NURSES' EXPERIENCES CARING FOR PATIENTS WITH DEMENTIA:
A PHENOMENOLOGICAL STUDY

VICKI C. EARLE

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by

Vicki C. Earle

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Abstract

Very little research has been conducted on the experiences of nurses who care for patients with dementia. This study is an attempt to fill in some of the gaps related to the experiences of these formal caregivers. Much research has already been conducted on the experiences of both family caregivers and patients with dementia, yet the experience of a formal caregiver may be quite different. There may be unique challenges associated with providing nursing care to patients with dementia. This study allowed for a greater understanding of the complex care associated with dementia. With this increased understanding comes the opportunity to improve the quality of care for patients and the work life of the nursing staff.

The purpose of my study was to explore the experiences of professional nurses who care for patients with dementia and gain an understanding of the lived experience of these nurses. Phenomenology was the method chosen. An unstructured interview approach was used to encourage participants to reflect on their clinical practice. Interviews were audio taped and transcribed for analysis. Eight nurses were interviewed from three long-term-care agencies in St. John's, Newfoundland. Several themes were identified from the data analysis including seeing beyond the confusion, caregiving as rewarding, meeting challenges, creating a caring environment, and being devalued by the nature of the caregiving work. These themes were interrelated and formed the essence of the nurses' experience caring for patients with dementia. Implications for nursing research, education, and practice were drawn from the research data.

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Chapter 1

Introduction

This study is an examination of the experiences of professional nurses who care for patients with dementia. Dementia is defined as a "reduction or impairment of multiple cognitive abilities, including memory, sufficient to interfere with self-maintenance, work, or social relationships" (Weiner, 1996, p. 3). More broadly, it refers to a loss of intellectual ability that interferes with daily functioning. Dementia has an overwhelming impact on all aspects of daily life for the individual and those who care for them, whether they are family members or formal caregivers (Andresen, 1995).

Background to the Study

The number of Canadians affected by dementia is rising with the demographic trends of the aging baby boomers and increasing longevity. The Canadian Study of Health and Aging (1994) found that 364,000 Canadians over age 65, or 1 in 13, have some form of dementia. The study also reported that 1 in 3 Canadians over the age of 85 have dementia. The most rapidly growing age group in Canada are those 80 years and older, which will more than double from 920,000 in 2000 to 1.9 million in 2026 (Statistics Canada, 2001). It follows then that as this group doubles, the number of Canadians affected by dementia will likely double as well.

Given the population projections and the fact that over 52% of Canadians know someone with dementia, and almost 25% have someone with dementia in their family (Alzheimer Society of Canada, 1997), increasing our understanding of this condition and the complex care associated with it is an important area for nursing research. The provision of nursing care to patients with dementia involves attending to all aspects of the individual's life and presents unique challenges for nurses (Joyce & Kirksey, 1996). Frustration can result as the nurse tries to deal with the many problem behaviors associated with dementia. These include agitation, aggression, wandering, paranoia, suspiciousness, and sleep disturbance just to name a few. The successful nurse caring for patients with dementia must have a large repertoire of coping skills, behavior management techniques, and communication skills (Holden & Woods, 1995).

Many researchers have explored the concept of caregiving from the point of view of informal caregivers, mainly a family member. Yet, very few studies outside of Sweden have examined the experience of professional nurses who care for clients with dementia on a daily basis. As a researcher, I was interested in the complexities of care required and the nature of the caregiving experience from the point of view of nurses. The experiences of professional nurses in long-term care institutions are very different from those of family caregivers and were worth exploring in more detail.

This study examined the experiences of individual nurses who care for patients with dementia on a regular basis. I was interested in discovering what it was like to care for these patients on a daily basis. My own clinical practice experience caring for patients with dementia suggested that the care was very complex and challenging and required a great deal of knowledge and skill. By interviewing the nurses and allowing them to reflect on their caregiving experiences, and analyzing the data using a phenomenological method, I hoped to gain an understanding of the lived experience of these nurses.

Purpose

The purpose of this study was to gain an understanding of the lived experience of professional nurses who care for patients with dementia.

Rationale for the Study and Problem Statement

The nature of caring for patients with dementia has implications for nursing practice, education, and research. There is a wealth of research on the effects of caring for cognitively impaired older adults by informal caregivers in the home setting (e.g., Acton & Winter, 2002; Almberg, Grafstrom, & Winblad, 1997; Koch, Marks, & Hofmeyer, 2002; Macpherson, Eastley, Richards, & Haq Mian, 1994; Moniz-Cook, Millington, & Silver, 1997; Moyle, Edwards, & Clinton, 2002). There is substantial literature on assessing the situation and improving care of cognitively impaired patients and their informal/family caregivers (Chappell & Novak, 1994). Research has also been carried out on the disruptive behaviors in patients with dementia but the focus has been on patterns and correlates of behavior or techniques to use when caring for a confused patient rather than the impact on formal caregivers (Eliopoulos, 2001). Very few studies have explored the experiences of formal caregivers, namely nursing staff who provide the complex care required by patients with dementia. Another area that is lacking in the research literature is whether there are differences in distress levels of staff who care for cognitively impaired older adults and those who care for mentally alert older adults (Middleton, Stewart, & Richardson, 1999). While my study is not comparative, it will help to determine some of the stressors that are specific to the care of patients with dementia.

Studies have shown that high stress levels in family members or informal caregivers result from caring for individuals with dementia and this high stress level is often referred to as burden (Morris, Morris, & Britton, 1988). It follows then that formal caregivers may also experience high stress levels (Macpherson et al., 1994). The research that has been conducted in the area of formal caregiving suggests that the nature of the heavy work, the agitation and aggression of patients, and the difficulty in forming meaningful relationships, results in stress for the staff (Ineichen, 1990; Mace, 1990). I was interested in exploring these stressors in more detail as well as other stressors that may exist. I was also interested in exploring rewarding aspects of this caregiving experience. Surely not all staff who work with this patient population over a long period of time, experience stress and burnout. What is it about those who find the experience rewarding that makes them different from those who develop burnout?

The experiences of nursing staff in long-term care agencies may be quite different from those of informal caregivers. It may be that the nursing staff experience much less stress than the informal caregiver. The nursing staff would likely not have known the individual prior to the development of the cognitive impairment and may not feel that same connection to the person as the family member would. It may be more difficult for staff to relate to the individual not having known their personality before the illness. Perhaps this difference makes the caregiving experience more stressful for the staff. These are just possibilities but are worth further exploration.

This study also has educational implications for nurses. One very important issue is whether nurses feel they have the necessary knowledge and skills to care for this client population. The study may identify specific learning needs of nurses who care for patients with dementia. It will also likely identify the strengths of the staff and specific coping skills they utilize. The literature demonstrates that there is a definite need for educational opportunities with respect to dementia care (Bowden & Leduc, 1994; Wagner, 1997; Wilen, Harman, & Alexander-Israel, 1997). The identification of learning needs would allow for the development of an educational program specific to the needs of this group of staff. Such an initiative has the potential to greatly enhance the quality of care provided to patients with dementia and improve the quality of work life for the nurses.

Enhancing the quality of care for patients with dementia will become even more important as our population continues to age. By the year 2030, it is estimated that three-quarters of a million Canadians will be affected by Alzheimer's disease and related dementias (Alzheimer Society of Canada, 1997). The costs to society will be high and the need for institutional care will become greater as the population ages. Thus any attempt to improve the quality of care, and the work life of nurses who provide this care, is an important research endeavor. Understanding nurses' experiences is an important first step.

The phenomenological method was an appropriate approach for examining the work life of nurses providing care to patients with dementia. The goal of this study was to understand and interpret the lived experiences of these nurses in their daily work life. The phenomenological approach allowed me to illuminate the rewards and challenges of the caregiving experience. It also allowed for a greater understanding of the knowledge and skills required by nurses and the complex care required by patients with dementia.

Research Question

The main research question for this study was what is it like for nurses to care for patients with dementia?

Chapter 2

Review of Literature

Research in the area of dementia caregiving has focused mainly on the experiences of informal or family caregivers. While these studies make a significant contribution to understanding the complexities of caring for a person with dementia, it is outside the scope of this chapter to review the experiences of informal caregivers. Studies that explore formal caregiving, specifically by professional nurses, are the focus of this chapter. Areas of interest include reflections on caregiving, stress associated with caregiving, attitudes of staff caring for patients with dementia, communication and dementia caregiving, support and education of staff involved in dementia care, and the importance of the physical and social environment in dementia care.

Reflections on Caregiving

How do nurses see their caregiving role with patients who have dementia? Several researchers have carried out studies asking staff to reflect on their caregiving experiences with this patient population. Much of the research comes out of Sweden by researchers at the University of Umea and Lund University (Berg, Hallberg, & Norberg, 1998; Hansebo & Kihlgren, 2001; Olsson & Hallberg, 1998). All three studies used a phenomenological-hermeneutic approach to examine nurses' reflections on caregiving. Some differences were noted in the setting and methods of data collection, yet the content of the nurses' reflections were very similar. The similarities relate to the interdependency between staff and patients, the difficulty interpreting the needs of patients with dementia, and the importance of considering the patient's past in order to provide quality care and maintain the patient's dignity.

One of very few studies to specifically examine the experiences of nurses was by Berg et al. (1998). These researchers interviewed nurses working on a ward for patients with severe dementia. The purpose was to encourage the nurses to reflect on dementia care, the patients, and themselves in their daily caregiving. Caring for people with severe dementia was seen as *an intertwined life world* that stems from *making and doing together.* It required *delicate interpretive work* on the part of nurses. The intertwined life world is a description of the relationships between the nurses and patients as being mutually dependent. *Making* referred to completing necessary tasks for the patient's well being. Depending upon the patient's reaction and the nurse's approach, this could result in positive or negative interactions. *Doing together* referred to the nurse and patient being together and sharing each day, which also had both positive and negative dimensions. The positive aspects centered on closeness with the patients, while the negative aspects included lack of feedback from the patients, suspicious/distrustful behaviors, and aggression. *The delicate interpretive work* related to the difficulty in understanding the needs of patients with dementia. Overall, the nurses highlighted the need to have a great deal of patience in order to provide quality care and maintain the patient's dignity.

Similarly, Hansebo and Kihlgren (2001) asked nurses to reflect on caring for patients with dementia. These researchers used videotaped interactions between nurses and patients as hermeneutic prompts to interview the nurses. Specifically, the caregivers reflected on themselves, the patients, the context, and the work itself. Caregivers described their experiences as rewarding and worthwhile. The main point that came through was the need to maintain a sense of dignity for the patients and themselves. When the caregivers reflected on themselves self-criticism became evident. They realized they were not always encouraging patients to use their remaining capabilities and not involving them in decision-making. They examined their own caring philosophy and highlighted the need to always respect the patients. Reflections about the patients focused on difficulty understanding and interpreting the world of patients, the patients' behavior and personality, the need for support, and the patients' awareness of the caregiver's mood. Reflections focusing on the context and the work itself revealed caregiver's satisfaction with their work but also identified was the need to have patience. Insufficient time, inadequate staff, and lack of response from patients were factors that led to stress, however moments of co-operation and mutuality were very rewarding. The caregivers' level of experience and training, along with co-workers' attitudes (positive and negative) were factors that influenced how they approached the patients.

Olsson and Hallberg's (1998) study also demonstrated that staff had difficulty interpreting the needs of patients with dementia but again the staff recognized the need to treat all persons with dignity and respect. They interviewed home care staff who received clinical supervision sessions while caring for clients with dementia in their homes or sheltered accommodations. The staff reflected on four key areas, the patients' personal situation, the patients' environment, the interaction between the staff and patients, and the staff's situation. Some of the findings of this study were unique in relation to caring for patients with dementia in their home environment. Reflections on the patient's personal situation focused on disease related behaviors such as agitation and suspicion, difficulty interpreting the patient's needs, the importance of social support for patients, and how dementia affects the patient's self-esteem particularly in the early stages. In relation to the patient's environment, the staff discussed the differences in care needs based on the type of housing. The benefits of staying in their own home versus a sheltered accommodation were discussed. The level of resources, access to activities, and inadequate space in the sheltered housing were other areas explored. When reflecting on their interaction with the patients, the staff explained that they were not always sure of the best approaches to care, whether it was better to validate the patient's feelings or orientate them to reality. Improving relationships with families was also discussed. With regard to the staff's own situation, they reflected on the importance of maintaining a good working relationship with other health care professionals involved in the patient's care.

In addition to the studies described thus far, a key project in Newfoundland and Labrador also explored how nurses in long-term care reflected on their practice. The Association of Registered Nurses of Newfoundland and Labrador (ARNNL) and the Newfoundland and Labrador Nurses Union (NLNU) formed a working group to "identify issues and recommend strategies to enhance the role of RNs in institutional long-term care facilities" (ARNNL & NLNU, 2002, p. iii). The working group conducted a literature review, surveyed nurses in long-term care, consulted with stakeholders in the long-term care sector, and examined their own professional experiences. The majority of nurses who responded to the survey, reported they did not feel valued by their coworkers and managers. They indicated that they enjoyed their work, but many issues such as workload, relationships with management, licensed practical nurses (LPNs) and others, had an impact on their work satisfaction. A total of 83% of the nurses indicated they did not feel valued by the work they do. Nurses felt valued by residents and their families, but felt undervalued by LPNs and by acute care nurses. A high majority (85%) indicated they felt like "second class nurses" (p.12). There was a perception that long-term care nurses do not require the same level of knowledge or skill as nurses in other areas of practice. Based on these and other findings, the working group recommended changes to the practice environment in long-term care to ensure quality professional practice.

Stress Associated with Caregiving

The stress associated with dementia caregiving has received much attention in the research literature. The stress of caring for patients with dementia could be expected to have a negative impact on nurses' work. At least five studies specifically examined the stress associated with caregiving for patients with dementia. While some of these studies examined the effects of disruptive behaviors on the staff (Hellzen, Asplund, Sandman, & Norberg, 1999; Middleton et al., 1999), others focused more broadly on the stress related to dementia caregiving (Chappell & Novak, 1994; Rodney, 2000), and one was more general in that it looked at stressors and reported coping strategies (Clinton, Moyle, Weir, & Edwards, 1995). These studies differed in the methods used to collect the data but the findings were similar in that all studies specific to dementia revealed that caring for the patients was stressful in some way.

One of the most difficult aspects of caring for patients with dementia is the disruptive and often aggressive behaviors of these patients. The philosophy and organization of care (e.g., special care versus traditional care units) can make a difference to the level of stress experienced by staff (Middleton et al., 1999). According to this study staff on special care units for dementia were less distressed with disruptive behaviors than those on traditional units. Staff on the special care units reported an increased incidence of disruptive behaviors but viewed aggressive acts as related to the disease, whereas staff on traditional units viewed it as an attempt to harm. The study indicated that staff on special care units have specialized knowledge and skill in handling disruptive behaviors.

Similarly, Hellzen et al. (1999) looked at the impact of disturbing behaviors on nursing staff. They conducted narrative interviews with 15 caregivers on a psychiatric ward in Sweden. While the study was not specific to dementia care, it is included here since the disturbing behaviors of clients with dementia are often the most stressful aspect of the caregiving experience. Several themes were identified. *Experiencing a sense of losing control* was related to the staff's inability to understand the patient's behavior. They found it difficult to see any meaning in their work due to their limited knowledge of the disease process. *Experience of an inverted position of power* related to the caregivers descriptions of feeling 'infected or soiled' by the patient. They saw the patient as a victimizer as a result of being exposed to physical violence and humiliation. *Experience of being a victim* was evident when caregivers described feelings of ambivalence about how they viewed the patient. They saw the patient as a person for whom they should feel compassion, yet they were crushed by the patient's actions and felt victimized. *Experience of their own dark side* related to the ambivalence they felt over the fact that they should be providing quality nursing care, but the reality was they felt hurt and humiliated by the patient's actions. This led them to see a darker side to their own personality.

Other studies specifically examined the stress related to dementia caregiving (Chappell & Novak, 1994; Rodney, 2000). These two studies were similar in design and findings. In Rodney's study, the stress associated with caring for a highly aggressive resident was significantly higher than caring for a less aggressive resident. Overall, nurse stress levels were moderate and resident aggression was significantly related to an increase in nurse stress.

The level of stress did not vary by level of nursing education. The stress of nursing assistants was similar to that of nurses in relation to aggressive behavior by patients (Chappell & Novak, 1994). Just over 88% of the sample reported they had spent some time in bed sick, missed days from work sick, or used pain relievers. Younger staff and those working full-time tended to have more physical stress. There was no significant relationship between the level of mental impairment of the patients and the difficult patient behaviors. In other words, the diagnosis of dementia was not a significant predictor of difficult behaviors. It would follow then that caring for patients with dementia is only stressful when the patient exhibits difficult behavior.

Nurses' perceptions of stressors and how they cope also indicates the degree of stress these formal caregivers experience. An Australian study addressed nurses' perceptions of stressors and their coping strategies in caring for patients with dementia (Clinton et al., 1995). A total of 92 stressors were identified. Nurses perceived difficult/disruptive resident behaviors as the most frequent stressor in their work (55%). In relation to the coping behaviors used by the nurses, 48% were adaptive strategies such as maintaining a professional attitude and problem solving, support from peers, family, and friends, and getting advice. Six out of the ten nurses in the study used maladaptive strategies (e.g. withdrawl coping and becoming detached) more frequently. This finding points to the need for support and education of nurses regarding coping strategies when caring for patients with dementia.

A second means of discovering the stress associated with dementia caregiving is to examine outcome measures such as psychological health, staff satisfaction, and burnout. Two studies dealt with these issues. One looked at satisfaction among nurses, licensed mental nurses, and licensed practical nurses caring for patients with dementia in Sweden (Welander Hansson, Hallberg, & Axelsson, 1995), while the other examined work stress among nurses, nurses' aides, and activity workers in rural Canada (Morgan, Semchuk, Stewart, & D'Arcy, 2002). These two studies differed in terms of the design, location, and the findings. Welander Hansson and co-researchers conducted a descriptive correlational study and recruited 134 nursing staff from the three long-term care agencies. They found that the staff were satisfied with their work and the nursing care they provided. Nurses were significantly more satisfied than staff with less training, such as nursing assistants. Overall, a low degree of burnout and work related strain was noted across all 3 sites and groups of staff.

In contrast, Morgan et al. (2002) found that job strain was a major theme identified among nurses, nurses' aides, and activity workers. Sources of work related stress included the workload itself, insufficient skills, and integration of patients with dementia in the general nursing home population. All of the staff were concerned about not having sufficient time to meet the psychosocial needs of patients. There was also a perception by the staff, particularly the nurses' aides, that they lacked the skills needed to care for patients with dementia. However, all three groups reported that as they learned specific behavior management techniques, they became more confident in their ability to care for patients with dementia. The specific behavior management techniques were not identified.

Other studies examined work-related stress in gerontology. These studies were not specific to caring for patients with dementia but are summarized here since a high percentage of patients in long-term care institutions suffer from varying degrees of dementia. It is possible that some of the sources of stress in gerontology could be related to care of patients with dementia. Two studies dealt with stress of caring for the elderly (Duquette, Kerouac, Sandhu, Ducharme, & Saulnier, 1995; Macpherson et al., 1994). Both studies used a descriptive correlational design but measured different outcome variables.

Macpherson et al. (1994) examined the psychological health of nursing staff caring for the elderly in the United Kingdom. Rates of psychological disturbance of nursing staff were consistently low across all sixteen units where staff were recruited. This was an unexpected finding given that the stress levels of family caregivers in the community are reportedly high. The finding was attributed to the fact that professional caregivers receive financial gain and have professional support structures in place, they work shift work, not twenty-four hours per day, and do not have the long-term personal relationships with the clients as is the case for family caregivers. Undoubtedly, the experiences of professional caregivers are quite different than that of family caregivers and warrants further attention.

The second study examined psychosocial determinants of burnout in geriatric nursing (Duquette et al., 1995). Hardiness and work stressors were found to be important predictors of burnout. Geriatric nurses with hardy personality traits were able to decrease strain and avoid burnout by attempting to understand and adjust to stressful events. Geriatric nurses who use positive coping methods and perceive support from management were also less likely to burnout. This study highlights the need to examine hardy personalities more closely. It leads to the question, how can nurses increase their hardiness in order to offset the chances of becoming burned out. Also noted was the importance of work support (e.g.

support of superior, peer cohesion, and group involvement) as a factor that decreased the likelihood of staff becoming burned out.

Attitudes of Staff Caring for Patients with Dementia

There is no doubt that the attitudes of staff toward patients with dementia, has an influence on the care they provide as well as how they experience that work. Negative attitudes can lead to poor quality of care whereas positive attitudes can greatly enhance the quality of care and quality of life for patients with dementia. Three studies were found that explored the attitudes of health professionals caring for patients with dementia (Astrom, Nilsson, Norberg, Sandman, & Winblad, 1991; McIntosh, Swanson, Power, & Rae, 1999; Normann, Asplund, & Norberg, 1999). These studies were quantitative but differed in design.

The choice of caregiving approach and the rationale for this choice was the focus of one study (Normann et al., 1999). Nurses' use of reality orientation versus a personhood focused approach to dementia care was examined. Reality orientation relates to reorienting a confused individual back to reality, in an attempt to reduce the confusion, whereas a personhood-focused approach relates to preserving and reconstructing the individual's personhood by examining their past. It focuses on attention to the person's life history, values, culture, and self-identity. Nurses were presented with a case study followed by a questionnaire outlining 13 sets of statements, each with one reality orientation response and a personhood focused response. The majority of nurses chose the reality orientation approach. Nurses with post-basic education tended to choose the personhood focused approach more often. Education was likely more important than nursing practice in determining attitudes.

Thus the need to increase education and training specific to dementia care is warranted, especially in relation to the need for a personhood focused approach rather than a reality orientation approach.

Less positive attitudes and reduced empathy correlated with burnout in one study of nurses on geriatric and psychogeriatric wards (Astrom et al., 1991). Staff with the lowest levels of empathy listed the patient's improvement and contact with colleagues as the most stimulating factors at work, while those with high empathy reported close contact with the patient as the most stimulating factor. Staff with high empathy were also at risk for developing burnout due to their deep involvement with the patient and those with low empathy were also at risk due to the lack of positive outcome in their work. Nurses and managers need to carefully examine these risk factors so that strategies can be developed to prevent the experience of burnout by staff who care for patients with dementia.

In the comparison of general practitioners (GPs) and nurses (RNs) with regard to perceived roles, attitudes, and stressors in the management of people with dementia, more than half of the sample reported that management of patients with dementia was moderately to very stressful (McIntosh et al., 1999). The GPs reported more negative attitudes toward patients with dementia than RNs. Since the study used a convenience sample of RNs and GPs who were attending an educational conference on dementia care, it cannot be considered representative of all GPs and RNs who care for patients with dementia. Those nurses who chose to attend the conference may have been the most interested and positive caregivers.

Communication and Dementia Caregiving

Caring for patients with dementia requires an adaptation of the communication techniques employed with patients who have normal cognitive function. It is important to explore research studies in this area in order to understand the complexities of communicating with patients who have dementia and what it contributes to the knowledge of the overall experience.

Three studies described by Jones (1992), a co-editor of the text *Caregiving in Dementia: Research and Applications*, examined communication patterns between nurses and patients with dementia. In the first study, the communication patterns between nurses and geriatric residents in a geriatric hospital in Vancouver, Canada, were explored (Jones & Jones, 1985). The second study, arising out of the first, examined nursing staff's perceptions of geriatric patients in terms of which residents they communicate with most or least and reasons for their lack of communication with certain residents. Following from the second study, Jones conducted a third study to determine whether specific training would lead to a positive change in the staff interaction patterns.

Patients with dementia and those who were very hard of hearing received the least amount of communication due to communication barriers with the average being less than 15 words spoken to residents during the times of peak personal contact (Jones, 1992). Commands were the most common type of interaction with all residents but were more frequent to residents with dementia and those with difficulty hearing. The absence of introductions and explanations of the care to be given was noted. The staff were aware that their interactions were being recorded and thus they may have said less because they were uncomfortable or fearful of saying the wrong thing. Nursing staff enjoyed caring for patients who were cheerful and could interact socially. They tended to avoid residents they did not understand. The least favorite resident was someone they could not please despite their best efforts, or someone who made them aware of their own limitations. The staff expressed a desire to have information about the cause and nature of the disease process associated with dementia and techniques to help them better interact with these patients. Education sessions were held with nursing staff to discuss difficult patient behaviors, and a specific individualized plan of care was then formulated for one patient. Nursing staff found this patient much easier to care for and they were starting to understand her better and as a result they spent more time talking to her. The patient's behavior had changed in that her "bad moods" were less frequent; she was spending more time out of her room and taking part in activities. Thus the planned interventions and educational sessions with staff proved successful. The researcher went on to develop a model for communicating with residents who have dementia.

Other researchers have examined how nurses initiate and terminate verbal interactions with patients experiencing dementia (Edberg, Nordmark Sandgren, Hallberg, & Axelsson, 1995). Decreased verbal communication and strong task orientation were noted. The nurses' communication style either increased or decreased the vocal activity of the patient. The researchers pointed out that the nurses' knowledge of the patient's impaired communication "creates a vicious circle" (Edberg et al., p. 165). When nurses do not expect patients to communicate appropriately, they become passive in their interactions, rather than providing the intense verbal cues needed by patients with dementia. There was very little evidence of reciprocity of communication in this study.

Three other studies dealt with issues such as how nurses come to understand patients with dementia (Haggstrom, Jansson, & Norberg, 1998), how nurses establish caring relationships with the patients (Rundqvist & Severinsson, 1999), and how effective the recommended communication strategies are when interacting with patients who have dementia (Tappen, Williams-Burgess, Edelstein, Touhy, & Fishman, 1997). All three studies were qualitative and used interviews to collect the data, but the study by Haggstrom et al. also used observation as a second method of collecting data. One difference in the study by Tappen et al. was that the researchers interviewed the patients experiencing dementia and not the nursing staff caring for these patients. Their aim was to determine whether moving away from traditional communication techniques such as closed-ended questions and simple concrete subjects, would benefit patients with dementia. Another difference relates to the methods used to analyze the data in each of these three studies.

Caregivers develop their own personal ways of understanding patients with dementia (Haggstrom et al., 1998). Their understanding stemmed from their personal experience with childhood and motherhood, their knowledge about the client's life history and nature of disease, and personal talent. Affect attunement, i.e., familiarity with resident's affective behaviors, was seen as central to understanding the resident with Alzheimer's disease. The caregivers chosen to participate were those who were believed to be skillful in communicating and interacting with the residents and therefore a "false picture of paradise" might emerge from the findings (Haggstrom et al., p. 236).

The caring relationships that nurses establish with patients who are experiencing dementia have been examined (Rundqvist & Severinsson, 1999). Six nurses who worked on a ward for patients with severe dementia were interviewed. The findings were interpreted within a hermeneutic transformative process. Three main themes were identified. *Touching* pointed to the importance of touch as a means of communicating caring and included body-contact, caresses, and hugs. *Confirmation* included factors such as 'inviting and being invited', being recognized by the patients, and demonstrating sensitivity for the patients' needs. *The values in the caring culture* included consideration, patience, and compassion. Factors in the physical environment such as the architecture and equipment and staffing resources impacted on their ability to create a caring culture.

Communication strategies for interacting with people who have dementia have also been explored (Tappen et al., 1997). The purpose was to identify whether evidence exists to support such strategies as use of simple vocabulary, slowing the rate of speech, using closed-ended questions, and use of distraction to avoid discussing negative feelings. Interviews with patients in the middle and late stages of Alzheimer's disease were conducted and revealed that nurses used more closed ended questions than any other type, but no significant differences were noted in length or relevance of the patient's response by type of question. Patients with dementia were able to respond to open-ended questions and over 80% of the patient's responses were relevant in the context of the conversation. Overall, this study identified several useful strategies for establishing a caring relationship with patients who have dementia. Broad openings, speaking as equals, establishing commonalities, and sharing of self were found to be helpful.

Support and Education of Staff Involved in Dementia Care

Some work has been done in the area of support for staff caring for patients with dementia and the need for ongoing education and training of nursing staff. Several research studies identified the benefits of clinical supervision for staff caring for patients with dementia (Berg & Hallberg, 2000; Berg et al., 1998; Berg, Welander Hansson, & Hallberg, 1994; Edberg et al., 1995; Graham, 1999; Hansebo & Kihlgren, 2001; Olsson, Bjorkhem, & Hallberg, 1998; Olsson & Hallberg, 1998). The clinical supervisor's direct role was to assist staff to regularly reflect on and interpret their work experiences and provide support to the staff. The clinical supervisors also assisted nursing staff in confronting the complexities of their daily work, the aim being to make the nurses own knowledge more explicit. The clinical supervisors were considered experts in the field of dementia caregiving and offered specific educational sessions to nursing staff on approaching and interpreting demented people, dealing with aggression, anxiety, and insomnia, attitudes toward demented people, and practical problem solving.

The clinical supervision studies overlap to some degree with those mentioned previously in the section *Reflections on Caregiving* because one of the main roles of clinical supervisors was to assist staff to regularly reflect on their nursing practice. Some of the specific benefits of the clinical supervision noted in the research include decreased feelings of burnout and tedium (Berg et al., 1994; Graham, 1999), nurses' perception of increased support (Berg & Hallberg, 2000), increasing nurses' knowledge, understanding, interest, commitment to caring for people with dementia, and better understanding of colleagues (Olsson et al., 1998), and increased quality of cooperation with the patients (Edberg et al., 1995).

The need for ongoing education and training of nursing staff caring for patients with dementia has been widely recognized. Keady (1996) pointed out that a review of mental health nursing by the Department of Health in London, England, found an under-investment in training, support, and supervision for nursing staff with respect to the complex needs of patients with dementia. In Canada, a needs assessment of home care workers was conducted by the Alzheimer's Society and Home Support Canada (1992) and indicated that there was a general lack of knowledge about the disease and inadequate training and information resources. Managers and front-line workers felt that training in dementia caregiving was essential. To address these issues, the two organizations worked together to develop a training resource specific to meet the needs of home care workers. They released the resource *Alzheimer Disease: Care at Home* in September 1993 (Bowden & Leduc, 1994).

At least four studies examined the benefits of educational programs for staff caring for patients with dementia (Ragneskog, Kihlgren, Karisson, & Norberg, 1993; Schonfeld, Cairl, Cohen, Neal, Watson, & Westerhof, 1999; Skog, Grafstrom, Negussie, & Winblad, 2000; Wilkinson, 1999). The findings of all four studies demonstrated the positive effects of education and training programs.

In one study, nursing staff were trained in *integrity promoting care* for a period of one week and then given support in applying the new knowledge during a three month intervention period (Ragneskog et al., 1993). A similar ward at another agency was used as a control. Compared to the control ward, improvements were noted in the patients' behaviors and the quality of care. The staff reported that they found their jobs meaningful, engaging, and stimulating but they also felt that the workload was heavy. They reported mental strain resulting from difficult patient behaviors. The stress of caring for patients with dementia has been noted in studies mentioned previously (Clinton et al., 1995; Macpherson et al., 1994; Middleton et al., 1999).

Similarly, a group of researchers at the University of South Florida, U.S.A., established a long-term-care training program to educate nursing home and assisted living facility staff to better manage residents with memory impairment (Schonfeld et al., 1999). They identified eight areas of content as the core of the curriculum including philosophy of dementia care management, individualized goals and activities, causes of dementia, identification of problem behaviors, behavioral management techniques, communication strategies, environmental modification, and staff stress management. Following the intervention, significant improvement was noted in the staff's knowledge base and this was maintained at a 3-month follow-up. With this increased knowledge of dementia care approaches, nursing staff were able to provide a higher quality of care.

Education leads to empowerment of staff and better outcomes for patients with dementia (Skog et al., 2000). The patient with dementia was seen as the 'teacher' in a study that examined the experiences of 18 licensed practical nurses in Sweden. They participated in an educational program that provided theoretical and practical training in dementia care and followed a single patient throughout the educational program. Four main themes emerged from the data. *Personal guide* focused on the trainee's role of supporting the patient. They were taught to create a positive atmosphere for the patient and make the patient feel important. *Developing a relationship* related to the trainee's ability to see the patient as a unique individual as a result of learning about the patient's interests, life story, personality, symptoms, and remaining function. *Reducing the working pace* focused on the need for trainees to 'adapt' to the patient's needs by remaining 'actively calm' while providing care. It saved time, helped their relationship with the patient, and prevented misunderstandings. It also allowed the trainees to enjoy the work more. *Investigative* *mealtimes* was the final theme and related to the many skills that were needed by trainees to make mealtimes pleasant for the patient. They had to be able to "integrate aesthetics, social skills, activity, communication, assistance/support, nutrition, environmental aspects, timing, observation of patient-patient relationships, symptoms of the disease, and ethnics [ethnicity of patient], etc." (Skog et al., p. 293). Overall, the trainees were able to put theoretical and practical knowledge to work and establish a caring relationship with the patients.

Similarly, Wilkinson (1999) conducted a study to evaluate an educational program designed to manage assaultive behaviors by patients with dementia. The number of assaults dramatically increased during the training program and may have been related to the Hawthorne Effect. That is, knowing that assaultive behaviors were being measured, the staff were more likely to report them or the education program may have improved the accuracy of reporting. The administration authorized hiring of additional staff. A key finding was a 58% decrease in the number of injuries to patients during the training period, suggesting that the nursing staff learned to handle the assaultive behaviors more effectively and thus the quality of life of the patients improved.

The Importance of the Physical and Social Environment in Dementia Care

One final category of studies relevant to dementia caregiving relates to the importance of the physical and social environment for patients with dementia. Special care units (SCUs) for patients with dementia are seen as having many advantages over traditional units in nursing homes. These include more individualized activities, less confusing stimuli, staff who are specifically trained to meet the needs of patients with dementia, and more space to allow wandering (Andresen, 1995). Perhaps in the ideal special care unit all of these advantages exist, but many units do not offer enough specific education and training for the nursing staff and as a result it can be difficult for nurses to optimize the physical and social environments for patients with dementia.

A total of four studies examined the importance of the physical and/or social environments in dementia caregiving (DeYoung, Just, & Harrison, 2002; Karner, Montgomery, Dobbs, & Wittmaier, 1999; McAiney, 1998; Morgan & Stewart, 1999). Morgan and Stewart examined the environment-behavior relationship in dementia care settings using a grounded theory approach. Nine staff and nine family members of patients with dementia were interviewed. In relation to the social environment, the following needs were identified, optimal stimulation and meaningful activity, human contact, safety and supervision, individualized care, and flexibility. In relation to the physical environment, the need for safety, homelike setting, optimal stimulation, cues, and options for privacy and social interaction, were identified. Overall, the social environment was perceived to have a greater impact on the patient's quality of life and functional ability than the physical environment.

The effectiveness of a behavior management unit (BMU) on difficult behaviors by patients with dementia was evaluated by DeYoung et al. (2002). A nursing home in northern New Jersey, U.S.A., opened the unit to provide intensive nursing, medical, and psychosocial management to meet the needs of patients with dementia who exhibit difficult behaviors. The sample consisted of all 32 patients on the BMU who were residents for at least 3 months. A one-group time-series, quasi-experimental design was used and data were collected at baseline, 2 weeks post-admission, 3 months post-admission, and 6 months post-admission.

There was a significant decrease in disruptive behaviors from baseline to 6 months post-admission.

Some special care units have advantages for staff as well as patients with dementia. Karner et al. (1999) examined the impact of special care units (SCUs) and family involvement in relation to staff satisfaction. Special care units do not necessarily lead to more satisfied staff, but the critical elements related to staff satisfaction tended to be more prevalent in SCUs. Factors that lead to staff satisfaction included appropriate and kind administrative supervision, fair and consistent organizational structures, coworker teamwork, support for relating to patients as individuals, and a home-like environment. Family involvement was seen as both positive and negative depending on the particular family's coping mechanisms.

There is a need to improve the quality of the work environment of nursing staff in order to improve the quality of care of patients with dementia (McAiney, 1998). *The Empowered Aide Model* (TEAM) was developed to enhance the work environment of staff caring for patients with dementia. The four components of TEAM include: empowerment, organization, education, and teamwork. An intervention study using the model was conducted to evaluate its effectiveness and feasibility of implementation. Successful implementation of the model resulted in reduced work related stress and improved staff's perceptions of the work environment. The use of such a model could certainly lead to improved work environments for nurses caring for patients with dementia.

Summary

Our understanding and knowledge of the experiences of nurses who care for patients with dementia is informed primarily by the work done on nurses' reflections of caregiving for this patient population. Studies on communication between nurses and patients with dementia offer additional insight. Other research areas that inform this phenomenon are stress associated with this caregiving, and attitudes of staff working with these patients. Work on support and education of staff and the physical and social environment of dementia care helps to understand the context in which nurses try to provide care to patients with dementia.

Some qualitative research has explored nurses' reflections about caring for patients with dementia. However, nurses in these studies received direct clinical supervision from experts in the field of dementia care. The clinical supervisors offered education and support to the staff and assisted the staff to regularly reflect on their nursing practice. In addition, the majority of these studies were carried out in Sweden where the work life of nursing staff may be quite different than in Newfoundland or Canada in terms of the workload, educational opportunities, support structures, etc. Nurses in my study were not receiving any direct clinical supervision on dementia care as described in these studies. It would be interesting to compare the results of these studies with my study to highlight the similarities and differences in nurses' experiences.

The research literature suggests that caring for patients with dementia involves multiple stressors for nursing staff. The studies revealed that the diagnosis of dementia alone is not necessarily what causes stress for the nursing staff rather it is the behaviors often associated with dementia, such as aggression and agitation that likely leads to stress.

However, one quantitative study of nurses caring for patients with dementia reported a low degree of burnout and work related strain. There are clear gaps in the literature related to the nature of the stress. We need to explore what specific stressors exist, other than difficult patient behaviors, and how nurses cope with the stressors. If dementia caregiving is indeed stressful, why do nurses continue to work with these patients over a long period of time? Is it that the rewards of the caregiving work outweigh the challenges and/or stressors? The answers to these questions need to be explored through further qualitative research.

In relation to attitudes of staff caring for patients with dementia, the studies located were quantitative in nature. The importance of education in determining attitudes of staff was noted. Further qualitative studies are definitely needed to closely examine attitudes of nurses and factors that influence attitude formation toward patients with dementia. Clearly, there is limited research in the area of staff attitudes toward patients with dementia.

Research studies were located that explored nurses' communication patterns with patients who have dementia. Deficiencies were noted in nurses' communication with patients who were demented as compared to patients with normal cognitive function. A lack of introductions to the patients was also noted. However, there was evidence to suggest that educating nursing staff and increasing their understanding of behavioral changes in dementia, would lead to improved communication. Further qualitative research is needed to explore how nurses adapt their communication techniques and what specific strategies they find most effective when interacting with patients experiencing dementia. One area of interest in my study was nurses' communication style in dementia caregiving.

The positive effects of educating nursing staff about dementia caregiving were noted in the literature. There was certainly support for the development of training programs to meet the educational needs of staff.

The final area of interest related to dementia caregiving was the importance of the physical and social environment. Illuminating the physical and social needs of patients has the potential to enhance their quality of life. It is also essential to highlight the needs of nursing staff in relation to the work environment. My study attempted to explore how nurses adapt the environment to meet the needs of patients and how the work environment impacted on their job satisfaction.

Chapter 3

Methodology

Phenomenology was the method chosen for this research study. This method is concerned with the lived experience of individuals, specifically understanding their life experiences. This chapter will explore the phenomenological mode of inquiry as described by van Manen (1990) and then describe my use of a phenomenological method to examine nurses' experiences caring for patients with dementia.

Phenomenology

The modern extension of human science pedagogy by van Manen (1990) served as a guide in employing the phenomenological method to examine nurses' lived experiences caring for patients with dementia. Phenomenology as a methodology originated in the work of Husserl and was later adopted by European existentialist philosophers such as Heidegger and Merleau-Ponty (Bochenski, 1965). van Manen was influenced by these European movements and began to examine human sciences, phenomenology and hermeneutics, while studying pedagogy in the Netherlands. van Manen's text serves as a guide for pursuing human science research using the methods of phenomenology and hermeneutics. He makes a distinction between phenomenology and hermeneutics by noting that phenomenology is "pure description of lived experience", while hermeneutics is "an interpretation of experience via some text or some symbolic form" (p. 25). van Manen points out that there are conflicting views in the literature about the need for such a distinction and therefore he chooses the term "description" to include both the interpretive and descriptive elements.

van Manen (1990) presents a list of methodological suggestions relevant for researchers in nursing, psychology, and other professions who are interested in pursuing hermeneutic phenomenology as a methodology. He views the research approach as an active interchange among six distinct research activities. These include turning to a phenomenon of particular interest to the researcher, investigating experience as we live it rather than as we conceptualize it, reflecting on the essential themes which characterize the phenomenon, describing the phenomenon through the art of writing and rewriting, maintaining a strong and oriented relation to the phenomenon, and balancing the research context by considering parts and whole.

Turning to the nature of the phenomenon requires a steadfast pledge to a phenomenon of particular interest to the researcher with the purpose being to "make sense of" the phenomenon under investigation. Phenomenology is always concerned with human experience and the goal is to gain a deeper understanding of some aspect of human experience. In this study, I turned to the phenomenon of dementia caregiving by nurses. I have a strong interest and commitment to this particular area of nursing research resulting from direct clinical practice experience with patients who have dementia. I am interested in what it is like for nurses to care for these patients on a daily basis. What are the rewards and challenges of this caregiving work? How well are nurses equipped to respond to the complex needs of patients with dementia? What coping mechanisms do nurses use to deal with behaviors such as aggression and agitation? This study attempted to find answers to these questions in order to gain a deeper understanding of nurses' experiences caring for patients with dementia.

Having experience or prior knowledge about the phenomenon under investigation can lead the researcher to make pre-suppositions or assumptions about the phenomenon. This can be problematic for phenomenologists. To avoid this problem, Husserl (1970b, p 33-42, cited in van Manen 1990, p.47) used the term "bracketing" to describe how researchers must put aside any pre-existing knowledge or assumptions they may have about the phenomenon. But van Manen asks the question, how do we truly put aside our knowledge of the subject? His answer to this is that researchers do not really need to "bracket" the information, rather they should make their knowledge explicit. He says that if we try to forget that which we already know, our presuppositions may re-surface into our reflections about the phenomenon. Thus for my study, I attempted to write about my own personal experiences caring for patients with dementia through the use of a journal. This journaling made me more aware of any biases or pre-suppositions I may have had and also helped to make my knowledge more explicit.

The second research activity van Manen (1990) describes is "investigating the experience as we live it rather than as we conceptualize it" (p. 31). This involves becoming immersed in the phenomenon in order to understand the true nature of the lived experience. It means not taking anything for granted, except that meaning can be found in experience. van Manen states that personal experience of the researcher is an "ego-logical" starting point for phenomenological human science research (p. 54). Such was the case for this study. I believe that my personal experience caring for patients with dementia could possibly be similar to the experiences of other nurses. van Manen explains that we gather the experiences of others to allow ourselves to become more experienced. I felt that interviewing nurses about their experiences with patients who have dementia would certainly increase my own knowledge base and understanding of the complex care associated with dementia.

There are three ways of collecting human science research data: writing, interviewing, and observation (van Manen, 1990). I conducted unstructured interviews with nurses about their experiences caring for patients with dementia. The interviews were audio taped and transcribed for analysis. The interview, in phenomenological research, serves two distinct purposes according to van Manen. First, it is a means to collect data in order to discover a rich, deep understanding of a particular phenomenon. Secondly, it can serve as dialogue between the researcher and the participant about the meaning of the experience. When interviewing nurses about their experiences caring for patients with dementia, I kept both of these purposes in mind as a way to guide the interview process, but the focus was the first purpose described above. The nurses described their personal life experiences with these patients, but did not reflect on the meaning of these experiences. The focus was always, what is it like to care for patients who have dementia. It was through the rich deep descriptions of their experiences that I was able to understand what the lived experience was really like.

van Manen (1990) describes the third research activity as “reflecting on the essential themes which characterize the phenomenon” (p. 30). He sees reflection as the method of grasping the essence of the experience. He defines themes as “meaning units” that give structure to the meaning of the phenomenon. The meaning then is constructed from the individual themes that are embedded in the experience under investigation. van Manen distinguishes between essential themes and incidental themes and points out that one of the most difficult aspects of human science research is delineating whether a theme is essential to the experience or incidental. To do this, the researcher must decide whether the meaning is lost or changed, as a result of the removal of the theme in question. He uses the method of "free imaginative variation" to identify essential versus incidental themes. (p. 107)

Three approaches to isolating themes from within the research data include the wholistic or sententious approach, the selective or highlighting approach, and the detailed or line-by line-approach (van Manen, 1990). These three approaches help in identifying the common themes of the experience. The researcher must then choose appropriate phrases from the data to "capture" the meaning of the themes. In my study, I used the selective or highlighting approach to identify the common themes of the nurses' experiences caring for patients with dementia.

The fourth research activity that van Manen (1990) outlines is "describing the phenomenon through the art of writing and rewriting" (p. 30). He states that creating a phenomenological text is the method of bringing meaning to light. It is a way to make external, that which is internal, or "giving appearance and body to thought" (p. 127). Through the writing and rewriting of themes, the structure and hence meaning of the lived experience, is illuminated.

Maintaining a strong and oriented relation to the phenomenon is another research activity that van Manen (1990) identifies. It requires an awareness of the human lived experience that aims for the strongest possible interpretation of the phenomenon. The research text must be deep and rich in meaning. It is through the writing of text that is rich and deep in meaning, that the researcher is able to externalize the lived experience. Throughout the research process, I maintained a strong and oriented relation to the phenomenon of caring for patients with dementia. I have a keen interest in the nature of this experience from the viewpoint of nurses who provide the complex care required by patients with dementia. It was through the writing and subsequent rewriting of text that I was able to illuminate the nurses' experiences.

The sixth and final research activity that van Manen (1990) outlines is "balancing the research context by considering parts and whole" (p. 31). While it is important to have clear research plans, van Manen warns not to get caught up in writing the details of the methodology until the actual study has been completed. He does point out that the researcher must have an overall picture in mind of how the study will proceed and how the text will be organized, but the details can be worked out as the research proceeds. For my study, I was better able to describe the research methodology once the data were collected and analyzed.

Methods

van Manen's (1990) six research activities were utilized as my guide in examining nurses' experiences caring for patients with dementia. The phenomenon of concern was dementia care, and the focus was the experiences of nurses who provide this care. I was interested in how nurses reflect on and interpret their experiences in the provision of dementia care. This section is a description of the specific methods used in my study, giving rationale for the choice of phenomenology as the research methodology.

The work life of nurses providing care to clients with dementia is an appropriate topic for the phenomenological method. The goal of my study was to understand and interpret the experiences of nurses in their daily work life with patients so affected. Many researchers have used the phenomenological method to study issues of direct nursing practice. Benner and Wrubel (1989) used this approach to examine nursing practice and the lived experience of illness, the findings of which are presented in their book, *The Primacy of Caring*. This study stemmed from Benner's earlier work, which also used a phenomenological approach to explore the experience of clinical nursing practice. Benner and Wrubel stated, "because caring sets up what matters to a person, it also sets up what counts as stressful and what options are available for coping" (p.1). It follows then that the caring experience is inherently stressful in some way and certain coping strategies are necessary. Using the phenomenological approach for my study illuminated the challenges and rewards of the caregiving experience as it relates to dementia care, as well as the specific coping mechanisms utilized by professional nurses.

Criteria for participation. Participants for this study were recruited from three long-term care agencies in St. John's, Newfoundland. I met with the clinical educator or clinical nurse specialist at each of the three sites to describe the study and seek their assistance in recruiting participants. The clinical educator and clinical nurse specialist were in an ideal position to assist since they were not directly involved in evaluation of the nurses. I asked them to explain the purpose of my study to nursing staff at their agencies. A letter was given to them clearly outlining the study purpose and method of data collection so that the same information was presented to all potential participants (see Appendix A). The clinical educator or clinical nurse specialist then discussed the study purpose with staff and contacted me with names and telephone numbers of nurses who agreed to participate. I made telephone contact with each nurse to obtain consent for participation in the study. At that time, I clarified any questions or concerns they had regarding taking part in my study. I arranged to meet participants at a time and place that was convenient for them. Written informed consent was obtained at that time. I made it clear to each participant, that I was not interested in obtaining information on individual patients. I was interested in exploring the nurses' experiences with patients who have dementia.

The participants for this study were selected based on their particular knowledge of the phenomenon of interest, caring for patients with dementia. Eight nurses were interviewed. Two other nurses had originally agreed but when contacted to set up the interviews, they both declined citing personal reasons. Demographic data was not collected on these nurse participants.

Data collection. I began the interviews after the initial contact had been made with all participants and telephone consent had been obtained. At the time of the first interview, the written consent forms were signed (see Appendix B). The purpose of the interview was to explore the caregiving experiences of nurses who care for patients with dementia. In other words, what was it like to care for these patients on a regular basis?

Data were collected using unstructured interviews. Each interview was audio taped with the consent of the participants. Some sample interview questions were developed as a guide (see Appendix C). Rather than using these questions in a semi-structured way, the questions were developed as possible prompts for occasions when the nurses may have difficulty reflecting or elaborating on their experiences. I engaged in in-depth conversations with the participants, with the goal being to help the nurses describe their lived experience, without leading them.

The time frames of the first interviews ranged from approximately 30 minutes to 75 minutes. Following each interview, the audiotapes were transcribed for data analysis. The time frame for data collection was 5 months. Data were collected during the summer months and thus some participants were difficult to reach due to holidays thus increasing the time frame for data collection beyond that which had originally been anticipated.

Setting. Each interview was conducted at a time and place that was convenient for the participant. Four of the interviews were conducted in the researcher's office and the other four interviews were conducted at the institutions where the nurses worked. The choice of location was the decision of the participant. The rooms were quiet and allowed the interviews to proceed with minimal interruptions.

Data analysis. In phenomenological research, data collection and analysis occur simultaneously. The data analysis component of the research study involved isolating themes based on the selective or highlighting approach outlined by van Manen (1990). I became immersed in the data as a whole by listening to the tapes and extensively reading and re-reading the interview transcripts. Selective reading allowed me to identify statements that were particularly revealing. These were then highlighted and underlined as essential to the experience. These became the main themes of the experience. The thematic analysis was written using quotes from the transcripts as examples that captured meaning and provided a realistic portrayal of the nurses' experiences. The themes identified were believed to capture the essence of the nurses' experiences caring for patients with dementia. The relationships between the themes were also examined in order to reveal the manner in which they fit together to form the essence of the lived experiences.

Several meetings were held with members of the researcher's thesis committee during the data analysis phase. During the first meeting, the main issues/topics arising from the interviews were discussed. Following this meeting, I identified several possible themes that were common to the interview data and sought feedback regarding these possible themes. I then proceeded with the thematic analysis and submitted a draft to the research supervisors. During the next meeting, the themes were discussed in more detail and feedback on the analysis was received. The themes were fine-tuned and re-submitted for examination by the research supervisors. I then proceeded further with the analysis phase to examine the relationship between the themes.

Ethical considerations. Ethical permission to conduct this study was obtained from the Human Investigation Committee at Memorial University of Newfoundland (see Appendix D). Permission to recruit participants was granted by the directors of nursing at each of the three agencies. Written informed consent was obtained from each participant and witnessed at the first interview. The consent form included permission to audiotape the interview. Each participant also received a copy of the consent form with the researcher's name and telephone number on the form.

Before the interview began, I again explained the study purpose and assured participants that they had the right to withdraw at any time. After the interviews had been transcribed, each transcript was numbered and coded to coincide with the consent forms. The consent forms, audiotapes, transcripts, coding notes, and my personal notes were all locked in a safe place. The consent forms were separated from the transcripts to further ensure confidentiality. Only the research supervisors and myself had access to the interviews and transcripts. I did not explore individual patient information, rather the overall experience of nurses caring for patients with dementia, was the focus.

The study did not involve any physical risks. However, the possibility existed that reflecting on work situations that were stressful or challenging, may lead to some degree of emotional discomfort. This potential risk was communicated to the nurses prior to the interviews and they all verbalized understanding of this risk. Despite this risk, the nurses agreed to participate and openly reflected on their experiences. At no time did any participant become emotional or upset.

The participants were informed that a written report of the study findings would be made available to all three sites where nurses were recruited. They were informed that the report would not identify any of the participants by name. They were also told that any quotes used in the report would be anonymous, and the purpose of using direct quotes from the transcripts was to capture the nature and meaning of their experiences.

Credibility. One of the most difficult tasks in qualitative research is to ensure credibility of findings (Sandelowski, 1998). A key question raised by Sandelowski was whether an outsider-expert can really give a "validity stamp" to a research project (p. 467). She believes that experts in a field can offer expert criticism rather than confer validity and encourages experts to help researchers move away from concerns over validation and focus on "craftsmanship and accountability" (p. 467).

For this study I attempted to achieve credibility in several ways. I worked in collaboration with two faculty members from Memorial University of Newfoundland, School of Nursing. Both of the research committee members have much experience with the phenomenological method. One of the committee members also has considerable background in the area of dementia caregiving. Several meetings were held with both of the committee members to assist me with the exploration and identification of themes. They consistently provided feedback and offered constructive criticism to allow me to move forward with thematic analysis.

Second interviews were conducted with some of the participants to further validate the findings. Following the first phase of data analysis, the participants were provided with a written summary of the themes enabling them to provide feedback on whether I had really captured their experiences. After several attempts to contact the participants, I was successful in interviewing four of the eight nurses who participated in the study. Three of the nurses confirmed that the themes captured their experiences. One nurse provided additional data to support slight revisions to the final theme.

The themes were further supported by research studies already conducted in the area of dementia caregiving. A more detailed discussion of the study findings in relation to published research literature will be presented in chapter five.

Chapter 4

Findings

What is it like to care for patients with dementia? How did the nurses reflect on and interpret their experiences? This chapter will explore the answers to these questions. The nurses in this study openly shared their experiences caring for patients with dementia and as a result I was better able to understand these experiences. The analysis of the interview transcripts revealed the following themes, seeing beyond the confusion, caregiving as rewarding, meeting challenges, creating a caring environment, and being devalued by the nature of the caregiving work.

From a phenomenological point of view, these themes formed the structure of the nurses' caregiving experiences. The themes were seen as interrelated and connected in such a way that each one was essential to understanding what it was like for the nurses to care for patients with dementia. Some overlap exists between the themes due to the nature of the caregiving experience. This chapter will explore each theme in detail, supported by direct quotes from the interview data. The quotes used were believed to best support the themes identified.

Seeing Beyond the Confusion

When looking at a person who has dementia, one will often see outward signs and symptoms of the disease process. One noticeable manifestation is confusion. Yet, when the nurses in this study looked at their patients, they did not focus on the outward signs and symptoms of the disease such as agitation and aggression. Instead they were able to see beyond the confusion and focus on the person inside the disease.

Seeing beyond the confusion meant that the nurses were able to understand the disease process and its influence on the patient's behavior and demeanor. It also meant that the nurses were able to imagine what life must be like for patients with dementia. Two main outcomes of seeing beyond the confusion were also noted. First, seeing beyond the confusion enabled the nurses to connect the patient's past with their present behavior and secondly, it enabled the nurses to treat the patients with dignity and respect.

It was quite evident throughout the interview transcripts that these nurses had a remarkable ability to understand the disease process associated with dementia and its influence on the patient's behavior and demeanor. They were able to cope effectively with the associated behaviors such as agitation and aggression. They did not focus on the confusion and symptoms of the disease. They were able to see beyond these behaviors and always focused on the person inside the disease. The nurses talked about being able to cope with these behaviors by "not taking it personal". They were fully aware that the patient's behavior and demeanor resulted from the disease process and realized that it was not meant to be a personal attack against the nurse. As noted by one nurse:

> *Well you just realize that it is not personal...They don't understand what they are doing, let alone what you are doing...All she knows, is that you are stripping her clothes off...You spent your whole life not letting strangers really touch you...So all of a sudden, you are expected, now that you have dementia, to turn around and okay do what you want with me...You have got to realize, that they are not comprehending. They are hearing what you are saying, but they don't know what you are doing. It leads to more frustration.*

The nurses noted that dealing with aggression and agitation was not without some struggle. They acknowledged that it is difficult at times, especially when the patient is verbally aggressive, to "not take it personal", but that requires "a lot of effort". One nurse said that it is only natural at first, to think that the person is being nasty, but her ability to understand the disease, allowed her to cope with the behavior. She stated:

> *I think it is human nature too…if somebody spits at you, you're first thought is oh, you are so nasty, but really with this* [dementia], *they wouldn't do that if they thought about it and were sensible.*

One nurse described it as "stepping back" to stop and think. This ability to step back, and stop and think about the behavior, allowed the nurse time to reflect on the situation. It demonstrated that the nurse could transcend the confusion and truly understand the nature of the person's behavior. As a result, she was able to depersonalize the aggressive behavior.

The nurses demonstrated further understanding of the disease process associated with dementia when they talked about the need to constantly assess the patients, in order to offset agitation and aggression, to find out if they are having pain, and to meet their basic needs. The nurses understood that patients with dementia are not always able verbalize their needs, and thus saw it as their responsibility to be vigilant in assessment of the patient. One nurse said:

> *You have to be always looking for clues and cues…and looking everywhere.*

Imagining what life must be like for patients with dementia was another aspect of seeing beyond the confusion. The nurses said that putting themselves in the patient's shoes, and trying to see things from his/her point of view, was one of the most important factors that helped them cope with caring for the patients. They each reflected on what it must be like for the patient, or how the patient would feel if they realized what their life had become. One nurse stated:

> *Would you really want somebody coming in and ripping the sheets off you in the bed, and you are not with it to start with,*

> *so now you have been assaulted, and you are cold, and you don't know who you are, where you are, or what just happened...I can just picture somebody doing it to me.*

Another nurse said that she imagines what it must be like to be lying in bed and have someone come in and start to wash you without ever speaking to you as a person. Other nurses talked about how frustrating and frightening it must be for the patient with dementia who doesn't understand what is being said or where they are. One nurse said that she attempts to experience what the patient is experiencing and see the situation from the patient's perspective. She summed it up in this way:

> *You have to...stop and think, where they are coming from...I always sort of use...an analogy...if for instance, you were over in China and you were in an airport... everybody around you is gibbering and jabbering and you don't understand one word they are saying...nobody is understanding you, nobody is able to give you any direction...so how frustrated would you feel...how confusing and agitating...you have to...get inside of their mind, and try to experience what they are experiencing, and how frightening it must be.*

The nurses imagined what life must be like for patients with dementia. This demonstrated that they were able to look beyond the patient's current state of confusion. They could move past the outward signs and symptoms of the disease and consider the question, "what if this was me who had this disease? "

Clearly then, the nurses' ability to understand the disease process and how it influences the patient's behavior, and their ability to imagine what life must be like for the patients, demonstrated that these nurses were able to look past the confusion. Some direct outcomes or results were then described by the nurses. Treating the patients with respect and maintaining their dignity was one outcome of being able to see beyond the confusion. The nurses were able to focus on the person inside the disease and realized the need to respect the person the same as any other patient. They treated the patients as they would want to be treated themselves, or as they would want their own family member to be treated. They placed much emphasis on the fundamental value of human dignity and showed respect for the life the patient had lived. One nurse stated:

> *If you don't value people as people...you don't see the whole person and the dignity of life...if you had it yourself, you would wish that somebody would treat you with some dignity and make sure that you were comfortable.*

The nurses did not view the patients as a disease to be treated and or cured, but as a person with needs and/or deficits. Their role was to "treat them as human beings and make up for their deficits." They felt that despite the patients' deficits, they still deserved to be treated like human beings, like people with needs. One nurse illustrated how she treated patients with respect by connecting with them on a personal level and communicating with them the same as with any patient. She stated:

> *You go over and speak to him as if he was as sensible as you or me, so if you go in and say, oh hi* [patient], *how are you doing today...even though you know, you are not going to get a sensible answer, in a lot of cases...you can see them looking at you...and they sort of like it, if there is a contact that you make...like you connect with that person.*

The nurses were able to focus on the person inside the dementia and this was fundamental to treating patients with dignity and respect. As noted by one nurse:

> *Letting them know that they are still a person, that is really important...when you look back and you realize they had lives, just like we have now, they were people, they had identities, they had jobs, they held very important positions.*

Understanding the disease process and its influence on the patient's behavior and demeanor allowed the nurses to focus on the *person* inside the dementia. One nurse described it in this way:

> *The way I see it, if they are demented, they are still a person inside…a normal person…not necessarily a patient, a person.*

Another outcome of seeing beyond the confusion was that it enabled the nurses to connect the patient's past with their present behavior. The nurses always considered the life these people had lived before the onset of dementia. They each described in detail how this approach helped immensely in understanding present behaviors. One nurse summed it up in this way:

> *It is a very important part of our job, nursing residents like this, because then there may be some little thing, especially if they get agitated or whatever, that you can recall from their past and you can talk to them about and it may just really calm them down.*

Another nurse talked about a very "hostile" patient, who had been a fisherman in the past, and had been a very active man. She said that thinking about his past helps to understand his current behavior.

> *When he goes around, he is starting to pick at things, like he is trying to fillet a fish…and we can relate it to that.*

Other nurses said when you are aware of the patient's past, you can better plan the type of activities they will enjoy, or keep them occupied, and you can talk to them about things from their past and this could be comforting for the patients.

In contrast, other participants noted that even though it helped to know about the patient's past in order to understand the behavior, there were times when this information revealed that the person "may have been nasty their whole life". In this case, the nurses described the need to remain nonjudgmental. One nurse summed it up like this:

> *Sometimes, these people you know, at the end of their life, this is the little bit of respect they get. You know, so they drank all their lives and they had a rotten life, or god knows what they did, terrible people somebody says, well now, at the end of it,*

> *maybe somebody can be kind to them and send them on their way, that is why you are there.*

Patients with dementia are not always able to describe their past or let the nurse know something of their past lives, therefore nurses are dependent on other cues to connect the past to the present. Pictures from the patient's past are one such cue. The nurses highlighted the value of pictures from the patient's past by noting that it helped them to remember the life this person has lived. One nurse stated:

> *I think it forces us to recognize what they were...and I think you will want someone to recognize what you were.*

It is interesting to note that the nurses talked about the patients' lives in the past tense, "the life that was lived" and "what they were". They saw the patient's life as already lived, yet they still focused on the need to continue respecting the person. They placed much emphasis on valuing the patient's dignity and maintaining their quality of life.

Caregiving as Rewarding

There was no question that caring in the context of a patient with dementia was rewarding for the nurses. To care for patients with dementia day after day, there had to be rewards. Finding these rewards, despite the challenges of the caregiving experience, was what kept the nurses in this work environment. Caregiving as rewarding and meeting challenges are two themes that were evident in the interviews transcripts. These will be discussed separately but with the understanding that they are closely connected and both are essential to the nurses' experience.

The nurses stated that they were not burned out by the nature of the caregiving experience. A lot of patience and the ability to take it all in stride helped to eliminate any feelings of burnout. They all enjoyed their work and most of them had many years of experience caring for patients with dementia. The key was that the rewards of the caregiving work outweighed the challenges. The nurses said they truly liked caring for patients with dementia. However, they pointed out, that not all nurses could see this type of caregiving as rewarding. As noted by one nurse:

> *I think you either like the demented patients or you don't. In some cases, you know, there are some people who just can't do it and it is no reflection on them, they are wonderful nurses. They just don't really have, ah, lots of patience maybe, or I don't know, they just would rather that the patient was sensible and could answer.*

Another nurse stated that to continue caring for the patients with dementia, "you really got to enjoy it." She had been caring for patients with dementia for eleven years and she felt that her level of patience was the most important attribute that allowed her to continue doing this type of work. She went on to say:

> *The good outweighs the bad or else I wouldn't stay here. So overall, it's pretty good. I like it here.*

The nurses provided many descriptions of the rewarding aspects of the caregiving experience. These included, but were not limited to making the patient comfortable and content, pleasing the patient and their family, improving the patient's quality of life, and reaching the person inside the disease.

It was clearly evident that making the patient comfortable and content was a reward that the nurses valued. They liked the fact that they could give the patients a certain level of comfort that perhaps other nurses would not be able to give. Being able to meet the patient's needs and make them comfortable gave the nurses a level of satisfaction with their work. One nurse summed it up in this way:

> *I think I just like these people. I find them, I don't know, sort of in a way, comfortable* (pause) *and then maybe again, it is the thing about people needing or ah, you can do for these people, you can make them comfortable, you can make them happy, you can make them contented, you can make them sleep, you can make them…just be…*

Another nurse described the "personal high" she felt from making the patient happy and content. Again, there was a level of personal satisfaction attached to being able to meet the patient's needs.

Patients with dementia cannot always verbalize their satisfaction or dissatisfaction with the nursing care being provided. They cannot always communicate their thoughts and feelings, so the nurse is dependent upon other cues to determine whether she is pleasing the patient and meeting his/her needs. One nurse described how rewarding it was to see the patient smile and laugh. This was an indication from the patient that the nurse was being effective in her caregiving. She went on further to describe the reward of being able to meet the patient's emotional and psychological needs. She stated:

> *When they are not agitated, or when they are kind of content…if you can make them content, if you can make their day go by so that they are not picking at things and constantly agitated and walking back and forth. If you can do something to make him calm or make him relaxed, you are not going to help their confusion, because that is physical illness. If you can do anything for their emotional and psychological needs hey, that is rewarding.*

In addition to making the patient comfortable and content, many of the nurses talked about how rewarding it was to please the patients' family members. Since the patient could not always indicate whether they were satisfied with the nursing care, when the families indicated they were pleased, it was that much more rewarding for the nurses. The nurses understood how difficult it was for families to have their loved one placed in a nursing home because of the disease process associated with dementia and they made it a priority to help the families cope. Whenever families gave the nurses positive feedback regarding the nursing care, they saw that as a significant reward. As noted by one nurse:

> *If a family member comes in and their father is dressed nicely, had a nice shave, smells nice, and is happy sitting down watching TV or whatever he is doing, but he is pleasant, to see the smile on their face…like you are taking care of one person but you are affecting probably ten, so that's very rewarding.*

The nurses said that it was extremely important to help the families cope with their loved one's illness. The nurses acknowledged that families suffer a great deal due to the loss of person associated with dementia. They said that when they could help ease some of the family's suffering, it was very rewarding. One nurse commented:

> *When you are being effective and you make things better for the patient and the family you realize how skilled you are…you know, it is really rewarding in a case like that cause there is so much anguish involved, like mentally for families…Sometimes I think it is more for families than it is for the actual patient himself, because where they are sort of, out of touch with reality…But you know, the families really suffer, so you can give good care so the patients are more settled and happy…and it is really rewarding to find you kind of helping the families as well as the patients.*

Improving the patient's quality of life, or making life "as good as it can be", was another notable reward. The nurses were realistic about the disease process. They did not expect to make the patients better, but they felt that if they could maintain the patient's current level of functioning for as long as possible, that was just as rewarding. They talked about doing the best they could for the patient and the rewards associated with maintaining the patient's quality of life.

Many of the nurses also described the reward of reaching the person inside the disease. They felt that they played an active role in this process. When patients experienced fleeting moments of cognitive awareness it gave the nurses a degree of personal satisfaction with their work.

Many examples were noted of reaching the person inside the disease. One nurse felt that she was able to reach some of the patients better than others. She described the reward of being recognized and feeling needed by the patients. She talked about being off for a few days and then coming back to work and a patient asking her where she had been. She felt that because the patient missed her or noticed that she had been away, she had been able to reach this person on some personal level. She described this as very rewarding. She also said it was rewarding when the patients displayed affection toward her.

> *It can be rewarding in lots of ways. Sometimes...if I am off the weekend and I come back, someone will say, where were you, or I missed you and another man we have here, everyday he looks so lost and bewildered, and every time I saw him, I gave him a big hug and now when I walk down the corridor to see him, he opens his arms and gives me a big hug and you know, little things like that and they say I love you, or something like that and it makes you feel, well it gives you a bit of a lift, right.*

The reward of reaching the person inside was also evident when the nurses talked about seeing the patient's personality and being able to bring that out when providing nursing care. One nurse described this personal connection with the patient as rewarding. She stated:

> *You can see their personality...Like we had a gentleman who is demented and he's got a really good sense of humor and a really good laugh, that doesn't always come out, but some people can bring it out...That is rewarding.*

Meeting Challenges

There were two sides to the caregiving experience with patients who have dementia, the rewards and the challenges. Despite the rewards of the caregiving experience, the nurses also described many challenges and/or difficulties. There was no doubt that caring for patients with dementia was very difficult at times. Yet, these nurses had the ability to meet the associated challenges without becoming burned out.

The nurses talked about many challenges of the caregiving role with patients who have dementia. These included, but were not limited to dealing with aggression and agitation, bathing and feeding patients with dementia, administering medications, and helping families to cope with the disease process. Some of the nurses reported that verbal aggression was more difficult to accept than physical aggression. One nurse commented:

> *The confusion part is not hard to deal with. I mean, if [patient] wants to take his clothes off a dozen times a day, you got to put them back on again, okay that is what you got to do, but when you go into the room and somebody calls you everything but a lady, that is a little harder to deal with.*

The nurses coped with the verbal and physical aggression by depersonalizing the behavior. They had a thorough understanding of the nature of the disease process associated with dementia and thus were able to realize that the behavior was a result of the disease, rather than a personal attack against them. Another important factor that helped the nurses cope with aggression and agitation was their assessment skills. Good assessment skills helped them recognize the symptoms of agitation before it got out of control. One nurse commented:

> *I do find it very challenging...because as you know, with the Alzheimer's dementias...you have to be kind of always trying to look for clues and cues and whatever, to kind of offset maybe their agitation.*

Some of the nurses described the challenge of administering medications to patients with dementia. Emphasis was placed on knowing the patient and using an individualized approach. They pointed out that it was even more challenging for casual nurses who were not as familiar with the patients and their backgrounds.

Continuity of care enabled the nurses to better cope with some of the other challenges as well. The nurses described feeding and bathing the patients as very challenging, especially for casual staff, but continuity helped them know how to individualize the care. The nurses felt that the patients reacted better to the regular staff on the unit than with casual staff. One nurse felt that the more confused and agitated patients should be assigned to a regular staff member rather than someone who is unfamiliar with the patient's care needs. Continuity of care helped these nurses recognize symptoms that may be out of the ordinary for a particular patient. As noted by one nurse:

> *You know sometimes, that there is something wrong, but exactly what it is, but you have to be kind of be looking everywhere and asking and just knowing your resident is the big thing. If you know them really well, well then you will be able to realize and see if there is anything specific that you know that is not regular for them.*

An additional challenge for the nurses was assisting the families to cope with the disease process associated with dementia. They talked about the role of providing support and listening to the families' concerns, making referrals as necessary, and keeping them informed on a regular basis. Despite their efforts, the nurses described occasions when families who were not coping with the disease process, took their frustrations out on them and they described this as very challenging. One nurse stated:

> *Sometimes I find...patients come in and their family hasn't accepted the fact that they have Alzheimer's and they expect you to work miracles. Like if they are really frustrated with the Alzheimer's and they sort of, sometimes they take it out on the staff.*

In addition to depersonalizing the aggressive behavior, good assessment skills, and the continuity of care issue, other factors helped these nurses meet the challenges of caring for patients with dementia, including being committed to their work, being flexible, realizing limitations, using humor, and feeling supported by co-workers. Being committed to the job required determination, dedication, persistence, a positive attitude, and often creativity. These qualities were evident throughout the interview transcripts and essentially helped the nurses meet the challenges of caring for patients with dementia. When asked about difficult patient behaviors and trying to get tasks done, one nurse described her persistence and creativity in the following way:

> *There is one man over there, who doesn't want to get washed. He didn't want to get dressed. He didn't want to take his insulin. He didn't want to do anything. Well, there is no way that I could leave him. If I was there, I had to find a way to do it. Sometimes it was to go in and start and say, well, I got it here now and you are going to make me leave, or will I just sit here until you are ready, and I know you are laughing, I can see you laughing, I can see you smiling, I can see you, you know.*

Throughout the interviews, the nurses emphasized the fact that this was their job to care for these patients, and therefore they were going to do a good job. They talked a lot about having pride in their work and being determined to get the job done. Their pride and determination helped the nurses to meet many challenges. One nurse commented:

> *I guess I was just going to do it...because that's why you are there. So you may not want to, you may be tired of it, you may...not want to go in there anymore, but really this is why you are there, so I am going to do it no matter what, even at the end of the day, that last round, you have to...maybe that's a pride thing too, that I am not going to say, I couldn't get him in the tub, he wouldn't go.*

Being flexible was another quality that helped the nurses meet the challenges of the caregiving role. Bending the rules at times was necessary when working with patients who have dementia. One nurse talked about the fact that the patients do not always sleep well at night, and therefore, nurses should be flexible and not become frustrated by this. She summed it up in this way:

> *Dementia patients, well patients in general, especially dementia patients, they don't always sleep all night…the frustrating part is that people want them to go to bed at nine and stay there…and they might not stay there, they might have to get up. Now you do the fifty things you can do for them to stay in bed, but if one night out of seven, two patients or three get up a couple of times through the night, who does that hurt and you are getting the same money at night. Now I wouldn't want twenty patients roaming the floor all night.*

Another factor that helped the nurses meet the challenges was their ability to realize their limitations when working with patients who have dementia. They talked about the fact that patients with dementia often refuse to have certain tasks done, especially in relation to activities of daily living. They described the many ways used to coax the patients to help get the task done, but they also recognized that there was only so much that they could do. The nurses were realistic in their expectations of the patients. One nurse said:

> *If he refused and he wouldn't have it done, that is all we could do. You know, I mean you can't do the impossible.*

Another nurse summed it up in this way:

> *You've got to be* [flexible] *and if you expect to come in here and say nine o'clock, they were going to have to be up for breakfast and nine thirty, they are going to be finished breakfast, forget it. If you can't go with the flow, then I'll tell you, you are going to have some problems. It is going to be more frustrating, because I mean you are not going to do it.*

The nurses described humor as another coping mechanism that helped them meet the challenges of caring for patients with dementia. They gave many examples of challenging patient situations where they were able to laugh and thus relieve the stress of the task at hand. It has been said that laughter is the best medicine. The nurses' ability to find humor in situations helped them cope with challenges and also ease some of the embarrassment for the patients. One nurse commented:

> *If you can make them laugh, I think it just shows them that you know, that you…can sort of see the situation they are in or something like that… If you can just… try to break the ice and somehow make a joke of it…make some crack and both end up laughing, well it sort of, that takes the sting out of it for him.*

Receiving support from co-workers was another factor that helped the nurses meet the challenges of caring for patients with dementia. They talked about having "good days and bad days" and pointed out that having support from co-workers helped immensely in relieving frustration. They said there was give and take with co-workers in terms of supporting each other. In other words, they were able to give support to co-workers when needed, but could also take support when they became frustrated with the caregiving work. One nurse described it in this way:

> *Maybe today I am so frustrated with all that and then I am just mouthing off and somebody says, yeah but you know you should still have said this, and maybe next week I will be in a better frame of mind and that person can mouth off and I will be the one, so you support one another like that… everybody got their times.*

It is important to point out that most of the frustration described by the nurses was not related to the direct care of the patients; rather it was related to other factors in the work environment. Although these stressors were outside of the caregiving experience, it is important to describe them in more detail as they affected the quality of care that the nurses were able to provide. Caring occurs within a particular context and cannot be separated from factors such as negative attitudes of co-workers, lack of adequate staff, perceived lack of support from management and or physicians, and limitations of the physical environment.

Despite the fact that some of the nurses talked about receiving support from co-workers, other nurses talked about how frustrating it was to work with individuals who portrayed a negative attitude toward the work. Some co-workers were described as not really understanding the nature of the disease process associated with dementia, lacking commitment to the job, and not demonstrating a caring approach with the patients. One nurse described how things changed on the unit depending on who she was working with. She stated:

> *Sometimes things can be wonderful on one day and then the wrong person is there so the mix changes and it is no longer a positive place. It is a place that you would rather slash your wrists* [laughing] *than spend another hour there, so you have to tune that out, but it is never about the patient.*

Some of the nurses reported that they were frustrated by the lack of adequate staff required to meet the specialized care needs of patients with dementia. They felt that there was also a lack of understanding by management of these care needs. Patients with dementia can often appear to be physically well. As a result, they can be seen by managers and others, as not requiring total care. The nurses felt that manager's lack of understanding of the cognitive deficits associated with dementia, resulted in less than adequate staffing levels. The nurses noted that even though the patients can outwardly appear to be well in a physical sense, their cognitive deficits led to many struggles in terms of getting tasks done, especially in relation to activities of daily living. The nurses reported that instead of management supporting them, they tended to focus on what the nurses were doing wrong instead of how to make things better for the patients and the nurses. One nurse described feelings of "burnout" due to this lack of understanding by others, but made the distinction that it was not related to the direct caregiving of patients with dementia. She stated:

> *Burned out yes, not necessarily by the work itself, burned out by the bullshit that goes along with the work from ah, having to straighten things out and the people that I am working with sometimes...The frustration of getting people to listen to you...the people who make more money than you...managers...and probably doctors sometimes.*

Other nurses reiterated that there was a lack of understanding of the disease process associated with dementia by many of the people involved in the caregiving role. One nurse summed up her frustrations and described how the extraneous stressors influenced the care she was able to provide.

> *I don't think it's ever really the patient...it is the work involved in trying to look after him. It is trying to get from the desk to the patient, with the med cart and everybody else following you, with fifty other things that you should be doing or shouldn't be doing, or should be solving or should have solved before you left the desk, and that could be from staffing to dietary to...your co-worker, and maybe five casuals, who might be saying to you, well I don't know, I haven't been here before. But that doesn't cut it...So it is not the patient, it is by the time you get to the first room, you are wondering how am I going do all this and look after you too sir.*

An additional extraneous stressor was the physical layout of some of the units. The nurses had no control over factors such as the number of exits on the unit, the gate at the nursing station, the size of closets in patient rooms, and whether the closets were locked. It was frustrating for the nurses who felt there was a need to fix these structural problems, yet they did not perceive support from management about the issues. One nurse described the issues as "little piddley things, which could be rectified."

Creating a Caring Environment

A caring environment can be described as an atmosphere of kindness, compassion, and concern for those within the environment. It implies gentility and sensitivity to others. It relates to thoughtfulness, consideration, and love for others. There is no doubt that the nurses in this study were able to create such an environment for patients with dementia.

In the context of this study, creating a caring environment was visible in many ways. The nurses conveyed acceptance of the patients and their families, and assisted families in coping with the devastating loss of the person associated with dementia. They provided the best possible care to meet the patients' physical and emotional needs. They attempted to make the physical environment as home-like and cozy as possible. They maintained the patients' dignity and treated them with respect. They showed the patients that they really cared about them. They were compassionate about their work and committed to providing quality care. Finally, they were very competent and effective in the dementia caregiving work.

It was obvious throughout the interviews that the nurses conveyed acceptance of the patients and their families and helped families cope with the disease process associated with dementia. The nurses took the time to listen to the families' concerns and provided support as needed. They recognized that families often struggle with the decision to place their loved one in an institution and even once that decision has been made the families continue suffering. The nurses felt that a big part of their role was to help families come to terms with the disease process. As noted by one nurse:

> *I just sit and talk to them, and make sure that, if I am on a weekend, I get a chance to have a chat...See how they are doing...Especially if there is somebody that is really disturbed*

> *about it and can't ah deal with it, I spend time with that person and or that family and provide support.*

Another nurse pointed out:

> *Because it is harder when it is your own family, than it is for us as nurses. We can go home at the end of the day.*

Another feature of creating a caring environment was providing the best possible care to meet the patient's physical, emotional, and spiritual needs. The nurses described the importance of providing holistic care to the patients with dementia. They cared about all of the patient's needs, not just the physical aspects. They talked about the importance of making the patient comfortable and content. One nurse summed it up in this way:

> *...making them comfortable, I am big on the comfort thing, tucking them in at night and making them cozy and feeding them...and I just don't mean physically comfortable. I mean so that they are not crying after the person who just left, or not in pain and they are not hungry...just comfortable and all of their needs are being met or that life is good as it can be.*

Another nurse described how she was able to identify the patient's spiritual needs. She talked about a patient who was very confused and agitated and it was difficult to interpret what the patient needed. After a period of time, the nurse came to realize that the patient needed his bible and by giving it to the patient, she was able to provide some spiritual comfort. It was obvious that the nurses continuously strived to create an environment where all the patient's needs were being met.

Creating a caring environment was also visible when the nurses described the importance of making the physical environment as home-like as possible. They did not want the patients to feel institutionalized and although they reported feeling frustrated by factors within the physical environment, they strived to make it "as good as it can be". One nurse stated:

> *You know, this is their home. This is an old building. It is not that glamorous or anything, but you try and make it comfortable and cozy and warm as you possibly can.*

She went on to describe the various "little things" that she did to make the environment more home-like and cozy such as putting extra blankets on the beds when its cold outside and giving the patients warm pajamas.

The nurses' ability to maintain the patient's dignity and treat them with respect was discussed earlier as one outcome of *seeing beyond the confusion* but it also relates to creating a caring environment. The fact that the nurses valued dignity and respected the patients demonstrated that they truly cared about them. One nurse said:

> *Keep their pride and dignity. That is very important.*

The nurses were sensitive and thoughtful and were always concerned about the patient's quality of life. One nurse commented:

> *You just have to make what quality of their lives that they have remaining as good as you can make it and I think the main thing is to give them lots of love.*

The nurses were able to find a way to demonstrate to the patients that they truly cared about them and this was another aspect of creating the caring environment. Their caring ability was remarkable. These nurses not only cared *for* the patients, they also cared *about* the patients. Caring *for* implies the provision of direct physical care, while caring *about* relates to concern for the overall well being of the patients and meeting their emotional and psychological needs. The nurses believed that the patients were able to "sense" that they really cared about them and this was very important to the nurses.

One nurse summed it up in this way:

> *I think if you just sit with them, and let them know that you care for them, just put your arm around them, you don't have to do*

> *very much, just put your arm around them...just let them realize that you really care about them. I think that makes a big difference to them.*

One method of demonstrating to the patients that the nurses cared about them was through the use of personal touch. One nurse said that she encourages the staff to just sit with the patients and hold their hand so that they patients realize they really care about them. Another nurse commented:

> *I think that...is the biggest part of our job...personal touch. I think that they really can sense when somebody is not, you know, is doing it as a job. I think they can sense it.*

It was evident throughout the interviews that these nurses were very compassionate toward the patients. Their level of compassion contributed greatly to creating the caring environment. The nurses were always considerate of the patient's situation. They were very aware of the tragedy of such a debilitating disease. The nurses' ability to imagine what life must be like for patients with dementia was discussed earlier as an outcome of seeing beyond the confusion, but is also important here in that it demonstrates their caring nature. One nurse said that she thinks about how the patients would feel if they really knew what was happening to them. She talked about the sadness associated with dementia and pointed out that it was her role to try and provide some comfort and happiness. Another nurse commented:

> *How terrible that must be, to not understand what's happening or why, to not be able to remember who you are.*

Creating a caring environment required that the nurses demonstrate competence with regard to dementia care. Competence relates to knowledge, experience and skill. The nurses were very knowledgeable about the disease process, and their expectations of the patients were realistic. They had many years of experience caring for patients with dementia and as a result, they were very skillful in their caregiving approaches. The need for individualized nursing care was noted as paramount when working with patients who have dementia. Other effective approaches used were calm and slow approach, come back later, short and simple explanations, personal touch, and stimulating the senses without over stimulating. The nurses approached the patients in a non-threatening manner. They listened attentively and were in tune with the patients' needs.

Being Devalued by the Nature of the Caregiving Work

Being devalued is a phrase that carries a very emotional connotation. One who is devalued in some way, feels diminished, lessened, or brought down. It implies a lack of recognition from others. It is obvious that none of these feelings are very positive. It is human nature to desire and expect to be valued for the work we do. Yet, being devalued by the nature of the caregiving work was a theme that surfaced during some of the interviews with nurses caring for patients with dementia.

This theme relates to the nurses' descriptions of how they were perceived by other nurses in terms of their knowledge and skills. It also relates to the difficulty some nurses had in defining their skills. It is important to point out that the nurses reported feeling confident about their own level of knowledge and skill, but they felt that other nurses failed to recognize caring for patients with dementia as exciting, or requiring a lot of knowledge and skill. This theme was more evident in some interviews than others, but certainly pertains to the overall experiences of the nurses caring for patients with dementia.

While some of the nurses felt they were devalued by others, they were able to defend their abilities to care for patients with dementia. The nurses stated that they acquired their knowledge and skills mainly from life experiences and nursing experience. They talked about many factors in their personal lives that contributed to their level of knowledge and skill to care for patients with dementia. These included age, experience as a mother, being the oldest sibling in a family, and coping with sick parents. They said these factors taught them to be caring and compassionate. They also talked about learning from co-workers who were very effective in providing care to patients with dementia. When asked what factors most prepared them to care for patients with dementia, the nurses responded that it was the combination of life experience and nursing experience that made them most effective. One nurse described it in this way:

> *That* [knowledge and skill] *comes partly with nursing experience and partly growing yourself and having, as you get older, you tend to have more compassion for other people, and because I am a mother too, maybe that has something to do with it…and the fact that I was the oldest child and I am also the oldest cousin on both sides so you're sort of used to looking after everyone too.*

Despite their knowledge and skill, the nurses felt that educational opportunities should be offered on a regular basis to keep them current with caregiving approaches and new developments in dementia care. The nurses placed much value on such educational opportunities but some nurses reported that these were offered infrequently. The deficiency of educational opportunities contributed to feeling devalued by the nature of their caregiving work. The idea was that if dementia care was a more important area within nursing, then regular educational opportunities would be made available to the nurses. In relation to educational in-services, one nurse felt that the number was adequate but noted:

> *They spend too much time emphasizing the pathology of the disease, rather than practical advice on dealing with disruptive behaviors.*

When asked about their nursing education programs and whether they received any formal training or information on how to care for patients with dementia, the nurses all stated that no such training/information was provided. As a result, they had to learn "by doing". They reported that they would like to see more emphasis placed on dementia care in nursing education programs. They recognized that caring for patients with dementia does require specialized knowledge and skill, and therefore, should be include in basic nursing education programs. One nurse stated:

> *They could update it more. I think you know, have some more...profile over it...*

Despite their competence with dementia care, many of the nurses had difficulty defining their skills. They recognized that they had the necessary knowledge and skills, but most were unable to verbalize these skills.

> *I don't know how to put it into words. It is skills...I guess, I am more old fashioned...I don't know. Well, I am older...I don't know. When you are here so long, you pick up things about the patients and the ways things are going.* (long pause) *I am trying to think of a few words. I can't think of anything to say now. People skills. I can't think of an example.*

The nurses talked about how they were perceived by others in terms of not needing any specialized knowledge or skill to care for patients with dementia. They felt that others did not see their work as important. In other words, people did not attach any value to caring for patients with dementia. The nurses recognized that their skills were hard to measure but they realized themselves how effective they were in caring for patients with dementia. They felt that the work they do is valuable, but were bothered by the fact that others see the work in a negative light. Some of the nurses reported feeling diminished by the lack of value that others placed on this type of work. As noted by one nurse:

> *People look at that kind of nursing and they don't think that there is any skills involved because it is so hard to measure, but sometimes when...you are being effective and you make things better for the patient and the family, you realize how skilled that you are.*

The nurses said that many people find aspects of dementia care degrading and that bothered them a great deal, further contributing to their feelings of being devalued. They felt that some people get too caught up in the symptoms of the disease and are not able to see beyond that in order to provide the necessary care. One nurse said that she could give whatever care was needed because it enhanced the patient's comfort and quality of life. She did not consider any aspect of her work degrading but she felt that some of her co-workers were not able to see the importance of maintaining the patient's dignity. These co-workers did not value the work they were required to do.

> *There is nothing in nursing in terms of having to clean anything...it doesn't bother me what so ever, and I really don't find it degrading. Like some people find it degrading, I don't, because I can do any type of nursing, and give any kind of care, and it doesn't bother me...Just say somebody is incontinent and they* [co-workers] *find it offensive that really bothers me.*

The nurses talked at length about the fact that other nursing staff working in long-term care devalued the caregiving work with patients who have dementia. One nurse said that some staff were more concerned about their own status than the patient's needs. She went on to say that these staff members placed more value on psychomotor tasks than caring for the patients with dementia. She summed it up in this way:

> *Some people I think they are worried about their status you know, like they think that it is only the* [name of the institution], *you know, that there is no glory in that, it is not a bit sexy. I mean...this girl, this nursing assistant, came and all that she did, she went on and on...how they didn't...get to do anything and now that she is down here she is going to get to do accu*

> *checks* [glucometer readings] *and I was thinking, my god that is very sad…you know it was like, all the work that she had done in terms of personal care and all that, whatever she did for the patients where ever she came from, that had no status, and it didn't make her feel very good about her work and her LPN training…because she wasn't running IV's…she didn't think it was worth anything.*

Another nurse reported that staff on other units in the institution, devalue the dementia caregiving work. Staff from other units would make negative comments about working on a dementia unit. The nurses were often asked questions such as, "How can you stay there so long?" They would hear other nurses say they would never be able to work on a dementia care unit. These comments and questions contributed significantly to the nurses feeling devalued by the nature of the caregiving work. Some of the nurses felt that at times, they had to defend the work of caring for patients with dementia. One nurse stated:

> *I hear staff from other units say oh they would never work over here, and how come you are over there so long. I wouldn't work anywhere else…I really wouldn't want to go anywhere else.*

The nurses reported that outside of long-term care, other nurses also devalued the nature of the caregiving work with patients who have dementia. One nurse described a particular situation where a nurse who worked in long-term-care was at a social event, conversing with another nurse who worked in acute-care. The acute-care nurse made a nasty remark that demonstrated devaluing the nature of long-term care work. The participant believed that this type of remark would make some nurses question their own skills and may lead them to devalue the type of work they do. She went on to say that she does not feel inferior to any other nurse because of the type of work she does. This nurse made the important point that it does not matter where you work as long as you possess the necessary knowledge and skill to carry out the work effectively. Again, the need to defend the caregiving work was evident.

> *...Some people would...go home and probably think, look where am I stuck to...I got no skills. I think I got lots of skills. I mean they're hard to measure exactly, but I have no problem with that...I think that I can do a much better job than a lot of people...that are in more...probably higher status areas...I really don't feel inferior to any body, wherever they are working...but some people do. They are embarrassed...they really don't want to be...but still they feel inferior, but see, I feel like...anybody can be a technician...I certainly don't think that because you can look after an IV that...it makes you a good nurse. I don't think it matters where you work as long as...wherever you work, whatever skills are required that you have.*

Other nurses described the "stigma" associated with dementia and this also leads to devaluing the caregiving work. One nurse said that people place dementia caregiving in the same category as caring for a patient with a mental illness and as a result, dementia care now carries the same stigma as other mental illnesses. She went on to say that because the patients are on a locked unit, this frightens some people, but what they do not seem to understand is, that the unit is locked for the patient's safety, not the safety of others.

> *Its probably a little bit of stigma to it, I think, dementia. In the* [psychiatric institution] *they used to say, years ago I mean, a locked unit, oh that is a terrible thing, you know. It is only locked because of their safety right. It is not keeping people out right.*

Chapter 5

Discussion

The findings of my study revealed that caring for patients with dementia was rather complex. It required much knowledge and skill on the part of nurses. It required patience and understanding in order for the nurses to see beyond the patient's state of confusion. Patience was the key attribute that allowed the nurses to continue working with patients who have dementia. A thorough understanding of the nature of the disease process and how it affects patient behavior was necessary in order to depersonalize difficult behaviors. The findings also revealed many rewards and challenges associated with the caregiving role. It became evident that nurses need to possess a large repertoire of coping mechanisms to deal with the challenges and avoid becoming burned out. In order to effectively care for patients with dementia, the nurses had to create an environment where the patients felt comfortable and content. They used many different caring approaches to demonstrate that they truly cared *for* and *about* the patients. A final key finding was the fact that the nurses feel devalued by the type of work they do.

The study findings will now be discussed in more detail. Each of the five themes will be explored and new insights into the dementia caregiving experience will be presented. These themes together formed the essence of the participants' experiences. All the themes were connected in such a way that removing any one theme would alter the understanding of that lived experience. This section is a discussion of the themes as they relate to each other and the research literature in providing a phenomenological description of the nurses' experience caring for patients with dementia.

Seeing Beyond the Confusion

The first theme identified was *seeing beyond the confusion*. This theme related to the nurses' ability to understand the disease process associated with dementia and its influence on the patient's behavior and demeanor. It also related to their ability to imagine what life must be like for patients with dementia. The nurses were clearly able to look past the outward signs and symptoms of the disease, and see the person inside. Focusing on the *person,* and not the disease, allowed the nurses to see their *caregiving* work *as rewarding*.

A key element of seeing beyond the confusion was a good understanding of the nature of the disease process and how it manifested in the patients. The nurses were able to interpret the patient's aggressive behaviors as indicative of the disease process, rather than a personal attack against them. This finding is congruent with other research, in particular that of Berg and co-researchers (1998) who found that caring for patients with dementia requires delicate interpretive work. The nurses' ability to interpret the patient's needs and understand their behavior was key to providing effective care. In other studies, nursing staff realized the need to interpret the verbal cues of patients with dementia, but they often found it difficult to understand the patients (Berg & Hallberg, 2000; Hansebo & Kihlgren, 2001).

The nurses I worked with recognized that it can be difficult to interpret the patient's needs and/or wishes, but they pointed out that continuity of care was an important factor that allowed them to understand the patient and enabled them to depersonalize aggressive behaviors. The nurses did not take it personal when patients behaved in an aggressive manner. Similarly, Jones (1992) reported that after nursing staff were educated about the nature of the disease process, they were able to "not take it personal" when a particular patient behaved in a disturbing manner. What my study illustrated was the importance of continuity of care in terms of individualizing the care and depersonalizing aggressive behavior.

Nurses I interviewed were able to see beyond the patient's confusion and focus on the person inside the disease. They treated patients with dignity and respect for the life they had lived. They saw the patient as a human being deserving of quality nursing care. Similarly, other studies noted the importance of looking past the patient's confusion to see the whole person and not as a set of deficits or a series of tasks to be completed (Graham, 1999; Kitwood, 1993).

Life experiences, particularly motherhood and caring for ill parents, and years of nursing experience, were the factors that best prepared nurses in my study to care for patients with dementia. They used their knowledge of the patient's past to better understand the patient's current behavior and demeanor. They used their personal abilities such as humor and flexibility to effectively care for the patients. A study by Haggstrom et al. (1998) supports these findings. Caregivers in that study each had their own ways of understanding patients with dementia, which stemmed from their personal experience with childhood and motherhood, knowledge about the patient's history and nature of the disease, and personal talent.

Caregiving as Rewarding

The rewards were many, but caring for patients with dementia was not without its challenges. Rewards and challenges can be found in any caregiving work, but the rewards and challenges presented in chapter four were very specific to caring for patients with dementia. It was disturbing to find that very few studies make any mention of dementia caregiving rewards. Nurses in my study were easily able to articulate the many rewards associated with caring for patients with dementia. The rewarding aspects included making the patient comfortable and content, pleasing the patient and their family, improving the patient's quality of life, and reaching the person inside the disease. Through my work there is a better understanding of the rewards associated with dementia caregiving.

Two studies did show that nurses caring for patients with dementia were satisfied with their work (Hansebo & Kihlgren, 2001, Welander Hansson et al., 1995), but the only mention of rewards was in Hansebo and Kihlgren's study, where nursing staff reported that moments of cooperation and mutuality were very rewarding. Ragneskog et al. (1993) reported that nurses found the work meaningful. There is certainly a paucity of research in this area. Nurses who are considering a career in gerontology, specifically caring for patients with dementia, need to see evidence of rewards despite the challenges.

Meeting Challenges

The two sides of the caregiving experience with patients who have dementia, became evident when the nurses described the many challenges of the caregiving work. There was no question that caring for patients with dementia was very difficult at times. Yet, these nurses had the ability to meet the associated challenges without becoming burned out.

The many challenges nurses reported to me included dealing with aggression and agitation, bathing and feeding patients, administering medications, and helping families to cope with the disease process. These challenges have been well documented in the research literature (Chappell & Novak, 1994; Clinton et al., 1995; Hellzen et al., 1999; McIntosh et al., 1999; Middleton et al., 1999; Rodney, 2000) but what is missing for the most part, is an adequate description of the coping strategies that nurses use to meet the challenges of caring for patients with dementia. Only two studies were located that looked at coping strategies. One found that six out of the ten nurses interviewed used maladaptive strategies more frequently (Clinton et al., 1995) and the other found that nurses used action coping strategies most often (Rodney, 2000).

My study showed that nurses used effective coping mechanisms such as depersonalizing aggression, good assessment skills, being committed to the work, being flexible, realizing limitations, humor, and support from coworkers. It was obvious that these nurses were very effective in caring for patients with dementia. They were aware of the challenges but were also able to use problem-solving skills and draw on their knowledge of the disease process to meet the challenges. My study makes a significant contribution to further understanding of how nurses cope with the challenges of caring for patients with dementia.

Coping with the challenges was not easy for the nurses and certainly required much patience. Three studies were found that lend support to the need for patience when working with patients who have dementia (Berg et al., 1998; Hansebo & Kihlgren, 2001; Rundqvist & Severinsson, 1999). The nurses who shared their experiences with me were kind and thoughtful to the patients. They recognized the need to wait and come back later when patients refused to have certain tasks done. They did not try to rush the patients so that they could get the work done more quickly. The nurses did acknowledge that it was difficult at times to have patience, but without this important attribute, they said nurses could not effectively care for patients with dementia.

The nurses I interviewed perceived patient aggression as indicative of the disease process and not directed at them personally. On the contrary, other studies have noted that nurses do take it personal when patients behave in a difficult manner (Hellzen et al., 1999; Middleton et al., 1999). In my study, all nurses, regardless of whether they worked on a traditional unit or a special care unit for dementia, saw aggressive behavior as related to the disease process. One study found that staff on special care units (SCUs) viewed aggressive behaviors differently than staff on traditional units (Middleton et al., 1999). The staff on SCUs related aggression to the disease process whereas staff on traditional units viewed it as an attempt to harm. Of course, I interviewed eight nurses experienced in caring for patients with dementia as compared to the study by Middleton et al., which had a sample of 77 formal caregivers.

My work makes a significant contribution to understanding the complexity of providing support to families of patients with dementia, an area that is certainly lacking in the literature. Supporting family members of patients with dementia was considered a complex aspect of care requiring a broad range of skills and knowledge on the part of nurses. Despite their efforts, nurses in my study reported that there are times when families blame the staff for the patient's deterioration. They recognized that families had different coping styles and needed to vent their frustrations at times. They also recognized the importance of not taking it personal when families took their frustrations out on them. Only one study was located that identified the need to support families as integral to quality care (Graham, 1999).

Stressors outside of the caregiving role were also noted by my participants. It is important to discuss these factors in order to understand the impact of outside stressors on the nurses' ability to provide quality care. The extraneous stressors included negative attitudes of coworkers, lack of adequate staff, perceived lack of support from management and/or physicians, and limitations of the physical environment. Having to listen to and work alongside individuals who portray negative attitudes was a significant factor that affected the quality of care the nurses were able to provide. They described it as "draining" to deal with such individuals on a daily basis. For the most part, the nurses were able to ignore negative comments and carry on with their caregiving work, always striving to provide the best possible care. At times, they would try to get the negative coworkers to see things from the patient's perspective, or tell them to stop complaining and carry on, but they pointed out that the approach depended on the individual and it did not always have a positive result. It is important to point out as well, that most of the nurses described their coworkers as supportive, but as one nurse noted, when the "wrong person" is working on a particular day it affects the whole unit. Olsson and Hallberg (1998) also noted the importance of a good working relationship with other health care providers.

The lack of support from management and physicians was another stressor for nurses in my study. This lack of support contributed to the nurses feeling devalued. Nurses reported that their ideas were not always recognized or supported by management and this contributed to feelings of dissatisfaction. A perceived lack of support from management was noted in the ARNNL and NLNU (2002) study.

Limitations of the physical environment was another stressor for some of the nurses, given the fact that they would identify possible solutions to the problems but again, they did not receive support from management in terms of rectifying the problems. Some of the nurses in my study discussed the challenge of meeting the safety needs of patients with dementia when they are on general units rather than protective care/locked units. This finding is supported by Morgan et al. (2002). Nursing staff in rural nursing homes in Saskatchewan reported significant job strain related to workload, insufficient skills, and the integration of patients with dementia in the general nursing home population. Rundqvist and Severinsson (1999) also noted that limitations of the physical environment had an impact on the care nurses were able to provide.

There is other evidence in the literature to suggest that factors outside the direct caregiving role have an impact on the nurses' ability to provide quality care. Factors such as insufficient time, inadequate staff, and paperwork result in stress and/or frustration for nursing staff (Clinton et al., 1995; Hansebo & Kihlgren, 2001; Rundqvist & Severinsson, 1999).

Participants I interviewed had considerable experience caring for patients with dementia and they reported that both their life experiences and nursing experience were critical factors influencing their effectiveness as caregivers. Studies by Hansebo and Kihlgren (2001) and Haggstrom et al. (1998) support the finding that the caregiver's level of experience and training influences how effective they are in approaching patients with dementia.

Overall, nurses in my study were very effective in meeting the challenges of caring for patients with dementia. They had not become burned out by the nature of the work. They all reported they enjoyed their work and felt a level of personal satisfaction related to being able to meet the patient's needs. The nurses reported that they felt it is not as difficult for them to care for a person with dementia, as it is for a family member. One nurse stated, "I can go home at the end of the day. Its different for us than it is for families." Two studies were found that support this finding (Macpherson et al., 1994; Welander Hansson et al., 1995). One study noted that rates of psychological disturbance of nursing staff were low as compared to that of family caregivers due to the fact that professional caregivers receive financial gain for their work, they have professional support structures in place, they work shift work, not 24 hours per day, and they do not have the long-term personal relationships with the patients (Macpherson et al., 1994). Another study found a low degree of work related strain and burnout in nurses caring for patients with dementia (Welander Hansson et al, 1995).

Creating a Caring Environment

The theme of *creating a caring environment* was closely connected to *seeing beyond the confusion* and *caregiving as rewarding. Seeing beyond the confusion* enabled the nurses to treat patients with dignity and respect. This ability was essential to *creating the caring environment* for patients with dementia. It was also rewarding for the nurses when they were able to *create a caring environment.*

The caring environment was essential to providing quality care for patients with dementia. The participants demonstrated to the patients that they truly cared about them. They were not only concerned about the patient's physical needs but also their emotional and spiritual needs. The nurses were very thoughtful, considerate, and compassionate about their work. They demonstrated pride and commitment to their work. They were very sensitive to the needs of the patient's and their families and always strived to provide the best possible care. They used personal touch as one method of demonstrating that they cared about the patients.

The methods used by nurses in my study to establish caring relationships with patients, are very similar to those reported by nurses in Rundqvist and Severinsson's (1999) study. The three themes identified in that study were touching, confirmation, and the values in the caring culture. The nurses demonstrated sensitivity for the patient's needs. They were considerate, patient, and compassionate toward patients with dementia.

Furthermore they told me about the need to treat patients as adults, and give them the dignity and respect that all people deserve. They treated patients as they would like to be treated themselves, or as they would like their own family member to be treated. The nurses made reference to comparing patients with dementia to children only in terms of the need to advocate on their behalf when the patients are unable to communicate their needs. They emphasized the need to treat the patients as adults and respect the life the person had lived. The theme *creating a caring environment* is very similar to a theme identified in Hansebo and Kihlgren's (2001) study. *Carer's own caring philosophy* related to the staff's belief in respecting patients and doing their best to provide quality care. The staff identified the need to treat the patients as adults and always consider their needs and wishes. *Creating a relationship* was a theme identified in a study by Skog et al. (2000) which is also closely related to themes in my study, *seeing beyond the confusion* and *creating a caring relationship*. Skog et al. examined how LPNs developed relationships with patients who have dementia. They were able to see the patient as a unique individual. Learning about the patient's life history, interests, personality, symptoms, and remaining function, helped the LPNs to see the person inside the disease.

Other studies have emphasized the need to create a caring environment for patients with dementia. One study found that home care staff caring for patients with dementia identified the need to form a relationship with the patient, as central to providing quality care (Olsson & Hallberg, 1998). Another study reported that nurses found it hard to establish a relationship with patients who have short-term memory impairment, but the nurses acknowledged the need to establish a caring relationship in order to provide effective care (Graham, 1999). They received clinical supervision to develop self-awareness of how they built relationships and communicated with their patients. These nurses focused their care on preserving the patient's personhood, a key element in creating a caring environment.

Nurses in my study displayed another aspect of their caring ability when they talked about the need to adapt the physical environment to meet the patient's needs. An important part of making the patients comfortable and content was making the physical environment as cozy and homelike as possible. They would do 'little things' to make things better for the patients. The importance of adapting the physical environment to meet the needs of patients with dementia, is supported by Morgan and Stewart's (1999) study. The need for safety, a homelike setting, optimal stimulation, cues, privacy and interaction, were identified by nursing staff and family members of patients with dementia.

Being Devalued by the Nature of the Caregiving Work

Being devalued by the nature of the caregiving work was a final theme identified, however it was much stronger in some interviews than others. This theme was closely related to the themes of *caregiving as rewarding* and *meeting challenges.* It was obvious that the nurses perceived themselves as being very effective in caring for patients with dementia. They were able to see their work as rewarding and were able to meet the associated challenges. Yet, they reported being devalued by others due to the nature of the caregiving work. It was reported that managers, LPNs, and even other nurses, failed to recognize the many rewards of caring for patients with dementia and this led some nurses to feel diminished and devalued. The deficiency of educational opportunities related to dementia caregiving was another factor that contributed to some nurses feeling devalued.

Support for these findings was noted in the literature. A lack of organizational support for psychiatric community health nurses was noted in Graham's (1999) study. The nurses felt that their work was not really understood or articulated at the executive level, leading to feelings of apprehension about their status and decision-making ability. They identified the need for more support and nurturing at the executive level. A key project in Newfoundland, explored how nurses in long-term care reflect on their clinical practice (ARNNL & NLNU, 2002). The working group found that nurses did not feel valued by their co-workers, managers, or acute care nurses. They did feel valued by the residents and their families, giving them some level of work satisfaction. A recent study by Jones, Cheek, and Ballantyne (2002) found that nurses caring for the elderly in the community also have to deal with negative perceptions of their work. The nurses were trying to cope with the changing and complex roles of elderly community care, everyday demands of the job, and a sense of powerlessness and lack of control became evident.

It is important to explore the issue of being devalued in more detail as it relates to job satisfaction and quality of care for patients. My study highlights that some nurses caring for patients with dementia feel devalued by the nature of the caregiving work. This study has the potential to increase public awareness and awareness within nursing of the need to address the issue of nurses being devalued. Some interesting questions arise related to this devaluing. What recommendations might nurses make on how to improve perceptions of dementia caregiving work? Is it dementia caregiving alone, or gerontological nursing as a whole, that has a negative connotation for acute care nurses and others such as LPNs and managers? What can nurse educators do to improve the perception of working in long-term care and specifically caring for patients with dementia? What can gerontological nurses do to improve their status and the appeal of gerontological nursing? What can nurse managers do to help staff feel more valued? The answers to these questions are crucial to improving the work life of gerontological nurses, and more specifically, nurses who care for patients with dementia. The issue of nurses being devalued warrants immediate attention by managers and long-term care agency executives. If nurses continue to feel devalued, their professional fulfillment and job satisfaction will deteriorate. This will inevitably affect the quality of patient care. Patients deserve quality care and nurses deserve to be respected and valued for the work they do.

Chapter 6

Limitations, Nursing Implications, and Summary

Limitations

This study describes the lived experience of eight nurses who care for patients with dementia on a daily basis. The complexities of the dementia caregiving work have been illuminated, but that is not to say that another phenomenological study with a different group of nurses would yield the same findings. Nurses in my study, all had many years of experience caring for patients with dementia and likely gained much knowledge and skill by *doing*. It would be interesting to interview less experienced nurses and ask them to describe what it is like to care for patients with dementia. Perhaps less experienced nurses would report more challenges and/or frustration resulting from a lack of knowledge of caregiving approaches. Perhaps nurses in other settings and from different cultures would report much different experiences. These are just possibilities but could be considered limitations of any phenomenological study.

I am also aware of the limitation that describing one's experience can never truly capture the entirety of that lived experience. According to van Manen (1990, p. 18), we must "remain aware that lived life is always more complex than any explication of meaning can reveal." Thus a possible limitation of my study is that I can only rely on the nurses' ability to recall and describe their experiences, but I can never truly know that I have captured that experience fully.

One final limitation relates to the difficulty in reaching all of the participants for a second interview. Phenomenological research requires working closely with the participants in the study. Four of the nurses provided feedback on the identified themes but four others did not. I provided all of the participants with a written summary of the themes and sought feedback. I was successful in receiving feedback from four nurses but I cannot say whether the other four nurses agreed with the study findings.

Nursing Implications

The findings from this research highlight the need for support, education, and training for health professionals caring for patients with dementia. The limited research on the experiences of nurses caring for patients with dementia, specifically rewarding aspects, has obvious implications for nursing research. Implications of the study findings for nursing practice, education, and research will now be discussed in more detail.

Nursing practice. The study findings revealed the many challenges and rewards associated with caring for patients with dementia. It is important to increase awareness of factors leading to work related stress in order to improve the quality of work environments for nurses caring for these patients. Studies discussed in the literature review clearly demonstrated that working in long-term care, and specifically caring for patients with dementia, involves multiple stressors (Chappell & Novak, 1994; Clinton et al., 1995; Hellzen et al., 1999; McIntosh et al., 1999; Middleton et al., 1999; Rodney, 2000). Many of these stressors could be eliminated or reduced through education, training, and the provision of support to nursing staff. Nurses and managers must work together to identify ways to reduce work related stress. Focusing efforts on stress reduction has the potential to improve nurses' work life and job satisfaction and will also lead to higher quality of care for patients with dementia.

It is equally important to increase awareness of the positive aspects and/or rewards of the dementia caregiving experience. The nurses I interviewed clearly described the rewarding aspects of their work. They were able to connect with patients on a personal level and work to maintain the patient's quality of life. Pleasing the patient and their family was a very significant reward. Highlighting the rewards of dementia caregiving would have a direct impact on promoting gerontological nursing.

Gerontology is an important specialty area within nursing and thus efforts are needed to improve the public perception and perceptions within nursing of the pivotal role that gerontological nurses currently play and will continue play in the health care of older adults. The fact that gerontological nurses are being devalued is a disturbing finding that warrants immediate attention. Gerontological nurses themselves will need to be able to verbalize their skills and identify ways to improve the perceptions that exist relating to lack of skill and excitement in gerontological nursing. They need to be supported in their efforts by mangers and recognized by other members of the interdisciplinary team for the important contribution they make.

In Newfoundland, work is currently underway by the ARNNL and the NLNU to make changes to practice environments in long-term care that will improve the status of gerontological nurses. The working group has recommended changes such as "RNs being more involved in decision making, staffing decisions based on the requirements for good resident outcomes, workplace policies promoting health, safety and well being of RNs, evidence based decision making as the basis of nursing practice, and dedicated resources for continuing education of RNs"(ARNNL & NLNU, 2002, p. 24).

One way to assist nurses in promoting the value of their work is through direct clinical supervision. The benefits of clinical supervision for nursing staff caring for patients with dementia have been clearly described in the nursing research literature (Berg et al., 1994; Berg & Hallberg, 2000; Edberg et al., 1995; Graham, 1999; Olsson et al., 1998). Clinical supervision involves direct support and training of staff. Nurses caring for patients with dementia could certainly benefit from more direct clinical supervision from those specifically educated and trained in dementia caregiving approaches. A Clinical Nurse Specialist (CNS) in dementia care is one such resource person who could provide ongoing clinical supervision for nursing staff. The CNS would possess the education, expertise, and experience to make a positive impact in long-term care agencies, specifically in relation to the complex care of patients with dementia (Ramsay & Dupuis, 2001). The CNS would be in a key position to assist staff with problem solving skills and could hold regular debriefing sessions with staff to reflect on the complexities of dementia caregiving work.

I believe that large long-term care institutions should have a clinical nurse specialist in dementia care and smaller institutions such as those in rural areas should at least have access to a such a specialist. The CNS would be directly available to staff as a resource person. He/she would have the time to devote to the particular problems or issues the staff may be experiencing. The staff could then feel more empowered in their ability to provide the complex care associated with dementia. I believe that if nursing staff had the direct support of a CNS in dementia care, they may not feel so devalued. They would see the CNS promoting the importance of their work and the knowledge and skill required. They would receive support for their ideas and feedback on their caregiving approaches. Some long-term care agencies in this province have a CNS on staff, but he/she is usually assigned to cover several agencies and thus cannot provide the direct support regarding dementia care that is needed. Other institutions have no CNS, but rely on clinical educators and/or managers to carry out these roles and most often they simply do not have the time to devote to the education and support of nursing staff in relation to dementia care.

Another finding from my study that has implications for nursing practice relates to the theme of *seeing beyond the confusion*. Nurses must be aware of the need to treat patients with dementia as persons with needs, not as a set of deficits. All nurses in this study emphasized the importance of treating persons with dementia with dignity and respect. Fundamental to caring for a patient with dementia is seeing beyond the confusion and focusing on the person inside the disease.

Nursing education. The findings of my study revealed that nurses were not satisfied with the amount of continuing education or basic education regarding dementia care. Nurses reported that they did not receive any formal education in their basic nursing programs on dementia care. They did point out that in-services were very helpful, but these were offered infrequently or did not address the issue of dealing with difficult behaviors. The need for education regarding dementia caregiving is well documented in the literature (Alzheimer Society & Home Support Canada, 1992; Keady, 1996; Ragneskog et al., 1993; Schonfeld, 1999; Skog et al., 2000; Wilkinson, 1999). One of the problems with continuing education for nurses is a lack of government funding due to health care constraints. Yet, there is a definite need for more funding for continuing education of staff caring for patients with dementia. Nurses and managers need to lobby for such educational funding. Nursing staff need to keep current with dementia caregiving approaches and nursing research in this area.

Clinical supervision of staff caring for patients with dementia has implications for nursing education. The introduction of clinical supervisors or clinical nurse specialists, is one very cost effective way to provide the necessary educational sessions with nursing staff on a regular basis. The CNS could be responsible for evaluating whether the educational sessions resulted in improved nurse satisfaction and improved quality of care for patients with dementia. Olsson and Hallberg (1998) recommended that clinical supervisors focus on what promotes or obstructs staff-patient relationships, and practice within a theoretical model to make staff more aware of the basis for nursing care.

Nurses must posses specialized knowledge and skills in order to meet the complex needs of patients with dementia. Education leads to empowerment of staff and improved outcomes for patients. The need to support nurses and acknowledge their level of skill and expertise is critical in order to improve the professional fulfillment of nurses. There is a need for nursing education to place more emphasis on care of the elderly, including specific training on how to care for patients with dementia. Currently in Newfoundland, there are no theoretical courses in the basic nursing program that focus on the care of the elderly and more specifically dementia care.

Currently, nursing students in Newfoundland spend one clinical rotation in long-term care, three weeks at the end of year one. At this time, students provide basic care to the elderly and focus on developing their communication skills. They do not get a *true* picture of the degree of responsibility associated with being in charge of unit with 20 to 30 elderly patients. Nursing students should have more opportunities for clinical placements in long-term care later in their program (year three or four) when they would be better prepared to understand the nature and scope of gerontological nursing.

I believe nursing students do not tend to choose long-term care as a placement in their preceptorship rotation (12 weeks at the end of year three), because nurse educators are not doing their part to encourage students to work in this area. It has been my experience, that students believe they must go to acute care to acquire psychomotor competencies. They are not informed of the many rewards and challenges associated with working in long-term care. They do not see it as exciting. The nurses in my study would make excellent preceptors for nursing students. They could help students to develop the skills needed to work in long-term care and show them the many rewards associated with this type of nursing. It is also crucial for nurse educators to begin promoting gerontological nursing as an exciting and rewarding career option.

Additionally, there is a need for higher education in the area of dementia care. Graduate level courses should be developed to prepare nurses to become experts in this field. Currently in Newfoundland, no such courses exist at the graduate level.

Nursing research. In an era of evidenced based practice, there is limited research on the experiences of professional nurses caring for patients with dementia. More specifically, there is an obvious lack of nursing research on the rewards of caring for this patient population. Nurses who are considering working in gerontology, need to see that rewards exist despite the challenges. While it is important to study the challenges of dementia caregiving in order to identify ways to cope with work related stress, it is equally important to study the rewards of the caregiving work in order to increase awareness of the positive aspects. A key question to be addressed is what is it about nurses who find dementia caregiving rewarding, that makes them different than those who develop burnout.

Further qualitative research, particularly grounded theory studies are needed to contribute to the body of knowledge related to dementia caregiving by nurses. Grounded theory studies could further explore the process of how nurses develop their expertise in this type of nursing care. It would also be interesting to examine the experiences of nurses with less years of nursing experience caring for patients with dementia. Their lived experience may be quite different than nurses in my study.

Further qualitative research in the broad area of dementia care is needed. This research will become even more important as the population ages. The trends of the aging baby boomers and increasing longevity will inevitably require concentrated research efforts into improving the quality of life of patients with dementia, and the work life of nurses providing the complex care. In relation to the issue of nurses *being devalued by the nature of the caregiving work* with dementia patients, future research is needed to explore why some nurses feel more devalued than others. Some nurses in my study described this devaluing piece more strongly than others. A qualitative study on this issue would provide rich data to help understand how to address this issue and make nurses feel more valued.

Quantitative research efforts are also needed in relation to the educational needs of nurses caring for patients with dementia. One important question to be addressed is what are the specific educational needs of nurses with regard to dementia care? Once the needs are clearly identified, educational programs could be developed to meet these needs. Clinical trials could then be carried out to test the effectiveness of educational programs for nurses.

Summary

Nurses' experience caring for patients with dementia has been explored using phenomenological methods as outlined by van Manen (1990). A total of eight nurses from three long-term care agencies in the St. John's region were interviewed. Five main themes were identified as essential to understanding the lived experience. The themes were seeing beyond the confusion, caregiving as rewarding, meeting challenges, creating a caring environment, and being devalued by the nature of the caregiving work.

These themes formed the structure or essence of the nurses' experience. It is through describing the themes that the researcher was able to move toward an understanding what the experience was really like. van Manen (1990) states that if the description is adequate, it shows us the significance of the experience in a fuller deeper manner. The researcher believes that the presentation of the study findings allowed for a rich, deep understanding of what it was like for nurses to care for patients with dementia.

The study findings were discussed in relation to the literature reviewed. Limitations of the study and implications for nursing practice, research, and education were presented.

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Appendices

Appendix A

Letter to Clinical Educators

Vicki Earle
Office 913, Centre for Nursing Studies
St. John's, NF
A1A 1E5

January 25, 2002

Ms. Sherida Healy (Clinical Educator)
L.A. Miller Center
100 Forest Road
St. John's, NF

Dear Ms. Healy,

I am a graduate student at Memorial University of Newfoundland School of Nursing. A partial requirement for the degree of Master of Nursing is a research study. This letter is to explain the purpose of my study and to seek your assistance in obtaining participants.

The purpose of my study is to explore the experiences of nurses who care for clients with dementia. The goal is to add to the body of knowledge related to dementia care. Allowing nurses the opportunity to reflect on their clinical practice has the potential to lead to greater understanding by the staff of the rewards and challenges of their daily work. It may also help to identify whether there are any specific learning needs of nurses who care for clients with dementia. Along with a greater understanding comes the potential to improve the quality of care being provided to clients with dementia.

This is a qualitative research study, which will involve two interviews each lasting about forty-five minutes to one hour. The interviews will be tape recorded and transcribed verbatim. The researcher and two faculty members of Memorial University School of Nursing will then analyze the transcripts to identify themes. A research report will be provided to the staff of your agency following completion of the data analysis. All transcripts, tapes, and notes will then be destroyed. There will be no names or distinguishing characteristics in the report. The Human Investigation Committee of Memorial University will review the proposed study and I will confirm approval to you prior to the start of the study.

I am requesting your assistance in obtaining the names of nurses who would be interested in participating in my study. I ask that you discuss the purpose of this study with nursing staff at your agency. I will be asking them to reflect on their clinical practice with dementia patients. The interviews will be unstructured, allowing participants to discuss any aspects of the caregiving experience. They may withdraw from the study at any time and all data is kept confidential.

I hope that you will consider my request. Your assistance is central to the success of obtaining participants for my study. Should you require further information or have any questions, please contact me. I look forward to your reply.

Sincerely,

Vicki Earle
709 782-2194 (home)
709 777-8186 (work)

Appendix B

Consent Form

FACULTY OF MEDICINE, SCHOOL OF PHARMACY, SCHOOL OF NURSING
OF MEMORIAL UNIVERSITY OF NEWFOUNDLAND;
NEWFOUNDLAND CANCER TREATMENT AND RESEARCH FOUNDATION;
HEALTH CARE CORPORATION, ST. JOHN'S

Consent to Take Part in Health Research

TITLE: **Nurses' Experience Caring for Patients with Dementia**

INVESTIGATOR: Vicki C. Earle RN BN

You have been asked to take part in a research study. It is up to you to decide whether to be in the study or not. Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

The researcher will:

- **discuss the study with you**
- **answer your questions**
- **keep confidential any information which could identify you personally**
- **be available during the study to deal with problems and answer questions**

You decide whether or not to take part or to leave the study at any time.

1. Introduction:

Very little research has been conducted on the experiences of nurses who care for client with dementia. This study is an attempt to fill in some of the gaps related to the experiences of formal caregivers. Much research has already been conducted on the experiences of family caregivers and dementia patients yet the experience of a formal caregiver may be quite different. There may be unique challenges associated with providing nursing care to patients with dementia. The study will allow for a greater understanding of the complex care required by patients with dementia. With this increased understanding comes the opportunity to improve the quality of care for the patients and the work life of the nursing staff.

2. Purpose of study:

The purpose of this study is to explore the experiences of professional nurses who care for patients with dementia.

3. Description of the study procedures and length of time:

As a participant you will be asked to take part in two interviews each lasting from 45 minutes to one hour. You will be asked to explore, reflect on, and describe your experiences caring for patients with dementia.

4. Possible risks and discomforts:

There are no immediate risks involved in the study. Emotional discomfort may be a possibility. Reflecting on work situations that are stressful or challenging may lead to some degree of emotional discomfort.

5. Benefits:

There is no guarantee that you will benefit from taking part in this study. However, through sharing of personal experiences, you may come to a greater understanding or increased awareness of the complexities of your daily work with patients who have dementia.

6. Liability statement:

Signing this form gives me your consent to be in this study. It tells me that you understand the information about the research study. When you sign this form, you do not give up your legal rights. You have the right to withdraw from the study at any time.

7. Confidentiality:

The information you provide will be kept confidential. Each interview will be audio-taped and then transcribed. Each transcript will be numbered and coded to coincide with the consent forms. The consent forms, audiotapes, transcripts, coding notes, and the researcher's personal notes will all be locked in a safe place. The consent forms will be separate from the transcripts to further ensure confidentiality. Only the researcher and the research supervisors will have access to the interviews and transcripts.

Signature Page

Study title: Nurses' Experience Caring for Patients with Dementia

Name of principal investigator: Vicki Earle

To be filled out and signed by the participant:

Please check as appropriate

I have read the consent.	Yes { }	No { }
I have had the opportunity to ask questions/to discuss this study.	Yes { }	No { }
I have received satisfactory answers to all of my questions.	Yes { }	No { }
I have received enough information about the study.	Yes { }	No { }
I understand that I am free to withdraw from the study	Yes { }	No { }

- at any time
- without having to give a reason

I understand that it is my choice to be in the study and that I may not benefit.	Yes { }	No { }
I agree to take part in this study.	Yes { }	No { }

Signature of participant ______________________ Date ______________________

Signature of witness ______________________ Date ______________________

<u>**To be signed by the investigator:**</u>

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

Signature of investigator ______________________ Date ______________________

Telephone number: ______________________

Appendix C

Sample Interview Guide

Interview Guide

Opening Statement

I am interested in discovering what it is like for you to care for patients with dementia. I would like you to share any experiences which come to mind. Feel free to discuss any aspect of the caregiving experience.

Interview Prompts

1. How would you describe your experience caring for patients with dementia?
2. What aspects of the caregiving experience do you consider rewarding?
3. What aspects of the caregiving experience do you consider stressful?
4. Which coping mechanisms work best for you when caring for patients with dementia?
5. What is it like to communicate with patients who have dementia?
6. What training have you received to prepare you to meet the needs of patients with dementia?
7. Can you describe the behavior of patients who have dementia on your unit?
8. How do you deal with behaviors such as aggression and agitation?
9. What are some of the issues that families express to you and how do you assist them to cope?

Appendix D

Letter of Approval

Human Investigation Committee

Memorial University of Newfoundland

Memorial
University of Newfoundland

Office of Research and Graduate Studies (Medicine)
Faculty of Medicine
The Health Sciences Centre

February 12, 2002

TO: **Ms. V. Earle**

FROM: Dr. F. Moody-Corbett, Assistant Dean
Research & Graduate Studies (Medicine)

SUBJECT: Application to the Human Investigation Committee - #02.04

The Human Investigation Committee of the Faculty of Medicine has reviewed your proposal for the study entitled **"Nurses' experience caring for clients with dementia"**.

Full approval has been granted for one year, from point of view of ethics as defined in the terms of reference of this Faculty Committee.

For a hospital-based study, it is **your responsibility to seek necessary approval from the Health Care Corporation of St. John's**.

Notwithstanding the approval of the HIC, the primary responsibility for the ethical conduct of the investigation remains with you.

F Moody-Corbett

F. Moody-Corbett, PhD
Assistant Dean

FMC/jjm

cc: Dr. C. Loomis, Acting Vice-President (Research)
Dr. R. Williams, Vice-President, Medical Services, HCC