship" (Lyman, 1993, p. 160), often involving a cycle of imposition of strategies of control by staff, which appeared to create feelings of loss of control by those receiving care, and resulted in subsequent behavioural problems. She also argued that there has been little research interest in direct care service providers compared to family care-givers.

Front-line service workers might be seen as the "third victims" of dementing illness. These workers play a critical role in maintaining quality of life for people with dementia and in offering respite to family care-givers so that they might continue to meet the needs of others while preserving their own health and productivity. But to date there has been scant research interest in dementia service providers. (Lyman, 1993, p. 160)

One explanation for the otherwise puzzling absence of nursing knowledge in respite care literature is connected to the dominance of biomedical knowledge and the needs of family caregivers in the professional discursive constructions of dementia informing policies, services and research. Nurses' everyday knowledges and practices have been marginalised in this discussion, along with the knowledge of the people requiring care. Another explanation draws upon a wider body of nursing literature arguing that nurses' everyday

work is generally invisible in health care discourses (Campbell, 2000; Colliere, 1986; MacLeod, 1994). Campbell (2000) suggests that nurses' positioning within a traditional gendered profession contributes to the disappearance of nurses' work. She suggests that those in more powerful positions in health care services such as managers (and I would suggest policy makers and researchers) are oblivious to the ongoing work necessary to produce satisfactory care within health organisations. In essence, registered nurses have "been so successful in this invisible mediation that the work process through which it gets accomplished is being, or is in danger of actually being, cancelled"(Campbell, 2000, p. 187). The disappearance of nursing work is signaled in this research context by the absence of interest in nurses' contribution to respite care services, and in how the care they provide affects people with dementia and families. Yet, as Campbell, (2000, p. 193) suggests,

in actual health care workplaces, unexpected things happen that continually require reliably intelligent intervention by nurses. No plan can be counted on exclusively...The eliminated nurse is constantly being expected to hold workplaces together, but she has to do so behind the scenes, in an unrecognized way. This is what I call the virtually disappeared nurse.

Campbell's argument is very pertinent to the context of dementia care in general and intermittent care in particular. As has been reiterated throughout the preceding discussion in this thesis, in the context of the institutional care of people with dementia, nurses work in a contested space, caught between organisational forces and the individual concerns of people with dementia and their families. Everyday practices by nurses in this arena are significant and it cannot be presumed, as seems currently to be the case given the gaps in the intermittent care research agenda to date, that nursing care is an instinctive, routinised, interchangeable and unimportant process.

Summary

Part of the work of this chapter has been to emphasise the extent to which the discourses informing community care policy development, one foregrounding family caregivers' needs and the other New Right economic principles, have shaped the research on and discussion about respite care, and the allied research interests. Respite care literature has focused extensively on the value of respite care services in terms of reducing caregivers'

burden. This account is, however, to some extent undermined by the studies that identify a number of factors that challenge assumptions that using respite services will relieve stress. Instead the quality of institutional care emerges as a major determinant of caregiver satisfaction with respite services. Clearly, if family caregivers are committed to the best interests of their family member, then respite care is unlikely to relieve their burden if the person receiving care is treated unkindly or receives substantially poorer care than what would be provided at home. In addition, if the person receiving care returns home with reduced abilities than on admission to the institution, this may well increase demands on the carer and result in twenty-four hour hospital or rest home care being required. The second major area of discussion in respite care literature is based on the premise that using respite services may enable families to care for longer periods of time and hence delay the more expensive option (for the state) of institutional long-term care. This premise has also been challenged by the contradictory research findings, which indicate that while using respite care in some instances, may delay institutionalisation, in other cases the possibility of institutional long-term care may be increased.

This privileging of caregiver and economic issues in the literature has been detrimental to the interests of the other central people in the field of respite care: the recipients of care and formal caregivers. Throughout much of the literature the experiences of the recipients of respite care service have received little attention. Existing studies make it clear that using respite care has a considerable negative impact on the health and wellbeing of some users while for others there seems to be some benefit. Once again, the quality of care provided by formal caregivers emerges as a critical factor in terms of providing the complex physical and social supports necessary to sustain frail and disorientated people temporarily relocated to unfamiliar environments. Yet, although nurses are central to the provision of quality respite care, their role and their impact on caregivers and care recipients using intermittent care services, remains unexplored, as does the role of the organisational environment in relation to facilitating or constraining nursing options.

This chapter marks the end of the first section of the thesis *Mapping the Field*. My engagement with the disparate fields of knowledge that have been the focus of the

preceding discussion began with the theoretical underpinnings of this study, the work of Michel Foucault. I have then examined the disciplinary representations of dementia, nursing and respite care as produced in published texts. In the next section of this thesis, *Representing Practice*, the discussion shifts to the representations and everyday micro-practices of the nurses and families who participated in this study.

PART II

Representing Practice

CHAPTER SIX

Researching Nurses' Everyday Practices in Intermittent Care

Introduction

This chapter marks a shift in the thesis focus from the examination of the published texts informing nurses' practices, to the production and analysis of accounts of nurses' everyday practices in intermittent care services. The aspects of Foucault's work that have informed my textual analysis have been discussed in chapter two. This chapter introduces the second part of the thesis with a methodological account of how I explored the research topic with nurses and family caregivers. Firstly, I describe the research sites where the study was undertaken and briefly outline the shifting politics and policies underpinning current intermittent care provision and the impact on local service provision. This research was carried out during a time of considerable change in the delivery of health care in New Zealand and the experiences of the families and nurses reflect the dynamic nature of contemporary health care provision. I then address the scope and process of data collection and the ethical issues along with the data analysis and, in particular, my reflections about the representational issues that inevitably occur as part of the writing up of the research account.

Locating the research

This research has been undertaken in five wards providing intermittent care services located in four hospitals. Originally, in 1994, data collection was undertaken in the intermittent care services provided by two publicly funded hospitals based in Assessment, Treatment and

Rehabilitation (AT&R) wards. These wards catered for people aged sixty-five and over requiring treatment for acute illness, assessment of medical conditions, rehabilitation and intermittent care. During this period I interviewed seven nurses and six family caregivers. In 1996 the responsibility for intermittent care shifted from the public hospital assessment and rehabilitation wards to private hospitals and I negotiated access to two private hospitals and interviewed eight nurses and six family caregivers (three caregivers had been previously interviewed in 1994).

The considerable complexity of collecting data from four different hospitals was forced upon me as a result of political contingencies. However, there were benefits in conducting this research during this shift away from public to private care. Firstly, it was possible to analyse the impact of organisational differences between the more acutely orientated AT&R wards and the privately owned and smaller private hospitals on nursing practices and family caregiver experiences. Secondly, I had the opportunity to interview some caregivers for a prolonged period, as they had to move their relatives to new providers of intermittent care. Their ability to contrast the care provided in different services provided valuable insights into the diversity of nursing practices and the organisational issues that impacted on family caregivers and the recipients of care. While, from a Foucauldian position, the search for causal or determinant elements is not a theoretically useful endeavor, there is space in this approach to search for the contingent factors that might influence certain events and actions (Kendall & Wickham, 1999). The following discussion signals the multiple factors such as the overarching political milieu, the material environment, and the social context, shaping the repertoire of practice options available to nurses caring for people with dementia in institutional settings.

The research sites in the New Zealand health care context

The restructuring of New Zealand's health care system in the last decade of the twentieth century has been characterised by the rapid and ongoing re-configuration of the services, and by an ideological shift from a community service orientation to a more market-driven and competitive health care service. New Zealand's respite care services are just one very small component of this radically reorganised health care system. In order to situate respite

care within in this broader New Zealand health care context, I will briefly outline the key organisational changes and policy shifts underpinning health care provision at the time of data collection.

The restructuring of health care services in the eighties was dominated by the introduction of Area Health Boards. The introduction of the *Area Health Boards Act* in 1983 enabled the amalgamation of the Health Districts previously responsible for public health activities with existing hospital boards into fourteen Area Health Boards (AHBs). Board members were elected by the local community at three yearly intervals, and population-based funding was also introduced. Specific provision for people with age-related disability¹ was predominantly through AHBs funded by the Department of Health. Services included assessment and rehabilitation, day hospital services, free of charge continuing care beds, intermittent care beds and community health services. Area Health Boards also acted as purchasers of private hospital continuing care beds, paid partly by a government fee-for-service payment known as the Geriatric Hospital Special Assistance Scheme (GHSAS). The Department of Social Welfare focused on community care and administered the Aid to Family subsidy which included a twenty-eight day provision for respite care, the Rest Home subsidy and the Home Help subsidy.

In the research region, intermittent care for people with age-related disabilities was provided by continuing care wards in public general and psychiatric hospitals, or by private continuing hospitals beds contracted by public hospitals. In 1985, a total of thirty-seven intermittent care beds were available in the region, thirty-two in public hospitals and five in private hospitals, and one hundred and fifty families were involved in the programme. This service was free of charge and available to older people with disabilities who lived with a caregiver, and who were assessed as requiring continuing care in a hospital. People eligible for this service received intermittent care in institutions on a prearranged basis, generally for two weeks with six to ten weeks at home depending on the degree of assessed need. The Aid to Families/Alternative Care Scheme, administered by the Department of Social

¹ Physical, intellectual or psychiatric disability related to the onset of old age. Conditions such as Alzheimer's disease that can affect younger people are included in age-related disabilities.

Welfare, provided financial assistance for up to twenty-eight days a year for the respite care of people requiring the continual presence of a caregiver who did not meet the criteria for continuing care in a hospital. This form of respite care was generally provided by a rest home or day care centre, but the financial assistance did not necessarily cover the full daily amount of rest home care.

The introduction of AHBs took from 1985 until 1989 to be completed, but by this time their future was already problematic. A report by the Hospital and Related Services Taskforce (1988), commissioned by the Labour government of the time, presented a case for the separation between funders and providers of health care. Members of the taskforce believed that this separation would enable “a market to be created in which prices are set by modified competition between hospitals” (Hospital & Related Services Taskforce, 1988, p. 26). The taskforce also recommended six Regional Health Authorities (RHAs) to be set up as purchasers for pre-specified treatments. These reforms were enacted within a broad framework of economic and social policy reform, which had commenced with the election of the Labour government in 1984, and involved measures to liberalise the economy and corporatise and privatise the public sector (Scott, 1994).

Within a few weeks of winning the October 1990 election, the new National government declared its intention of radical reorganisation of the health care system. This announcement was quickly followed up with the dismissal of AHBs in 1991 and their replacement by commissioners. In July 1991, the paper *Your Health and the Public Health* was released by the (then) Minister of Health, Simon Upton. This paper drew upon the work of a small group from the health and business sectors. Their brief was to analyse all previous research and reports and develop a model of health care which, among other objectives, “emphasised the need for recognising and fostering individual responsibility for health” (Upton, 1991, p. 10). Reform of the health system was justified because of perceived issues such as problems with accessibility, lack of consumer voice, and increasing expenditure without obvious allied benefits. While these premises for change are debatable (see Bowie, 1992; Martin, 1992), there were significant concerns about poor integration between primary and secondary health care and the lack of incentive to provide

the most cost effective services (Scott, 1994). As a consequence, far-reaching reforms were proposed. These included the integration of primary and secondary care funding and the separation of the purchasing and provision of care. Four Regional Health Authorities² were developed to act as purchasers, and the current AHB hospitals were established as Crown Health Enterprises (CHEs).³ The CHEs were to be “established on more business-like lines...with appointed boards of directors drawing on business as well as health sector expertise” (Upton, 1991, p. 4).

Restructuring of services for people with a disability was announced with the government report, *Support for Independence for People with Disabilities: A New Deal* (Shiple & Upton, 1992) and enabled by the *Health and Disability Support Service Act* (1993). The critical components of the suggested reforms included the ring fencing of disability support services and the administration of general health services by the RHAs. The RHAs assumed the responsibility for purchasing services for all people with disabilities from private, public and voluntary agencies funded by government on a population-based formula. All prospective recipients of disability services contracted from the RHAs were now required to go through a standardised assessment process undertaken by contracted assessors in an attempt to improve the matching of client needs to service provision, and to reduce expensive institutional care (National Health Committee, 1999).

Considerable uncertainty was expressed by the nurses and families interviewed in the AT&R wards about the future of intermittent care in the region as the local CHEs were actively withdrawing from offering continuing care services. Continuing care wards were in the process of being closed and people requiring continuing care were being transferred to private hospitals. The future of intermittent care in the CHEs was tenuous as intermittent care beds were funded under continuing care provisions. As it transpired, the local CHEs did not contract with the RHA for either the coordination or provision of intermittent care.

² The four RHAs were amalgamated into one organisation, the Health Funding Authority, in 1997. This organisation has been merged with the Ministry of Health in the year 2000 following the election of a Labour government in 1999. Reduction of administration costs is the major rationale for the return to the previous organisational structure. Twenty-two partly elected District Health Boards are also being formed.

³ CHE's were renamed Hospitals and Health Services in May 1998 and changed in status to not-for-profit companies.

A private organisation, already coordinating home care services in the region, took over the coordination of intermittent care services during 1995. Its role involved negotiating intermittent care contracts with hospitals and rest homes, informing families about the institutions, and monitoring the quality of care provided. The service was still subsidised, but there was no longer access to the same degree of free medical care, occupational therapy and physiotherapy.

At the time of the transition to private providers there were about one hundred and twenty people in the intermittent care programme in the research region. By the beginning of 1996, when I recommenced data collection in the new intermittent care sites, ten private hospitals in the greater region had one to four intermittent care beds with a total of twenty-five intermittent care beds. This was a reduction in beds from the thirty-seven offered a decade before, but the decrease may have been offset by the availability of more flexible respite options, including respite within the person's home.

The sites

In this section I provide a description of each research site in order to highlight the physical similarities and differences between each area. My aim is to draw attention to the effects of organisational practices on the material environment that the nurses worked within. In following analytic chapters the physical environment emerges as a significant factor influencing the repertoire of practices available at any particular time to individual nurses.

The two AT&R wards focused on the assessment, treatment and rehabilitation of older people. These people were usually acutely ill, or in the early stages of recovery and requiring rehabilitation. Each ward had five beds dedicated for the use of people requiring intermittent care, that is, pre-determined periods of in-patient care provided for twelve consecutive days. The amount of time between admissions varied from six to twelve weeks depending on factors such as the health professionals' judgement of the degree of need, the caregivers' determination of what best fitted their pattern of caregiving and the availability of beds. These wards have been labeled sites one and two in this research.

The private hospitals, identified as sites three and four, provided long term care for significantly disabled older people. Each private hospital ward had three intermittent care beds providing intermittent care and one of the hospitals had two wards providing respite care services. The distinctive features of each of the wards are briefly described in the following discussion. Table 6.1 summarises the key characteristics of each site. Readily identifiable aspects of the sites have been altered or omitted where, in my judgment, this would lead to a ready identification of the hospital.

Site one: Site one was part of an upper floor level of a large multistorey building. Access to the ward was through a network of long linoleum-covered corridors ending up at a glass-paneled door which was locked in such a way that entry into the ward just needed the turn of a knob. Leaving the ward was more complicated, requiring the entering of a numbered sequence on a keypad lock. My most vivid first impression on entering the ward was of yet another long and wide corridor stretching into the distance with technical equipment related to body care, such as wheelchairs, commode chairs and a linen trolley and skip, lined up along the walls. Cubicles and service rooms opened on to the corridor.

Elderly people sat on or by their beds, and were generally dressed in night attire although it was day time. They could be seen by people passing by, both through the open cubicle doors and the windows opening into the corridor. Some people watched the television in the very small lounge at the end of the corridor. Recreational activities organised by an occupational therapists also took place in this room. There were few signs of personal possessions in the mainly four and two bedded cubicles, and bed linen was generally white with occasional pastel covered cotton quilts. The presence of nursing staff was most evident in the ward office, especially at the change of shift in mid-afternoon. Activity levels in the ward varied but generally there were people on trolleys being transported to various destinations, nurses and physiotherapists walking or wheeling people along the corridor, and occasionally doctors' rounds in progress.

Site two: Site two, like site one, was located in an upper floor of a large ward block. Once again access was through a system of corridors. This site had recently changed from a

residential ward to a unit with an assessment and rehabilitation focus. The ward was relatively recently built. The corridor was a U shape with central service rooms and an open plan nurses' station. All the single, double and four bedded cubicles were spacious with pleasant views of hills and trees from the windows, and there was a lounge where daily activities were organised, as well as a separate dining room. The walls and floor, although functional in appearance, were clean and well maintained, and efforts had been made to decorate the ward with posters and paintings. As in site one, the staff were most in evidence working in the nursing station at times of shift change, otherwise they tended to be hidden, working behind curtains with individual people. Most patients in the ward were generally in their cubicles although, occasionally, immobile people were placed in their wheel chairs actually in or by the nursing station. Presumably this assisted in supervision in case of falls or, perhaps, because they may have been disturbing other people.

Site three: Site three was a private hospital providing continuing care for about thirty people. Intermittent care had only been offered for six months prior to the data collection. This hospital had three beds used by twelve families. Over half of the people living in the hospital had a diagnosis of a dementing illness. The hospital entrance was easily accessible from the street but the front door was kept closed and had two handles to manipulate, requiring coordination skills. Visitors entered directly into a foyer close to the nurses' office, kitchen and dining room. This area was the center of activity in the hospital, and I found that I was immediately greeted by both staff and some residents. Like other sites the décor gave a functional impression with wide corridors and linoleum covered floors. However, there were marked variations from the previous two sites in other aspects of the environment. For instance, the evidence of everyday life was immediately apparent with the foyer desk being covered in reading books, and knitting and pet animals were in evidence. The residents' rooms varied in size from quite large double rooms to less spacious multi-bedded cubicles. People's personal belongings, such as furniture and photos, were very much in evidence. There were rooms, in addition to their bedrooms, that could be used by residents: a dining room with spectacular views; a lounge that was the focus for daily recreational activities and television viewing; another room for smokers; an outside deck with generous seating; and another small lounge with a television. There was easy access to

Table 6.1 Intermittent Care Sites

	SITE 1 Public Hospital	SITE 2 Public Hospital	SITE 3 Private Hospital	SITE 4 Private Hospital	
HEALTH CARE INSTITUTION	Assessment and Rehabilitation Unit Five intermittent care beds.	Assessment and Rehabilitation Unit Five intermittent care beds.	Continuing Hospital Care Three intermittent care beds.	Continuing Hospital Care Two intermittent care beds.	Rest Home Care One intermittent care bed.
SITE LOCATION	Ward above ground floor level in a multistorey building in an inner city suburb.	Ward above ground floor level in a multistorey building. A quiet suburban location.	Ground floor level in a small hospital building. A quiet suburban location.	One ground floor ward in a complex of several wards. A quiet suburban location.	One ground floor ward in a complex of several wards. A quiet suburban location.
SITE ACCESS	Complicated access, multiple entrances and long corridors to negotiate. Ward door has a key pad lock, code clearly displayed.	Complicated access- multiple entrances and long corridors to negotiate. Open access to ward.	Direct access from the street. Door has handles that need some degree of dexterity to open.	Complicated access through corridors. Initially the ward had open access, but later changed to a keypad lock with the code clearly displayed added to ward door.	Complicated access through corridors. Open access to ward.
SITE DESIGN	Central corridor, cubicles to one side, service rooms on other side. One, two and four bedded cubicles. One small TV lounge No outside access.	Circular corridor, cubicles on rim, service rooms in the center. One, two and six bedded cubicles. TV and lounge room and dining room. No secure outside access	Rooms off several hallways, One, two and six bedded cubicles. Lounges and dining room. Secure outside areas. Free access throughout the home.	Circular corridor, cubicle on rim, service rooms in the center. One, two and four bedded cubicles. Large lounge and recreation area. No secure outside access.	Central corridor, single cubicles to one side, service rooms on other side. Small lounge. Open access to wider home facilities.
PARTICIPANTS	Three nurses Four family caregivers	Four nurses Two family caregivers	Four nurses Four family caregivers	Two nurses One family caregiver	Two nurses One family caregiver

the outside enclosed garden. The residents were dressed and generally sat in wheelchairs or reclining chairs, some were in their bedrooms, and others were in the recreational rooms. The rhythm of life in the hospital varied while I was there, sometimes quiet, other times bustling with the activity created by visitors, various kinds of deliveries, and the relatives of staff dropping by. There was often the noise of one or two people calling out repetitiously.

Site four. Site four was much larger than site three, and had several wards and a small resthome section. There were three respite care beds in total, but all in different parts of the hospital. One family caregiver that I had interviewed when using site two now used the intermittent care bed in a large thirty bedded continuing care ward. This ward was complicated to find, even though it was on the ground floor, as access was through other parts of the hospital. Like site one, there was a locking system on the entrance door to the ward. The ward had a similar design to site two but the corridors, cubicles and the recreation rooms were much larger. Some parts of the building were carpeted, giving a warm and comfortable impression.

Many of the patients' rooms, single, double and four bedded, had numerous personal possessions. The design of wall decorations and bed coverings reflected the diverse cultural backgrounds of residents. There were surrounding gardens but they were not enclosed and confused residents required supervision if they wanted to go outside. The residents were dressed, and many spent considerable time in the lounge where recreational activities such as games and reading occurred. Several active, but confused people, walked around the circular corridor, resting occasionally on chairs placed at strategic intervals in the corridor.

There was also an intermittent bed in the rest home section of site four. This was a small ward with open access to the larger institution. All bedrooms were single and private. These residents required much less help than those being cared for in the continuing care section. There was a small lounge in the unit but residents could also use the main, much larger, hospital facilities.

Environmental features: Site one and two were standard wards that could be used for medical or surgical purposes. The staff in both wards expressed identical concerns related to design issues. Confused people in both wards had to share four or six bedded rooms with non-confused people, which could be a problem if there was disruptive behaviour, such as wandering or repetitive noise. The location of the public hospital wards above ground floor level also caused difficulties. One ward had a security lock system but confused people still managed to leave the ward. The other public ward had no security system, and so nurses had considerable difficulty in monitoring patient activity and ensuring that people with dementia were safe. Nurses in both AT&R wards stated that lack of safe outside access and a place for patients to walk freely were significant issues for them. In situations where a confused person was very active and persistently left the unit the nurses would recommend transfer to another more secure environment.

In site three an enclosed perimeter allowed safe activity within its borders. The issues related to the environment that were prominent in the commentary of nurses from other sites were barely referred to by nurses working in this institution. The majority of people had some degree of confusion and the environment had been modified to accommodate their safety needs. People with dementia could walk about unrestricted in most parts of the hospital, and had access to a safe enclosed outside area. People still managed to leave the institution unnoticed, but the location of the hospital in a quiet suburb and the presence of supportive neighbours who would provide hospitality and notify the institution, made this occurrence a less stressful event for these nurses compared to those in the other institutions.

All the sites were hospitals designed to accommodate people with severe physical disabilities. They had in common wide corridors, functional decor and furniture, easily supervised living accommodation, shared personal facilities such as bathrooms and the paraphernalia of body care aids such as wheelchairs, lifting hoists and commode chairs. However, the sites were also divergent in several areas. For example, the overall architectural design varied from a simple linear layout of a central corridor to the more prevalent circular corridor with service rooms at the hub and bedrooms on the circumference. The styles of interior decoration also varied from relatively bare walls to

colourfully decorated rooms expressing the diversity of the residents' backgrounds. The accessibility of each hospital for families was also contrasting. One institution was located in a busy inner city suburb with all the attendant parking difficulties while the others were situated in small quiet communities.

The social organisation of nurses' work in the research sites

Intermittent care services are not just buildings and beds. In the family and nurse interviews the organisation of nursing care of people with dementia emerged as a prominent factor impacting on family caregivers' experiences and nursing satisfaction. It was also apparent, from both the participants' texts and my observations, that there were considerable organisational differences between the assessment and rehabilitation wards and the continuing care sites.

In sites one and two, the care of intermittent patients was provided by a predominantly qualified nursing work force of registered and enrolled nurses at the time of initial field work (in site one a hospital assistant was also part of the team). Nursing responsibilities in these sites included making a preliminary assessment of the patients' needs on admission, developing a care plan in conjunction with the other team members, providing ongoing direct care for about five patients,⁴ and liaison with the family caregivers. These nurses were able to provide care on a regular basis each time the person with dementia was admitted for intermittent care.

When I commenced another round of data collection a few months later the organisation of work in site one had changed to a system where nurses were designated rooms rather than particular patients. The rationale for the shift was predicated on a more efficient use of nursing time, as patients were located in close proximity, and more effective surveillance, an important aspect of care if a person is confused or very ill. But there was a significant cost to the patient and, in the case of intermittent care, the family caregiver, as there was little opportunity for continuity of care. Patients were admitted to particular cubicles by virtue of their condition, gender and bed availability rather than any established relationship

⁴ The number of patients one nurse is allocated to care for can vary according to staff availability and the condition of the patient.

with the nurse. As a consequence, the nurses had little opportunity to develop knowledge about the patient and family during the visit as patients could be moved around the ward dependant on the exigencies of the moment. This change in the organisation of care had a major impact on the family caregivers in this study who were using site one at the time, and this issue will be revisited in the discussion in the following chapters.

The shift of intermittent care services to the private sector also entailed a shift from an almost all qualified workforce to a mixed group of mainly unregulated and unqualified caregivers. The use of unregulated caregivers is based on the assumption that care delivery costs will be decreased.⁵ In sites three and four many aspects of direct care of patients, such as hygiene care, was provided by the nurse aides, while the registered and enrolled nurses carried out procedures such as patient assessment on admission, care planning, medication administration and wound care. Qualified staff also supervised the work of the nurse aides, managed unexpected health events, communicated with other health professionals and relatives and provided direct care for some patients. The patients in continuing care wards required less medical intervention and monitoring than in the assessment and rehabilitation wards, and there were fewer admissions and discharges, activities that constituted a substantial proportion of nursing work in the acute care setting. But the one or two qualified staff on each duty in both sites had the overall responsibility for at least thirty patients.

The research participants

In preparation for this study I talked to the managers and charge nurses working in intermittent care services for elderly people about the feasibility of the research project. Following indications of support for the project, permission to access participants through the intermittent care services was gained from the relevant manager of the CHE or private hospital. Potential participants, nurses and family members were contacted through an intermediary person in each setting after the research proposal was approved by Massey

⁵ There is considerable ongoing debate in both international and New Zealand nursing literature about the role of unregulated caregivers in health care services. The major issues for nurses in working with these caregivers is in the decision making about what tasks can be safely delegated and the necessity to supervise and be accountable for unregulated caregivers work. For a discussion on unregulated caregiving in the New Zealand context see Ministry of Health (1999).

University Ethics Committee and the RHA Ethics Committee. I contacted all the family caregivers that met the criteria of caring for a person with a diagnosis of a dementing illness and had used the intermittent care for at least two admissions previous to this study. One caregiver had recently admitted her husband to continuing care but wished to be included in the research. Two other caregivers felt too stressed to be involved in the research. Originally I had planned to interview registered nurses so as to be able to research the nursing care practices of a homogeneous group. However, the people arranging initial contact with nurses suggested that only interviewing registered nurses would limit the full exploration of caring practices as enrolled nurses made an important contribution in the caregiving teams in the planning and providing of nursing care. Consequently, all nursing staff were approached. Most of the nurses contacted were willing to be included in the research, but one person withdrew for reasons unknown to me after expressing initial interest.

The nurses

Twelve registered nurses and three enrolled nurses participated in the study. Seven of these nurses had worked in continuing and intermittent care services for over fifteen years and, at the other extreme, five had worked in these services for less than two years. Three of the twelve registered nurses had a comprehensive nursing registration. The nurses in the study had varying degrees of post-registration education ranging from little more than an orientation to the ward to a nursing degree. Only female nurses were interviewed as no male nurses were working with intermittent care patients at the time of the data collection. All of the nurses, except one, were New Zealanders of European descent.

I acknowledge that, particularly in the continuing care setting, nurses are by no means the only health care workers, and that nurse aides contribute substantially to the direct care of patients in the hospital. However, registered and enrolled nurses, while not directly providing every aspect of care, play an important role in establishing caregiving cultures and standards of care within institutions through the example they set and the coaching they provide for nurse aides in the continuing care context. The care of the elderly sector is also a significant specialty area for registered nurses. In 1998, eleven percent of practising

registered nurses in New Zealand were employed in continuing care and three percent in assessment and rehabilitation (New Zealand Health Information Service, 1998). In 1999 the percentage of registered nurses working in continuing care had risen to twelve point one percent of the total workforce (New Zealand Health Information Service, 1999).

Preparation for practice: The nurses participating in this study had varied backgrounds in terms of their experience and nursing education. The three nurses interviewed from site one consisted of one general and obstetric registered nurse (RGON)⁶ who was the manager of the ward, one nurse with comprehensive registration (RCompN)⁷ and one enrolled nurse (EN).⁸ They had all worked in this ward for at least three years but none had formal preparation for caring for people with dementia.

Of the four nurses participating in the research from site two, three nurses had RGON registration, and one was an EN. Three of the nurses had worked in the ward for over six years, the other nurse for about two years. The majority of the staff did not have post-registration education in relation to caring for people with dementia. The nurse manager had a nursing degree and was undertaking a postgraduate qualification.

One of the four nurses from site three who participated in the study had a RCompN registration, the others had RGON registration. All had worked in the hospital for over fifteen years, although two of the nurses had worked at other hospitals as well during that time. These nurses had substantial ongoing formal education. One of the nurses had completed post-registration study days in a variety of topics. Another had completed various post-registration courses, including a gerontology course. The nurse manager had an Advanced Diploma in Nursing (a one year post-registration course) in addition to management courses. Another staff member had completed a Bachelor in Nursing as well as other post-registration courses.

⁶ Nurses with general and obstetric registration had completed a general hospital based three-year training.

⁷ Nurses who had completed a three diploma programme in a Polytechnic.

⁸ Enrolled nurses trained in a twelve to eighteen month hospital programme and are required under current legislation to work under the supervision of a registered nurse.

Four nurses (one EN, two RGON and one RCompN) participated in the study from site four. They had worked for the institution for periods varying from a few weeks to a maximum of one year, although most had considerable work experience in other hospitals. None of these nurses had had the opportunity to attend any particular professional development sessions while working in this hospital but one of the nurses had completed a gerontological course while working for another hospital.

This short synopsis of the participants' educational/professional backgrounds reveals considerable diversity in their preparation for practice in gerontological settings. The majority of nurses did not have further formal post-registration specialist education in their area of practice. The nurses in site three were the exception, with each having substantial educational preparation.

Family caregivers

I have included family caregivers in this study for two reasons. Firstly, they have provided some insight into the experience of the person with dementia. The person being cared for is the *raison d'être* for this research but, paradoxically, they are not participants in this study in terms of being interviewed about their experiences. There is interest in developing a body of research knowledge about the experiences of people with dementia (discussed in chapter three) but the people using intermittent care in this study had substantial difficulties in communication, both in understanding questions and in verbal expression. Cotrell and Schulz (1993) note that the use of proxy respondents becomes increasingly necessary as the capacity for verbal expression declines, and that caregivers can be a valuable source of information about the person with dementia's experience, but always from the caregivers' perspective. The second important contribution made by family caregivers was in their contribution of the viewpoint of a recipient of the service, able to validate or, alternately, contradict nursing representations of care and relationships.

Nine family caregivers participated in the study, four women caring for their mothers, two women caring for husbands, one man caring for his mother, one man caring for his wife and the other man caring for his father. The age of the caregivers ranged from thirty-six to eighty-five years of age while the people being cared for were aged between sixty-five and

ninety-four. One spouse caregiver had a part time job, the others were retired. Five of the six children caring for parents were not in paid employment, three leaving former occupations in order to care for parents. One daughter had a part-time job and worked from home. The caregivers were of European descent. The length of time people had been providing care for their relatives varied from one year to twenty and the time range for using intermittent care was from a few months to seven years. Four of the people being cared for died during the time of data collection.

Ethical considerations

On the first visit with potential participants I explained the purpose of the research and the commitments involved in terms of repeated, recorded interviews. I also explained my responsibilities of researcher in terms of preserving confidentiality and anonymity, in ensuring that the participants would be able to withdraw at any time during the research and that the participants would have the opportunity to check the accuracy of the interview transcripts. I left an information sheet (Appendices 1 & 3) and consent form (Appendices 2 & 4) with the participants to allow them time to reconsider if they wished to be involved and organised the initial interview about one week later. From the outset the anonymity of participants was protected through several strategies. The participants chose a pseudonym, which I immediately used as I transcribed the tapes. I also removed or changed any other identifying information at the time of transcription such as the name of the hospital or ward, the names of other health service workers, and patient and family names. The tapes and transcript were kept in a secure cabinet. The consent forms and list of names were kept in another location.

Although the people requiring nursing care were not the research participants in this study, their presence and experiences could not be ignored. Observing nursing interactions was an important aspect of my research and necessitated obtaining consent from all involved. The ethics of conducting research with people who have dementia are not explicitly discussed in many of the published research studies involving this group (see, for example, Foley [1992], Froggatt [1988], Lyman [1993], and Silverman and McAllister [1995]). In Silverman and McAllister's (1995) intensive ethnographic study in a residential care setting

carried out over three years there is no mention of any process of ongoing informed consent. The researcher commented that she was “able to blend into the group and was treated by residents as either a fellow resident or as a familiar visitor” (Silverman & McAllister, 1995, p. 200). Given that detailed case histories have been produced, some discussion of consent processes would seem appropriate. Similarly, Lyman (1993), in another ethnographic study of several Alzheimer’s day care centers, does not address the issue of consent from people with dementia or staff, instead focusing on how access was gained through the programme administrators. A fundamental requirement for informed consent is the capacity to understand what the research is about, and to judge possible implications. When the ability to give informed consent is compromised, judgements in favour of assumed competency must be made and objections cannot be overruled by proxy consent given by the person’s legal guardian (Department of Health, 1991). After discussion with the RHA Ethics Committee, I developed a proxy consent form (Appendix 5) for the family member to sign. But, most importantly, I undertook to explain at every encounter the purpose of my presence to the person with dementia with the commitment to withdraw if there were any objections to my presence.

The development of an ethical process for addressing the issue of the consent of people with dementia proved to be useful when several interviews with three family caregivers were carried out in the presence of the person who required caring. Initially, I felt uncomfortable during these interviews as I was concerned about whether the person with dementia felt included in the conversation, and also from more self-serving motives I believed the interviews were probably constrained in terms of the caregivers discussing problematic dimensions of caregiving. It was tempting to ask if the interview could take place away from the presence of the person requiring care, but I came to the conclusion that this would exclude the person with dementia in a very overt fashion from other peoples’ company. I also recognised that I was a guest with no legitimate right to determine the choice of interview setting in another person’s home. However, alerted by the previous exploration of the issues of consent, I was careful to explain the purpose of my visit as clearly as possible to the person being cared for and to ask for consent to carry out the interview with the caregiver. During the interview I periodically asked the person with the

dementia if it was all right to carry on with the conversation. The degree of understanding about the purpose of the visit was difficult to judge, particularly as two women were very deaf but there were no objections to my presence. Similarly, when I was observing nurses caring for people in the various research sites I introduced myself each time to the person being cared for and explained that I was observing nursing interactions with patients as part of a research study. There were no objections to my presence.

My role as nursing educator was another complicating aspect of this research requiring discussion from the time of the first submission of the proposal to the University Ethics Committee. This role has some degree of ascribed power and status and also meant that I was known to some of the participants as a colleague and a teacher. The University Ethics committee asked for assurance that participating in the research would not be to the detriment of nurses who could also interact with me in an educational setting. As it eventuated this did not prove to be an issue as I was not involved in teaching any of the participants.

Producing the research texts

Attention to variation has been an important analytic tool in my attempts to develop a robust account of nursing practices that can allow for shifts in the discursive positionings of participants and surface the various contingent factors shaping nurses' adoption of particular practices. Variability in the research texts used as a basis for analysis has been maximised in this study by interviewing as diverse a group of nurses and family caregivers as possible and using multiple data sources; interviews, field notes, documentation and published literature. Fifteen nurses and nine family caregivers were interviewed, some for up to three times, and the duration of these interviews has ranged from thirty minutes to an hour and a half. All interviews were taped and transcribed. The time length of data collection, although initially unplanned for the reasons discussed earlier in the chapter, has been fortuitous. I was able to maintain contact with most research participants over at least six months and some family caregivers were interviewed over a three year period as I followed them through different intermittent care services. The collection of interviews over this extended time period enabled the development of texts that reflected the changing

nature of intermittent care services. I also worked alongside nurses in the two private hospitals and recorded my observations. In addition, I analysed written texts such as nursing care plans and ward policies. I followed up questions and issues that emerged as a result of my observations in the wards. The opportunity to compare nurses' and families' accounts of intermittent care has also strengthened the analysis of nursing work.

The interviews

In the initial interviews I used an interview guide to ensure I covered certain topics with all participants. I asked nursing staff why they chose to work in intermittent care settings, what their experiences were working with people with dementia, what they considered to be good nursing practice in this context and about their relationship with family caregivers. I asked family caregivers about their expectations and impressions of intermittent care, the effects of intermittent care on the person cared for, and their relationship with nursing staff. However, in practice, every interview was structured differently because, as Rubin (1995) comments, the "content of the interview, as well as the flow and choice of topics, changes to match what the individual interviewee knows and feels" (p.6). The interviewing process was conversational in style, participants contributing examples to illustrate their ideas and at times asking for my opinion about the issues that concerned them. At times there was also the demand for some degree of reciprocity in sharing personal views, a dimension of research that has been commented on in feminist literature (Devault, 1990; Oakley, 1981). The following interview extract illustrates the tentative and constructive nature of the interview process as both the participants and myself grappled with developing and communicating to each other difficult ideas about the nature of dementia.

R⁹: But what do you think, do you reckon, about being more one to one sort of, spending more time with them, because you have had more experience?

J: Well yeah...it's interesting with the, what can I say about it...well one I think, with it is, that it must be very lonely, you know, when you have got memory loss and you can't communicate, it could be very lonely as it seems to me that it would be very easy to get quite depressed wouldn't it with people with Alzheimer's Disease or something, very lonely and depressed.

R: Especially in second stage

⁹ The letter of the alphabet identifying the speaker is the first letter of the pseudonym chosen by the participant. In all interview texts I have used the letter J to identify myself.

J: But just generally, because you are not actually able to function as well as what you have been, and it's harder to reach out, so you probably need people to come to you more but that doesn't necessarily happen.

R: No, but with the early stages, don't they go through a denial, they don't really know/

J: In terms of lack of insight?

R: Yeah they just think, oh its one of those things, like we do, like what did I go into that room for? That sort of thing.

J: Initially, but I suppose I was thinking more of the middle stages.....

(Nurse 8, 2:2-3, Site 3)

The nurse I was talking to in this extract provided a valuable lesson in alerting me to the considerable difficulties involved in surfacing underlying assumptions and beliefs. My incoherent statements, pauses and repetitions are indicators of the considerable effort I had to make to respond to the nurse's seemingly quite simple question. Mishler (1986) suggests that questioning is part of a circular process whereby the question's meaning and answer is created through the evolving discourse between the researcher and participant as each tries to make sense from the conversation. Devault (1990, p. 100) takes a similar position.

It is the interviewer's investment in finding answers, her own concern with the questions she asks and her ability to show that concern, that serves to recruit her respondents as partners in the search.... The researcher is actively involved with respondents, so that together they are constructing fuller answers to questions that cannot always be asked in simple, straightforward ways.

An important and complicating aspect of critical discourse analysis is that, in contrast to more interpretive methodologies such as ethnography and phenomenology, the researcher has to attend to every word "with a *suspicious* eye" (Parker, 1992, p. 124). The researcher has to be prepared to challenge participants' assumptions (and her/his own) and to request the rationale for particular explanations and actions, if there is to be any possibility of surfacing the hidden or taken for granted determinants of discursive practices. Questions are seen as active and constructive, rather than passive and neutral, and just as much a focus for the analytic process as the participants' replies (Lupton, 1992; Potter & Wetherall, 1987). Paying attention to the structure and organisation of the stories, the questions asked,

and the disruptions and misunderstandings is a critical aspect of the analytic process, if the analysis is to move beyond the descriptive validation of commonsense knowledge.

However, this injunction to the researcher to be ever vigilant and questioning of participants' accounts is in practice difficult to achieve at the interviewing stage. Questioning tacit knowledge requires a self consciously rigorous approach difficult to achieve consistently during the face to face work of interviewing, particularly when there is the possibility that the researcher shares some of the same assumptions about caregiving with the person being interviewed. Reissman (1987, p. 190) saw the sharing of tacit knowledge as a research strength in her description of the interview process with a participant in her study of marital separation.

In Susan's case, the interviewer was exquisitely sensitive to the subtle cues provided by the narrator, thereby helping Susan develop a coherent account of her marital failure....This collaborative process was aided by gender, class and cultural congruity, which produced the unspoken but shared assumptive world of the two women.

In contrast, I found that my previous involvement in caring for people with dementia, while useful in developing a rapport with participants, also blunted my ability to identify contradictions and assumptions in participants' accounts during the interview. My failure to ask important questions about the underlying rationale for participants' comments was exposed with depressing frequency in retrospect as I transcribed and read the interview transcripts. For example, the following interview extract illustrates my omission to follow up a nurse's use of the analogy of family when talking about how she found satisfaction in her relationship with the people she cared for.

J: And you made a comment about the residents being like part of your family.

S: Yes I think it is. I think it is because they are here so long, the biggest majority of them, they do become part of your life and you are seeing them four days a week, and I think too, because I don't come from a big family maybe it makes you sort of think, or maybe you can compare them to someone in your own family. But I think they have all these nice traits, some of them don't (laugh).

J: Okay so that is some of the satisfaction of working here?

S: Yes. (Nurse 9, 1:1, Site 3)

Obviously, rather than cutting off the discussion, I could have usefully explored more fully why the family analogy seemed appropriate in this caregiving context. This comment could have opened up discussion about what the possible implications were of using a family comparison when talking about caregiving for nurse, patient and family caregiver relationships. But, at the time, I didn't explore why the nurse used the term *family* in this context because, as a nurse myself, I have used the term in a similar way. However, in a somewhat contradictory manner, I also believe, like Reissman (1987), that it is valuable to come from the same background as the participants. There is a potential from this position as an insider to question ideas and practices that to an outsider might seem insignificant or irrelevant to the topic being studied. There is also a danger in making the assumption that if I had been rigorous enough to follow up with searching questions at the time that the respondent would have been able to answer them. I have already illustrated the difficulty of working through taken-for-granted notions in the interview context. The use of the word family by the respondent, while not fully explicated, still emerges as a productive construct whose discursive effects can be more fully followed up in the interpretative work of the analysis.

An important characteristic of discourse analysis is the attention paid to transcribing conventions when representing spoken language through written texts. The transcription of spoken interviews into written texts is a constructive activity (Potter & Wetherell, 1987), with the preciseness and detail of the transcription dependent on the mode of discourse analysis being attempted. Some transcription conventions serve to clarify material or to exclude material. Other conventions have an interpretative function, such as indicating a particular vocal emphasis in speech, and need to be used with care as "an artefact of transcription reflecting *interpretation* of the material on the part of the researcher, should not be seen as windows through which we may divine the true intentions of the speaker(s)" (Parker, 1992, p. 125).

I have used the following transcription conventions in the interview texts:

1. Pauses in speech are marked with full stops, ... ,each full stop marking about one second in duration.

2. A rise in speech volume is written in **bold**.
3. Any information that is excluded from the analysis for reasons of confidentiality or audibility is recorded in square brackets, thus [].
4. Any clarifying comments or the documenting of an emotional response is recorded within conventional brackets like this ().
5. A change in speakers created by an interruption, rather than a natural break is signaled by a diagonal line like so /.
6. An omission of part of the dialogue is indicated by a double diagonal line //.

I have also avoided editing the texts in such a manner that the incomplete phases and interruptions that are part of the messiness of everyday speech are excluded. As Opie (1997) points out, to produce a more immediately readable text for the reader involves major editorial interpretation and the danger of prematurely closing or altering aspects of the discussion.

Copies of the interview transcripts were returned to all participants to provide the opportunity for correction of transcribing mistakes, clarification of ambiguous comments, and opportunity for comment. Participants also were made aware of the right at this stage to delete any material that they did not wish included in the analysis and research report. Generally interview texts were not altered though some participants took the opportunity to elaborate on particular points made during the interviews. One participant took the opportunity to write copious and useful notes to clarify her position. When reading this transcript I felt the conversation with her was still ongoing, highlighting that the interviews used as a basis of the analysis are not the final word, but rather are partial and fluid accounts, as understandings about the phenomena under scrutiny shift through the constructive act of speaking

Fieldwork

During 1996 I spent several days with nurses participating in this research study as they carried out nursing work in the two private hospital intermittent and continuing care wards. I wrote detailed descriptive field notes recording my observations and also kept a personal

journal recording my interpretations of the various events that had occurred during the visit, possible theoretical connections, and questions that needed to be followed up with the nurses on the next visit. The time spent in the wards contributed to the research in several ways. Firstly, I had the opportunity to view nursing work from a perspective other than that of the nurses and the family members. The questions that emerged as I worked alongside nurses providing care for people with dementia were explored more fully in follow up interviews. Secondly, I developed a fuller appreciation of the environmental and organisational context of nursing practice, a perspective that proved valuable in informing my reading of the interview texts. For instance, work load issues emerged very prominently in my early observations.

Most people really enjoyed their food and said the porridge was nice. They were not rushed at all. Breakfast went from seven-thirty and we were finished about ten but the nurse said it often goes on till ten-thirty and some just sit there as long as they can. The demands on the nurses seem quite high as I fed six or seven people and normally it would just be one person giving out the pills, giving out the meals and feeding residents who need help. That seems quite a heavy workload to me. (Field notes)

I became actively involved in each research site at the insistence of the nurses, my positioning as a nurse as well as researcher creating certain privileges as well as obligations.

In terms of participant observation as soon as the mealtime started the nurse asked me if I would help feed people. It was evident that that needed to be done and I was quite happy to get involved in that way. I found that I could observe very easily. Feeding of course makes an impact on the situation but it was good for me and the nurse appreciated it and said so several times. There is no way I could be other than a participant. In fact my supervisor's comment that you could just be an observer is an interesting one for me. In an area where you are familiar with the nurses and you have certain skills, I don't think the staff would let you just observe. And it is their territory and you are bound by their requirements. (Journal)

In retrospect, the blurring of boundaries between my work as a researcher and that as a nurse was inevitable. The residents had profound physical and mental disabilities and nursing work was routinely intensive, demanding and complex. Often the demands of

caregiving required two nurses or nurse aides to share the physical work of moving people from place to place. Because I was a nurse as well as a researcher I lessened the immediate work of the nurses as I helped to feed residents and assisted with transferring and hygiene cares. This opportunity for full involvement in the research setting highlighted the embodied nature of nursing work as I experienced the pain and fatigue caused by the heavy work of lifting and shifting disabled people. My immersion in academic nursing discourses with the associated comfortable habitual patterns of thinking was rudely but usefully disrupted. As Parker (1992, p. 39) states:

The behavioural aspect to patterns of speech and the 'reading' of texts is ingrained habit. The real body, bent in a variety of postures of deferment and position in different discourses, is such that only a shock, a break can release the potential for the development of new repertoires.

My willingness to get involved in caregiving work was also motivated by my awareness that my presence as a researcher could potentially be an unwelcome added burden to the nurses in the hospital. I recorded the following after my first day in one of the research sites.

I was very aware of the whole role of participant observation in terms of research and the tensions for me as a nurse in really wanting to contribute and do and not be a drain on the nurse. I thought I don't want to be like a polytech student where at the end of a day the nurse feels exhausted having communicated to someone extra and feeling that they get very little out of it. So it's a real issue for me. At the same time I tell myself, sit on your hands, sit on your hands, just sit and watch. (Journal)

As this journal extract highlights, at the same time as I was actively providing care I also had to keep my research focus in mind and therefore the need to observe and record interactions and attend to environmental factors. Furthermore, I also needed to explain to each resident and nurse I encountered why I was present and what I was researching. This created considerable personal dissonance as I juggled many competing demands. Paramount in my mind was the need to carry out the research component of my role rigorously but I also felt the obligation to fit into the routines and requirements of the nurses and residents in the research setting. Over time I found that the most productive way

to manage these requirements was to work with the nurses for about two hour intervals and then to leave the immediate work area for a short time and dictate my observations into a handheld recorder to be transcribed at a later time. The nurses had no problems with this practice, and may well have felt relieved to have a break from my otherwise constant presence.

The analysis

There is no set of principles to guide the process of a critical discourse analysis but there are some conventions which I have discussed in chapter two. The key concepts from Foucault's work that have been instrumental in guiding my reading of the texts have also been described, along with Parkers' (1992) approach to the analysis of the operation of power. In addition the work of Opie (1993) has been useful in working through issues such as reflexivity and power relationships in the process of doing and writing up the research account.

I have not attempted to unify and homogenize the characteristics of nursing practice in my reading of the research texts. To the contrary, my aim has been to develop an account that highlights diversity and variation between nurses' practices and unravels some of the tacit as well as articulated knowledge and assumptions informing those practices. Furthermore, exploration of the organisational structures shaping practices and the implications of nursing discourses in relation to the operation of power within the caregiving context, are critical dimensions of this account. From my reading of Parker's (1992) work and the questions developed by Foucault (1977) directing attention to the functions and effects of power I developed a set of questions that directed my reading of the research data.

1. What categories emerge in terms of issues, objects of knowledge, specific practices?
2. Are there identifiable discourses?
3. Are there contradictions within texts and between texts?
4. How are the main parties represented?
5. What are the positioning implications for people with dementia, for families, for nurses?

6. What are the taken-for-granted assumptions underlying the discussion?
7. What differences are there in representations, in beliefs and assumptions between participants
8. How is power exercised?
9. How are institutions supported or challenged by the discourses?
10. How are power relations manifested?
11. Who controls the discourse?

Discourse analysis, as with other forms of qualitative research, requires the coding of text extracts so as to facilitate comparison within and between texts. The generation of hundreds of pages of textual data necessitates the development of techniques for the search and retrieval of text. Initially I used Ethnograph 3 (Seidel, Kjolseth, & Seymour, 1988), a computer programme especially developed for qualitative data management to assist in the organisation of coded interview extracts. This software enabled the fast search and retrieval of interview extracts but also required a significant amount of time to learn the functions of the programme as well time to transfer interview extracts to the required format. I eventually abandoned the use of Ethnograph in favour of the already familiar functions available in the word processing programme, Microsoft Word 6. Collating groups of textual extracts from all the interviews was slower without the use of a specifically designed data management programme. However, I found that the effort and new learning required to use Ethnograph was better employed in the interpretative work of analysis. I also enjoyed working out my own, idiosyncratic method of organising the analytic record, coding and collating the interview extracts in an integrated fashion with my own ongoing interpretative writing.

The key textual practice in discourse analysis of foregrounding difference in and between participants' accounts highlights tensions between interpretative and poststructuralist research practice in relation to research rigour. Interpretative researchers argue that validating research interpretations with research participants is a crucial element in the process of establishing the credibility of the research, the researcher checking that

...he or she has represented those multiple constructions adequately, that is that the reconstructions (for the findings and interpretations are also constructions, it should never be forgotten) that have been arrived at via the enquiry are credible to the constructors of the original multiple realities. (Lincoln & Guba, 1985, p. 296)

However, there are some major difficulties associated with participants checking research interpretations. Potter, Wetherell, Gill, and Edwards (1990, p. 211) state that at times researchers need “to question in detail one’s culturally available understanding about what constitutes a topic, or to hold them in suspension” in order to question common sense understandings. Research participants are unlikely to have the same level of awareness about the assumptions informing the discourses and practices discussed in the research as the researcher. The accounts of researchers and the study participants are not merely juxtaposed as each construction is influenced by varying purposes and emphasises different aspects of experience. The reactions of the participants and other interested people to the research interpretation will also be influenced by the power relationships inherent in the research process and the constraints of polite social interactions. In addition, there is also the possibility that the research participant may not be interested in the validation of the researcher’s representations. Checking out analytic conclusions with participants may have some value in ensuring the researchers’ account has at least some relation to those of the participants but care must be taken to avoid the analysis merely becoming a description of common sense understandings of events and practices (Potter, Wetherell, Gill, & Edwards, 1990). As importantly, the concerns of poststructuralist thought,

...de-center validity as about epistemological guarantees. Such post-epistemic concerns reframe validity as multiple, partial, endlessly deferred. They construct a site of development for a *validity of transgression* that runs counter to the standard *validity of correspondence*: a nonreferential validity interested in how discourse does its work. (Lather, 1993, p. 675)

The discussion about validating the research interpretations with research participants also surfaces the issue of the operation of power within the research process. Opie (1992b) suggests that the appropriation of data in order to support the researcher’s theoretical positioning can result in the concurrent silencing of other perspectives that might contradict that interpretation. Stenner (1993) and Parker and Burman (1993) also comment on the

power of the analyst to control what meanings are conveyed in the final account. Furthermore, the techniques of data collection have overtones of the 'gaze' and the confessional in a Foucauldian sense as Crowe (1998) points out, the subject constructed and governed by the researcher in a position of power in terms of determining what to study, how, and of what significance the recorded representations have. Given these considerations I believe I had an obligation to open my interpretation up to the scrutiny and challenge of the people involved in the research. Simultaneously I was also aware of the dangers of this process in reifying the implicit and explicit power relations embedded in research practices. Marks (1993) commented, after feeding back discourse analysis results to research participants, that the participants were "forced into a defensive posture" (p. 150) through this process which created difficulties in the development of a personal critique of the produced texts. This author suggested that the researchers' positioning, as the expert who is positioned outside the account, became reinforced through the feedback process. However, this issue was not obvious when I did report back to both participants and other nurses who were not involved in the study but worked in similar contexts. Rather, the account has generated substantial discussion and new ideas for extending the analysis.

Several textual strategies are suggested to address the issue of data appropriation (Opie, 1992b). From the outset the study should be presented as conditional and partial, the limitations of the study explicitly discussed along with the implications of that positioning for the research participants. For instance, the people interviewed in this study presented particular constructions of events at one point in time for particular purposes, just as any producer of text does, whether it be published or unpublished, spoken or written. This stance challenges the notion of research as being definitive and authoritative. This author also suggests that the analytic reading attends to the

...paradoxical, the contradictory, the marginal, and by foregrounding (not suppression) of these elements. Its focus on difference and on marginality within a text means that it specifically attends to what might be quantifiably insignificant but whose (remarked) presence may question a more conventional interpretation and expand theoretical understanding. (Opie, 1992b, p. 59)

The research account should also incorporate the diverse voices of the study participants through the judicious selection of quotations (Opie, 1992b). Lupton (1992) also suggests that extensive use of the textual material analysed in the research account enables other readers to trace the reasoning processes leading to a particular reading. These textual strategies have been incorporated into the following account of nurses' and family caregivers' discourses and practice.

My supervisors have also had a major role in challenging my evolving interpretations of the research data. In particular, the need to provide sufficient transcript material to back up interpretative claims emerged as an issue as I wrote up of the analytic chapters. My in-depth immersion in participants' accounts led to a degree of obliviousness to the need to ensure all the linkages between the research accounts and my interpretations needed to be made explicit to the reader. Both supervisors have been quick to critique aspects of the analysis that have appeared undeveloped in this respect.

Summary

My objective in this chapter has been to locate nursing work in dementia care in the wider political and organisational health care context and to briefly outline the major structural changes that have affected intermittent care services over the last decade. The second part of the chapter addresses the major methodological issues: identifying who the participants were, the processes of text production, the ethical issues encountered along the way, and finally an account of the decisions that have shaped my approach to the textual analysis. In the next three chapters I provide an account of the nurses' and family caregivers' texts. The first of these chapters explores the dominant nursing discourses that were apparent in nursing texts, the second, family caregivers' representations of intermittent care, while the third chapter foregrounds a particular nursing representation evident in one research site.

CHAPTER SEVEN

Creating Relationships and/or Controlling Risk: Nurses' Discourses and Practices

Introduction

The prominence of nursing writing about the management of disruptive behaviour discussed in chapter four reflects the everyday concerns and realities of nursing work. Nurses generally care for people with dementia within an institutional context. They are required, from both a professional position, and as part of their employment contract within health care institutions, to ensure that patients'¹ bodily needs are met and that safe care is provided. Nursing discourses privileging caring and holism also suggest that attending to patients' emotional and social needs is a critical aspect of practice (Potter & Perry, 1997). However, people with dementia may resist such nursing attentions, possibly from a perception that being cared for is both unnecessary and demeaning. In addition, resistance to nursing attentions may be exacerbated as a consequence of the considerable disruption to usual lifestyle patterns associated with being admitted to a health care institution.

The difficulties associated with caring for people with dementia in a hospital setting were a prominent feature of nurses' accounts of care in this study. Their texts stressed the problems of caring for people who were bewildered and disoriented as a consequence of being relocated from home to hospital for intermittent care. A range of discursive positions were also evident which, in turn, produced varying inscriptions of the person with dementia

¹ The term *patient* is used at times in the following chapters and refers to people with dementia being cared for in a hospital setting.

and nursing practices in response to caregiving issues. In this chapter I will describe these representations of care, which I have suggested are informed by *psychosocial*, *risk management*, *ageist* and *New Right* discourses. Another more marginal discourse, that of *care as family and home-like*, was dominant in one site only and will be discussed in chapter nine. Each discursive positioning entailed particular inscriptions of the person with dementia and certain sorts of power relationships. Nurses' location in these discourses was fluid and reflected the multiple and contradictory discourses informing practice.

Representing behaviour as problematic

The behaviours that the nurses defined as difficult to manage in the collective living situation of the hospital ward included hostility, wandering and the making of repetitive noises and they particularly emphasised the stresses engendered by aggressive interactions. Hostile acts by people with dementia included hitting out, throwing objects, making threats, spitting and being verbally abusive. Coping with hostile behaviour is a significant issue for nurses caring for people with dementia. Studies of aggressive behaviour in nursing homes found that at least one third of residents in the homes surveyed were aggressive at times, and that the majority of these people had some degree of memory impairment (Hoeffler, Rader, McKenzie, Lavell, & Stewart, 1997; Whall, Gillis, Yankou, Booth, & Bell-Bates, 1992). As attempts to care for a person who is extremely angry or distressed are seldom successful, nurses have a dilemma in that they cannot neglect the person needing care but forcing caregiving attentions on a resisting person is hardly a satisfactory solution. This dilemma is played out in the following text illustrating two differing discursive positions and their material effects on the practices available to the nurses in this study.

Basically, he was an intermittent patient, it was a trial period for him perhaps to be admitted for long term care.....He didn't want to be here. All he wanted was to be at home with his wife and the first night he was fine the second night, the second morning he was actually quite loud mouthed in his words....and really it was down hill from about midnight onwards, where he absolutely just ran amuck, ripped an iron bar off the wall, smashed a window um..and was just flaying this iron bar....flaying this iron bar around and anybody in the way would have copped it sort of thing.//There were actually three staff on the premises but they actually rung the after hours doctor. They also rang the daughter who had always said that if they had any problems to ring, they rang

me and they rang the security guard..but, from that point of view, you saw this fellow like this and your automatic reaction was that this guy is absolutely nuts. He's run amuck and he shouldn't be here he should be at [name of a psychiatric hospital] was the first reaction.// But I think to that I am surprised how we did all cope with it because he...he really was quite frightening and it took six of us to actually hold him down and give him an injection. Something that doesn't happen all the time so therefore it's a new experience.// When you talked about it the next morning and you sort of think I'm sure when you really look at it in a calm sense you think he knew what he was doing and when you actually talk to him um... he said he could remember what had happened last night and I asked about the iron bar and he was hanging his head. So our general feeling was that he really did know what he was doing. He just really wanted to go home. He didn't want to be here you know. Really, is that dementia or it is just a very upset man? (Nurse 9, 1:2-3, Site 3)

This text illustrates Foucault's (1990) comment that the world of discourse is not divided between the accepted and the excluded but is rather a "multiplicity of discursive elements that come into play in various strategies" (p.100). Two contradictory representations of the event are evident in the above account. In one representation the man who was an intermittent care patient is described as "loud mouthed", as "ran amuck", "absolutely nuts" and "frightening". In this representation the man's behaviour is decontextualised, he is inscribed as mad and as the other, as alien and out of control, his actions attributed to a disease process. This account emphasises the fear and the physicality of the situation requiring nursing practices focusing on the control and discipline of an unruly body. The second representation is developed after the event and after time for reflection and discussion with other staff and the man himself. The nurse talks about him as being aware and upset and as wanting to return home. In this alternative representation, the behaviour is contextualised and the social and psychological reasons prompting that behaviour are emphasised. The person is inscribed as bewildered and frightened, but as also purposeful. In this situation the man's behaviour is finally interpreted as an expression of frustration at being held against his will in the hospital and he went home the day after the incident.

In the following analysis of the interview texts I suggest that several discursive frameworks were available to the nurses in the study as ways of explaining their practice. I also suggest that the organisational environment in which the nurses worked influenced their discursive location and that their positioning was fluid, shifting in response to factors such as

familiarity with patients and experience, safety concerns and workload issues. I also discuss how nurses' discursive positioning influenced the type of power relationships between them and people with dementia.

Pyschosocial discourse: "It's about patterns and getting to know the person"

A significant representation of care surfacing in the nurses' texts emphasises the individuality and the humanity of the person with dementia, while simultaneously stressing the major communication barriers created by dementing illnesses. In this representation hostile behaviour was normalised, interpreted from a social and psychological perspective as a reaction to frustration and stress.

S: I think after you have actually got to know them for a while you actually do learn to um ..work out what they are wanting, um.

J: It might not be through language?

S: Yeah, yeah. It might be, I think a lot of eye contact and things like that go on with the patients. A lot of hand signals and things like that um a lot of thumping (lowered voice, laugh).

J: A lot of thumping?

S: (Laugh) But then, on those occasions, you sort of feel more it is frustration on their behalf so you can be the punching bag for a little while. Sometimes it does get up your nose a bit. (laugh) I sort sort of think, I quite often try to put myself in that position and sort of think god if I ever have, if I end up like this I hope somebody would look after me (laugh). (Nurse 9, 2:6, Site 3)

.....

We are trying to keep it as much of a routine as they have at home, to make them comfortable. It's bad enough that they are in a strange place every five minutes and you are in strange environment, you know you've got people in the room when normally you are there on your own and you can't understand why those three people are there. It's very hard, you face when you put yourself in that person's shoes if you were uprooted and put in a strange country where you couldn't speak the language and you don't understand a word that's being said, which is basically what's happening if you think about it and you've got to actually turn around and try and make that person understand what you are doing. So, the easiest way to do it is to find out that person's routine and keep them in that routine as much as possible... and try and be understanding to that person, I mean, so you don't understand the language but that's no reason to be nasty you know just get on with it. (Nurse 3, 3:10, Site 1)

These texts position nursing work as taking place in difficult circumstances with people who were highly stressed by unfamiliar environments and who could react in a physically aggressive manner. Both accounts also construct barriers to communication as the major problem for nurses. The nurses responded by adopting an empathic approach to care and by attempting to imagine how they would react in a similar position to the people they caring for, putting themselves “in that position” and “in that person’s shoes”. The people with dementia were represented as people like the nurses, frustrated at not being able to communicate. Because these nurses recognised the person’s reduced ability to interpret environmental and social cues the nursing practices they spoke of were those that involved making the effort to learn about the person requiring care and their everyday routines, and as far as possible trying to preserve those familiar routines in the hospital setting. This type of care was dependent on each nurse knowing the person “intimately so we can adapt to the individual needs and wants” (Nurse 11, 1:7, Site 3).

Their long term carers know how to deal with a moment, a cranky moment or the difficult moments and we don’t have those skills and sometimes it doesn’t matter how much they tell you, sometimes you have to discover for yourself what works. Sometimes I think cues are identified that will trigger behaviour and sometimes it can be they rush them. I can remember one specific instance of this guy who did go to another institution and who was walking out of the ward and a nurse who was not familiar with him thought he was escaping because we don’t have locked doors here so she rushed him and he lashed out and was very aggressive. The other girls who were familiar with him would have rushed around the other side and walked quietly to him and that’s just the difference about thinking how to handle these people. And it is something that if you don’t have that experience and know how to keep them calm that you could upset them.// What I find interesting is hear how the nurses’ attitudes change as they get to know them. There can be a sort of ratty “oh God not another one of these”, meaning difficult person, “how do we cope I’ve got to think about this”, and it’s interesting that as they get to know them they really come to love them, yeah, it’s about patterns and getting to know the person and the attitudes. (Nurse 4, 2:7-8, Site 2)

A significant dimension of the nurse’s initial responsibility towards a new patient was getting to know them thus ensuring that her nursing practice became orientated to the person and their needs, rather than her reacting to, and trying to control, the other’s disturbing behaviours. Knowledge of the person’s usual routines reduced the problems that

might otherwise occur during the work of washing, dressing and helping people with their elimination and nutritional needs, and avert otherwise hostile reactions.

Barriers to empathic care

Nurses' representations of care discussed in the previous section emphasised the in-depth knowledge required about the person with dementia's usual routines and preferences in order to provide effective care. This requirement is not unique to this research context and is considered necessary in order to provide safe and effective care in diverse health care settings (Campbell, 1992; Jenks, 1993; McLeod, 1992; O'Connell, 1998; Radwin, 1995; Tanner, Benner, Chesla & Gordon, 1993). But, as Campbell (1992) and O'Connell (1998) point out, organisational strategies that, from a management perspective, are cost effective such as employing minimal levels of full-time staff and using casual staff as needed, in practice work against nurses acquiring the knowledge they need to provide effective care.

In this study, for instance, organisational practices were pivotal in either facilitating or preventing the development of knowledgeable relationships between nurses and people with dementia. Continuity of nursing care is required over the two weeks of the respite care admission period if individual nurses are to have the opportunity to develop a reasonable degree of knowledge about life style patterns and the needs of people with dementia. Much of this information is gained by working closely with individual patients as there are major difficulties in documenting the myriad of details required to convey the routines of everyday life. As one nurse pertinently commented, full documentation needs "screeds and screeds of paper for all the little bits and pieces" (Nurse 3, 2:14, Site 1). Discontinuity of nursing care was introduced in two of the sites with the frequent use of agency nurses who might work just one shift in the ward at time of staffing shortages. This organisational practice is aimed at reducing expensive staff costs and is embedded in management discourses privileging cost containment and efficiency. As I have discussed earlier in chapter five, nursing work is an routinised and interchangeable process in this discourse, managers oblivious to the ongoing work required to produce satisfactory care within health organisations (Campbell, 2000). The ability of nurses to provide continuity of care was further undermined by the organisation of workloads. In one assessment and rehabilitation

ward, patients were initially cared for by a specific team of nurses no matter where the patients were placed in the ward, a system both nurses and families commented favorably on. However, this organisation of nursing care was later changed and the nurses were allocated to cubicles rather than people. Consequently, the person admitted for intermittent care was cared for by different nurses on each admission as there was no continuity in their assignment to particular cubicles.

Another factor that impacted on the nurses' ability to articulate a representation of caring that drew upon a psychosocial discourse was the necessity to work against the grain of dominant representations of people with dementia in popular and medical discourses.

S: I still think you have to treat them like basically like normal human beings, I don't think you can look at this person and say you have got Alzheimer's forget about her because really there's there's...um...one Alzheimer's in particular um she could sort of one minute be really frightening you and the next minute her repartee is just amazing and it is repartee that would be appropriate for any normal person in this situation. Sort of thing, you know.

J: Is there is a tendency without effort to treat people not as human beings, is that a possibility? With Alzheimer's Disease?

S: I think it could be a possibility, I don't think it is here but I do think, yeah it could be a very high possibility that that, ah, though I don't know things are changing but I am still sure that out there, there are people saying that person's mad, they sort of do stupid things and I'm sure, I'm sure that must still go on. You sort of have people say to you I don't how you do your job um...I..they are still individuals, there is still some personality there. Whether it's, whether it's the person that was I don't know but you can always still find some sort of personality. (Nurse 9, 2:4, Site 3)

Here, the nurse drawing upon an representation of the person with dementia as fully human, and thus operating in a marginalised professional discourse of dementia care, was at pains to argue that these persons were "normal human beings". In the context of dementia, being represented as human is no longer a taken-for-granted, but something that must be defended in the context of a discourse which represents the person as other, as non-human, abnormal and "mad". This representation of people with dementia is perpetuated in professional literature, the person with dementia located outside "the usual criteria to describe humanness" (Butler, 1992, p. viii).

Caregivers often thrive on relationships. Caring for others helps activate their caring in return. But the norm of reciprocity which is at least partly present in some caregiving has absolutely no place here. Of course, caregivers can pretend that certain meaningful responses and gestures of appreciation exist, and this may in some sense strengthen them. But the potential for relationship, like knowledge, is very limited. The severely demented elderly will often manifest an emotional presence replete with gaiety and even laughter, but generally this is directed to anyone and everyone, if it is directed at all. (Martin & Post, 1992, p. 58)

In this account the people with dementia are represented as empty shells, their behaviour constructed as random and unconnected, devoid of meaning. A questioning of the humanity of the person with dementia at the latter stages of their illness was alluded to in other accounts of nurses participating in this study.

J: What gives you satisfaction caring for people with dementia?

R: Um...

J: What sort of meaning do you find in the work?

R: Well, it depends how badly demented they are. I mean, if they are not so badly demented, well and you have got a sense of humour, it's quite good. We can bring it out. And, for those who are quite terribly demented, it's quite nice when they say thank you.

J: Feedback.

R: Yes, if I can get feedback that's, I think I have achieved something too. Even the abusive feedback! They have been really sick and they have abused you, but, oh yes, they must be getting better.

J: So any sort of feedback?

R: Yes.

J: Do you think that it's not getting any feedback that makes it?..

R: Oh yes it gets depressing. Yeah they are like a vegetable, and they just sort of lie there// No, I think they just want to go then. There is no stimulus, nothing. (Nurse 8, 2:8, Site 3)

A responding client, active at least to the degree of being appreciative of the nurse's input, was of considerable importance to many of the nurses in this study. After all, our own humanity is constructed in a dialectical sense through continual sensory interactions with the social and physical world around us. Any feedback was important to this nurse even if it was abusive, a response being a sign that something has been accomplished. The person who does not respond was equated with a vegetable, a pervading and persistent analogy in the discourse of health professionals. For example, Feil (1993) uses this term to characterise people in the terminal stage of Alzheimer's disease in relation to validation

therapy: “old-old people in Vegetation differ only in the ways they die. Curled in a fetal position, toileted, turned to prevent bedsores, tube fed, some hang onto life for years” (106-107). This use of language strikes a discordant note, given that Feil’s aim in developing validation therapy was to enable caregivers to learn empathy and respect for the person with dementia. To talk about a person as being like a vegetable is a particularly provocative representation; the ultimate objectification of a human being. The person’s status as a sentient human being is questioned in the use of this term, memory loss equated with loss of personhood. Feil crosses, as did the nurse, discursive boundaries, illustrating that people can occupy conflicting discursive positions.

In contrast, the nurses whose representations of care emphasised attention to psychosocial concerns as a necessary part of professional work represented the person with dementia as an experiencing human being. This inscription invests the person with the dementia with some degree of power, albeit at a micro-level and unintentionally, to influence the delivery of nursing care.

T: I do notice with the intermittent care clients they have their own routine at home and they seem to like to, somehow they get themselves into a routine here. I know it sounds weird but they somehow get themselves into a routine here. And as much as possible it’s really important to try and keep that going if we can.

J: Is there routine here much the same as their routine at home do you think?

T: I don’t think so but I don’t know for sure. With some of them, you are lucky you can sit and chat with the reles and they can give you an insight but I don’t think so. I think just somehow they adapt themselves into a routine which is theirs, separate from perhaps the rest of our routine and that’s fine and we fit into that. It doesn’t usually cause any problems.

J: And what are the things that make up the routine, a certain time of getting up?

T: Yes they seem to be I guess, no not time orientated but I suppose it is to a point, but specific times they like to do this, to have that, to be there.

J: Like getting up?

T: Like getting up, going to bed all those times actually um, taking part in activities, they like to go at certain times. They seem to, it’s quite peculiar to them. They seem to just like to go to activities at particular times. They start earliest about ten-thirty in the morning but they set their own times, they will just refuse to go if you suggest that. Yes they have their own routines. I don’t know how they do it or how it happens but it does. The intermittent care clients, they are just slightly different. Yes and I guess the other thing with intermittent

care is that we are aware, they are not, that they are not permanently with us and we should not drag them, and I say drag, it sounds awful, into our routine.

J: Because you would have to drag them, is that what you are saying?

T: Yes you would, I think you would. If they are set in their own routines yes I would say yes you would actually have to drag them to come in. (Nurse 12, 1:6, Site 4)

This relationship between the nurse and the person being cared for fits with Foucault's (1983b) conceptualisation of a relationship of power. In this type of relationship the person with dementia upon whom power is exercised is recognised as active and nursing care is adapted accordingly. However, while it could be argued that a person with dementia has some power to preserve their normal way of doing things, this influence is precarious. It is absolutely dependent on the nurses' interpretation of the behaviour and their philosophical stance on how care should be provided. The following interview extract surfaces the possibility of a resisting person being abused by harassed staff.

Oh yes, yes, sometimes we have patients hitting out, throwing things like throwing their drinks and throwing trays of food. I don't take that too well, I just tend to get angry. It probably doesn't help but if you are tired or you are busy and somebody throws a drink at you or hits out at you, obviously we are not allowed to hit back and we don't..but you tend to get a bit upset, swear to yourself and swear out loud. (Nurse 6, 1:3, Site 2)

As Potts, Richie and Kaas (1996) comment, patients as well as nurses can suffer when resistance to care occurs and "mental or physical abuse may be directed toward the patient in the forms of actual or threatened assault, restraints, or neglect" (p. 11-12). Nurses cannot disengage themselves completely from abusive comments and behaviour, particularly when they might be stressed themselves.

The adoption of an empathic position also produces the requirement to mediate between institutional practices and confused or resisting people with dementia, a potentially stressful positioning for the nurse. Altering the organisational environment to support changes in the psychosocial environment is essential if flexible caregiving approaches are to be successful (Hoeffler et al., 1997). Adapting care to the usual life patterns of the person with dementia requires a change in collective institutional routines away from, for example, pre-set meal

times for both clients and staff, and prescribed times for activities of daily living such as sleep and exercise. Considerable adaptation of conventional institutional routines is possible with sufficient staff commitment without added financial resources (Owen, 1995), but organisational changes require the support of ward managers and other nurses. The philosophical shift to a flexible and person-centered approach requires all ward staff to share a common philosophical position.

Discourse of risk management: “Eyes in the back of your head”

Nurses’ representations of people with dementia in this study highlighted the latter’s problematic behaviour. A major issue for the nurses was the supervision and control of the movements of people with dementia because of concerns about safety.

Safety is a big issue umm..because they get into other people’s bits and pieces and a couple of them are up just about twenty-four hours a day. And, because they are confused, their elimination patterns are up the kybosh and of course they are peeing and slipping in their own urine, and of course, you can’t have eyes in the back of your head and be attending to the other patients as well. So, of course, meanwhile this patient peeing in the corridor she’s gone for a fall but you are at the bedside with another patient. (Nurse 2, 1:6, Site 1)

The impossibility of constantly monitoring the movements and behaviour of each person with dementia was illustrated by the need for “eyes in the back of your head”. The implication was that the nurse’s gaze must be all-encompassing in order to protect other patients from the unruly, unpredictable dementing body. Foucault (1995, p. 197) suggests that hospitals, along with other modern institutions are models of a “disciplinary mechanism”, closed segmented spaces where all movements of the objects of attention can be observed and where “each individual is constantly located, examined and distributed amongst living beings”. The hospital ward can be equated with the panopticon (see chapter two), a structure designed to subject individuals to the imperceptible but all-seeing gaze of authority. But, for the panoptic mechanism to work effectively, those subjected to the panoptic vision are required to be self-surveilling, to constrain their own practices to fit with the normalised behaviour of the context. Active people with dementia do not comply with the established order as they wander without an easily discernible purpose, breaking

ward boundaries geographically by leaving the ward and socially, by invading other patients' spaces.

I mean they're interfering with other people's property, patients' property, and it's just really difficult trying to explain to other patients who are *compos mentis* that this person has no longer got the brain power not to interfere with anybody else. They are not *compos mentis*, they are confused, it's part of the aging process that has affected them and it's hard to explain it to another patients. They get very irate, people are working back and forwards picking up chocolates and clothing and bits and pieces and sitting on their beds and peeing on their beds, it takes a toll. (Nurse 2, 1:2, Site 1)

.....

We have had other people also that are totally lost in this environment and have taken a lot of settling. Some we have had major concerns about because they wander and they have still been physically fit enough to get themselves outside and that's quite a risk. (Nurse 4, 1:3, Site 2)

As discussed in chapter three, in biomedical discourse the person with dementia is constructed as a problem, a pathological body that is sick, and as at risk through dangerous behaviour. As Dewing and Blackburn (1999) state "it is generally accepted that people with dementia are 'at risk'...likely to harm themselves or even others, because they do not know what they are doing " (p. 803). This notion of on-going risk to the person with dementia situates nurses within a discourse of risk management and the associated need to intervene and to provide care and services that may reduce harm (Chater, 1999). Nursing surveillance in this context becomes a necessary, albeit oppressive, practice aimed at controlling a body that is represented as unruly and disruptive. But the practice of surveillance is also oppressive for nurses. It is a time-consuming encumbrance that can originate because of environmental factors, and it leaves little time for activities other than ensuring safety and basic life-sustaining care. Nurses' positioning within the discourse of risk management and the maintenance of patient safety as a pre-eminent focus of care can be shaped by organisational factors such as the physical environment and staffing factors. The lack of safe outside access and a place to walk freely was a significant issue for nurses in three of the study sites. The need to know the location of the person with dementia at all times was imposed on nurses because of structural issues that resulted from caring for people with dementia in wards that were not designed with their needs in mind.

J: Particularly caring for people with dementia, how does the institution support you or doesn't with the structures around you?

T: The structures don't support it at all because ah I think there should be areas inside and out that are completely safe um where they can just wander and I have always thought that and it's not going to happen here I doubt, I mean this area here is computerized now.

J: Yes I saw.

T: But it doesn't, it's an institution, it doesn't give them a nice garden where they can wander around and be safe, it doesn't have that and it's not going to have it, so it is frustrating that's um. The client ends up annoying nurses and other people because they are right there, but they haven't got anywhere else to go, there is no where else for them to wander. (Nurse12, 2:7, Site 4)

The two public hospital wards were standard wards that could be used for medical or surgical purposes and the private hospitals were designed for the residential care of predominantly physically disabled elderly people. Intermittent care was a very small adjunct to the core business of these wards and therefore intermittent care patients with dementia were at the margins of these services. The lack of environmental adaptations dedicated to supporting the care of people with dementia in three of the research sites reflected that marginality.

Controlling risk

Nursing options in managing the behaviour of mobile people with dementia whose activity places them in some degree of physical risk were limited.

S: I think I worry about their safety because I have had one or two actually go and really go. I had the police involved. One lady walked to [name of suburb] from the [name of hospital]. I think, so how she got there I don't know. But the families didn't find it a problem but I did, and I find that I couldn't handle it. I just worried too much and I mean it was my responsibility. But, as someone else said, you can't take full responsibility because you can't actually tie them down. But then at that stage they are not rest home care anymore.

J: So, it was frustrating in that this was a situation out of your control, in that the physical environment couldn't support you in a way could it?

S: But that's not very many of the confused. That's the thing that I really didn't like about looking after confused people. The fear for their safety that I couldn't impose what I wanted on them, when I knew it was right for their safety but they should be still allowed to wander and walk. (Nurse 14,1:6, Site 4)

The use of the words “wander and walk” draw attention to two competing discourses nurses work within. The word “wander” is only used in nursing literature to describe the behaviour of active people with dementia.

Wandering is one of the most difficult management problems encountered in institutional settings. Each year some residents wander away from a facility and are later found injured or dead. Media attention and litigation may suggest that staff as been lax in allowing this to happen. Some elders are obsessed with the thought of leaving a facility. (Ebersole & Hess, 1998, p. 422)

In this discourse the person with dementia is represented as a problem which creates liability issues for the institution and practitioner. This discourse privileges safety and risk management, with the control of behaviour being justified on the grounds of preventing the risk to life that might eventuate from exposure to inclement outside elements or as a result of an accident. The use of the word “walk” in the nurse’s account contradicts this representation by positioning the behaviour within a context of normal human activity. Here the focus is on human rights, with the person with dementia having choices just as any other member of society. Crisp (1999) and Thomas (1997) go further and argue that the activity framed as wandering in nursing literature could alternately be represented as an expression of personality, a normal pattern of behaviour for a previously industrious and active person rather than purely the dangerous consequence of a dementing illness. A tension is therefore created for nurses as a result of the incompatibility between these discourses. The person with dementia is positioned as simultaneously an adult with the right of autonomy, as well as a person requiring protection from self-harm as well as physical support in order to survive.

One response to problematic behaviour was the use of medication although this was considered a last resort.

On the first time basis when a patient comes in it can be very upsetting, not knowing how to control it what’s wrong, how to make things better. It’s terrible to think you have to jab people to quieten them down, that’s a terrible thing, sometimes you do though, but very rarely here. (Nurse 3, 2:14, Site 1)

The main situation when the use of a restraint such as medication was considered by the nurses was in relation to controlling noise. Nursing practices such as ensuring there was not an underlying need or illness that needed to be addressed, and the adaptation of the physical and social environment to suit the person's habitual patterns of living were not always effective. Yet noise cannot be ignored as it profoundly affects others' wellbeing. While, in theory, every one has the right to express themselves verbally, living in a group means that the rights of all need to be considered. Ultimately, nurses must judge when the degree of noise is so harmful to the wellbeing of all inhabitants of the home that action must be taken for the benefit of the whole community. This is an unenviable position because the treatment of last resort, a pharmacological remedy, might well impact negatively on the health of the person with the dementia. Interestingly, nurses in the study did not suggest that the use of physical restraints was an acceptable response to unsafe behaviours.

An alternative location in the risk management discourse was not to attribute the problem to individual issues, but to identify how the construction of mobility as a problem was organisationally produced, and to work towards enabling more freedom in a safe environment. In site three, an enclosed perimeter allowed safe activity within its borders. The issues related to the physical environment that were prominent in the texts of nurses from other sites were barely referred to by nurses working in this institution. The following comment by a nurse working in site three about the issues related to patients wandering represented nurses as active and influential in changing the environment to provide a secure perimeter.

S: Um, well I think, for example, we have addressed some of the issues of wandering patients, having the double locks, on the door and the property is basically fenced off so they can actually walk around.

J: So the environment has changed?

S: Yes, the environment has changed a wee bit that we can cope with them a wee bit better. (Nurse 9, 1:2, Site 3)

However, while environmental modifications created extended geographical boundaries, secure hospital wards were, very obviously, a forced place of residence for people with dementia.

It's like a prison, we have some of them actually trying to throw chairs to get through the doors, Alzheimer's patients saying I don't want to be in this jail I don't want to be in, and it is like a jail to them. They can only walk from there to here and back again all day long, that's what [patients name] does..back and forth all day long up and down the passage. (Nurse 3, 1:8, Site 1)

Relationships within a discourse of risk management where physical safety is paramount are characterised by the existence of relations of force, rather than those of power. The person is an object or thing acted upon, passivity is enforced and resistance is futile and disregarded (Foucault, 1983b).

Representing care as inadequately resourced: "We have never had enough staff and we never seem to have the time"

Nurses' work in the research settings was driven by the physical needs of frail, disabled older people. *Workload* was a particularly apt term used to describe work dominated by the necessity of continually moving heavy, immobile bodies from either bed to chair, or from side to side in bed. The following extract from my field noted records my experience one morning.

Over a period of three hours the nurse I was working with got nine people washed, up and dressed including showering three people. The work was carried out in a very focused fashion with conversation limited to the task at hand. My final impressions are of a blurred array of very old and disabled bodies being lifted from bed to chair, groomed and then sent on to the breakfast room where another nurse takes over the task of feeding the body. The nurse knew these people in terms of their past, in terms of what they liked and tried to ensure that they were comfortable and nicely dressed. However, my most dominant thought was that that the work is so physically demanding on the nurse that it must impact on the energy to communicate. To care for bodies means the use of the nurses' body and the physical work required takes a lot of energy and concentration. How much energy is left for relationships, getting to know the person? (Field notes)

The nursing documentation in the research settings focused on physical care. Issues such as mobility, nutrition, elimination, dressing ability and medication featured prominently in the care-plans. The oral exchange of information at the change of nursing shifts also reflected an emphasis on body care.

The nurse went through all the notes, there's about twenty-six patients in the ward. The three nurse aides sat quietly, two of them talking about the duty list to each other and waited. She checked whether there were any changes. She said to me that normally nothing much happened and then ran through with the nurse aides information about the care required. She used the person's first name, very few details, no diagnosis. Taken for granted every one aware of them. The information was fundamentally about skin care, people with lesions needing lotions, that sort of thing. Nothing about mood, behaviour, activities, the sort of day they had had. (Field notes)

.....

The morning registered nurse briefly ran through the names and any changes for all of the thirty-four clients. Would have taken no more than fifteen minutes to the one registered nurse and four aides working in the afternoon. Major information was about condition of skin, poor eating or the need for fluids. Most comment that there was no change. (Field notes)

This focus on the person with dementia as a physical object of care is not unique to this research context. Patients are positioned as the object of routines and procedures in the care plans developed in other settings such as acute care and rehabilitation (Cheek & Rudge, 1994b, 1994d; Heartfield, 1996; Parker, Gardner & Wiltshire, 1992). It can be argued that this narrow focus evident in written documentation and the formal transfer of information during the change of nursing shifts is an efficient use of time, an important attribute, given that nurses' texts in this research constructed time as a very scarce resource.

T: We never have enough staff since I have been here we have never had enough staff and we never seem to have the time (laugh).//

J: So at the moment the ratio is one nurse to seven clients and that dictates how much time you spend .

T: Yes, yes and obviously they don't get, and for me I sometimes don't feel that I have done things properly.

J: What do you mean by properly?

T: Well you can do a good shower or do a good bed sponge and you can get them dressed beautifully and they can choose their clothes um. But sometimes you don't feel like you are finishing off, racing off like "okay there you are love", already "good bye see you later". That's not the way I like to nurse, I like to chat, I like to find out what they are up to too and um particularly here I like to make sure they are being able to get plenty of fluids. We seem to have a lot of UTIs [urinary tract infections] and when I first came here very dry skin and that and it doesn't need to be that way. A lot of them can't reach out and get fluids but that because you are restricted for time like you are racing them, like .

okay and you are racing off again and that's not complete. (Nurse 12, 1:4, Site 4)

.....

We took them out for a walk and sat them over in the garden just behind us and sat there// and they sat there wandering around and they loved it they were going picking the flowers and smelling and it was just wonderful. But of course we were only limited time and we were only ten minutes off the ward and that's all we could do. (Nurse 2, 1:6, Site 1)

.....

W: We have had a lot of staff taking annual leave at the moment, and of course we have had casual or agency staff and they have no idea of the running of the hospital. And some of them have never ever been in a rest home before and I think it is completely different nursing to an ordinary hospital. You have got different ways to look after patients. The way you wash someone, dress them. And it's just that like today I have two nurses down today so I have two agencies [agency staff] coming in and they have never been here before. So I have got to spend time with them making sure they get all their things done. And that means the ward, half the things in the ward, will not get done.

J: So what would be your priorities?

W: Making sure patients are clean, dry, fed, and if we have got time to do a bath, showers, and if there are any dressings to be done they can be done last.

J: And what gets dropped off?

W: Usually the showering, that gets dropped off. But as long as they have dry beds, clothes on.

J: So you will tend to their physical/

W: Their physical needs yes and just make sure they are comfortable. (Nurse 15, 2:4, Site 4)

These texts highlight organisational resources such as staff numbers as a major determinant shaping nurses' discursive positioning and the subsequent inscription of the person with dementia. As a consequence of staffing problems, the nurses were located within an organisational imperative privileging the efficient completion of measurable tasks and physical care. Nurses are anonymous and interchangeable within this discourse, as are the people requiring care. Both are positioned as objects rather than as experiencing human beings with desires and aspirations. In the short term, working as an automaton, without consciousness and by routine, is potentially less stressful for nurses than the alternative position of empathy in a situation where certain tasks have to be done within a certain time frame. But when care is pared down to the completion of physical tasks there is little work satisfaction and no time for developing relationships with the people being cared for.

Furthermore, the opportunity to practise skilled and knowledgeable care is compromised even at the most fundamental level of ensuring that people have enough fluid to drink in order to avoid complications such as dry skin and urinary tract infections.

Judging from the nurses' accounts in this study, stable and skilled staff in adequate numbers and a safe and familiar environment are both necessary requirements to care for people with dementia in an appropriate and supportive manner. It is also apparent that, in the majority of the sites, these requirements, although reasonable and unsurprising, were not always met. This situation put nurses in a difficult position of trying to provide safe care despite the inadequate resources. I suggest that the inadequate resourcing of health care for people with dementia is embedded in the discourses around ageing and New Right economic policies. Discourses of ageing, in Western societies, portray ageing as a time concerned with loss and decline, a representation that Opie (1995) argues has resulted in a lack of health service provision because health problems are seen as the inevitable consequence of ageing. Clarke (1999c) also argues that "contemporary dementia care practices, and the care of family carers, are underpinned by discrimination" (p. 351), in part because of widespread discrimination against older people, but also because of pessimistic attitudes to the development of therapeutic options in the area of dementia care. This author argues that this has resulted in "case management strategies which emphasis containment, behaviour management and critically, a shift away from caring for people with dementia to caring for their family carers" (Clarke, 1999c, p. 355).

The adoption of New Right economic policies in the last decade, underpinned by beliefs about the necessity for a free market and competition along with a limited state role and fiscal restraint, has also impacted on residential care provision with the policy emphasis on cost containment (see discussion in chapter five). In New Zealand while admission of older people with increasingly severe and complex health needs to long-term care have increased over the last five years, the funding to these services has not increased to reflect the increased costs of care (National Advisory Committee on Health and Disability, 2000). Responses to this climate of fiscal restraint have included employing minimal levels of full-

time staff, high patient to staff ratios, and the shift from an almost all qualified workforce to a cheaper workforce of of mainly unregulated and unqualified caregivers.

The person with dementia: Inscribed as object of care

While working in a task-orientated manner may be problematic for nurses in terms of job satisfaction, the person with dementia was in a much more vulnerable position. People with dementia were, at times, referred to in nurse's texts as "dementias" and "the Alzheimer's". The use of the term dementia as the descriptor of a person could be interpreted as a casual verbal ascription with no particular representational power. Alternatively, the collapsing of the person into a disease category can be challenged as having quite profound representational implications as the disease category and the aligned medical discourse creates certain images and social possibilities (Oliver, 1999). The inscription of the person with dementia as a disease shapes nursing interactions with that person, as an extract from my field notes illustrates.

The woman the nurse was washing kept calling her a bitch and telling her that she didn't like her and to leave her alone as well. The nurse carried on washing and dressing the woman. It seemed quite demoralising at this stage to come to work, to be really busy and to have very negative interactions with patients in terms of them telling you off continuously. I asked the nurse I was working with what she thought about that and she said from her point of view, she didn't mind it, that she realised that they couldn't help what they said. (Field notes).

The nurse used the woman's diagnosis of a dementing illness to explain her behaviour and resistance to care, an attribution that enabled her to complete her allocated work of washing and dressing without the need to respond to the woman's comments and expressed desire to be left alone. In the above instance the person with dementia could be interpreted as being constructed as an object of care without feelings and desires that required some response, rather than regarded as a fully experiencing and reacting human being. This type of relationship could be described as characterised by force rather than power. For relationships of power to exist the person must be "thoroughly recognized and maintained to the very end as a person who acts and... faced with a relationship of power, a whole range of responses, reactions, results, and possible interventions may open up" (Foucault; 1983b, p.220). The attribution of the very negative interactions to specific disease processes

was useful for the nurse. It allowed the comments to be dismissed and depersonalised, even though they are provocative and hurtful, as the manifestation of a disease process. The physical work of caring can also proceed unabated. This is important in a situation where the competing needs of several patients must be met within a tight time frame. However, this attribution of behaviour to the underlying illness denies any possibility of the person with dementia influencing the pacing and type of care received. This woman was rendered invisible, forced to get out of bed, washed and dressed.

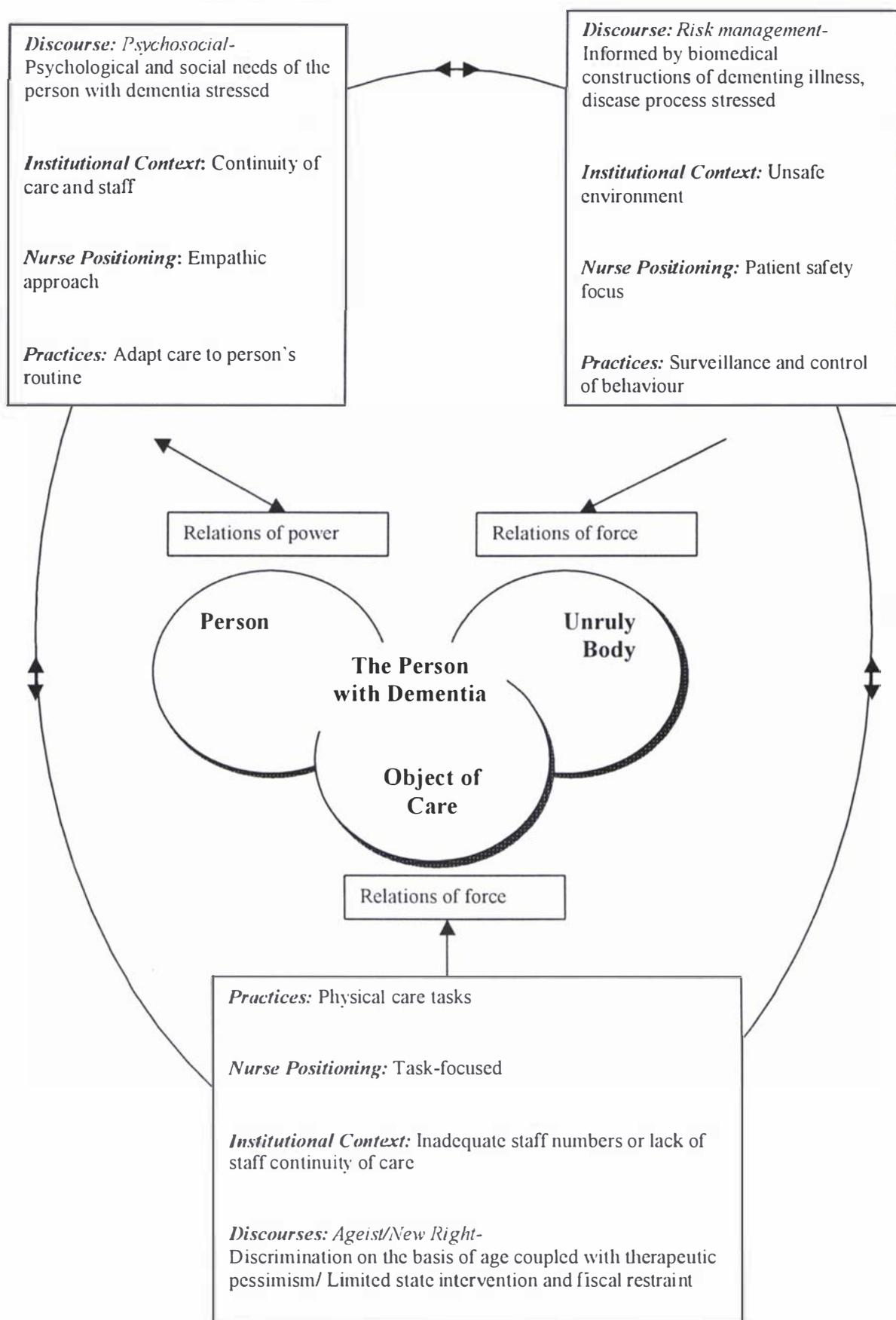
Summary

Figure 7.1 outlines in diagrammatic form the three discursive positions adopted by nurses that have been discussed in this chapter, along with the ensuring inscriptions of people with dementia, and the power or force relations in play. Within the psychosocial approach to care the interpretation of difficult behavior as an expression of need, psychological or physical, demanded an active nursing response to address the underlying issues precipitating the behavior. The development of empathy with the person with dementia required an in-depth knowledge of the person in order to be able to interpret, and appreciate as valid, their desires and frustrations. This knowledge was gained through the experience of caregiving and required continuity of caregiving staff over the intermittent care stay. The person with dementia was inscribed within this discourse as a fully experiencing person possessing agency, the nurse responding to resistant and aggressive behaviour by adapting caregiving practices.

Nurses' positioning in discourse of risk management was precipitated in the research sites by an environment that presented risks for people with dementia. Preserving physical safety was the imperative in this approach to care and the caregiving practices included surveillance in order to monitor the degree of risk, and control of behaviour through securing the ward perimeter and, as a last resort, chemical restraint. Relationships in this situation were characterised by force, with the focus on control of unsafe behaviour. Nursing actions were legitimised by the biomedical constructions of person with dementia as the pathological, sick body in need of protection. Similarly nurses working in a context where there were inadequate organisational resources to support appropriate professional

care reduced the person with dementia to an object of care without the capacity to engage in negotiated relationships. This discourse dominated in situations where there were inadequate staff numbers to meet other than the most basic of physical needs, or where staff did not have the opportunity to develop knowledge about the usual routines of the people they were caring for.

Fig 7.1 NURSES' DISCOURSES, POSITIONINGS AND PRACTICES



CHAPTER EIGHT

Dis/integrated Care: Family Caregivers' Representations of Intermittent Care

Introduction

In this chapter I focus on family caregivers' accounts of intermittent care in order to provide a fuller representation of how nurses' location in particular discursive frameworks influenced the provision of intermittent care services. Significantly, given the minimal research interest in the nursing contribution to date in this particular practice context, an analysis of the family caregivers' texts suggests that family caregivers' relationships with the nurses providing intermittent care, along with the effect of the hospital stay on the person with dementia, were critical factors in determining the degree to which family caregivers were able to relinquish care during the time their relative was in hospital and utilise the time for personal activities. Furthermore, the effects of the organisational changes and resource constraints are shown to similarly be disruptive for both family caregivers and nurses, and as exacerbating the complexities of care in this context. As I have already discussed in chapter five, the provision of intermittent care is based on the key assumption that respite will relieve caregiver burden and may possibly extend the duration of home care. The research evidence discussed previously suggests that this is a simplistic perspective which fails to account for caregivers' concerns about the quality of care provided in respite care institutions, and the impact of relocation on the person being cared for.

The initial focus of this chapter is on the experience of family caregiving, in order to provide some background as to why some families in this study persevered with intermittent care despite feelings of considerable ambivalence about the service. My analysis of the family caregiver texts then explores the differences in family caregivers' positioning in terms of their feelings about intermittent care, and the factors that influenced their perception of the service.

Family Caregiving: "I'm the pivot of her existence"

Given the considerable ambivalence some caregivers in this study felt about using intermittent care, their decision to use the service needs to be seen in the context of the daily demands of caring for physically and mentally disabled relatives. The nine family caregivers who participated in my study included six adult children (four daughters and two sons), and three spouses (a husband and two wives). Three of the daughters lived in extended family situations, their mothers sharing the house with the daughters, their spouse and their children. All other participants lived with just the spouse or parent requiring care. Four caregivers had used intermittent care services for over five years, the others for a shorter period of time, ranging from eleven months to two years. Their collective caregiving experience was extensive with six participants having cared for their relative for six years or longer.

All the people with dementia in this study had other chronic illnesses and disabilities such as paralysis related to a stroke, arthritis, blindness, deafness, diabetes and the loss of mobility due to injury. They all had little comprehension of verbal and written communication and difficulty understanding simple instructions. Complete assistance was needed with all the activities of daily living: washing, dressing, eating and elimination. Behaviour such as calling out repetitively or wandering away from home occurred at times. Many of the people being cared for were in a fragile state of health and four died over the three year period of data collection.

Research studies, such as Opie's (1992a), stress the extent of the work, organisational skills and expertise involved in caring for people with dementia. The following quote from a

caregiver in this study gives some insight into the complex interplay between the affective and physical domains of caregiving, as well as the temporal dimension of caring as activities are carried out day and night and repeated time after time.

Well if Dad wakes of a night time and appears to need attention such as prolonged coughing or discomfort, he may have passed urine in the bed, go and change pajama trousers, might need a sponge, assistance to move up in the bed, to empty his urinal bottle, warm up his hot water bottles, just generally to make him comfortable. During the course of the day you have to provide hot and cold drinks, the meals..um..He often has difficulties in mobility with the chair [wheelchair]. He often collides with furniture and doorways and becomes frustrated and impatient, so you have to go and lessen that frustration by moving the chair. Trying to keep him, jolly him along and empty the bottle out for him if he can't undo the top. Or sometimes can't undo a water tap. You have to assist him at toileting from the chair to the wall bar to the commode over the toilet and then should he wet you have to change his clothing. Um..there are areas that certainly take up twenty-four hours of the day. (Son caring for father, 1:2, Site 3)

This son, as did the other caregivers in the study, used a wide range of skills to care for his father who was substantially physically disabled and wheelchair bound. He had to learn by trial and error how to assist his father with mobility, hygiene and toileting, and how to judge what actions might make his father more comfortable. In addition, he learned to cook and manage the household chores. The emotional investment of caregiving relationships also surfaces in this text, as he supported and encouraged his father. It is also evident that the minutia of everyday existence expanded to take over the day.

The family caregivers in this study had little preparation for caregiving work and learning predominantly took place experientially through trial and error to find out what worked best at home.

As you do things you can work out a routine for yourself, a pattern and now I figure out what's the best way to wash. Instead of lying on the bed which they [community health nurses] used to, to wash her all over, I lie her on the side, make her sit on the edge with her feet on the ground so she'd be more upright. So I told the nurse and now they do that. (Daughter caring for mother, 1:15, Site 2)

They always seemed to have an idea that I was more capable than what I thought I was. They seemed to have that feeling that I was handling the situation very well and I had more knowledge than what I really did. Mine was just common sense. (Wife caring for husband, 3:3, Site 2)

Generally, there was limited input from health professionals although one son approached the hospital staff before his mother was discharged following a stroke and asked for lessons on how to care for her. Community health nurses were important sources of information, but not all families had access to those services. This lack of preparation for complex and intense caregiving is not unique to the family caregivers interviewed in this research. Twigg and Atkin (1994), in a British study of ninety caregivers, found that families repeatedly mentioned that lack of information was a problem for them: "They faced the classically circular difficulty of not knowing what it was they did not know until they found it out" (p. 94). These authors concluded that the lack of information was connected with the multiple and fragmented nature of the services provided and the resultant lack of a central source of comprehensive information. This constraint to easy access to information could equally apply in the New Zealand context. The families in this study had contact with many health service providers including general practitioners, the assessment and rehabilitation units, community health services and respite care services.

Another caregiving complexity was that caregiving work changed over time because of the unpredictable and very individual impact of the dementing illness on people's functioning. One caregiver commented that "suddenly you find him doing something that you hadn't even envisaged him doing, and that's the process and now you think he is going into that stage. I can see a stage coming" (Wife caring for husband, 3:1, Site 2). In addition, also as a consequence of dementing illnesses, all the people requiring care in this research needed almost constant supervision. The maximum time reported spent away from the immediate vicinity was an hour to go shopping. In one situation a son took his mother "everywhere I go. The only place I don't take her is to the clothesline because she pulls everything off" (Son caring for mother, 1:2, Site 1). These caregivers had small family support networks and minimal relief from caregiving from this source, a finding that is congruent with other studies in this area (Duffy et al., 1989; Opie, 1992a; Richmond et al., 1995). Formal support, other than respite care, consisted of community nurse help with physical care

requirements such as bathing. Paid employment opportunities were limited although two caregivers were able to carry on very small part-time jobs. The demands for continued supervision also conflicted with the activities of other family members, for instance attending children's sporting activities.

Relationships of commitment

Opie (1992a) used four terms: *commitment*, *obligation*, *dissociation* and *repudiation*, to represent the range of caring positions the families in her research were located in when caring for people with dementing illnesses. In my research the caregiving relationships families spoke of fitted with a position of commitment as defined by Opie. This type of relationship is described by the caregivers as being significant both in terms of the past and the present. One daughter described herself as "the pivot of her [mother's] existence, if she can see me, she's safe I feel" (Daughter caring for mother, 1:9, Site 3). In common with Opie's (1992a) findings, family caregivers believed they were able to positively assist the person with dementia because of their more effective responses made possible by an in-depth knowledge of that person.

We had a lot of fun, a sense of humour, tremendous, because he did have a sense of humour....so instead of, when he was getting irritable, if I could say something that could turn back, a quick remark.....Our relationship was as good but in, not on....when he was well it was a companionship. This time it was a feeling of closeness, an affinity....it was a lot of fun.... We saw the funny side of things when I was trying to get him to walk. He would growl at me and I'd turn a quick remark and we would both end up laughing. (Wife caring husband, 3:1, Site 2).

As Opie (1992a) also points out, the relationship becomes central to the caregivers' lives and other activities diminish.

G: I find it isolating in the sense that my life style is restricted and limited. I don't mind it but it is isolating for me, I often feel on a limb.

J: You lived somewhere else too.

G: Yes I have given up social work. I feel divorced from it although my heart is still there. (Son caring father, 1:3, Site 3)

This son, like others in the study, had given up full time employment and moved back to his father's home. In this text a strong image is presented of involuntary disconnection from the wider world in the use of terms such as "on a limb" and "divorced from it". Given the sacrifices made by family caregivers in changing their previously established patterns of living, one of the issues faced by these family caregivers in committed relationships, according to Opie (1992a) is that it can be difficult to accept that the work of caring has become too much and the decision not to undertake certain caregiving tasks can seem like "a repudiation of the other and perhaps a negation of their relationship" (p. 112). An indicator that the work of caregiving had become too much for families was the personal health consequences of caring. One woman in her seventies participating in this study still felt physically exhausted several months after her husband's placement in a rest home because of the heavy lifting required in caring for him. A daughter, reflecting on how caregiving affected her, said "it's hard enough when you are young and healthy let alone much older. It's a physical thing and emotional, it's really draining emotionally" (Daughter caring for mother, 1:8, Site 1). A son caring for his father constructed caregiving as an energy depleting concern.

I am in good health but I am not so fit at the moment so I just need to have the battery recharged. I need to talk to different people, I need to do what I enjoy doing like walking and talking to people and perhaps even having a run. Not that I have been involved in any sports but even some sporting activities..so that's how I see it anyway. I know that I wouldn't be as effective with Dad if I didn't have those breaks. In fact I am sure that I would have gone under by now. (Son caring for father, 1:6, Site 3)

These effects on caregivers feelings of wellbeing and health fit with the findings of other studies focusing on the physical and mental health effects of caring for chronically ill people (Anthony-Bergstone et al., 1988; Brodaty & Hadzi-Pavlovic, 1990; Rabins, 1993; Richmond & Moor, 1997; Teel & Press, 1999). However, despite the considerable and ongoing health issues reported by families, most of the caregivers in this study did not emerge as suitable subjects for health professionals' attention until the health of the person being cared for deteriorated to such an extent that continuing care at home was in jeopardy.

Legitimising the need for respite

The use of intermittent care services to enable family caregivers some respite was, in some cases, suggested by health professionals after the person with dementia had deteriorated in health, or had an accident, and had been admitted to hospital. For example, one daughter's mother had been living with her for a year and was able to walk with a stick until she fell, broke her hip and never walked again. The staff in the orthopaedic ward suggested to the daughter that her mother needed to be admitted to residential care. However, the daughter's text surfaces her considerable feelings of ambivalence about the quality of care her mother received in hospital at the time.

I said that I wanted to take her home. I didn't want her to go into a home. And they said that "you would never be able to manage, that you'd never be able to manage". Because she was virtually...well I don't know how much they commoded but every time I went up there, which I probably shouldn't say, she was sitting in a pool of urine or lying in the bed wet. And I said "you know I brought in pads" and I said "why don't you" and they said they would rather change the bed when it was wet. But she was wet every time I went in. (Daughter caring for mother, 1:6, Site 1)

The mother is represented in the daughter's discussion as requiring intensive, ongoing care, but significantly the daughter perceived that her mother did not get the care she required in the hospital setting. This perception influenced her decision to carry on caring at home and the decision to accept intermittent care was then presented as a foregone conclusion by the health professionals, choices subsumed in the greater decision as to whether it was time to relinquish the caregiving role.

I just couldn't put her in the home so anyway they said okay, I had to think very carefully about it, which of course I had already done. And if she came home the nurses said they would catheterise her and the social worker said they would see about intermittent care sort of thing if she came home. (Daughter caring for mother, 1:7, Site 1)

Other caregivers were informed about intermittent care services by their general practitioner. A daughter caring for her mother and four children said that her family doctor belatedly suggested that she needed some added support. "We took her down one day and he said 'You need a rest, you have got to get away.' He said 'You haven't had a break for

two years' and he said 'Right, that's it.' ” (Daughter, 1:3, Site 4). An issue that is surfaced in this interview is that some families in this study cared for very disabled relatives for years before intermittent care emerged as a possibility which suggests that the access or knowledge about intermittent care services in the research region was restricted at the time. These findings are similar to other New Zealand studies (Jack, 1987; Opie, 1992a). Health professionals suggested intermittent care in another situation after a home assessment.

J: Who suggested intermittent care. You brought him home after that stoke and you were managing at home so how did intermittent care come up?

J [Wife]: Dr [name of doctor] and the social worker These people came and saw me and saw the conditions here and saw [husband's name] and the way I was handling him and they said then that intermittent care would be necessary because it would give them the chance to check on him. And at the same time I was able to have something there to give me the rest. (Wife caring for husband, 1:5, Site 2)

Health professionals were positioned authoritatively in these accounts, their opinions about the desirability of intermittent care presented as being irrefutable. The caregivers' initial decisions to accept intermittent care were spoken about as though they had no choice, their difficult decision to relinquish the caregiving work for a time represented in their texts as inevitable and sanctioned by medical authority. This construction of intermittent care as a medical intervention developed to support family caregivers' health was useful in enabling family caregivers to justify taking respite time from caregiving.

Using intermittent care services

Le Navenec and Vonhof (1996) used a case study approach to follow thirty-nine families caring for people with dementia over a period of two years. They found that events occurred during the caregiving process, which they called *destabilising*, where the families' usual routines and ways of relating to the person with dementia were disturbed. Destabilising events included new caregiving demands, perceptions of actual and potential losses, and inadequate and inappropriate informal and formal care support. Other events were interpreted as *restabilising* in that they were perceived as restoring a sense of balance to patterns of caregiving and relating. Emotional and practical caregiving support from both

an informal social network and the formal support system were restabilising factors. Intermittent care has both destabilising and restabilising potential. The usual patterns of family caregiving can be undermined by institutional routines, or alternately, families' investment in care can be affirmed and recognised by the provision of focused services supporting family caregiving patterns.

The restabilising aspects of intermittent care for the families in this study had several dimensions. All the family caregivers valued the opportunity to use respite care services just as has been reported in other studies (Homer & Gilleard, 1994; Levin et al., 1993) and they persevered with its use despite of the problems. They talked about how they appreciated time to be with their friends and their relatives.

M: It gives me a chance (laugh), it gives me a chance to catch up on all my social life.

J: Would it be normal social life?

M: No it wouldn't because it is fitting into two weeks what I would probably do in about three months. Going out. It means that you structure your social activities...My life's completely different because I don't stay at home one day, I'm catching up on, I'm going to do this and I'll go somewhere else um. But I just seem to have that compulsive urge too be out and doing something. Where as if Mum's at home I'm quite happy to be at home. It's like two lifestyles really. (Daughter caring for mother, 3:12, Site 2)

This speaker described her strongly contrasting lifestyles, the insular nature of her caregiving work placed against the period of frenetic activity when the social activities normally carried out over a much longer period of time are collapsed into the two weeks of respite care. Two caregivers were involved in part-time employment during the respite care period. Several also commented on how the respite period gave them time to recover from the physical work of caregiving. The opportunity for some personal space, freedom from the other wise constant need to supervise the person with the dementing illness was also a positive aspect of respite care.

It gives me time to have a break. I can get out. I'm not always sort of worried if I go and park somewhere. When I go up to the supermarket I have to park the vehicle so she can't get out the door. So I park against the concrete wall. And when I haven't got her with me I can go in there and spend half an hour, three

quarters of an hour and I can go around and see what I can buy. (Son caring for mother, 1:4, Site 1)

Some caregivers also talked about how respite from caregiving was an important factor in reducing relationship tensions between family members.

You have the bickering, and then Mum can have a bicker, and I scream at her or something and she just won't do it, and that time's coming and she is going in for a break and it is just a relief, I can have those two weeks to myself and to the kids. (Daughter caring for mother, 1:8, Site 4)

.....

J: What prompted the decision to use intermittent care?

E: I think once again the [name of day care center] could see that [name of husband] and I were getting a little bit too stressed.

J: By too stressed, what was happening, can you think back that far?

E: We were finding it very difficult, there were arguments in the house and we don't like that sort of lifestyle and I was at work too and so it was all getting a wee bit on top of us.

J: Sort of getting tired and frazzled?

E: Yes it was, it was it was tiring and I mean mother would do unusual things you know and it was really quite hard to cope with it at the time. (Daughter caring for mother, 1:5, Site 3)

However, many of the families found there were also considerable tensions between their desire to have some respite and the added emotional and physical burdens associated with the service. The destabilising aspects of intermittent care will be discussed in some depth in the following discussion. Three positions were evident in caregiver texts, in terms of their feelings about intermittent care. I have described them as *acceptance* of the legitimacy of taking respite from caregiving, *qualified acceptance* of the legitimacy of taking respite from caregiving, and *marked ambivalence* about taking respite from caregiving. Family caregivers changed in their perceptions about respite care so their positioning in these categories was fluid in nature. Critical factors that influenced caregiver perceptions were the impact of the stay in the intermittent care ward on the health and functioning of the person with dementia, and the relationship of the nursing staff with the family caregiver.

Acceptance: "A part of the place"

Some caregivers (one husband, two sons, and one daughter) generally talked very positively using intermittent care services. Another caregiver shifted dramatically from profound ambivalence to a positive acceptance and satisfaction with intermittent care when her husband was moved to a new intermittent care service. These caregivers expressed confidence in the care that the hospital staff gave to their relative. They believed that the person with dementia settled down quickly in the ward, and that normal home routines were regained quickly when the person returned home.

J: Do you feel some confidence in the care.

A: Its AI as far as I'm concerned. Even better hands than a lot of people, in the best...

J: And that actually helps you go away and feel okay about it.

A: Oh yes, my minds at rest.

J: So that's pretty important?

A: Oh yes of course it is because I knew she's in good care. (Son caring for mother, 1:5 , Site 1)

.....

J: The other thing you said last time was that the nurses in ward [previous intermittent care ward]...you were concerned because they weren't carrying on the normal routine that you had at home of him dressing him-self and his activities.

H: They do here, they do here.

J: At [name of hospital] what do they do?

H: Most...well they won't allow him to lie on his bed like they did there [previous intermittent care ward] and I just say to them "please keep him walking." And she said "we realise that if we don't it's harder for you when you get him home." And that's not only me who has said that.// But they are aware, well aware of the situation.

J: Because you have told them what you do during the week.

H: I tell them how I keep him to a routine, and I do because I find it easier for myself.

J: And they've kept to that within [name of hospital] ?

H: They have kept to that apart from spoiling him with pancakes

J: So you are finding when he gets home, how do you find him when he gets home?

H: he was great when he came home last time ..

J: Mmm great in what sense?

H: He was happy and a lot easier, just stood up and went into the bathroom. (Wife caring for husband, 1:6, Site 3)

In the upper extract of text the son constructs the nursing care as being the best possible, as “A1”, which enables him take advantage of the respite time from caregiving with a clear conscience. In the second extract the participant provides greater more detail about what constitutes good care for this particular person. A critical element, in this text, was the nurses’ attempts to follow the home pattern of caregiving and their acknowledgement that it was important to preserve pre-admission levels of functioning. This participant judged acceptable levels of care by her husband’s state of health and fitness when he returned home.

Possible interpretations of these texts are that these caregivers were very relaxed, adaptable or detached in their approach to caregiving and accommodated to the changes on the return home, or that the person with dementia was able to adapt readily to changing circumstances. However, both these interpretations are challenged by this account comparing experiences between two different intermittent care sites.

J: So you are finding when he gets home, how do you find him when he gets home?

H: He was great when he came home last time..

J: Mmm great in what sense?

H: He was happy and a lot easier, just stood up and went into the bathroom.

J: And when he came home from the [name of AT&R ward]?

H: Oh he was terrible, he really was// It took me at least a fortnight..They just used to leave him lying on his bed, put him in his pajamas about three in the afternoon. That’s not on for people that are like that. (Wife caring for husband, 1:6, Site 3)

This extract suggests that the type of nursing care provided in the intermittent care ward played a critical role in determining whether the pattern of home caregiving was easily regained or compromised, in the short term at least. In intermittent care, where the gauge of a successful service is the degree to which the caregiver can relinquish care with confidence, interactions with nurses become the main indicator for families of the quality of care experienced by the person with dementia. The families who represented intermittent care in a positive manner trusted that the nurses would care for their relative as the family caregiver would at home and valued their relationships with the nursing staff. The initial reception at the ward was an important part of setting the tone of the stay for families.

The patients come out and the nurses come out and the head nurse, she comes out and everyone has a yarn and she wanders off [name of mother] and goodbye me. As I said one time she walked away and I was dropped like a bit of dirty old rag and I thought “Well God that’s **good**”. (Son caring for mother, 2:1, Site 3)

.....

J: So you were greeted?

H: You were greeted at [name of hospital].

J: By all the staff?

H: By all the staff of the [name of hospital][name of nurse] she’s the assistant charge and....they were showing a new registered nurse taking over that two to ten shift and, no it was really nice, put him at ease, I could see him relax.

J: Right from the first greeting?

H: Whereas in comparison with ward [name of AT&R ward] you stand for about half an hour before any one takes any notice of you. (Wife caring for husband, 1:1, Site 3)

In these texts, family caregivers describe the nurses as actively coming out to meet the family. There is a sense of welcome and due ceremony in these accounts in contrast to the comment in the second text about the lack of welcome in the previous intermittent care service. One husband spoke of how he felt “a part of the place” and included in the everyday life of the ward. “They are community types not a type apart// when you walk in there you don’t kind of creep in and look all round the place. You walk straight in and ‘Hi how are you doing’ and they treat me the same as her”(Husband caring for wife, 1:4, Site 1). In this quote the nurses are represented as being people like the caregiver, and he as a person rather than an anonymous stranger. Another participant appreciated friendly, personal contact by the nursing staff.

They have been very supportive of the family and they had been very professional but very practical, in their care for Dad. Prior to going to [name of hospital] the first time the nurse in charge wanted to know what Dad’s daily and weekly routine was at home. And that in itself was a great help for me and I believe for Dad. So they are very much like a family there, they are very friendly although professional. As nurses there is a very nice spirit about them, they do not appear to be overly concerned. They are concerned but they take things in their stride and take the person in their stride and seem to make allowances for that particular patient or resident at the time, which has been the case with Dad. And I think have very much got on to his wavelength. No, they have asked the right questions before going, so have had a little history there,

um, and something to work on while he has been with them. They have been very interested in his medication and his general functioning while at home so all those things have helped them at there. No, I have got nothing but gratitude and praise for what they have done. (Son caring for father, 1:12, Site 3)

This son believed that the care provided by staff in the hospital had both professional and personal dimensions. The professional aspects of care included asking the “right questions” so that he felt confident that staff had adequate information to care for his father appropriately. The personal aspect focused on the emotional dimensions of care. The staff seemed like a “family” and the nurses have a “very nice spirit about them.” There is a sense here of continuity between home and hospital care, that the family caregiver’s patterns of caregiving were valued and perpetuated in the hospital and that there was also emotional investment by staff in well-being of the person with dementia.

Participants also constructed the intermittent care time as being beneficial for their relative in terms of increased opportunities in intermittent care for medical and nursing care, as well as social interaction, as compared to the home environment.

I always thought of it as being important for Dad too to go into a different environment, a different atmosphere where the people caring for him are professionals, where I’m not in a sense medical or nursing, and where they would be able to attend to things in a more professional manner and he would benefit from that. Plus what they would provide within the private hospital situation in the way of therapeutic activities that I couldn’t offer here plus perhaps meeting people of his own age group that he could talk to and talk with. I’m limited as to what I can talk to him about in the course of a day. (Son caring for father, 1: 6, Site 3)

.....

I think one of the very important things of being in intermittent care or permanent care for elderly people is that they have entertainment, they have something to stimulate them rather than just sitting in a chair and watching TV and other people walking around, I think they need to have activities whether it is only someone reading the newspaper or somebody singing a song or somebody just talking to them. I think occupational therapists are a very important part of a home. (Daughter caring for mother, 1:5, Site 3)

Intermittent care is framed by these participants as being much more than a custodial service and as having therapeutic dimensions in the care provided. The doctors and nurses

are represented as having expert knowledge, able to detect and treat problems that otherwise would be missed. This emphasis on medical and nursing care in the first interview text is not surprising given the fragile and changing state of health of most of the people with dementia using intermittent care. Activities in both accounts are also framed as having *therapeutic* qualities, important in enhancing general health.

The caregivers located in a position of acceptance relinquished the physical care of their relative to the staff while he/she was in hospital. Two caregivers did not visit at all, and other family members and friends substituted for their presence.

H: I completely shut off now

J: When he's away?

H: Yes I do. (laugh) Terrible isn't it?

J: No. When you say completely shut off?

H: I know he's well looked after and when he goes to day care I know he's well looked after. But I didn't relax when he was down in ward [name of AT&R ward] no way.

J: So how do you mean now?

H: Well I suppose I don't have the niggles that I'm wondering whether he's eating his food, because twice he was in there (previous intermittent care ward) he lost about two stone. So his food was cold. He won't eat cold food. (Wife caring for husband, 3:7, Site 3)

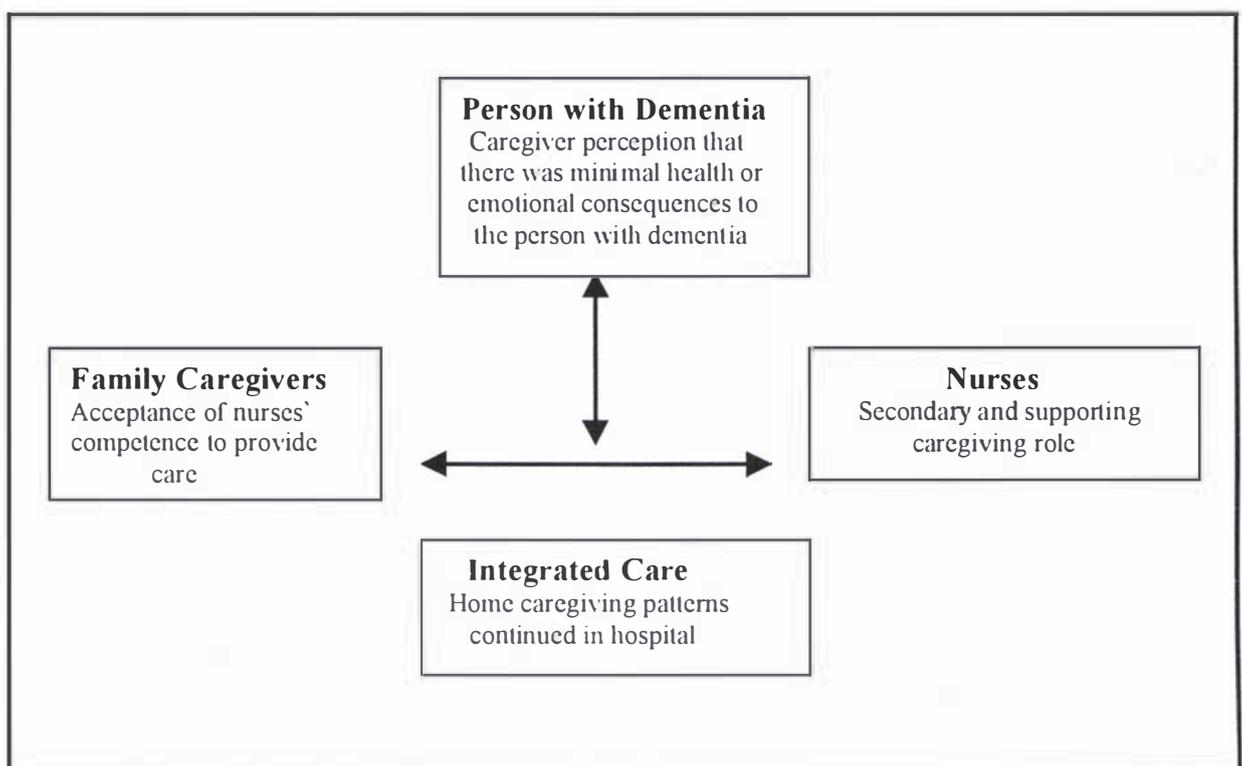
Respite care, to be effective, must be so unproblematic for the family caregiver that life can be compartmentalised into non-caregiving blocks of time when the person they are caring for recedes in the background and other activities take precedence over the times of caregiving with the intense work and relationship that entails. The other two caregivers, while very positive about intermittent care, felt the need to visit occasionally.

It all depends. Sometimes I will be sitting here and I think, the one thing about it is when I walk in there is her face. It brightens up, cheery and all things like that. And she says "I wondered if you were coming up here tonight" and this makes you sitting home here sometimes makes you feel a bit guilty// When you see the face of the person you have come to see there the guilt goes and you think I'm glad I've come in no..it's excellent, it's very very good there. (Husband caring for wife, 1:5, Site 1)

The essential tension in intermittent care, the temporary severing of close emotional bonds in order to maintain the caregiving relationship in the long term, is exposed in this text. There is slippage between the need for respite and feelings of guilt about inflicting the stress of living in a strange environment on a dearly beloved wife, assuaged in this case by the husband's confidence in the unit's staff. Caregivers visited because they wanted to maintain the continuity of relationship and care.

Figure 8.1 outlines in diagrammatic form the critical factors surfacing in family caregivers' texts that enabled them to use intermittent care services with confidence and accept, without major reservations, the need to take respite from the work of caregiving.

Fig 8.1 ACCEPTANCE



I have called the approach to respite care, as represented in these family caregiver texts, *integrated care*. My reading of family caregivers' accounts highlights the relationship

between the nurse and the family caregiver as a critical factor in enabling the latter to relinquish the work of caregiving to a professional. The nurses were represented in these accounts as being both professionally and personally caring in their interactions with the family caregiver and the person being cared for. Crucially, nurses, according to the family caregiver, inquired as to how care was carried out at home and attempted to adapt nursing practices in the hospital to the home caregiving patterns. As I have already discussed in chapter seven, this stance to care also surfaced in the nurses' texts who were empathic and emphasised the individuality and humanity of the person with dementia. This relationship between the family caregiver and nurse suggests a form of power relationship where the nurse adopted a supporting and augmenting role, and the family caregiver was positioned as primary caregiver and as possessing the in-depth and intimate knowledge required to meet the needs of the person with dementia. This relationship was characterised by collaboration and communication.

Qualified Acceptance: "They don't have time to spend an hour"

Qualified acceptance refers to a position where caregivers were able to use the respite time constructively but caregiving was only partly relinquished. The two daughters located in this position felt the need to visit frequently; one to feed her mother each night, the other visiting every second day as she was worried that her mother was sitting in her room alone all day. The distinctive difference between these caregivers, and those who relinquished care more completely, were the concerns expressed about the quality of care provided in the intermittent care service. Their texts describing a qualified acceptance were characterised by a repeated contradiction. On one hand, the daughters spoke of the nurses as being generally friendly and cheerful but, on the other hand, at times they observed that their mother's needs were overlooked or possibly not met.

J: How have you found it?

M: Very good actually.

J: How did the transition between [name of previous intermittent care ward and this site] go?

M: Mum doesn't know where she is or anything. Doesn't make any difference to her and I found the staff very nice. I think they have one nurse who seems to be on at night but I found they were very good. I try to go down in the evening

at tea time to try and get her so she will try and eat her tea because I don't think she eats much for lunch because she takes a long time to eat and they don't have time to spend an hour so I try and go down there at tea time but no she seemed to be quite well looked after there. It's worked out really well really. (Daughter caring for mother, 3: 1, Site 4)

The lack of nursing time available to provide care was emphasised in this account rather than an alternative interpretation that the nurses were intentionally neglecting this speaker's mother. Respite care was an important service for the caregiver. Her account noted the organisational issues that comprised the quality of care given. It did not, however, suggest intentional neglect by the nursing staff.

Unlike those who were very positive and accepting of intermittent care, the two daughters noted the absence of any discussion with the nurses about how care was provided at home. Consequently they both felt unease about whether the care was adequate in hospital.

J: You haven't been asked for much information?

E: No.

J: But they would have got something from [previous intermittent care ward] presumably?

E: But even when I took her up on Tuesday they didn't have any papers to sign or didn't ask if there was any change in her or anything.

J: Did you tell them anything?

E: No, there was a nurse on who wasn't usually there and I have never met the head nurse up there. She was at a meeting// they don't ask you, you know any change in her..and um a few times we have noticed, the last time she was up there, she is always sitting in her room and I know they have activities. If she joins in I don't know, if they go in and get her to join in or what. (Daughter caring for mother, 1:6, Site 4)

Nurses in this account are strangers, with little personal investment evident in developing a relationship with the family caregiver. My reading of these texts is that there was little continuity of care between hospital and home, nor were there opportunities to address any concerns that the family might have. However, their relatives described the person with dementia as relatively unaffected by the stay in hospital and as settling down quickly at home.

J: How does it affect your mother do you think going into intermittent care?

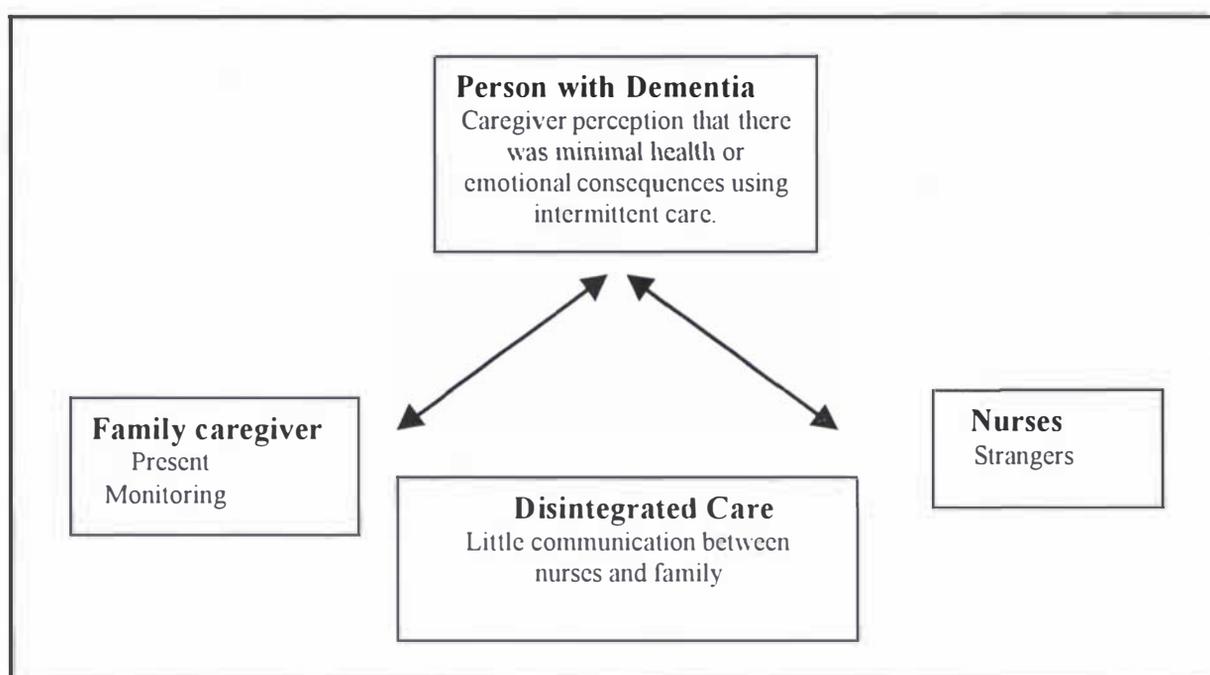
M: Well half the time here she thinks she's in hospital and she calls me matron. She doesn't know where she is half the time.

J: You've been elevated.

M: Or otherwise she says I don't think much of you as a nurse I'm going to report you to your superiors. So she doesn't really know where she is half the time. This house has been built on to since she been here but she doesn't remember and half the time she thinks she is in a shop. She doesn't know where she is most of the time even though she's been up here for the last twenty-five years a lot, at least once a year, she doesn't remember any of it.....(Daughter caring for mother, 1:11, Site 1)

Figure 8.2 highlights the critical factors evident in the study texts influencing the family caregivers located as accepting of the need for respite from caregiving, but also still feeling the need to visit frequently in order check on their relatives' welfare. I have called this approach to intermittent care, *disintegrated care*. Sharp divisions are evident between the patterns of home and hospital care with little communication evident between the nurses and family caregivers. However, patterns of caregiving are quickly regained when the person with dementia returns home.

FIG. 8.2 QUALIFIED ACCEPTANCE



Marked ambivalence: "All that hard work and two days in bed for her and that's the length of the hall gone"

The most fluid and contradictory position, that of marked ambivalence, highlights the conflicting emotions associated with intermittent care. Caregivers valued the time for respite but simultaneously had difficulty relinquishing care because of concerns about the negative impact on the person needing care. Family acceptance of intermittent care was fragile and tenuous. They were committed to caring for their relative because they felt they could make a positive difference and any action that caused distress was dissonant with this goal. These caregivers moved between ambivalence and/or acceptance as they changed hospitals, or the style of care changed in the ward. In the following discussion I have focused on the times when they felt ambivalent as they related to the nursing care that was provided that they articulated as being problematic.

The texts of the three carers located at times in this position highlighted the impact of hospital care on the person with dementia. The reactions of each person created concern; one wife spoke of her confused husband calling the hospital a "jail" and a daughter spoke of how "you could see the whole change in her"(Daughter caring for mother, 1:5, Site 1) when she told her mother of the impending hospital stay. The fact that those being cared for experienced weight loss, constipation, and decreased mobility as a consequence of their admission concerned the caregivers greatly. Furthermore, extra care was required at home at home to help the person regain their previous level of health.

Physically exhausted and didn't know me for a while, that sort of thing, he didn't know me or didn't know the house and then I'd just get him back on his feet and back into our chatting ways and he'd be going back in. (Wife caring for husband, 3:3, Site 2)

As a consequence of their relatives' deterioration after a period in intermittent care these caregivers worried about whether their relative was receiving adequate care in hospital. One wife thought about her husband at meal times, wondering "whether he was eating his meal and whether he was walked to the toilet or whether he was getting put into a wheelchair or something" (Wife caring for husband, 1:10, Site 1). The context of this comment was that her husband (who was blind) had been found by relatives sitting in front

of meals that he had not been told about, and which had subsequently become cold. She also believed that walking her husband to the toilet was important to retain mobility but nurses had used a wheelchair in the past. She expressed frustration about the communication processes between her and the nurses.

J: How much information are you able to give to the ward staff?

H: I give them plenty.....of what he should be doing.

J: Do they ask you?

H: No, they probably screw it up and put it in the rubbish.

J: You actually write it down?

H: I do tabulated general..

J: Like a care plan?

H: Yes.

J: So you hand it in?

H: Each time.

J: And do they give it back to you for next time?

H: It's probably not even in the notes, one of them said to me 'You don't need to write the instructions,' and 'I said I think I do..you see the example I gave you before with the meal. I have told them every time about meals.

J: That point was that because your husband is blind..to plonk down the food without any explanation

H: And the same with a cup of tea, cold and he doesn't know it's there, they just put it on the locker and if he could see he would know it was there.

J: And that you write it down and they obviously, well as you say its a common sense thing but for some reason..does that happen all the time?

H: Every time.

J: But presumably not all the nurses?..

H: I don't know..my daughter-in-law was there last night and he was eating his cabbage with his hands because he couldn't find a spoon, well really..

J: So you give them good instructions?

H: I give then good instructions but they go out the window.

J: Do you usually go up with your husband?

H: I always admit him.

J: How much chance do you get to talk with the nurses at the stage of admission?....

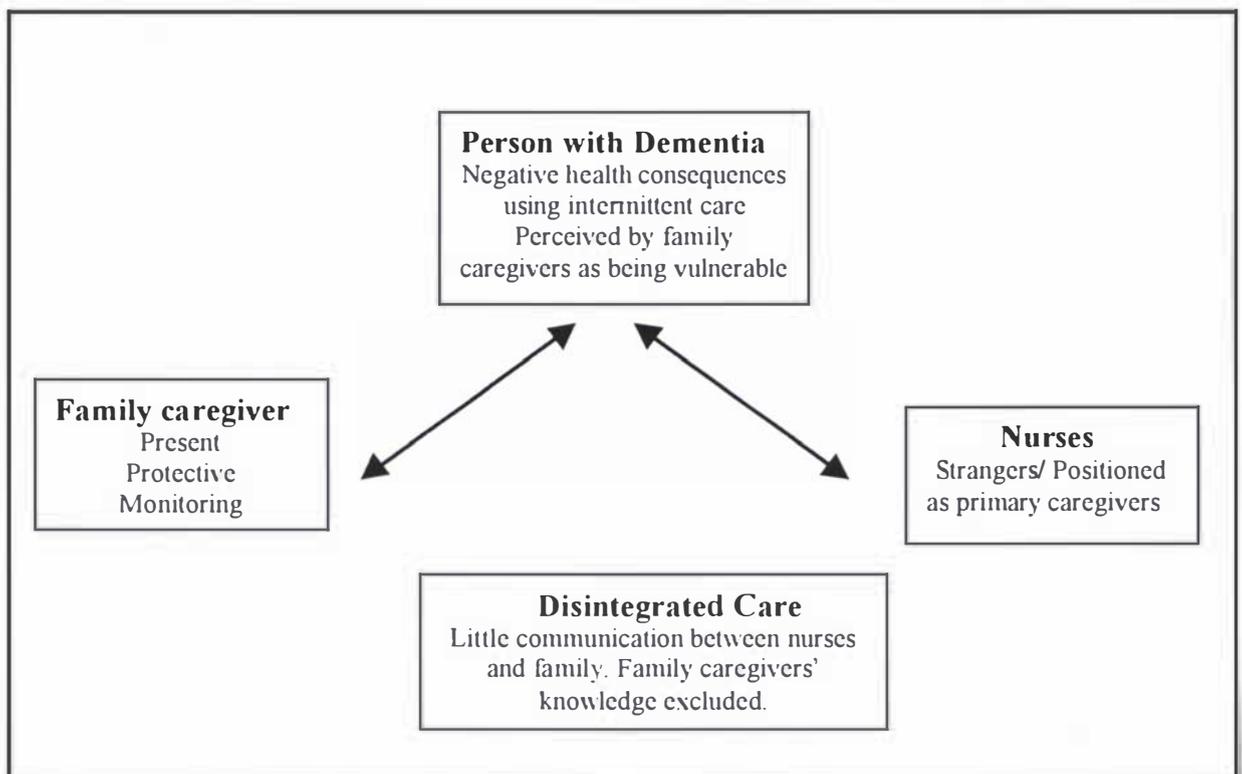
H: It's different these days, you never seem to find who is around or who is in charge...**don't get me started on that please...** (Wife caring for husband, 2:4, Site 1)

The family caregiver is inscribed as marginal and without power in this text while nurses are represented as actively resisting, screwing up information and throwing it out of the

window. This is a much stronger image than the representation of nurses as being overworked that the caregivers in the qualified acceptance position provided.

Once again, as in the qualified acceptance position, a disintegrated care approach is apparent in the marked ambivalence position (fig 8.3) with division between home and hospital care. In addition, family caregivers who felt very ambivalent about using the service believed that there were a range of health consequences, ranging from minor to major, for the person with dementia. Furthermore, in this representation, nurses were perceived by the caregivers as actively disregarding the knowledge and expertise

Fig 8.3 MARKED AMBIVALENCE



of the family. The validity of this perception is supported by some nurses' accounts. For instance, one nurse said; "You don't see the family usually. They just don't come and that's pretty well with all intermittent care. They drop them in and run" (Nurse, 1:5, Site 4). A

very different image of families is conveyed in this extract from the families' representations of their concerns discussed earlier in this chapter. The choice of the phrase "drop them in and run" describes the person with dementia as an inanimate object and depicts an easy transition between home and hospital with no feelings and thought involved. Furthermore, not all the nurses agreed with adapting hospital routines to the routine of the person being cared for.

C: Some of them I find manage better in the ward than what they do at home because of more set routines, haven't got as many people coming and going. While they might want to care for their relatives, and I can understand that, some would be better off in an institution with more routine.

J: So you think the routine is quite important?

C: Yes, very important. They become more accustomed to knowing what they are supposed to do, rather than at home when things happen differently with people coming and going. (Nurse, 1: 2, Site 2)

In this text the nurse is positioned as the primary caregiver and the hospital as the most desirable site of caring for the person with dementia. The instrumental dimensions of care are privileged, emotional needs marginalised.

Caregivers' feelings about the quality of care provided did change over time depending on the organisation of nursing work and the personal qualities of the nurses employed at the time, as the following account illustrates.

J: How much opportunity do you have providing information or getting support, that kind of thing?

Z: Um..Perhaps twelve months ago I would have said, I would have been lucky, I wouldn't know who the nurses were, and perhaps that was because there were changes in the wards or there was a lot more people on intermittent care. And I used to have a lot of run ins with the doctor and I think the reason was that she was so on the administration side and she was cutting back our hours and our days. It was terrible but it wasn't, but it wasn't as though, it was terrible for us but I mean they get so confused these people that going in for five days and coming home for weekends and you have got to come back again, it was just cruel. So the medical side of it then, or the nursing side of it then, was horrific, it was absolutely horrific. And again the changes have come in the last twelve months and I think, I don't whether I'm lucky or the nurse that Mum's had has been her nurse each time she goes in, that's [nurse's name] she's on morning or afternoon and she's so..I listen to her talking to all the patients and she is really

bright and she chats to them, she tells them what she has been doing and she does their hair. You know, nice personal touches, that normally you don't see. It sort off, you know I've heard them the way they talk to them, it's not nice. It's business-like I suppose but its not caring. You have got to be a special nurse to do elderly people..You have got to be able to relate to them as adults but also, um, certain things they do are like children do..but always remember that they are an adult..So, at the moment I have no complaints about..and whether it just I'm lucky my mother's got a good nurse, some used to put, she used to hate going to bed early and things like that but that's the system in hospital. (Daughter caring for mother, 1: 6, Site 1)

In the first part of this text some earlier cutbacks in intermittent care as a cost saving measure in this site are referred to. People were admitted for five days each week and returned home in the weekend for a two week period, a fourteen day stay reduced to two five day stays. The ward doctor was positioned as closely associated with hospital management and indeed driving the changes that made care more difficult for families. This daughter's strong feelings about the injustice of this change were still evident a year later. In the latter part of the text the previous conflicts with hospital staff are juxtaposed with the current situation and the "good" nurse who provided "personal touches." However, organisational practices in this ward remained fluid and there had been more changes when I interviewed her some months later.

Z: They decided about three visits ago they were going to put patients, instead of having all the intermittent care patients together, each nurse had a ward...And isn't it funny, the nurses who are looking after my mother don't know her. I mean, years ago nurses would stay in that ward for quite a while but there's a lot of new, I don't know what the turnover's like but a lot would have known her five years ago. Yeah so that was fun. All explained to us.

J: So handing over care for nurses was a problem because they have to get to know the person, all the fine detail. To do that you have to have consistency of staff.

Z: I think we get very protective ...and it's an important part of maintaining the person at home And if anything like walking..I always think that walking, if you don't use it you lose it. And really every day we do this walking and then I go into hospital and she would be sitting in bed and I would think "oh all that hard work and two days in bed for her and that's the length of the hall gone." So that used to make me angry. Because I know that it is easy to put her on a chair to push her but now that's what's happens. (Daughter caring for mother, 2; 9, Site 1)

The change in the way staff were allocated to patients resulted in the disruption of the close and knowledgeable relationships that had been valued by families using intermittent care. This change may have resulted in greater efficiency for the organisation but the cost for the family caregiver was exorbitant. As a result of impersonal, unknowing care, this daughter's caregiving work was perceptively increased when her mother came home. The length of a hall in terms of mobility is the distance between bed and the toilet or the lounge. Visits to the ward in this situation had protective dimensions and this caregiver visited every second day unless she went away.

I'm actually her voice I think, I think.....umm.....I'd hate to think of her beingummm...things, something was being done to her that she didn't like or she knew that she didn't like but she couldn't speak for herself or, I know what she likes and what she doesn't likeand it's just making sure that ...that they don't do things to her that they wouldn't do, if someone could speak they wouldn't do, yeah, so it's her voice, her voice. And hopefully, you put yourself in that position and think well I would like that done to me, would she have liked that done for if anything happened there. Because there is still the person there and you always wonder how much of the person is there ...so you have to, you know her rights and emotions. (Daughter caring for mother, 1:10, Site 1)

Vulnerability and protection are key elements in this text. That vulnerability is constructed in terms of the caregiver's mother being unable to voice her needs combined with the assumption that she is still cognitively and emotionally present, albeit rather tentatively. The nurse's actions are potentially detrimental to that person because they do not know her as the daughter does. So the daughter represents herself as surrogate for her mother, able to voice her mother's preferences and desires, based on the knowledge formed during a lifelong relationship.

In this ward families were positioned on the margins of an acute medical care service. In the caregivers' representations, the care of the person with dementia is delivered on the nurses' terms within a medical model, and the family caregiver is excluded from decision making. Similarly, Schofield (1996) found in her study of families' experiences of caring for a relative with dementia in residential care that "the medical model of care and hierarchical structuring of many residential facilities contributed to the exclusion of family members" (p. 332). This approach is equally problematic in the context of intermittent care, in an

ambiguous site located on the margins between home and permanent hospital care. The person with dementia is admitted to hospital but is not a patient in terms of requiring medical treatment. In fact, being admitted to hospital can be a health risk for the person with dementia, both emotionally and physically. The family caregivers expressing marked ambivalence about intermittent care highlighted the vulnerability of the person needing care and took a protective role, which conflicted with needs for respite.

Summary

Family caregiver texts were not amenable to simple categorisations and were distinguished by difference rather than by homogeneity. Caregivers occupied different spaces that changed over time in terms of their ability to take advantage of the respite time intermittent care offered. My reading of these texts has highlighted the aspects of nurse-family relationships that ameliorated, or alternately exacerbated, the tensions felt by caregivers, as they were torn between the necessity to have a break and their anxieties about the impact of intermittent care on the person with dementia. The variations in the family caregiver descriptions of the different approaches to the care of their relatives supports the notion, discussed in chapter seven, that nurses in the intermittent care context draw upon conflicting and overlapping discourses to inform practice options.

CHAPTER NINE

Transgressing Boundaries: An Alternative Representation of Nursing Care

Introduction

In this chapter I focus on the texts of nurses working in one of the four sites used in this study. During the process of analysing these texts it became apparent that there was a distinctive representation of nursing relationships with patients and families in this setting that was not evident in the texts from other sites. Nurses in site three consistently talked about the hospital as a home for the people they were caring for, and their relationships with patients as like those which can exist in a family. There were also micro-practices within this setting which blurred the boundaries between professional and personal domains. These representations are minimally addressed in nursing literature and yet this transformation of the hospital into a domestic setting could be interpreted as a counter discourse to the dominant biomedical and organisational discourses informing care. I argue that the possibilities for nurses to situate themselves within this discursive constitution of work were shaped by the organisational context in which nurses work, as well as individual preference. I also discuss the implications of this representation of the site as a home for nurses and for people with dementia and their families

Representing the hospital as a home

The dominant nursing representations of care evident throughout the majority of nursing accounts have been discussed in chapter seven. Diverse constructions of nurse-patient relationships were evident through participants' texts, informed by influences such as organisational context, disciplinary constructions of people with dementia and the life

experiences of the nurses. However, the texts of the nurses in site three differed in some respects from the nurses working in the other hospitals in that site three nurses consistently spoke of the hospital as a *home*, and the nursing relationships with patients as being like those within a *family*.

R: We are more personal than the public hospital.

J: Personal?

R: Personal as..I think as in most of the patients, I don't mean in most of the wards, not all the wards they don't treat their patients like family, they are a bit more impersonal.

J: How do you treat them like family?

R: We like to call them by their names, we know their likes and dislikes, we know how they act because they are there all the time. We don't have many patients turn over.

J: Like they stay here until they die?

R: Yes. (Nurse 8, 1:2, Site 3)

Because they are long term you don't get people coming in short term and the quick turnovers, so you get to know them, all their, they are part of your family really. (Nurse 10,1:1, Site 3)

S: I think you really get attached to the patients. They sort of become part of your life mmm and if you lose a patient it's very much like losing a relative. Most of them..some of them.

J: So when you say part of your life...

S: I think because you spend so much time, the hours of the time you work um you do become very attached to them, although I can reasonably turn off when I leave here, when I finish a duty....I just, they have each got their own individual little things//

J: And you made a comment about the residents being like part of your family.

S: Yes I think it is. I think it is because they are here so long, the biggest majority of them, they do become part of your life and you are seeing them four days a week and I think too because I don't come from a big family maybe it makes you sort of think, or maybe you can compare them to someone in your own family. But I think they have all these nice traits, some of them don't (laugh). (Nurse 9, 1:1, Site 3)

In these texts the nurse-patient relationship is constructed as being a very personal and significant relationship for the nurse, the patient becoming "part of your life". Metaphors for family were used to emphasise the depth and the emotional dimensions of the relationship such as "it's very much like losing a relative" and "you can compare them to someone in your own family". The critical element underpinning this particular

representation of a formal caregiving relationship, appearing throughout these nurses' accounts, was the existence of an ongoing sustained relationship which created the opportunity for the development of considerable knowledge about the individual characteristics of the people being cared for. Along with this transposition of nurse-patient relationships into family relationships, both nurses and family caregivers at site three represented the hospital as a *home*.

J: My first question is if you could tell me a bit about the changes from the previous hospital as compared to [Name of site 3].

H: Well he is far happier there, I think it is because it is more like home.

J: Ah mm now how do you mean home?

H: It's, ah, far more homely in the fact that they, there's more individual attention I suppose that is what it is. (Wife caring for husband, 3;1, Site 3)

.....

R: The principal nurse has emphasised that this is their home so you treat them as if this is their home.

J: What does that actually mean though?

R: It means that for me they bring their personal stuff in, keep it nice, keep them, like appearances like, as they were in their own home as if they were normal.

J: What's normal?

R: Treat them with respect, like if they weren't sick or anything. Like at home they would like to look nice, um, don't talk down to them, talk at the same level, that sort of thing. Just like you would treat your own mother. (Nurse 8, 1:2, Site 3)

.....

They are doing their best to treat the person as if the person was in their own home, homes. That's really what I mean by family, they most certainly don't come across as if it was very much a hospital atmosphere as we understand the word hospital. (Son caring for father, 1:10, Site 3)

The micro-practices associated with the construction of the institution as a home for patients in these accounts included acknowledging the individuality of each patient, developing positive and personal nursing relationships with patients and family members, and normalisation of the environment with personal possessions. Respect in the nurse's text is aligned alongside normality, with the ensuing implication that *sick* people are abnormal and not respected. The hospital and home in these texts are constructed as very different and opposing entities in terms of individual choice and expression, a position congruent with wider societal discourses.

Opposed to the idea of the 'total institution' may be countered the notion of 'home'. It is at home that one is able to express individuality and exercise a limited degree of choice over the use of time and space which institutionality denies...The separation of different parts of social life through the specialized use of spaces for work and play, as well as private family space, key elements in the 'total institution' concept, also has its origins in the historical forces of industrialism and urbanism. In this way the home as the opposite of the institution can be seen as part of a contradiction. It has been formed by the privatization of domestic space, taking it out of the community as previously understood as much were the places of work. (Hugman, 1997, p. 196)

However, nurses, in the act of deploying a discourse of home and family to represent care, cross the boundaries between private and public spaces, the hospital simultaneously a public work site and a private domestic space. Normally in hospitals there are clearly demarcated spaces for patients, and restricted areas that only the staff can use, as in the other research sites described in chapter six where the private and public spaces, environmental and social, were clearly indicated. In contrast, in site three, the residents had complete freedom of movement in the building and the grounds within an enclosed border. This was a highly unusual organisation of the physical environment in a hospital setting.

There's lots of room here, two or three people in the dining room, more listening to the newspaper readings in the lounge and then there are six people listening to the cricket and you can go outside. It seems spacious enough. The cook is very involved in the every day activity and you walk through the kitchen all the time. There don't seem to be any spaces that are out of bounds. All the staff are chatty and warm, and they talk about their personal lives to the residents. Children were popping through the hospital although I have no idea who they are related to. Looking around its slightly messy. In the foyer there are reading books, knitting, clutter and a dog sleeping on the floor. (Field notes)

Many of the people living in the hospital were physically disabled and immobile, and this aspect of the environment would be of minor importance to them. But there were some people with dementia who were very obviously active, and they included the kitchen on their circuits of the building.

Along with the extension of spatial boundaries, the social boundaries in this hospital were flexible and inclusive. For example, the staff regularly ate with the patients. The nurse manager of the home talked about her feelings about this practice.

J: And I have noticed that the nurses eat lunch with the residents.

P: Yes, yes, that's probably habit that developed many years ago and I have just inherited and when I initially came here probably I had firm ideas that this wasn't going to go on. But then perhaps if you just stand back and some people would say "well okay I don't think that is a good idea" but when you look at possibly the other things, it's not just eating a meal. The other things that are going along with all that sort of thing.

J: What are the other things?

P: Ah that they (the staff) are auditing the food for one thing.

J: That they are actually seeing that people are eating?

P: They are auditing the food and can say this is awful or isn't, or is cold or hot. That they are sitting eating with the people so hopefully it will slow down the eating process. That the resident will not feel hey there is someone standing over me feeding and I have got to rush. That we are doing it together, it's not something you are doing to me, we are doing together. (Nurse, 11, 1:13, Site 3)

The nurse manager signalled the transgression of usual boundaries between staff and patients with her comment about her initial discomfort with the staff eating with patients. But, in this account, the practice is justified as being useful in terms of nursing work, the practical benefits including the opportunity to monitor the quality of the food and the production of a social environment that will encourage a sense of relationship and shared activity. Role boundaries in the hospital were also elastic and the caregiving staff relieved the cook on her days off if they wished to have a break from caregiving.

These practices were important to the families using intermittent care. They were read as signs that the well-being of the person being cared for would not be compromised while in hospital.

They are very relaxed, the casualness, the way they dress the patients um to the particular person the right name used whether it be the surname or the Christian name or whatever. It just gives me the impression they are doing their best to treat the person as if the person was in their own home, homes. That's really what I mean by family, they most certainly don't come across as if it was very much a hospital atmosphere as we understand the word hospital. Yeah laid back in a good sense um they have created a nice atmosphere where I believe they go out of their way to make that person comfortable because they know how important it is for the caregiver, how concerned we are going to be and that if I had any bad vibes while away, therefore I probably wouldn't continue the process. But I haven't. I have been certainly impressed. (Son caring for father, 1:10, Site 3)

Another family caregiver also spontaneously talked about the hospital as a home and that the staff seemed to be “devoted”. When she arrived with her husband “ about half a dozen of them came out and said how nice to see you. Now that, those little things mean a lot” (Wife caring for husband, 3:1, Site 3). Although, theoretically, it could be possible that the family caregiver could be supplanted by the nurse in the transposition of nurse-patient relationships into family relationships, in these texts the family caregiver is included in the every day world of the hospital. Significantly, this site was the only hospital in this study where all the family caregivers were located in a position of acceptance of intermittent care and did not feel the need to visit frequently. These families also kept up contact with the ward staff between intermittent care admissions by ringing to discuss caregiving problems.

On the margins

This representation of nurse-patient relationships as being family-like, and the construction of the hospital as a home has, until recently, been invisible in academic nursing discourse. The accounts that do foreground this representation are all studies informed by practitioners’ constructions of caregiving relationships such as those by Taylor (1994), and Savage (1992, 1997), and the work of the Scandinavian nurse researchers discussed in chapter four (Häggström & Norberg, 1996; Rundqvist & Sverinsson, 1999). Taylor’s (1994) phenomenological study took place in a Professorial Nursing Unit where the people were admitted for predominately nursing care needs. The care was directed by nurses and the physical and social environment was intended to be as *homely* as possible with freedom of movement in and outside the unit. Specific practices in this unit included nurses and patients dressing in normal clothing rather than uniforms or night attire, nursing work was organised so as to facilitate continuity of nursing care, and personal relationships were emphasised as being “integral to therapeutic outcomes in nursing care” (Taylor, 1994, p. 36).

Savage’s (1997) ethnographic study took place in a small ward catering for men with chronic gastro-intestinal disorders. These patients were in hospital for long periods and needed readmission periodically. Most of the nurses on the ward had worked there for several years and had the opportunity to develop long-term relationships with the patients. In this study the nurses constructed the space in the ward as being the patients’

space with no specific designated space for the nurses. All nursing documentation was completed by the patient's bed. Savage suggests that this collapse of the ward space was integral to the development of a physical and emotional *closeness* between nurses and patients. Similarly to the nurses from site three, good nursing care was represented in family-like terms as "caring for the patient as if he were a brother, father or grandfather" (Savage, 1997, p. 242) and the patients in this ward described the ward as being like a home. The intermingling of physical and emotional boundaries, once again as in site three and Taylor's (1994) research, was represented as being an important element in developing a therapeutic nurse-patient relationship.

The surfacing of this previously private discourse informing the everyday practices of some nurses in nursing texts has interesting implications for nursing as an academic discipline. Nursing work in the discourse of family and home is modeled on that of the domestic sphere and resonates with a vocational discourse, the disciplined and hard-working nurse synonymous with the good woman, as nursing is predominantly women's work (Gardner & McCoppin, 1986). This is a dangerous space for a gendered discipline that has, in the latter part of this century, made the transition from a vocational service to a professional occupation informed by a specialised body of knowledge. The home is a site of devalued knowledge such as child care, cooking and cleaning, while the academy and hospital are masculine spaces containing authoritative and socially valued knowledge such as medicine (Spain, 1992).

Men see "women's work" not as real human activity - self chosen and consciously willed (even within the constraints of a male-dominated social order) - but only as a natural activity, a kind of instinctual labor such as bees and ants perform. (Harding, 1991, p. 128)

This representation sits uneasily with an overall drive for recognition of nursing as a research-based, applied discipline taught in the academy. However, despite the problematic aspects of representing care in terms of home, the most comprehensively prepared and experienced participants in this study spoke about care in terms of home and family, choosing a discursive framing of practice that was characterised by intermingled personal and professional spaces, socially, emotionally and physically. This domestication of care has interesting implications for nurses. One reading of this discourse could focus on the gendered nature of nursing, and that nurses, as women, are

unconsciously acting out a patriarchal script positioning them as docile and nurturing, invisible and oppressed in the private world of the home/hospital. Alternately, as Savage (1997) contends, nurses' challenges to conventional hospital social and spatial boundaries could be interpreted as resistant practices challenging medical jurisdiction. People being cared for in long term settings are generally stable in terms of their medical needs and the nursing challenge is to develop a culture which attends to social and psychological needs and desires. Nurses are positioned in such settings on the margins of medicine with, consequently, the space to develop nursing models of care responsive to context specific needs. The geographic and social boundaries between professional and personal lives, rigorously divided in many sectors of health care, are permeable within the family and home discourse. While these individual practices breaching conventional boundaries may appear insignificant, the collective impact of these practices have considerable implications in terms of power relations between nurses, patients and families. The use of space in all institutions, family, hospital or the prison is embedded in social relations and imbued with power as different bodily inscriptions are produced and reproduced through spatial arrangements. Spatial segregation is a technique of power, the control of space also controlling access to knowledge and resources (Spain, 1995). Border-crossing practices mark a major deviation from traditional hospital practices and the usual clear demarcation between the health service workforce, and ill people and their families.

Implications for the person with dementia: "Not...bad, but...dangerous"

In site three there was an explicit and articulated philosophy of care from the nurse manager stressing the importance of maintaining the person's usual way of life as much as possible, and promoting the need for personal choice.

J: What's your philosophy, how do you think you care for people with dementia here?

P: Well I would say our philosophy is that we are out to establish, maintain normal lifestyle patterns and..um..respecting peoples' privacy, peoples' right to make choices. I still think whether they are demented or not they have the right to make choices. And I think at the end of the day if our man down there because he is confused says he doesn't want a shower, what's the big issue? What's the big issue? (Nurse 11, 1:7, Site 3)

The perceived importance of preserving normal home practices also emerged in the nurses' texts.

The most important thing is that you have got to be completely aware of the routine that is done at home, um, really, perhaps their eating patterns um, just their general everyday routine things. Because I think that is something really important that we actually keep up here. Because, after all, they have got to turn around and go back home again. So, we really have to try and keep that routine, that daily routine up here// you know wouldn't change a routine without having discussed it first um..quite often if we feel something is not quite right we actually might even ring the relative first to find out if this is a normal sort of course of events that has taken place..Um..We have one woman who has the complete list of his drugs, um his condition since the last visit. It's absolutely excellent. (Nurse 9, 2:12, Site 3)

Quite clearly for this nurse, the care at home is the template upon which she bases her care. The family is central in this account, consulted at times when care in the institution deviates outside the usual home pattern. My own observations also supported the notion that in site three there was considerable fluidity in the delivery of care, depending on the needs of the person with dementia. The following extract from my field notes details my observations of a nurse relating to a very disoriented and distressed man trying to leave the hospital.

The nurse tried to talk him into sitting down but he started pacing back and forth across the room. She asked if he would like to walk somewhere else. He then asked, "Where is the police station? I need the police". The nurse replied "There are no police here. Where would you like to go? Why do you want the police?" He then walked off down the corridor to another lounge looking more and more agitated. It was then suggested that he went outside which he refused. He then went through another door and into a laundry with very steep stairs but came out when asked. She got him to sit outside and got an umbrella to shelter him from the sun. She sat down beside him and asked him what he was worried about, what was the problem. Eventually he indicated that he was in pain, that he had a very sore neck. The nurse then got one of the aides to massage his neck, and he visibly relaxed and at the end of it he said "That was very good, very well done." She then got a cigarette for him and he had a cup of tea and a muffin. She stayed with him chatting about sports, later getting some documentation that needed to be written and sat with him doing her work. (Field notes)

This nurse handled this crisis situation calmly, staying with the man, ensuring that he did not hurt himself and patiently going with him, rather than trying to control his behaviour. Significantly, she did not leave him immediately when the crisis was over

and shifted the initial anxious and potentially confrontational interaction to a pleasant, social relationship. Providing a cup of tea and food created an atmosphere of normality, as did her conversation about sport. She was also flexible in her approach to other nursing work, completing it at his side rather than in the ward office.

In another site though, other, less desirable implications were surfaced for people with dementia in terms of inscription and relations of power, in the use of the discourse of family and home to construct nursing care. In site one a nurse spoke of how intermittent care was “like putting a baby in a crèche” and later went on to say “I would prefer them to be treated like human beings with love and respect, it’s because they are like children. I mean you couldn’t get a lovelier person than [patient’s name] you really couldn’t. He’s like an eight year old....and he is so loving and caring and most of them are” (Nurse 3, 1:3-4, Site 1). The inscription of people with dementia as being child-like is not without a certain logic. The people with dementia using intermittent care services had intensive caregiving needs. They were profoundly disabled by the effects of dementing illnesses, as well as other illnesses and disabilities. Given this context of long-term and increasing dependency, and the requirements for assistance with the bodily needs which are also associated with infancy, there are obvious dangers of slippage into representations of the person with dementia as a vulnerable child. By implication, the nurse is positioned as the substitute parent and protector.

Interestingly, the problems that arise from this representation in terms of power relations and agency were also surfaced by the nurse quoted above in her later comment that some occupational therapy activities seemed childish and demeaning for adults. “I really do find it degrading, they sit them there and glue on cardboard like a two or three year old working in kindy and that’s actually taking away a lot from them” (Nurse 3, 1:7, Site 1). Her contradictory statements are informed by a particular discursive context where people with dementia are commonly represented as childlike in terms of their abilities, in both popular and professional literature. For example, Michael Ignatieff (1993, p. 165) in a novel about a son’s experience of caring for his mother who had a dementing illness, wrote: “at the end she recognised me as an infant recognises its mother. When she was bedridden and unable to speak, I could extend a finger close to her hand, and she would reach up and take it.” The following extract in professional literature from Naughtin and Laidler’s (1991, p. 191) work based upon the experiences

of family caregivers and people with dementia also emphatically positions the person with dementia in infancy:

The most appropriate image or metaphor to describe the progress of the disease is that of a reversal of the growth process. If our early childhood is the process of development from birth to adulthood, then dementia can be characterised as the gradual reduction and loss of physical and cognitive capacity, a second infancy. The analogy is also apt for primary caregivers, in that their experience appears similar to the stresses and roles of parenthood.

The positioning of the person with dementia in between childhood and adulthood is also a persistent theme in nursing literature, despite criticism of the conflation of dependent older people with infants because of the associations with dependency and powerlessness (Dolinsky, 1984; Miller, 1995). Tyson's (1988, p. 36) account of caring for an elderly woman with Alzheimer's disease talks about this woman playing with her food, creating "mud pies" and as being at the functional level of a two year old child. In another more recent and disturbing example in nursing literature, Matteson, Linton, and Barnes (1996) developed a stage model of Alzheimer's disease correlating various levels of dysfunction with Piaget's developmental levels in children (Table 9.1). Profound representational issues emerge in this uncritical adoption of Piaget's work. The person with dementia is represented solely in this text as lacking, as deficient and disabled, this representation juxtaposed with childhood developmental stages which, in contrast, focus on the incremental development of abilities. Piaget discusses childhood developmental stages in terms replete with agency such as *effort*, *plan*, and *dawning recognition* while the descriptors of the *Alzheimer's stage* are passive terms such as *inability*, *generally unaware*, and *low will power*. It is impossible to ascertain from this table alone what, if any, productive outcomes there are, in making the comparison between the development of childhood abilities with the incremental losses from dementing illnesses, in terms of informing caregiving practices. This table reifies the centrality of the cognitive model in dominant conceptualisations of dementia and the notion that there are predictable stages in decline in relation to Alzheimer's disease. The conflation with childhood also has dangers in the associated inscriptions of infancy in terms of agency and power.

Table 9:1 Piaget's Developmental Levels and Stages of Alzheimer's Disease

Piaget Developmental level	Alzheimer's Stage
<p>1. Sensorimotor Period (<i>first 2 years of life</i>):</p> <p>Substage 1 – Use of Reflexes Automatic innate or reflex responses to external stimuli</p> <p>Substage 2 – Primary Circular Reactions Effort to reproduce behavior that was first achieved by chance; development of habits</p> <p>Substage 3 – Secondary Circular Reactions Beginning association of events that occur close together; dawning recognition of symbols; beginning recognition of causality; object permanence</p> <p>Substage 4 – Coordination of Secondary Circular Reactions Simple problem-solving using behaviors that have already been mastered; anticipatory behavior, object permanence</p> <p>Substage 5 – Tertiary Circular Reactions Rudimentary trial and error, manipulation of objects; object permanence</p> <p>Substage 6 – Invention of New Means through Deduction Well developed understanding of the nature of objects; concepts of causality; use of mental symbols and words to refer to absent objects; ability to remember, plan and imitate someone else's previous actions; object permanence</p>	<p>Late Dementia: Speech and motor dysfunction; few words spoken, inability to walk, incontinence; inability to eat</p> <p>Middle Dementia (moderately severe Alzheimer's disease): Recall own name; recent memory loss; little remote memory; disturbed diurnal rhythm; generally unaware of surroundings; personal hygiene dysfunction; fear of bathing – requires assistance; difficulty putting clothes on properly; inability to handle mechanics of toileting; urinary incontinence; fecal incontinence; agitation, wandering, obsessive symptoms; low willpower; difficulty counting to 10</p>
<p>2. Preoperational Period (<i>age 2 to 7 years</i>):</p> <p>Stage 1-Preconceptual Stage Formation of mental images (symbolic thought); imitation of previously viewed activities; parallel play; instructions taken literally</p> <p>Stage 2 – Perceptual or Intuitive Stage Prelogical reasoning experiences and objects judged by outside appearances and results; selective attention (centration) can only concentrate upon one characteristic of an object at a time; beginning use of words, but thoughts still acted out; more social; transductive reasoning</p>	<p>Early Dementia (moderate Alzheimer's disease): Unable to recall phone number, can recall own name and name of spouse and children; no assistance required with eating or toileting; difficulty choosing proper clothing; coaxing required for bathing; difficulty in subtracting 3 from 20</p>
<p>3. Concrete Operational Period (<i>age 7 to 12 years</i>): Think and reason with inductive logic at beginning, deductive later; conservation and reversibility; capable of decentration (ability to focus on multiple aspects of an object, event or situation at the same time); understand the value of rules; judgement based on reason; inability to comprehend the future and the abstract.</p>	<p>Early and Late Confusional (borderline to mild Alzheimer's disease): Decreased ability to perform in demanding employment and social interactions; deficit in memory and ability to concentrate; difficulty with serial 7s.</p>
<p>4. Formal Operational Period (<i>age 12 onward</i>): Logical reasoning and ability to think about hypothetical and abstract</p>	<p>Normal Forgetfulness: No impairment, but subjective concern about memory loss</p>

From Matteson, M. A, Linton, A. D., & Barnes, S. J. (1996). Cognitive developmental approach to dementia. *Image: Journal of Nursing Scholarship*, 28(3), 233. Used with permission from publishers.

It is, therefore, most disturbing to see this table replicated in a major nursing gerontological text (Ebersole & Hess, 1998) with no critique and little discussion other than a brief reference to the possibility of applying Piaget's work to the assessment of the cognitive ability of people with dementia.

Piaget's influence (1952) was important in the understanding of cognitive development in childhood. He characterized a gradual progression of cognitive development and the idea that each stage must be evaluated by tools appropriate to the stage and task. The observation that aged individuals with dementia may go through a similar progress in reverse is being given

serious consideration and study (Matteson et al., 1996). [McDougall & Ebersole, in Ebersole & Hess, 1998, p. 809]

However, while in the preceding discussion the potential dangers for people with dementia have been foregrounded in terms of being positioned as child-like, it is important to reiterate that this danger did not materialise in the nurses' and families' texts and observed practices in site three. In these texts people with dementia were constructed as possessing a degree of agency with rights and choices that should be respected.

The organisational context of care

The construction of nursing care as being home and family-like did not have financial implications when compared to the costs of care in other private residential care hospitals in the region according to the nurse-manager of the home.

J: What you are saying though, or what I'm hearing you say, which may be wrong, is that there's sufficient money coming in to provide care, it's not a constraint?

P: No, and the last time the RHA came round, when I went in to negotiate, I said to them that all I want is an increase for nurses' pay. The nurses have not had a pay increase, because when we had empty beds people had to cut back on hours and every thing, all that money was used for/

J And did you get that?

P: Yes

J: So when you had a request you got it.

P: From the RHA. But then..we were one of the cheapest facilities around so I had grounds. And I could say, I could produce evidence. I said "My registered nurses are one of the best qualified people in [name of hospital]. Why are you paying us so much less than you are paying everybody else. All I want is to at least to come up to everybody else". (Nurse11:1:9, Site 3)

However, it could be argued that the practices of care at site three placed extra emotional demands on the caregiving staff. Caregiving is not *just a job* in this discourse, patients are inscribed as people with needs for satisfying social relationships as well as physical care. Nurses are inscribed as social agents responsible for generating an environment that feels like home, with all the physical and social freedom that implies, and with blurred personal and professional boundaries.

D: Its probably the ongoing, just being part of these peoples' lives that I find appealing and you can identify with them. They are somebody that you are mixing with every day and taking on board their various problems or special, their humour and a closeness, the closeness does develop there.

J: With all of them?

D: No I wouldn't say with all of them. No. Just like an ordinary, if you belong to a club or something there is always some people you get on with better than other people and I certainly couldn't say that I felt that with everybody that I have ever nursed. (Nurse 10, 1:2, Site 3.)

.....

I mean not everybody you get on with because some you do have clashes and it's the same with the nursing world with your patients and things like that but generally I think you always find some lovely little point in them that really makes them endearing to you. (Nurse 9, 1.1, Site 3)

In reality, the patient is not a relative of the nurse and it is inevitable that she will have varying degrees of affiliation with the people she is caring for. Another point of possible tension in the representation of nurse-patient relationships as being family-like is opened up with the comment that "because you spend so much time, the hours of the time you work, um you do become very attached to them, although I can reasonably turn off when I leave here, when I finish a duty" (Nurse 9, 1:1, Site 3). In nursing literature excessive involvement with patients is considered problematic (Benner & Wrubel, 1989; May, 1991; Morse, 1991). Benner and Wrubel (1989, p. 374-375) argue that:

Overinvolvement with patients may also be a way of avoiding intimacy in relationships outside of nursing. Patients become intimate strangers who provide a safe sense of being close without the obligations that go with long-term relationships. Nursing becomes the person's whole life, and the nurse may withdraw from close relationships and intimate relationships outside of work.

Taylor (1994, p. 227) also commented on the "vulnerability of closeness" in family-like relationships between nurses and patients. The nurse manager of site three recognised the potential emotional demands and the flexibility required to work within this particular construction of nursing care. She took the stance that if staff are expected to care like a family member and with the commitment that implies, they also needed to be supported in a similar manner at a management level.

P: It's the patients' home ...but it will never be as good as home right, it will never be as good as the patients' home ...um but..the girls, I expect them to treat peopleah, it can't be just a job, I don't want it to be just a job to them. At the bottom line it is but I don't want them, the patients, to feel that these girls are just....are just a job. So for that reason, from where I'm coming from, I have to be flexible with them. I have to show them, the staff, the sensitivity and the interest that I expect them to show the residents. So they come to me or ring up and say "The school outing tomorrow I would like to go?" "Okay fine. Let's sort that out." It's really important because it brings that whole thing together. I still expect them to have responsibility because they have accepted responsibility for employment. But it can't be that I have to make sacrifices for my work. Do you see where I am coming from?

J: So that's a relationship with the staff, so that it is a bit more than being just a job. Would you say that it's more personal?

P: For me I feel I have to have that relationship because I can't expect me to have a very hard formal relationship here and them to have a caring relationship there. (Nurse 11, 1:13, Site 3)

This account is unique in the research texts as being the only reference by any of the participants about the desirability for organisational support to help meet the personal needs of the nurses. In this text care is constructed as a negotiated activity, defined and shaped not just by individual caregivers but also by management processes. Taylor (1994, p. 35-36) also made explicit mention of the organisational support underpinning the practices of the nurses in the Professional Nursing Unit who produced a similar construction of care to the nurses in site three.

The PNU was set up with the intention of transcending, as far as possible, the institutional constraints of the hospital environment. On a practical level, this includes a tea room and games area for patients, and freer rules for patient mobility within and outside the unit. The unit gives approval to first name bases between staff and patients, and it consents explicitly to nurses and patients spending time together as people. Involvement of family and friends in the person's hospitalisation is encouraged, and interpersonal relationships are emphasised as being integral to therapeutic outcomes in nursing care.

The impact of the organisational discourses in shaping the production of particular caregiving discourses and practices can be illustrated by changes in care delivery in another research site in this study. In site one, one nurse talked about care as being family-like: "being an intermittent caregiver, if you like, we actually know these people. We get to know them over a period of time and that being the case we get to know these people like a family" (Nurse 3, 1:4, Site 1). She also suggested that the hospital had

home-like characteristics: “For them it’s a home away from home, if you know what I mean, without the surroundings, and they know us after a while too” (Nurse 3, 1:2, Site 1). Like the nurses in site three, she suggested that a major factor enabling this conceptualisation of care was the opportunity to develop an in-depth knowledge of the personal characteristics of the person over an extended period of time.

However, the organisational reconfiguration of physical and social spaces in site three supporting the inscription of the hospital as home, and the person as family, was not evident in site one. Site one, an assessment and rehabilitation ward, was managed in an orthodox manner with clearly delineated staff and patient areas and very limited living space. The usual hospital rituals such as many of the patients remaining in night attire and limited personal effects were also apparent. More importantly, there was little opportunity for continuity of care. Originally, as previously stated, the intermittent care patients in this ward had been cared for by a specific team of nurses no matter where the patients were placed in the ward. Both nurses and families commented favourably on this system and this particular practice seems a critical element in enabling nurses to develop in-depth relationships with patients. The organisation of nursing care was later changed, and staff were allocated cubicles, care organised by physical spaces rather than by people needs. Consequently, people admitted for intermittent care were cared for by different nurses each admission. This change in practice was legitimised by an organisational discourse emphasising an efficient use of a scarce resource, in this instance nursing time. With this change the nurses in site one were always in close proximity to their allocated patients. But, there were major consequences as a result of this change, intended or more likely unintended, given the impact on people using the ward. One nurse commented on the impact for confused people using the intermittent care service.

They’re actually more settled at home because they are in their own home, they know their environment, they know where the toilet is, they are with their caregiver that they have known for many years. And they come in here and the environments completely different, there is always a high turnover of staff so the faces aren’t always familiar so they’re totally lost. (Nurse 2, 1:3, Site 1)

The impact on the family caregivers participating in this research who used site one over this period has been extensively discussed in chapter eight. The issues surfaced in

this discussion were the disruption of the previously close and knowledgeable relationships between nurses and family caregivers and a loss of confidence in the quality of care provided. So, while one nurse did construct care as being family and home-like in site one, her practices were unsupported at an organisational level. Nurses in this site were located in a contested space between the competing discourses of medicine and nursing. On one hand, they work within a medically dominated institution while, on the other hand, they are inscribed by nursing discourse and the construction of professional nursing care as a therapeutic relationship. This positioning is further complicated because, as May (1990) contends, any failure in nursing relationships is attributed to individual nurses even though individuals cannot address and resolve the collective organisational issues underpinning nursing care.

Summary

The representation of care as being family-like is minimally addressed in academic nursing texts and only surfaced in the research exploring practitioners' construction of caregiving. This finding supports the central argument in this thesis, that nurses' knowledge in the context of caring for people with dementia is dominated by biomedical discourse, with the consequent relegation of other forms of knowledge to the margins of awareness and action. The alternative representation of nursing care evident in site three can be read as a challenge to the existing dominant discourses in nursing and as offering alternative possibilities in terms of power relationships and subject positions for people with dementia, families and nurses.

But, it could also be argued that this representation does have dangerous implications in that the departure from models of care underpinned by biomedical medical discourses and conventional professional boundaries in relationships entails a degree of risk for nurses and people with dementia. Firstly, there is a danger in the family and home discourse that nursing is positioned as being women's work, as requiring tacit knowledge, commitment and socialisation, but not formal knowledge and acquired skills; a positioning which has implications in terms of societal valuing of the work. Secondly, the expectations that nurses will create close emotional relationships with long-term care patients involves a high degree of commitment and added vulnerability for both nurses and patients. Finally, there are dangers of slippage into representing the

person with dementia as a child within this discourse, given the commonality of this representation in popular and professional texts. The critical element that emerged in site three participants' texts in terms of enabling the productive construction of care as being family-like and the institution as a home was that of organisational support and flexibility of management relationships with staff. Significantly, family caregivers using site three expressed a high degree of satisfaction with the nursing care provided, in very sharp contrast to families using intermittent care at the other three sites.

CHAPTER TEN

Rethinking Nursing Representations: Rewriting Nursing texts

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 sharpened sense of reality, but one is never immobilized before it; a readiness to find out 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; a passion for seizing what is happening now and disappearing; a lack of respect for the traditional hierarchies of what is important and fundamental. (Foucault, 1997, p. 325)

Introduction

It seems fitting to begin the final chapter of this thesis with the words of Michel Foucault and his, by now familiar, challenge to endeavor to work against ingrained patterns of thinking in order to open up new and productive avenues of inquiry. My aim in this chapter is to draw together the research findings from part one of the thesis, *Mapping the Field*, and part two, *Representing Practice*. Initially, my discussion focuses on the uncritical appropriation of medical knowledge in formal nursing representations of dementing illnesses, and how the dominance of this representation has suppressed the knowledge and experience of people with dementia. The positioning of people with dementing illnesses within this literature has paradoxical qualities, simultaneously central as the object of concern and the focus of nursing care, but marginal in terms of voice. As an example of how using Foucault’s ideas as a *toolkit* can open up new discursive possibilities I have produced an

alternative account of dementing illnesses to foreground the power of discourse to generate different subject positions.

Next, I explore the possibilities for changes in nursing practice in intermittent care as suggested by the research findings. More than one discourse informed nurses' accounts of caring for people with dementia, each evoking particular practices and inscriptions with people with dementia and their families. Tensions were particularly evident between nursing practices aimed at reducing risk and providing physical care and practices focused on developing empathic and satisfying relationships with people with dementia. Wider social discourses about dementia and the economic discourses underpinning health care policies inform the organisational practices that facilitated or alternately constrained nurses' practices. Significantly, given that a central argument of this thesis is that nurses play a crucial role in the provision of quality respite care, nurses' practices in this study were found to be a critical element in facilitating, or alternately constraining, family caregivers' ability to relinquish care on a temporary basis and to take full advantage of the respite time. One research site provided particularly successful respite care as judged by family caregivers' expressions of confidence in the service. The dominant nursing discourse in this site framed the hospital as home and the relationship with patients as being family-like. The permeability of social and geographic boundaries in this discourse signaled inclusion for family and patients in contrast to the traditional boundaries demarcating spaces evident in the other sites.

I then critically re-view the use of Foucault's ideas in this thesis and discuss the issues that arose as I struggled to apply dense theoretical notions to the everyday concerns and practices of the nurses and family caregivers participating in this study. Finally, limitations of this study are discussed, along with suggestions for future research studies.

Re-writing nursing texts

Part of the task of this project has been to ask what were the conditions that enabled particular discourses and practices to emerge in the research context, and what differences

emerge in practice possibilities when knowledge presently suppressed in the nursing discourses currently accepted as authoritative is foregrounded. In the first part of this thesis I adopted Foucault's genealogical approach to trace the shifting definitions of dementia over time with the intention of destabilising the idea of biomedical discourse as being always internally consistent. In my analysis of the historical development of the concept of dementia I emphasised the political as well as scientific influences informing knowledge development in this area, as well as the minimal contribution biomedical knowledge can make to the every day care of people with dementia at this time. My purpose has been to challenge the notion that biomedical knowledge has an automatically justified central position in fundamental nursing literature texts by virtue of utility.

The discursive construction of dementing illnesses in the major contemporary texts used in undergraduate nursing education, such as Ebersole & Hess (1998), Frisch and Frisch (1998), and Stuart and Laraia (1998), situate nursing knowledge and concerns after detailed descriptions of pathological changes and current medical research findings. But, as Apple and Christian-Smith (1991, p.1-2) argue, these texts are not simple

...‘delivery systems’ of ‘facts.’ They are at once the results of political, economic, and cultural activities, battles, and compromises. They are conceived, designed, and authored by real people with real interests.

Fundamental nursing texts are critical in shaping nursing possibilities and material practices as the first, and possibly the only, formal representation of nursing practice for many practitioners working in older adult areas. The marginalisation of the knowledge of the ill person, along with, surprisingly, nurses’ concerns, in nurses’ textual representations, can be attributed to the historical forces shaping nurses’ education and, in particular, the relationships between the disciplines of medicine and nursing. Medical practitioners had a major role in nursing education when nurse students worked for the hospitals in an apprenticeship mode of training. Nurses were lectured by doctors and read texts written by doctors (texts still being produced in the 1970s; for example, Rudd [1970]) in a system that “socialized nurses to become intellectually subordinate” (Meleis, 1991, p. 52). In North

America, nursing education began shifting to educational institutions in the 1950s, a move that resulted in the development of grand theories to explain practice (for example, Neuman, 1995; Orem, 1991; Parse, 1981; Peplau, 1988; Watson, 1998). But, while the move to the academy may have produced theoretical representations of nursing practice, as Hiraki (1992) notes, undergraduate clinical texts have remained embedded in medical discourse and “medical authority and dominance over nursing practice emerges as a primary theme” (p. 8). Crowe and Alavi (1999) argue that nursing in the mental health context is underpinned by psychiatric discourse, limiting nursing possibilities to the dispensation of medication and the controlling of the behaviours that are the result of mental distress. They argue for the centralising of people’s experiences and that “it may be useful for mental health nurses to attend to the significance embedded in the narratives of those they care for” (p. 32) in order to develop a wider range of therapeutic interventions.

The limited contribution of medical knowledge in the context of caring for people with dementia provides the space to challenge existing nursing representations and to construct nursing accounts very differently from current accounts. In keeping with Foucault’s (1990, p. 9) injunction to “endeavor to know how and to what extent it might be possible to think differently” two descriptions of dementing illnesses are presented in table 10.1. The text on the right hand of the table is an account written by Johnson (1998). This discussion commences with a short description of the medical characteristics and stresses for caregivers which leads in to a review of current medical knowledge in relation to the characteristics, prevalence, diagnosis and pathophysiology of Alzheimer’s disease. This account is unusual in that excerpts from the accounts of people with dementia and family caregivers are included in later discussion. However, the inclusion of this knowledge at the end of the section after the biomedical viewpoint does not challenge existing hierarchies of knowledge. As Apple and Christian-Smith (1991) argue, new and potentially transformative knowledge is likely to be *mentioned* rather than developed in-depth in textbooks, with the dominant ideological frameworks underpinning the work remaining substantially unchanged over time. I have produced an alternative text on the left-hand side of the table, foregrounding the experience of people with dementia and family caregivers, as well as nursing concerns. This

Table 10:1 Representations of Dementia

<p>Dementing Illnesses</p> <p><i>Mostly I feel insecure, confused, frightened and as though I am dancing as fast as I can. But I still have loved ones. I still have a home. I still have my private enjoyments which make life worthwhile. And although there are many days when I am painfully aware that less of me exists than the day before, for now, I can say, I am still here! (McGowin, 1994, p. 126)</i></p> <p>Living with a Dementing Illness</p> <p>Diana McGowan began having problems with memory loss and confusion in her forties. The onset of Alzheimer's Disease began insidiously with momentarily losses of balance, occasional periods of slurred speech and a gradual loss of her sense of direction. Short-term memory loss impacted increasingly on her life as she increasingly became unable to remember workmates and relatives. Dementing illnesses such as Alzheimer's disease are subtle on onset but progressive neuronal damage leads to increasing and disabling short-term memory loss, disorientation and decreasing cognitive functioning in areas such as reasoning and comprehension. The term <i>dementia</i> is used as an umbrella term to describe the behaviour manifestations associated with the three major categories of dementing illnesses; Alzheimer type, vascular type and a mixed type of where the former two are combined.</p> <p>At the time of diagnosis of Alzheimer's Disease Diana McGowin (1994, p. 66) wrote;</p> <p><i>What I wanted, no, what I needed, was someone to assure me that no matter what my future held, they would stand beside me, fight my battles with me. Or if need be, for me. I wanted assurance from someone that I would not be abandoned to shrivel away. They would give me encouragement, love, moral support, and if necessary, take care of me.</i></p>	<p>Alzheimer's Disease ¹</p> <p>Characteristics and Prevalence</p> <p>Approximately 60% of dementia in people over the age of 65 is caused by Alzheimer's disease (Dawes, 1996). Alois Alzheimer has been credited with the first known description of the disease in 1907. Alzheimer's disease (AD) is now often cited as the number 1 mental health problem among our rapidly increasing aging population. Alzheimer's disease is a progressive disorder characterized by stages of increasing impairments and dependency. Although memory impairment is generally characterized as the key diagnostic criteria for AD, the earliest objective signs of the disease may more often be of a behavioral type. These may include behaviors such as suspiciousness and paranoia, irritability, aggression or angry outbursts, hoarding, withdrawal, or a report from others of poor performance at work (Oppenheim, 1994). As the disease progresses, gait and motor disturbances may appear with severe cognitive impairments and behavioral manifestations such as wandering. In the latter stages, the person may become bedridden and nonverbal. The onset of the disease is generally insidious, with the average duration of the illness from onset of symptoms to death being 8 to 10 years (American Psychiatric Association, 1994, p. 142).</p> <p>Diagnosis and Pathophysiology</p> <p>The cause of AD is still unknown, although numerous genetic, viral, environmental, and immunologic etiologies are being explored. It has even been suggested that Alzheimers's may be a multitude of disorders. Latest developments in Alzheimer's research have linked disease that occurs early in life (forties to sixties) to a gene on chromosome 21 and late-onset disease to a gene on chromosome 19. Defective genes on chromosomes 1 and 14 have been identified as certain predictors of AD. People with AD are nearly twice as likely as the general population to carry an allele on chromosome 19, which codes for a plasma protein, apolipoproteinE, involved in the transport to cholesterol and other hydrophobic molecules</p>
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¹ Johnson (1998, p. 541-542).

From Psychiatric Mental Health Nursing, 1st edition, by N.C. Frisch and L.E. Frisch. © 1998. Reprinted with permission of Delmar Publishers, a division of Thomson Learning. Fax 800 730-2215. References used by Johnson can be found in appendix 3.

McGowin's concerns that someone would be there to care are very real. Families are the main source of support and in New Zealand at least 80% of people with dementia live in the community (Sainsbury et al., 1997). But frequently one family member is the main caregiver (Duffy, Hepburn, Christensen & Brugge-Wiger, 1989; Opie, 1992; Richmond, Baskett, Bonita & Melding; 1995), a stressful position because of the need for supervision and assistance with activities of daily living.

Nursing Support

Nurses, working with other health professionals, have a critical role in supporting people with dementia and their families throughout the course of the disease. Initially information may be the most critical contribution; about possible progression and impact of the dementing illness, possible lifestyle adaptations to promote maximum quality of life and the community support services available such as the local Alzheimer Society services and support groups for family member and the person with dementia. Over time nurses will become more involved with assisting with direct personal care at home and in respite services. Respecting the family's expertise at this time is particularly important to ensure that nursing routines do not undermine home patterns of caregiving. Eventually, in many situations people with dementia may require residential care. Adapting nursing care to fit with the daily activity patterns of the person with dementia in order preserve their normal level of functioning and enable some control over the social environment requires considerable skill and expertise.

The Medical Perspective

Intensive research over the last thirty years into the causation of the organic changes in the brain associated with Alzheimer's disease has explored areas such as genetics and the role of the Apolipoprotein E gene, protein studies and the prevention of beta-amyloid accumulation, inflammatory and autoimmune responses, toxins, viruses, and the study of deoxyribonucleic acid (DNA) and the damage caused by calcium and free radicals (Advisory Panel on Alzheimer's disease, 1995; National Institute of Aging & National Institute of Health, 1999). Two cholinesterase inhibitor drugs, tacrine and donepezil have been developed but their contribution is very limited as tacrine is associated with liver toxicity and donepezil has a minimal impact on the improvement of quality of life and functional ability (Pryse-Phillips, 1999).

(JAMA 1995). Evidence is also accumulating that disease risk increases and the age of onset decreases with the number of these alleles found on chromosome 19. Although an association between the $\epsilon 4$ allele and risk of AD has been found, the correlation is not perfect. Thirty-five percent to 50% of persons with AD do not carry an $\epsilon 4$ allele and approximately 24% to 31% of the non affected adult population carry the defective gene. Genetic testing, therefore, remains a controversial issue, especially in the absence of effective interventions for the prevention and treatment of AD (JAMA, 1995). Much research effort has also been directed toward finding neurotransmitters that might play a specific role in AD. Since the observation of deterioration in the nucleus basalis of Meynert (the primary site of acetylcholine synthesis in the brain), acetylcholine has been the most frequently studied neurotransmitter and seems to hold the most promise for a role in AD treatment (Keltner, 1994, pg 37).

The location of pathological lesions associated with AD in brain tissue complicates the definitive diagnosis of this disorder. Only brain biopsy upon autopsy can identify the accumulation of excessive amounts of amyloid plaques in cortical gray matter and neurons filled with neurofibrillary tangles, hallmarks of AD pathology. Because of the difficulty of obtaining pathological evidence, the diagnosis of AD can be made only when all other etiologies for dementia have been ruled out. The diagnosis, therefore, is typically made via a battery of medical tests that rule out other reversible and irreversible etiologies and a battery of neuropsychological tests that rule out depression as the basis for deficits in memory cognition.

representation intentionally positions the voice of a person living with memory loss and confusion centrally in the account. The first quote is carefully chosen to illustrate both the stresses of living with dementia, along with the things in life that provide enjoyment and meaning. This account conveys information derived from biomedical construction of dementia, alongside family caregiver and nursing viewpoints, in the attempt to develop a description that represents more fully the diverse knowledge circulating in the field of dementia care.

While my account is incomplete, just as I have included only part of Johnson's (1998) text, it is still evident that writing representations incorporating the experiences of people with dementing illnesses and family caregivers with nursing and medical knowledge is not a difficult exercise, even within the space limitations of a fundamental nursing text. The person with dementia, inscribed as a pathological object of study in medical discourse, is produced from the very outset as an experiencing speaking subject in the alternative account, with desires and needs as like other human being.

Re-thinking models of care

The second part of this thesis focused on nurse's everyday work in the research sites. The most well developed discursive positionings in the research texts privileged psychosocial aspects of care, risk management and resource constraints. Organizational resources were important in shaping nurses' discursive location and the key elements that emerged were continuity of staff, adequate staff numbers and a safe environment. Without these base line resources an empathic style of care that was able to adapt to the needs of people with dementia was difficult to achieve. These requirements would seem to be modest and undemanding but the participants of this study reported varying degrees of inadequacies in the resources available to support care. Intermittent care services have been created to support family caregivers with, it could be argued, minimal attention and resources directed towards providing for the specific needs of the person requiring care during their hospital admission. The person with the dementing illness, whilst the catalyst creating the necessity

for intermittent care services can be, paradoxically, marginalised and voiceless in the enactment of the service.

Some explanation for this situation is provided if the rationale for the provision of intermittent care is motivated by economic considerations on the basis that supporting family caregivers is believed to facilitate the continuance of caregiving by an unpaid work force. From this perspective the actual care provided within the institutions is of minimal importance, and the unique and complex needs of the person requiring care are low in health care priorities. The problem with this construction is that family caregivers in this study clearly articulated that their ability to fully utilise the period of respite from caregiving was reliant on feeling confident that their relative was receiving substitute caregiving of a quality that was able to ameliorate the stress of relocation from a familiar environment.

Given the difficult circumstances in which some of the nurses worked, a positive interpretation of some of the practices adopted in the research settings is that safe care was provided to people with dementia in complex and, at times, unsupportive institutional environments. Nurses individually endeavored to provide good care, as they tried to mediate between inflexible institutional requirements and the equally inflexible needs of the person with the dementing illness. They also worked within, and between, contested discursive spaces, shifting between the contradictory organisational and risk management discourses stressing safety and workload concerns, and nursing discourses privileging psychosocial approaches to care. These nurses had to reconcile the tensions between these circulating discourses when the need to control unsafe behaviour conflicted with individual nurse's desires to develop the empathic relationships congruent with contemporary representations of nursing care.

The above interpretation highlights the demanding nature of nursing work in the research context but does little to critique the organisational structures that resulted in controlling practices in order to manage difficult behaviour. Intermittent care could also be interpreted as a site where oppression of the person with the dementing illnesses can be enacted, and

where unnecessary added distress is/can be caused by constraining environments, rigid routines and inappropriate staffing organisation. From this viewpoint nurses continued institutional practices that oppressed the people being cared for while the inadequate resources underpinning care remained unresolved by the various actors in these settings, people in management positions as well as nurses.

My reading of the study texts also foregrounds the materially different range of discursive positions adopted by nurses in site three, and the resultant different practices and inscriptions of people with dementia and their families. The *family and home* discourse was the most developed discourse that could be read as a counter discourse challenging the dominance of biomedical discourse in health care services. In this construction of care the relationships between nurses, patients and family caregivers were central in the nurses' accounts and family caregivers were positioned as primarily caregivers with ensuing practices of ongoing communication between nurses and family caregivers and continuity of care between home and hospital. Significantly, family caregivers using site three were able to confidently relinquish the work of caregiving to the nursing staff and to fully utilise respite time.

The existence and acceptance of the family and home discourse in one site suggests that the location of long term care for older people on the margins of medicine (as I have discussed in chapter nine) is a potentially powerful position for nurses, given sufficient organisational support. This possibility of personal power and autonomy is not precluded in a Foucauldian analysis. Although, in Foucault's earlier studies, power emerged as a monolithic and dominating force, the body represented as passive and docile, his later work drew back from this overly deterministic view of subjectivity to a position emphasising a more mutually deterministic relationship between the individual and society (McNay, 1992).

I am interested, in fact, in the way in which the subject constitutes himself in an active fashion, by the practices of the self, these practices are nevertheless not something that the individual invents by himself. They are patterns that he finds in his culture and which are proposed, suggested and imposed on him by his culture, his society and his social group. (Foucault, 1988c, p. 11)

The adoption of a social rather than biomedical model of care in site three did not involve extra resources but created very different subject positions for nurses, residents and families, in contrast to the other units. Staff development and education is a critical factor in supporting the provision of quality care for people with dementia (Garratt & Hamilton-Smith, 1995; Kitwood, 1997). The nurses working in site three all had post-registration nursing education and preparation in caring for people with dementia, and their approach to care fits with recent discursive shifts in the discourses of dementia care. The dominant biomedical representation of dementia and the problem-oriented inscription of the dementing body is being challenged by an alternative discourse promoting a style of care that recognises and enhances the personhood of the person with dementia (Bell & McGregor, 1995; Buckland, 1995; Kitwood, 1995, 1997; Woods, 1995). The notion of personhood as used by Kitwood (1997) is the “standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust” (p. 8). This discourse is an important challenge to the conventional representations of dementia care. Along with the change in status of the person with dementia from an object of care, to an experiencing human being, there is a shift from the representation of the professional caregiver as an anonymous, interchangeable manager of behaviour to the caregiver as a reflexive developed individual, “one who is open, flexible, creative, compassionate, responsive, inwardly at ease” (Kitwood, 1997, p. 120).

This new *culture of care* has exciting possibilities for nurses. Some nurses and families in this study privileged relationships in a representation that fits comfortably with wider professional discourses of nursing. But, it must also be acknowledged that this shift in thinking about dementia care entails a change in the conventional institutional practices currently informed by the twin discursive demigods of contemporary health care, namely New Right economic policies and the biomedical approach. As the nurse manager of site three suggested, the management of the hospital must demonstrate flexibility, sensitivity and interest in the staff, if there is to be an expectation that the staff demonstrate these qualities in their professional work/caregiving relationships. In other words, the people managing an organisation set the template for relationships within it. This view is supported by

Huntington's (1999) research in the gynaecological setting where the nurse leader/manager's role was particularly important in shaping the nursing culture in the ward. This nurse stated that she would

...see that there are resources they need [the nurses] or whatever they think that they need I can put into place for them...emotional support mostly and supporting them through...you can't have happy clients unless you have happy nurses..I would like to think I treated them the way that I would like to be treated. (Henrietta cited in Huntington, 1999, p. 182)

From this perspective, people in management must model relationships that respect and maintain the personhood of the staff if there is to be any possibility of developing a caregiving environment where the personhood of the person with dementia will be maintained. As Code (1995) argues "a person cannot *be* an appropriately autonomous, self-creating and -sustaining human being when she is constantly aware that she is known as treated as object, as other" (p. 100). Without the development of new and congruent collective organisational practices in health care settings, a new culture of care may end up as a frustrated desire of individual nurses, rather than a material shift in practices that result in a radically different inscription of people with dementia and their families.

Knowledge and power in nurse-family relationships

In this research the relationship between family caregivers and nurses influenced the degree to which the family caregiver was able to take advantage of the respite opportunity provided by intermittent care. Patterns of caregiving had a fundamental importance for family caregivers in creating a sense of mastery and control over caregiving work. Family caregivers felt confident about relinquishing the care of their relative because they were able to provide full accounts of their patterns of home caregiving to the nurses. They also believed that their information was actually used by the nurses to inform their care of the person with dementia. These family caregivers were acknowledged and welcomed into the ward along with the person with dementia, and their relationship with the nurses was close and personal rather than distant and professional. These findings highlight the necessity for nurses to locate themselves in a secondary and supporting caregiving role in intermittent

care, rather than as the primary caregiver role more usual in the acute care context and the long term residential care. The recognition that in the respite care context the family caregiver is the authority on the personal and intimate care required by the person with dementia, rather than the nurse, is fundamental to the development of a meaningful nurse-family relationship. Families were most able to fully relinquish care when they were confident their relative was receiving comparable care to the home environment and their relative appeared substantially unaffected by the institutional stay. However, as Clarke (1999a) notes, nurses working from this positioning must also work against the grain of the dominant health service discourses which value *expert* and *professional* knowledge over other forms of knowledge such as family caregiver knowledge.

This study also surfaces areas of nursing practice that could usefully be developed in respect to providing intermittent care services. The process of information sharing emerges as a particularly important aspect of intermittent care and could be seen as an enactment of the handing over of the control of caregiving by families; a handing over that can vary in degrees of completeness. The main time that information was shared in any detail appeared to be at admission time, however, this time is extremely constrained and seems inadequate to convey the amount of information required to provide knowledgeable care. I learnt from undertaking this research that visiting the home was extremely enlightening in terms of appreciating the person with the dementing illness as part of a family living in a particular context, and as a person of importance to the caregiver. Many of the nurses in this study stressed the importance of adapting care as much as possible to home routines. Providing the opportunity for these nurses to visit the home and develop a fuller appreciation of what the family caregivers consider to be of importance would be a useful strategy. The fragmentation of services, and consequently nursing work, because of service boundaries creates obstacles to this notion but these barriers are not insurmountable given organisational support. Carrying out a nursing assessment at home by the nursing staff who will be acting as substitute caregivers could be a feasible proposition if there was sufficient commitment to the notion of creating as comfortable and least disruptive intermittent care stay as possible.

From the families' experiences in this study it would also appear that there is a need to be presented with the option of intermittent care in a way that more truly represents the choice as problematic. The initial use of intermittent care in this study generally occurred when the existing order of caregiving was already disrupted by health-related changes. At this time family caregivers accepted health professionals' opinions that the use of intermittent care services was essential to support their caregiving. Many families did not, however, recall any preparation from health professionals about how using intermittent care services can cause added stress initially because of the conflicting feelings experienced by the caregiver, the stressed reactions of the person requiring care, and the learning required by both to adapt to an unknown institution and a new group of people. What is necessary then, is a full and frank discussion of the problematic aspects of intermittent care so that families can make choices about what support services are most suitable for their needs and prepare for the work of using the service.

Reconsidering Foucault

Developing a Foucauldian analysis of the nurses' and families' texts has proved to be a difficult and painful exercise. I have struggled to develop a theoretical reading of the participants' accounts informed by Foucault's work, continually fighting a desire to conform to my habitual patterns of thought. My initial analysis was thematically structured, and I presented participants' texts as homogenous and stable. The step from description to theoretical analysis entailed a distancing from individual nurses' and family caregivers' narratives to a view of meaning as constructed, discourse shaping what can be thought and spoken. Working within a Foucauldian framework entails a shift from the notion of a free, autonomous human being who uses language to express meaning, to a position that language creates meaning, and in which individuals and practices are discursively produced. But nurses' and family caregivers' texts were not shadowy documents from the archives, they were accounts generated from words of people, with whom I had formed a relationship, and who had willingly included me in part of their life for a short time. My desire, constantly and uncomfortably resisted, was to reproduce these narratives in a descriptive manner in

order to reveal the demands, challenges and complexities of caring for people with dementia from participants' perspectives.

However, as the analysis progressed the advantages of an approach informed by Foucault's work have surfaced. Rather than attempting to identify common themes, the task of identifying the different discursive positions individuals have been located in has foregrounded diversity rather than homogeneity together with the different organisational conditions and modes of professional education shaping nurses' practices. In addition, stepping back from the viewpoint of individuals being constructed as autonomous and active, to a viewpoint that overlying discursive structures shape possibilities, has allowed an exploration of how things have come to be the way they are in the research sites, rather than adopting a position of blaming individuals for problematic practices. This approach opens up new possibilities in exploring the political dimensions of nursing practice, the contestable nature of the knowledge informing care and provides the opportunity to challenge taken-for-granted aspects of nursing practice.

Research limitations and possibilities for further studies

This research is partial in scope and there are many facets of the intermittent care of people with dementia that could be further explored. Firstly, nurse aides have been assigned an increasingly important role in contemporary health care services in New Zealand, especially in continuing care and in supporting family caregivers in the home. A study of the discursive positions and practices adopted by this group of caregivers would provide yet another reading of intermittent care services.

Secondly, a representation of respite care positioning the people being cared for as central to the service, with family and friends as partners with formal care providers, has major implications for future research directions. A research agenda arising from this model would need to begin with a recognition of the diverse needs of people with dementia, and more broadly speaking, of people with disabilities, challenging the tendency to treat the users of respite care services as a homogeneous group. Research studies identifying the

characteristics of successful and unsuccessful respite care for particular groups of people with disabilities, as indicated by the experiences of people requiring care, care-givers and service providers could make an important contribution to respite care service development.

Thirdly, the cultural viewpoints in this study are limited to those of people of European descent. In New Zealand due consideration must be taken of Māori views and aspirations in this area. One current issue of great pertinence for this thesis is that there appears to be no culturally acceptable options for residential services for Māori as well as other groups such as Pacific Island people (Ministry of Health, 1997). There are also concerns about inadequate research information about the quality of life of older Māori people at the present time, and about possible future needs (Maaka, 1993; Public Health Commission, 1995; Richmond et al., 1995).

The distinctive context of health care in the New Zealand context cannot be ignored with respect to this issue. The Treaty of Waitangi² is a fundamental consideration in the development of health services in New Zealand, and of critical importance in the face of significant health disparities between Māori and non-Māori (Te Puni Kōkiri, 2000). Māori, as the indigenous people of Aotearoa/New Zealand, have rights accorded by the Treaty of Waitangi, not just as individuals, but as members of iwi and hapū³ (Fleras & Spoonley, 1999). The centrality of the Treaty in New Zealand politics (Fleras & Spoonley, 1999) necessitates the state, and New Zealand citizens, to ensure that Māori knowledge and experiences are centrally positioned in the development of health services, rather than being marginalised, as currently seems to be the case. A major finding of this thesis is that the successful intermittent care of people with dementia requires flexible practices and organisational structures which have the capacity to adapt to the specific needs of the people requiring care. There is already debate about the appropriateness of long-term care services for the people using them because of the way some services seem to be developed in response to providers' needs rather than those of the recipients' (Richmond et al., 1995).

² The Treaty of Waitangi, an agreement between the British Crown and Māori in 1840, is considered to be the founding document of a distinctive New Zealand society.

³ Tribal grouping and clan or sub-tribe (Fleras & Spoonley, 1999).

Given the lack of information at this time about the needs of Māori people with dementia as well as the support needs and preferences of family caregivers, this area is a high priority for future research studies in order to support appropriate and responsive service development.

Concluding statement

In conclusion I must reiterate that this account is tentative and partial. However, this partiality, the recognition that the world is made up of many stories and many truths, is at the heart of poststructuralist theorising. What this account does do, is foreground the discursive field of nursing care in the context of intermittent care of people with dementia, and the consequent relations of power and the positions that are generated for nurses, family caregivers and people with dementia. Productive aspects of this work that have created considerable interest and debate have been the topic of representation in nursing, and the issues of what is foregrounded and what is suppressed in nursing educational texts. Dementia has proved to be a fruitful area of study in that the dominance of medical constructions of health and illness can be easily contested as socially constructed, contradictory and marginal to nursing concerns. The subsequent discussion of how nurses have marginalised the knowledge and interests of people with dementia and, indeed the knowledge of nurses themselves, provides a productive starting point for wider discussion about issues of power/knowledge in nursing representations generally.

Furthermore, this study highlights the institutional bases of powerful discourses such as biomedicine as well as the existence of alternative discourses. The marginal discourse of care as being family and home-like may lack the authority of biomedical and formal nursing discourses, situated as it were outside the academy, but space is provided in this representation to produce a social environment, and nursing practices, that encourage a sense of relationship and social inclusion for people with dementia and their family caregivers.

Appendix 1

Nursing Staff Information Sheet

My name is Jean Gilmour and I am a registered nurse undertaking post-graduate study at Massey University. I am employed as a lecturer in the School of Nursing, Health and Environmental Sciences at Wellington Polytechnic. My study requires me to undertake a research project with a focus on nursing practice. My research is a study of nurses' experiences of caring for people with dementing illnesses and nursing relationships with families, in the context of intermittent care.

If you agree to participate in this study, at a time and place of your convenience, I would like to discuss nursing practice issues related to caring for people with dementia in intermittent care. Initially two discussions will take place lasting up to one hour each. I will also be spending some time in the ward observing what happens there and I would like to consult with the nursing care plans.

I would like to tape record or to take notes during the interviews in order to accurately record what has been said. The information will be kept in a safe place and any identifying information removed. The tapes will be typed out without using your real name and the interview returned to you so as to check the accuracy of the transcription. The transcription will only be seen by myself and my thesis supervisors. If a typist is used, she/he will be required to sign a statement assuring confidentiality. You have the choice of having the tapes of the interviews destroyed, returned to you or archived. No identifying information, such as your name, will be included in the research report, however some of your comments may be quoted to illustrate the research findings.

Careplans will not be removed from the ward and no identifying information will be recorded. The family caregivers consent will also be obtained before reading the careplan.

The research report will be submitted to Massey University Department of Nursing and Midwifery so as to fulfil the requirements of a Doctor of Philosophy degree. Sections of the research report will also be submitted for publication in international nursing journals such as the Journal of Gerontological Nursing and presentation at conferences on dementia and nursing practice.

If you take part in this study you have the right to :

- * ask any further questions about the study that occur to you during your participation.
- * refuse to answer any particular question, and to withdraw from the study at any time.
- * ask that the tape be turned off at any time.
- * provide information on the understanding that it is completely confidential to the researcher and supervisors. All information is collected anonymously and it will not be possible to identify you in any reports that are prepared from the study.
- * be given access to a summary of the findings from the study when it is concluded.

Should you at any time be a student at Wellington Polytechnic and have contact with me as a staff member there, you may be assured that this will not in any way be influenced by your participation in the study. Participation in this study may not be of benefit to you, however the knowledge gained through this study will contribute to the knowledge base of nursing and has the potential to influence nursing care in intermittent care services.

If you wish to discuss the project at any time you can contact me at work on 8012794 Ext 8325.

You may also contact my principal research supervisor, Dr Judith Christensen at the Department of Nursing and Midwifery, Massey University, Ph 063504332.

The Regional Health Authority Ethics Committee and the Massey University Human Ethics Committee has approved this study.

Thank you for considering participation in this research project.

Jean Gilmour

Appendix 2

Nurses Consent Form

Research Title: Nursing Practice in the Context of Intermittent Care for People with Dementing Illnesses.

Researcher: Jean Gilmour, RGON, BA, Dip Soc Sci.

Lecturer, School of Nursing, Health and Environmental Science,
Wellington Polytechnic.

8012794 Ext 8325 (Work)

This research is being undertaken in fulfilment of the requirements for a PhD at Massey University under the supervision of Dr Judith Christensen, Senior Lecturer, Dept of Nursing and Midwifery, Massey University, and Dr Anne Opie, Health Services Research Unit, Victoria University.

Aim of investigation: The purpose of this qualitative study is to develop a better understanding of nurses experiences in caring for people with dementing illnesses and nursing relationships with family caregivers. Participation in this study may not be of benefit to you personally however the knowledge gained through this study will contribute to the knowledge base of nursing and has the potential to influence nursing care in intermittent care services.

What you will have to do: You are asked to give time for interviews in your home or elsewhere if more convenient for you.

Your confidentiality will be protected at all times

All information is collected anonymously, and it will not be possible to identify you in any reports that are prepared from the study.

Consent

I have read the information provided for this study and have had the opportunity to discuss the study with Jean Gilmour. My questions about the study have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I also understand that I have the right to withdraw from the study at any time and to decline to answer any particular questions in the study.

I agree to provide information to the researcher on the understanding that it is completely confidential. I understand that I have the choice of having the tapes of my interviews destroyed, returned to me or archived.

I understand that the research has been approved by the Massey University Human Ethics Committee and by the Central Regional Authority Wellington Ethics Committee.

Signature of participant..... Date.....

Signature of researcher:..... Date.....

Statement by witness. I have discussed this consent form with the participant and I am satisfied that she/he fully understands it and that her/his consent is freely given.

Signature of witness..... Date.....

Appendix 3

Family Caregiver Information Sheet

My name is Jean Gilmour and I am a registered nurse undertaking post-graduate study at Massey University. I am employed as a lecturer in the School of Nursing, Health and Environmental Sciences at Wellington Polytechnic. My study requires me to undertake a research project with a focus on nursing practice. My research is a study of nurses' experiences of caring for people with dementing illnesses and nursing relationships with families, in the context of intermittent care.

If you agree to participate in this study, at a time and place of your convenience, I would like to discuss your experience of using intermittent care services and your relationship with the nursing staff. Initially two discussions will take place lasting up to one hour each. I will also be spending some time in the ward observing what happens there and I would like to look at the nursing care plans. I will also ask your relative if I can observe what the nurses do during such times as admission, discharge and visiting as obviously my presence affects their privacy. Any objection will be respected.

I would like to tape record or to take notes during the interviews in order to accurately record what has been said. The information will be kept in a safe place and any identifying information removed. The tapes will be typed out without using your real name and the interview returned to you so as to check the accuracy of the transcription. The transcription will only be seen by myself and my thesis supervisors. If a typist is used, she/he will be required to sign a statement assuring confidentiality. You have the choice of having the tapes of the interviews destroyed, returned to you or archived. No identifying information, such as your name, will be included in the research report, however some of your comments may be quoted to illustrate the research findings.

The research report will be submitted to Massey University Department of Nursing and Midwifery so as to fulfil the requirements of a Doctor of Philosophy degree. Sections of the research report will also be submitted for publication in nursing journals and for presentations at conferences on dementia and nursing practice.

If you take part in this study you have the right to :

- * ask any further questions about the study that occur to you during your participation.
- * refuse to answer any particular question, and to withdraw from the study at any time.
- * ask that the tape be turned off at any time.
- * provide information on the understanding that it is completely confidential to the researcher and the two supervisors. All information is collected anonymously, and it will not be possible to identify you in any reports that are prepared from the study.
- * be given access to a summary of the findings from the study when it is concluded.

Participation in this study may not be of benefit to you however the knowledge gained through this study will contribute to nursing knowledge and potentially could influence nursing care in intermittent care services.

If you wish to discuss the project at any time you can contact me at work on 8012794 Ext 8325.

You may also contact my principal research supervisor, Dr Judith Christensen at the Department of Nursing and Midwifery, Massey University, ph 063504332.

The Regional Health Authority Ethics Committee and the Massey University Human Ethics Committee has approved this study.

Thank you for considering participation in this research project.

Jean Gilmour

Appendix 4

Family Caregiver Consent Form

Research Title: Nursing Practice in the Context of Intermittent Care for People with Dementing Illnesses.

Researcher: Jean Gilmour, RGON, BA, Dip Soc Sci.
Lecturer, School of Nursing, Health and Environmental Science,
Wellington Polytechnic.
8012794 Ext 8325 (Work)

This research is being undertaken in fulfilment of the requirements for a PhD at Massey University under the supervision of Dr Judith Christensen, Senior Lecturer, Dept of Nursing and Midwifery, Massey University, and Dr Anne Opie, Health Services Research Unit, Victoria University.

Aim of investigation: The purpose of this qualitative study is to develop a better understanding of nurses experiences in caring for people with dementing illnesses and nursing relationships with family caregivers. Participation in this study may not be of benefit to you personally however the knowledge gained through this study will contribute to the knowledge base of nursing and has the potential to influence nursing care in intermittent care services.

What you will have to do: You are asked to give time for interviews in your home or elsewhere if more convenient for you.

Your confidentiality will be protected at all times:

All information is collected anonymously, and it will not be possible to identify you or any of your family members in any reports that are prepared from the study.

Consent

I have read the information provided for this study and have had the opportunity to discuss the study with Jean Gilmour. My questions about the study have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I also understand that I have the right to withdraw from the study at any time and to decline to answer any particular questions in the study.

I agree to provide information to the researcher on the understanding that it is completely confidential. I understand that I have the choice of having the tapes of my interviews destroyed, returned to me or archived.

I understand that the research has been approved by the Massey University Human Ethics Committee and by the Central Regional Authority Wellington Ethics Committee.

I wish to participate in this study on the understanding that if (name of person with dementia), has an objection it will be respected.

Signature of participant..... Date.....

Signature of researcher:..... Date.....

Statement by witness. I have discussed this consent form with the participant and I am satisfied that she/he fully understands it and that her/his consent is freely given.

Signature of witness..... Date.....

Appendix 5

Proxy Consent Form: Family Caregiver Consent on Behalf of the Family Member with a Dementing Illness.

Research Title: Nursing Practice in the Context of Intermittent Care for People with Dementing Illnesses.

Researcher: Jean Gilmour, RGON, BA, Dip Soc Sci.
Lecturer, School of Nursing, Health and Environmental Science,
Wellington Polytechnic.
3850559 (Work)

This research is being undertaken in fulfilment of the requirements for a PhD at Massey University under the supervision of Dr Judith Christensen, Senior Lecturer, Dept of Nursing and Midwifery, Massey University, and Dr Anne Opie, Health Services Research Unit, Victoria University.

Aim of Investigation: The purpose of this qualitative study is to develop a better understanding of nurses experiences in caring for people with dementing illnesses and nursing relationships with family caregivers. Participation in this study may not be of benefit to you personally however the knowledge gained through this study will contribute to the knowledge base of nursing and has the potential to influence nursing care in intermittent care services.

Description of Inconvenience: You are asked to give time for interviews in your home or elsewhere if more convenient for you.

Your Confidentiality Will Be Protected At All Times

All information is collected anonymously, and it will not be possible to identify you in any reports that are prepared from the study.

Proxy Consent Form.

I understand that the researcher, Jean Gilmour, will be spending some time in the ward observing what happens when (name of family member requiring intermittent care) arrives and goes home from intermittent care visits. I also understand that she will read the nursing care plans.

I give consent on behalf of(name of family member requiring intermittent care) to Jean Gilmour's presence during admission and discharge procedures and access to nursing care plans on the understanding that verbal permission will be sought from (name of family member requiring intermittent care) and any objections respected.

Signature of family caregiver.....

Date.....

Signature of researcher.....

Date.....

Statement by witness/patient advocate. I have discussed this consent form with the participant and I am satisfied that she/he fully understands it and that her/his consent is freely given.

Appendix 6

References used in Table 10.1 from Johnson, B.P. (1998). The elderly. In N.C. Frisch & L.E. Frisch (Eds.) [6th ed.], *Psychiatric mental health nursing* (pp. 526-527). Albany, New York: Delmar Publishers

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