

FULFILLING THE COMMITMENT:
THE ADJUSTMENT PROCESS OF PRIMARY FAMILY
CAREGIVERS OF NURSING HOME RESIDENTS
A GROUNDED THEORY STUDY

CENTRE FOR NEWFOUNDLAND STUDIES

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EUNA E. FERGUSON



Fulfilling the Commitment:
The Adjustment Process of Primary Family Caregivers of Nursing Home Residents
A Grounded Theory Study

by

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Abstract

Prolonged caregiving of older relatives has become common in families as people live longer, often with multiple chronic health problems. Primary family caregivers are characteristically women with a strong attachment to their role. For many who provide high levels of care at considerable personal cost, relinquishing their duty of care is unthinkable. Thus, admitting a relative to a nursing home is a most difficult experience for family caregivers, accompanied by emotional turmoil and a sense of failure. How family caregivers make the adjustment to nursing home caregiving in order to maintain their duty of care, and how nurses might support caregivers were the questions that stimulated this inquiry.

A grounded theory approach was chosen to study the process of caregiver adjustment. A convenience sample of 10 primary family caregivers of residents who had been in nursing homes in western Newfoundland for 5 to 16 months, were interviewed. Constant comparative analysis revealed a basic social process called fulfilling the commitment, which occurred throughout three phases of the caregiving experience. These were home caregiving, admission caregiving and nursing home caregiving. Three adjustments were identified in each phase: taking it on, accelerating responsibility, and reaching an end in the home caregiving phase; finding a place, getting the relative settled, and feeling the loss in the admission phase; and getting used to it, rebuilding life, and coping day to day in the nursing home phase. Dimensions of each adjustment and factors affecting progress were identified. The common factors sustaining and constraining adjustment were: rewards, social support, and emotions. Findings were discussed in relation to pertinent literature, and contributions and limitations of the study were

identified. Implications for health care policy, and nursing practice, education and research were proposed.

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Chapter 1: Introduction

Families giving care for prolonged periods to dependent older relatives is a phenomenon that is becoming more visible as people live longer and as governments promote home care for those with chronic health problems (Brody, 1985). Increased home care assumes the availability of family caregivers (McKeever, 1996; Wuest, Ericson, Stern & Irwin, 2001). Thus, adult children and spouses find themselves adding frequently extensive caregiving to their other life roles. The duty of care remains a prominent family value, with the result that caregivers of older family members receive considerable social reinforcement (Friedman, Bowden, & Jones, 2003; Greenberger & Litwin, 2003; Kellett, 1999; Tipton-Smith & Tanner, 1994). Consequently, the decision to give up caregiving at home and admit a relative to a nursing home is often perceived as a failure to care, and is one of the most difficult choices that family members have to make (Matthiesen, 1989; Nolan & Dellasega, 2000; Penrod & Dellasega, 2001; Ryan & Scullion, 2000b). The move to a nursing home by an older relative is a major life transition for the whole family (Lundh, Sandberg, & Nolan, 2000; Ross, Rosenthal, & Dawson, 1997).

The duty of care is not easily relinquished to others. The responsibility for the dependent relatives' well-being remains paramount for many family caregivers (Kellett, 1999; Kelley, Swanson, Maas, & Tripp-Reimer, 1999; Lundh et al., 2000; Ross et al., 1997). Their challenge is to learn how to satisfy their duty in the new world of the nursing home where other caregivers are charged with responsibility for their relative's care. Because nursing home admission is most often a last resort and unplanned, the adjustment of roles and relationships that accompanies admission is also unanticipated

(Matthiesen, 1989). These role changes are required of families during a period typically wrought with emotional turmoil. It is well documented that admission of a relative to a nursing home is accompanied by feelings of anxiety, failure, grief, sadness, relief and guilt (Dellasega & Nolan, 1997; Kellett, 1999).

The process that a new resident undergoes in adjusting to life in the nursing home has been described as occurring over a period of 3 to 6 months and having distinct stages: disorganization, reorganization, relationship building, and stabilization (Brooke, 1989; Manion & Rantz, 1995). It would seem to follow that an adjustment period would be needed for family caregivers when their relative takes up residence. No consensus was found in the literature about a similar adjustment process for family caregivers of nursing home residents. However, theory development has begun about phases of family caregiving. Wilson (1989) described a process of family caregiving, called surviving on the brink, in which stages of the home caregiving process were identified. Several others have focused on investigating the caregiver's experience when placing their relative in a nursing home (Dellasega & Nolan, 1997; Lundh et al., 2000; Penrod & Dellasega, 2001). The question of how family caregivers make the adjustment to the nursing home world in a way that allows them to satisfy their continuing duty of care for the duration of their relative's life in the nursing home stimulated this inquiry.

Registered nurses have a primary responsibility for the provision of quality care to the residents of nursing homes. Viewing the resident within the context of the family is a tenet of gerontological nursing by which nurses are encouraged to form partnerships with families to enhance the resident's quality of life (Duncan & Morgan, 1994; Nolan & Dellasega, 1999; Specht, Kelley, Manion, Maas, Reed & Rantz, 2000). Maximizing

family resources for continued caregiving by developing supportive nurse/family relationships has the potential to positively affect the resident's quality of life (Ryan & Scullion, 2000b). Facilitating family caregiver role adjustment is an important aspect of the nurse's responsibility. It serves to maximize the caregiver's ability to continue giving care to older relatives (Kellett, 1999).

In practice, nursing home staff are frequently frustrated by the behaviours of family caregivers (Specht et al., 2000). Personal observations by the researcher have revealed a wide variation in family interactions with staff. These range from a lack of interaction, to frequent participation and instruction of staff in caregiving activity, frequent observation and at times, criticism of staff's caregiving methods. Staff find these caregiver behaviours demoralizing and at times, become defensive (Ryan & Scullion, 2000a). Rarely it seems, do family caregivers seek the staff's opinion about resident care or otherwise recognize their knowledge and experience. More often, caregivers enter the institution having had extensive experience in providing care to their relatives at home, and present themselves as having expert and unique knowledge about their loved one's needs (Lundh et al., 2000; Wuest et al., 2001). A better understanding of the family caregiver's perspective, how they make the necessary adjustments to find a preferred role, the factors that impede or accelerate their progress, and their vision of successful adjustment would be important to nurses. It could enable them to develop strategies for bringing the two knowledge bases together, the nurse's and the family's, to promote productive relationships, and ultimately enhance the resident's quality of life.

Those family members who describe themselves as primarily responsible for their relative's well-being could be said to demonstrate the greatest commitment to the caregiving role. In an ethnographic study of 16 rural family caregivers in the United States, Bell (1996) reported that principal caregivers were the decision-makers and family leaders in the implementation of the family's plan for nursing home placement. Knowing how primary family caregivers progress through the role adjustment process would be instructive for nurses. It could enable them to develop better interventions to support these committed family members whose leadership could influence the experience of others in the family, including that of the dependent relative.

Purpose of the Study

The purpose of this study was to identify and theoretically analyze the adjustment process experienced by primary family caregivers of relatives who had been admitted to a nursing home. A grounded theory approach was used to illuminate the basic social process that influenced the caregivers' development of new roles and relationships. A beginning substantive theory to describe the adjustment process experienced by primary family caregivers was developed.

Objectives

The study was proposed to meet the following objectives:

1. Describe primary family caregivers' perceptions of the adjustment required of them when they placed a relative in a nursing home.

2. Identify personal and situational conditions that primary family caregivers felt facilitated or interfered with their adjustment.
3. Identify primary family caregivers' views of properties of successful and unsuccessful adjustment.
4. Identify a sequence and/or time frame for primary family caregiver adjustment.
5. Develop a beginning substantive theory about the process of adjustment experienced by primary family caregivers whose relatives have been admitted to a nursing home.

Chapter 2: Literature Review

The caregiving literature, as it relates to families whose dependent relative is admitted to a nursing home, has developed in several directions. Most studies have been qualitative, describing the caregivers' often-stressful experiences of home caregiving and placement, and their development of a continuing role in the nursing home. Additionally, the development of middle-range theory has begun to explain aspects of the family caregiving process. The following literature review concentrated first on descriptions of the caregiving process, placement experiences and caregiver experiences in the nursing home, which formed the foundation for the current study. Secondly, relevant literature supporting findings related to caregiver commitment, support and emotional consequences, was reviewed. Finally, family caregiving, particularly the placement experience, has been described as a transition in family life. Thus, the middle-range transition theory developed by Schumacher, Jones and Meleis (1999), and Meleis, Sawyer, Im, Hilfinger Messias, and Schumacher (2000) was reviewed for its relevance to the caregiver adjustment process described by participants in the current study.

Family Caregiving Processes

Wilson (1989) conducted a grounded theory study among 20 primary caregivers who were looking after relatives with Alzheimer's dementia in their homes. The purposive sample of 14 females and 6 males had a mean of 6 years of caregiving experience and a mean age of 62 years. From the constant comparative analysis of in-depth interviews, there emerged the core problem of coping with negative choices, and a basic social process of surviving on the brink. Wilson's process of home caregiving was

divided into three stages: taking it on, going through it, and turning it over. She identified taking on the role as a moral imperative and a last resort for family caregivers, and one that took self-dialogue and social support to accept. Going through the experience was characterized as a sequence of problems for which caregivers developed coping strategies, but which pushed them to a breaking point of stress and exhaustion. Turning the care over to others in the nursing home was a decision reached gradually and characterized as a dreaded eventuality and ultimate negative choice. Wilson recommended additional investigation of factors influencing caregivers' decision-making and support needs, as well as exploration of other populations for further theory development.

Dellasega and Nolan (1997) conducted a cross-national study among family caregivers in the United States and Great Britain to build on Wilson's work and to examine validity of the last two stages of Nolan and colleagues' empirically derived model of caring. The model has six stages: building on the past, recognizing the need, taking it on, working through it, reaching the end, and a new beginning. The study extended understanding of the family caregiving process beyond Wilson's home caregiving period to include the admission to care experience. A convenience sample of 48 British and 54 American family caregivers participated in structured post-placement interviews. Content analysis techniques were used to reveal common themes and differences. Twenty-four hour care and safety were the principle benefits of placement that was prompted by the caregiver's failing ability to provide care rather than failed commitment. The majority found acceptance of the need for placement emotionally difficult due to feelings of sadness, guilt and loneliness. Acceptance and negative

emotions were modified positively by an ability to rationalize that placement was the only reasonable alternative and by the dependent relative's apparent contentment with placement. It was made more difficult by worries over quality of care, financial matters, and lack of support. Emotional support and practical assistance, as well as good communication with nursing home staff were identified as potentially helpful for caregivers after placement. Dellasega and Nolan viewed family caregiving as a temporal and contextual process with a series of implicit and explicit stages during which caregivers benefited from support that facilitated achievement of a new beginning in the nursing home. The authors recommended that, although not always overwhelmingly negative, the placement transition of caregivers would benefit from proactive supportive nursing intervention before and after placement.

Dellasega and Nolan's development of caregiving process theory was extended in a Swedish study by Lundh, Sandberg and Nolan (2000), in which 14 spouses whose partners had been admitted to a nursing home within the previous 6 months, participated in a grounded theory study of the placement experience. Semi-structured interviews were analyzed using a constant comparative method, which resulted in the identification of four temporal dimensions of the placement process: making the decision, making the move, adjusting to the move, and reorientation. Among these spouses, the first step of making the decision to place a partner was often initiated by others and expert driven, leaving the stressed spouse with a feeling of having let the partner down, despite legitimization by family and professionals. Powerlessness, emptiness and self-accusation were prominent among spousal caregivers as the move to a nursing home was orchestrated. Despite feeling swept along by the process, some spouses refused

inappropriate locations, opting to wait for a more attractive placement. Negative emotions were ameliorated for some spouses through immersing themselves in the practical aspects of the move. Adjusting to the move was made more difficult for spouses when they felt like outsiders in the nursing home and had difficulty influencing staff about their partner's care requirements. During this period, caregivers' moods characteristically alternated between the elation that accompanied increased freedom and the painful loneliness they felt without their life partner. The last phase of the placement experience was called reorientation and was one in which new daily patterns were developed to include caring for the partner and developing more community contacts. Lundh et al. described a return to a more normal life in this final stage, suggesting that those whose adjustment was less successful failed to reach a stage where they could see a future beyond day-to-day caregiving. The continued commitment of spousal caregivers in the life of their partner in the nursing home was not always recognized or actively promoted in nursing homes in this study. The authors identified the neglect of support needs as a critical problem before, during and after placement.

The last report reviewed was by Penrod and Dellasega (2001), who delineated the placement process of family caregivers further by secondary analysis of two previously reported American studies. Data were integrated from a study of placement decision-making and role change among caregivers whose dependent older relative was in hospital and unable to return home, and another study about the consequences of placement for caregivers within 6 weeks of nursing home admission. The authors' focus was primarily on identifying phases of the placement process and beneficial interventions. Grounded theory methodology using circular analysis of interviews and field notes, yielded a six-

stage process for which feelings of isolation and distress was the basic social-psychological process. The phases were: upsetting the status quo, deeming the situation inadequate, experiencing conflict, reaching the decision to place, looking for a place, and redefining the caregiver role. The first three phases represented a growing crisis that built toward the fourth stage of reaching the placement decision. They were characterized by conflict between the caregivers' decreasing ability to meet care needs and desire to meet their obligation as an ideal caregiver. Professional validation was said to be significant during these phases. Reaching the decision to place the relative was accompanied by self-justification efforts and brought transient relief. Looking for a place was often fraught with undesirable options and feelings of being pushed along by the system. Ambivalence over the permanence of the decision was common at this stage. Lastly, redefinition of the caregiving role was identified as being undertaken in an atmosphere of emotional turmoil and guilt as reality set in for caregivers. Penrod and Dellasega made stage-specific recommendations for nursing intervention which were summarized as maximizing healthy coping, minimizing caregiver health problems, and promoting positive relationships among the resident, the family and care providers. The authors also recommended research into effective nursing interventions and further exploration of professional perspectives to improve alliances between care providers in nursing homes, the recipients of care and family caregivers.

Summary

Considerable overlap was apparent in the processes described in the studies reported here. Wilson's description of home caregiving dovetailed with the efforts of the following three investigators who focused more on the placement experience. There was

considerable consistency in the experiences described by caregivers in the various cultural contexts. However, it was evident that these studies of caregiver role adjustment focused on home, placement and the early phase of nursing home caregiving. The fuller length of the caregiving experience in the nursing home, often lasting for years, has not yet been fully explored.

Caregiver Placement Experiences

The experiences of caregivers during placement were described in a number of reviewed studies that revealed much commonality in the emotions and meanings, decision-making stresses, and resulting effects of placement. One study also identified resources helpful for successful transition through the placement process.

Matthiesen (1989) used a grounded theory approach in the study of 32 daughters who had placed their mothers in nursing homes in the United States. Her analysis revealed common themes of unresolved guilt and recurring grief as the daughters moved through the caregiving processes that Matthiesen called becoming the chosen daughter and redefining roles. Guilt was related to the perceived selfishness of placement. The grief was due to loss of the mother, which caregivers felt was misunderstood and unsupported by others. Matthiesen recommended a role for nurses in facilitating successful role transitions and psychosocial interventions for daughters of nursing home residents.

Support for caregivers during transition was also recommended by Kellett (1999), who conducted a phenomenological study of 14 family caregivers experiencing nursing home placement in Australia. She used hermeneutic analysis to isolate five shared

meanings: guilt, simultaneous sadness and relief, a sense of failure, and being forced to make negative choices. She stressed the value of caring partnerships between nurses and family caregivers in assisting caregivers to develop meaningful caregiver roles in the nursing home.

The need for assistance to families during the move of a relative to a nursing home was reiterated by Johnson, Morton and Knox (1992) in their case study of 22 family members during the 6 months after placement. Content analysis revealed two main categories of emotional response to the situation: uncertainty and conflict. Uncertainties arose about the relative's condition, the unknown environment, and the caregivers' undefined role in the nursing home. Conflicts were both intrapersonal and interpersonal, primarily related to disparity between institutional and family values and goals, and changing roles and relationships. The authors recommended that nurses could provide assistance to help family caregivers manage their emotions and promote positive family/staff relationships focused on quality care for the relative.

The decision-making experience of nursing home placement was the subject of two reviewed reports. Nolan et al. (1996) reviewed a variety of studies and developed a typology of four styles of admission decision-making: the positive choice, the rationalized alternative, the discredited option and the *fait accompli*. These were based on a variety of perceptions and processes of admission documented in the literature and reported studies. The positive choice represented an admission process that was anticipated, planned and desirable. Such a decision was described as ideal but rarely experienced. In the rationalized alternative, which was the most commonly experienced type, the decision was less anticipated but perceived as legitimate and/or reversible. The

discredited option started as a positive choice or rationalized alternative but deteriorated after admission when disillusionment set in. Finally, the *fait accompli*, considered the worst experience, was an admission which was not anticipated or desired, and one in which the decision was made by others. The authors recommended that action was needed at society, government and facility levels to create an environment where positive choices are facilitated and placement, when it occurs, is a more desirable option for care.

Ryan and Scullion (2000b) conducted a study that examined the placement decision, the factors leading to it, and the family caregivers' feelings about admission of their relative to a nursing home. They conducted in-depth interviews with 10 family caregivers whose relatives resided in nursing homes in Northern Ireland. Content analysis resulted in the identification of two main precipitating factors of admission: changing health status of the care recipient and/or caregiver, and an inability to cope related to inadequate family and professional support. Two dominant themes in the decision-making process were the influence and participation of family and professionals, and the significance of the admission route, whether from home, respite care or hospital. Reactions to placement were grouped as negative, positive or mixed. Negative feelings of reluctance, lack of choice, failure, guilt, helplessness, a need to justify the decision, loss, loneliness, regret, and sadness dominated the caregivers' reactions to placement. One caregiver in the study expressed relief and contentment with the decision, and several had mixed feelings. The authors stressed the need to support the decision-making process and the emotional reactions of caregivers, and to develop caring relationships that would assist caregivers to find new and meaningful roles in the nursing home.

The stress of the placement transition was identified in a study by Zarit and Whitlatch (1992). They examined caregiver stress, role competence and well-being during placement and afterward in 101 caregivers of relatives who had been in American nursing homes for an average of 190 days or 6.3 months. Their quantitative analysis showed most change in the caregivers' physical distress and daily routines after placement, but no meaningful improvement in their subjective sense of well-being. The authors concluded that placement of a relative positively affects physical stress levels, but stressors in the new environment continue to negatively affect the caregiver's sense of well-being. They suggested that evaluation at a later point in the experience might have shown greater well-being among caregivers who may have adjusted more fully to their new role in the nursing home.

Lastly, a study by Gaugler, Pearlin, Leitsch and Davey (2001) sought to identify sources of difficulty and mediating factors for family caregivers during the placement transition. One hundred and eighty-five family caregivers of relatives with dementia in the United States were interviewed before and after placement. Their results showed that 20% of caregivers experienced multiple difficulties during placement and perceived inadequate help from family and professionals. Those who experienced family conflicts had increased difficulty and perceived less help. In comparison, those who had better personal health and socio-emotional support had less difficulty and perceived more help. Additionally, those with a high sense of role mastery perceived less help. The authors concluded that transition was facilitated for caregivers by adequate social and personal resources. They recommended that a focus on enhancing these resources prior to

admission by creating partnerships between professionals and caregivers would have significant benefits for families and residents in nursing homes.

Summary

The placement experience has been described as negative and stressful for most caregivers. Negative emotions and difficult decisions and adjustments predominated the reports in the literature. Nurses have been encouraged to support family caregivers throughout the process by attempting to bolster their resources and develop caring relationships. Policy makers were challenged to create environments and resources that would make placement a positive choice for those caregivers who could not sustain home caregiving. Research into caregiver adjustment beyond the placement stage of the experience in the nursing home was recommended.

Caregiver Experiences in the Nursing Home

Studies of family caregivers' experiences after admission of their relative to a nursing home have been numerous. Researchers have examined themes of meaning, visiting patterns and purposes, and roles and relationships. Most have used family caregivers as their population, while two recent studies have compared the perceptions of family caregivers and nursing home staff about the family's role in the institution.

Kellett (1996) explored shared meanings of caregiving in nursing homes among eight family caregivers in a phenomenological study in Australia. The qualitative data management package, NUDIST 3.0, was used to isolate five common themes of meaning in the caregivers' experience. These were identified as a sense of break from the familiar, a sense of change in engaged involvement due primarily to role loss, a sense of worth

related to their expert knowledge of the relative, a sense of concern about loss of control and not being heard by nursing home staff, and finally, a sense of continuity actively pursued in the new environment. The author emphasized the need of caregivers to maintain engaged involvement with their relative, and the importance of nurses fostering an atmosphere of collaborative caring.

The desire of caregivers for continued involvement with their relatives' care in the nursing home and the need for nurses to share the care with caregivers were common themes in the reviewed literature. Developing caring partnerships was the way Nolan and Dellasega (1999) expressed the latter theme. They analyzed questionnaire responses from 54 caregivers in the United States and 48 in Great Britain who had relatives admitted to nursing homes. Content analysis revealed enduring emotional ambivalence and concerns about quality of care among caregivers. They recommended that nurses should actively promote an alliance with caregivers, and that nurses and family caregivers needed to learn how to create equitable relationships in order to develop achievable goals in shared care. They proposed that intervention research should be conducted to implement their recommendations.

Likewise, Duncan and Morgan (1994) recommended that families and nursing home staff share the care of the relative. Their research involved content analysis of 30 focus group discussions and 10 individual interviews with family members of American nursing home residents who had dementia. The results were focused on caregivers' views of staff behaviour and family/staff relationships. They concluded that the family caregivers' evaluation of quality care was based on perceptions of the staff's sensitivity to the relative's emotional needs rather than technical expertise alone. For them, caring

about their relative was a prime measure of staff competence. The family/staff relationships they valued were those in which information was shared and caregivers could actively influence the care provided to their relative. Participants noted difficulties in relationship building due to frequent turnover of staff. The need for more research into staff perceptions and how families and staff can work together was identified.

Family caregiver roles in nursing homes were the focus of several studies. Kelley, Swanson, Maas and Tripp-Reimer (1999) identified being faithful as a core value among 30 family members who were interviewed in the United States, and whose relatives resided in specialized dementia care units. Content analysis revealed three themes of visiting: being faithful, being their eyes and ears, and being family. Changing relationships and the social support needed from family to share the caregiving burden were described as dominant themes of the nursing home experience. The authors' recommendations included the need for family education to assist coping with relationship changes during the dementia trajectory, and a facility philosophy and environment that supported maintenance of family relationships.

Studies by Ross, Carswell and Dalziel (2002) and Ross, Rosenthal and Dawson (1997) also identified purposes for family visiting. Additionally, their studies investigated meaningful tasks of caregivers in the nursing home. The 1997 study was conducted among a convenience sample of 78 wives of residents in a long-term care facility in Ontario. Interviews were conducted at 2 weeks and repeated at intervals during the first 9 months after admission. Responses to fixed answer and open-ended questions were analyzed using univariate statistics for quantitative data and thematic analysis of meanings for open-ended questions. Changes with time were identified with bivariate

techniques. The results showed consistent frequency of visiting over 9 months and identified motivational factors for visiting as love and devotion, duty and obligation, and provision of assistance to the spouse and staff. The majority felt satisfied with their visits, particularly when they felt useful and there was evidence of the spouse's continued well-being. For approximately half of the wives, visiting was associated with guilt, sadness and depression. More than one-third maintained a persistent focus on the husband's situation to the exclusion of other dimensions of their lives. This group was more inclined to have symptoms of depression and low morale. Nearly two-thirds of the wives demonstrated an emerging focus on other aspects of life and had high morale without evidence of depression over time. An increased focus on other dimensions of life was also associated with greater satisfaction with the spouse's care and the staff. Wives whose husbands were cognitively impaired were more inclined to diminish their involvement with time. Ross et al. speculated that for these wives, the separation process may have begun earlier, even prior to admission to the nursing home, compared to wives whose husbands were cognitively well and who remained more involved. The authors recommended that wives should be considered clients by nursing home staff and orientated and supported during their transition to the nursing home setting. Mutual exchange of information about the resident and encouragement to participate would serve to reassure wives and facilitate trust. The need for nurses to be observant for low morale, depression and dissatisfaction, and to intervene appropriately was stressed.

The study by Ross et al. (2002) also added to the literature on roles assumed by families in nursing homes. They performed secondary analysis on results obtained in a larger study of 122 family members whose relatives had been residents of 9 nursing

homes in Ontario for an average of three and a half years. Visiting frequency and tasks performed were identified through analysis of responses to questionnaires containing fixed answer and open-ended items. They found that more than 70% of respondents visited at least weekly for an average of 110 minutes. Family members continued to feel responsible for monitoring, providing, and advocating for care. More than half did not enjoy visiting and were unsure how to use their time. Many had difficulty in their relationships with staff and with watching the deterioration of their relative. The authors recommended policies in nursing homes to include families as members of the health care team, orientation programs and support for task performance by family members.

The family's role expectations compared to their actual role performance in nursing homes was the subject of a study by Friedmann, Montgomery, Rice and Farrell (1999). They interviewed a purposive sample of 216 family members of residents in 24 nursing homes in the United States. Using regression analysis, they found that expectations for involvement accounted for up to 23% of actual participation activity in the nursing home, and that family patterns of open emotional expression were related to information seeking activities in their role development in the nursing home. Families with expectations of less involvement responded more positively to team membership and learning activities for families. The authors speculated that families expecting high levels of involvement might lack trust in the staff's ability to provide appropriate care for their relative. In conclusion, the authors recommended that roles could best be implemented through a process of negotiated partnership between families and staff.

In a 2001 review of literature related to family involvement in care of older adults in nursing homes, Janzen concluded that most of the emphasis up to that date had been on

family caregiver views of the experience. She stressed the need for comparison studies of family and staff views, and made several recommendations for support of family caregivers as integral members of the care team. In addition to the need for facility policy development and educational support for families and staff, she emphasized the development of open communication strategies to facilitate family-staff and staff-staff relationships. It was her opinion that these were essential for good quality care and quality of life for residents.

Two recent studies have included perspectives of staff as well as family members about the role of families in nursing homes. Walker and Dewar (2001) used a case study design to interview 20 family caregivers and 29 multi-disciplinary team members in a geriatric psychiatry unit in Scotland about family involvement. Interviews and field notes of non-participant observations were analyzed using constant comparative methodology. The authors reported that the majority of family caregivers were dissatisfied with their involvement in decision-making. Staff tended not to be proactive in seeking family input, responding at times with defensiveness when family members initiated contact about care of their relative. Families felt disempowered by care meetings they felt were dominated by the professionals' agenda. Like Friedmann et al. (1999), the authors recommended that families and health care providers should negotiate a mutually satisfying relationship. Walker and Dewar also stressed the need for professional development in nursing to improve understanding of the reciprocal relationships required to achieve best practices in family/staff relationships.

The other joint study of family caregivers and nursing home staff relationships was conducted by Ryan and Scullion (2000a) in Northern Ireland. Questionnaires were

completed by 44 family members and 78 nursing staff in 15 nursing homes that had volunteered for the study. Semi-structured interviews were also conducted with a convenience sample of 10 family caregivers and 10 nursing staff. Questionnaires were analyzed to determine care tasks predominantly viewed as nursing or family responsibilities and these results were combined with content analysis of the interview data. Concurrence was shown between families and staff about the family's role in social care, although responses by nursing staff often demonstrated their sense of control over resident and family activity. A variety of views on the personal care role of families were evident. Some nurses were restrained from encouraging family care by professional accountability concerns. Family members identified a role in providing information to nursing staff and monitoring care. Nursing staff acknowledged no role for families in planning care. Family caregivers indicated satisfaction with the status quo, while nurses indicated they would prefer more family involvement. Analysis of questionnaires showed that family caregivers rated their involvement higher than nursing staff perceived it to be. Tasks performed by families tended to involve social and personal care, while nurses' care was predominantly technical and administrative. Both categories of participants agreed that attitudes were critical to encouraging or limiting family involvement. The authors recommended that improved communication and sharing of information between families and nursing staff as equal members of the care team could minimize misunderstanding of roles and optimize family caregiver involvement in nursing homes.

Summary

Common themes in the reviewed literature on the preferred role of families in nursing home care of relatives were the desire for continued involvement in meaningful

ways, and the need for nursing staff to consider family as part of the health care team. Nurses were challenged to develop collaborative relationships that share the care and satisfy the individual family member's need for maintenance of a caregiving role with their relative. The limited data to date on nursing staff's views of such sharing relationships with families suggests there may be obstacles to implementation of partnership models of care in nursing homes. Interventions to facilitate effective family/staff and the need for better understanding of family and nursing staff perspectives, and relationships were commonly recommended by the authors of the studies.

Caregiver Commitment

Several sources were found that contributed to understanding the commitment of family caregivers to their dependent relative. These related primarily to aspects of the caregiver role that helped to explain the lasting bond shared between caregiver and care recipient.

In the report of a lecture by Brody (1985), filial duty in the care of older parents was described as a normative family stress. She proposed that the original paradigm for parent caregiving was the model of a parent caring for a young child. In her hypothesis, the stress of parent care originated from the notion that the lifelong care of parent for child can never be fully reciprocated. She postulated that this failure to reciprocate the care was the source of guilt experienced by so many adult caregivers of older parents. Adult children feel they can never do enough to repay the parent's devotion. Further to this, Brody speculated that this perceived failure may be the source of a persistent social myth

that adult children don't take care of their relatives as well as they did in the 'golden past' of three generation households. Drawing on her previous research, she cited many examples that illustrated parent care as a normative experience in families, and condemned the notion that admitting parents to nursing homes constituted abandonment. Rather, she believed it symbolized the failure of society to provide adequate caregiver support and services in the community, as well as in long-term care institutions. Brody also identified the predominance of women, most commonly adult daughters, as family caregivers, and noted that these 'women in the middle' face many stresses.

A further report by Brody, Dempsey, and Pruchno (1990) described a quantitative study that compared the mental health of daughter and son caregivers of institutionalized older parents, by identifying predictors of strain. Significant predictors were: female gender, younger age, poor caregiver health, poor quality of visits with the parent, negative perceptions of staff, and time pressures. They concluded that daughters experienced more negative emotional effects of caregiving, more burdens, and more health problems than sons, and speculated that the socialization of women as nurturers may contribute to higher expectations of themselves as caregivers. They stressed the need for a family focus in nursing homes and, as it was shown in their study that daughters who were most involved in caregiving were least depressed, they proposed a continued role for the caregiver in the nursing home as a means of mitigating some of their stress.

Friedman, Bowden and Jones (2003), in their family nursing text, discussed the caregiving role as integral to family life and noted that women have traditionally been the nurturers, health leaders and caregivers in families. They described the reciprocal bonds that developed between caregivers and care recipients as arising from their

complimentary roles. The shared emotional bond was identified as an essential ingredient of the caregiver's continued commitment to the caregiving role.

Summary

The reviewed literature illustrates the function of a strong emotional bond in maintaining the commitment shown by many caregivers. That bond was shown to arise from the traditional family roles and duties in society, and to contribute not only to the enduring commitment of caregivers in their roles, but also to the many stresses described among caregivers of older relatives.

Caregiver Support

Social support of caregivers has recently been examined in terms of beneficial characteristics of support, effects of non-support, and its value as a resource for continued adherence to caregiving. A clearer understanding of the contribution made by social support to continued caregiving emerged from a selected review of literature on these topics.

Wuest, Ericson, Stern, and Irwin (2001) reported a grounded theory study in which they interviewed a convenience sample of 15 Eastern Canadian family caregivers of persons with Alzheimer's disease. Constant comparative analysis of their data revealed social support as a significant factor influencing the caregiving process. Positive support was characterized as connected, and negative support as disconnected, the two being distinguished by the degree of congruence of support with the perceived need of the caregiver. It was their conclusion that social support could be available to caregivers from family, community and professional sources, but the most critical factor in its

effectiveness was not its availability, but whether it was perceived as helpful by the caregiver. Wuest et al. recommended that nurses could have a greater presence in the lives of family caregivers, particularly in the early stages of caregiving, when they could assess coping strategies and assist caregivers to gain access to supportive resources. Wuest et al. also recommended that intervention research could be conducted to determine the most helpful support strategies for caregivers. They noted that most caregivers were women and that women had been found to be reluctant to relinquish responsibility to others. Thus, finding ways to support them in a continuing role could prove to be most fruitful.

Neufeld and Harrison (2003) reported results of analysis of non-support of 8 Western Canadian female caregivers, who were part of a larger grounded theory study of support and caregiving among 20 women caring for relatives with dementia. They identified two types of non-support: unmet expectations and negative interactions. Expectations for support that went unfulfilled, whether due to missing offers for assistance and social interaction, or incompetent or mismatched aid, were sources of stress to caregivers. Neufeld and Harrison noted that caregivers had greater expectations of family members for assistance, and their failure to provide assistance contributed to the caregiver's stress. Non-support was also perceived by caregivers from disparaging comments about the caregiver's experience or appraisal of the care recipient's needs, criticism of the caregiver's decisions, and from longstanding family conflicts. These negative interactions, particularly with family members, often resulted in isolation of the caregiver from important sources of support. The authors recommended that nurses could

assess caregivers' expectations and assist caregivers to build stronger connections with those perceived to be their most supportive resources.

The value of social support to caregivers was also underscored in a large cross-sectional study of 240 randomly selected caregivers in Israel conducted by Greenberger and Litwin (2003). They used path analysis techniques to identify indicators of caregiver adherence, and measured relationships among burden, social support and personal competence. Among their observations was the positive correlation that existed between social support and caregiver competence measures, including role mastery and self-esteem, and the relation of both to burden. They concluded that quality caregiving could coexist with burden, given adequate social support and role competence. In their analysis, increased burden did not diminish caregiving adherence. Indeed, they speculated that higher competence may lead to higher levels of caregiving involvement and result in higher burden. The authors recommended that efforts be made to bolster personal and social support of caregivers to facilitate caregiving longevity.

Summary

Social support for caregivers was demonstrated in the above studies to be of critical importance to the maintenance of the caregiver role. Effectiveness of support was shown to vary with the needs of individual caregivers, and was positively related to caregiving competence. These reviewed studies have begun to determine some of the unique contributions of social support in the caregiving situation. More specific understanding of effective social support variations could be of assistance to nurses in the development of nursing interventions for caregivers at all stages of the process.

Emotional Consequences of Caregiving

Two reports on the related topics of prolonged grief and chronic sorrow among caregivers contributed to the analysis of findings in the current study.

Lindgren, Connolly, and Gaspar (1999) characterized the prolonged grief of caregivers whose relatives had dementia as a reaction to loss of the future. They conducted a correlational study retrospectively among 33 family caregivers. Their results showed that so-called non-death grief persisted throughout the caregiving experience. It was most related to the loss of a future and changes in the caregiver's life, but not significantly to loss of companionship caused by degenerative changes of dementia in the relative. The authors speculated that this latter finding could imply that the continued presence of the relative offered some sense of togetherness, despite cognitive decline. Lindgren et al. also reported that caregiver's negative emotions of anger and guilt were inversely related to satisfaction with their relationship with the care recipient. The authors suggested that the grief that accompanies the losses of dementia may be related in some situations to loss of hope for future repair of an unsatisfactory relationship. Lindgren et al. concluded that grief among caregivers was primarily anticipatory in nature, but could be rekindled with each new loss along the relative's illness trajectory. The authors recommended more investigation of the emotional state of caregivers to assist the development of interventions that would help caregivers continue to give care while grieving.

Eakes, Burke and Hainsworth (1998) reported the development and validation in 10 qualitative studies of a middle range nursing theory of chronic sorrow. They described

chronic sorrow as a normal response to ongoing disparity associated with significant loss, and noted that it may be triggered among caregivers by management crises of their relative's illness. They proposed that sorrow persisted in caregivers due to the perceived disparity between an idealized future and their present reality. Their theory was suggested to have utility for understanding responses of caregivers to ongoing losses. Eakes et al. recommended that conceptualizing chronic sorrow as normal could assist nurses to develop strategies for all caregivers to help them cope with this anticipated phenomenon throughout the caregiving experience.

Summary

The two reviewed reports contained many common themes, all of which added credence to the discussion by many others of persistent negative emotions during caregiving. The work of these two researchers demonstrated evidence of the continuation of grief and sorrow as predominant emotions through the entire caregiving experience.

Transition Theory

Schumacher et al. (1999) defined transition as a passage between two relatively stable periods in which an individual moves from one status, life phase or situation to another. It has been proposed by Meleis et al. (2000) as a central concept of nursing in that clients of nursing are most often experiencing health problems which create a need for a change of status, lifestyle or situation, or are in changing circumstances which make them susceptible to health risks. Transition is a period of disequilibrium, often accompanied by loss and vulnerability, in which the individual perceives a need for profound change in his or her world (Schumacher, 1999). Schumacher contends that in

order to make the necessary transition to a new way of living, individuals must learn new skills and coping strategies and form new relationships.

The middle-range theory proposed by Schumacher, Meleis and colleagues, identifies types and patterns of transition, that is, developmental, situational, or health/illness, and single or multiple, sequential or simultaneous. The theory also includes properties of transition, such as awareness, engagement, time span, and critical events. Facilitating and inhibiting conditions which may be created by personal, community or societal influences are identified, as are patterns of response which include process and outcome indicators of successful transition, such as integrity, mastery and connectedness. Lastly, these researchers have proposed that nursing interventions to facilitate successful transition should include assessment, role supplementation and resource mobilization strategies, among others. They note that transitions are complex and varied, and the concepts proposed in their theory require further development and refinement through research with diverse populations in diverse types of transition situations.

Summary

While the concept of transition has been used at times to describe the adjustments of caregivers in the placement situation, no evidence was found in the literature of the application of transition theory to the life changing situations caregivers find themselves living through. A review of the middle-range transition theory being developed by Meleis et al. (2000) and Schumacher et al. (1999) identified many characteristics of transition that, when applied to the caregiver experience described in the current study, assisted in developing a fuller analysis of the caregiver adjustment process.

Summary of the Literature Review

The review of current literature related to the family caregiving experience demonstrated several research foci. These included investigations of the meanings, stresses and negative emotions of the caregiving role at home and during nursing home placement. Steps of the caregiving process from home to nursing home placement have been identified with considerable similarity among research reports. Also, conflicts and uncertainties of the caregivers' role in the nursing home have been reported. That caregivers intended to maintain involvement in their relatives' lives in the nursing home seemed a universal finding among studies. Several sources were found which explored the rationale for the caregiver's continued commitment to the care recipient. Others identified issues related to social support for maintaining the caregiving role.

Many authors made recommendations about the need for health care providers to consider family caregivers as members of the care team, and for nurses to develop partnerships with family caregivers, which would facilitate the caregiver's continued role in the relative's life in the nursing home. However, recent studies indicate conflicting perspectives and lack of understanding between staff and family caregivers about roles and relationships in nursing homes. This needs further investigation.

In order to intervene and support caregivers effectively, it has been recommended that nurses need more understanding of caregivers' perspectives on their experience and their changing roles across the spectrum of caregiving. Review of the literature demonstrated that various aspects of caregiving, particularly the placement and nursing home experiences, have been studied in recent years using descriptive and theory-generating methods of research. Further theory development about how caregivers

progress through the different phases of the experience and factors which influence their ability to adjust to their changing roles, as was the focus of the current study, could contribute meaningfully to growing scientific knowledge of the caregiving experience. Grounded theory could be an effective method for such a purpose because it provides an ability to examine and explain the social world of people experiencing a particular phenomenon (Chenitz & Swanson, 1986). The constant comparative method of analysis used in grounded theory could identify the process by which caregivers develop and adjust their roles in order to interact effectively with others throughout the caregiving experience. Nurses who interact with caregivers at all phases of the experience could benefit from better knowledge of the caregiving process by using it to plan appropriate interventions.

Chapter Three: Methodology

Study Design

A qualitative approach using the grounded theory methodology of Glaser and Strauss (1967), supplemented by the methods described by Strauss and Corbin (1990), was used to explore in depth the experiences of adjustment of primary family caregivers whose dependent relatives had been admitted to a nursing home. The purpose of using this method of study was to develop a beginning substantive theory about the adjustment process of these primary family caregivers. Theory developed using this method of inquiry emerges through interaction with and observation of the participants in the experience. The researcher gained access to the participants' experiences by conducting in-depth unstructured interviews. The process of adjustment to a relative's changing needs requires family caregivers to develop new roles and relationships as they seek to meet their continuing duty of care to their relative. The basic characteristics of grounded theory methodology provided a suitable means of exploring and explaining this phenomenon. According to Glaser (1978), these characteristics include: 1) It is inductive, deriving concepts from analysis of real experience; 2) It has a sociological base, that is, it attempts to elicit basic social processes influencing a phenomenon; and 3) It is derived from Blumer's symbolic interactionism, in which social behaviour is seen to be a result of people's interactions with the social world and the meanings they attribute to its symbols. Thus, meaning is created by the people experiencing a phenomenon, and the grounded theory method permits the researcher to discover and explain the meanings participants attribute to their experience.

Grounded theory is characterized also, by its use of constant comparative analysis (Chenitz & Swanson, 1986). This analysis is circular and exhaustive, going back and forth between new information and previous data until all new information about the phenomenon is exposed (Glaser & Strauss, 1967). It is a process of discovery that starts with verbatim recordings of participant's experiences and coding of these at gradually more conceptual levels. It includes the researcher's observations and deductions through the use of memos written throughout the research experience. Ultimately the researcher proposes a middle range theory, which seeks to explain the social behaviours studied and the relationships among them (Chenitz & Swanson). The richness of data gathered with this method was ideally suited for describing the complex experiences of family caregivers' adjustment while they were characteristically in a state of emotional turmoil (Dellasega & Nolan, 1997). Developing a beginning theory to explain this stressful social process was undertaken to help nurses understand the experience of caregivers more fully, and to provide a basis for facilitative nursing interventions.

Participants

Eligible participants were self-identified primary family caregivers contacted within 12 months of their relative's admission to a long-term care institution in Newfoundland, and who lived within the catchment area of the institution. Further criteria to facilitate the interview process were that they spoke and understood English and had adequate hearing for normal conversation. Family members of residents in the two units managed by the researcher were excluded from the study.

The secretary who keeps the statistical database at the long-term care institution identified potential participants from departmental records of residents' next of kin. A form letter was sent by the Director of Resident Care Services to the next of kin describing the study and requesting primary caregivers to telephone the researcher if they were interested in participating (see Appendix A). When contacted, the researcher explained the purpose of the study, answered questions, assured prospective participants of anonymity and confidentiality, and arranged a private interview. Participants were advised that one interview of approximately 1-hour duration would be expected, with the possibility of brief further contact, if necessary for verification of information.

The number of participants in a grounded theory study is undetermined at the outset. Interviews were conducted with new participants until no new information was forthcoming. Theoretical sampling, that is the ongoing selection of suitable data for the developing theory as it emerges (Glaser & Strauss, 1967), was used to guide subsequent interviews, ensuring adequate representativeness and variation in the data, relative to the categories emerging from analysis of prior interviews (Chenitz & Swanson, 1986). In total, 10 primary family caregivers were interviewed.

Demographic data were obtained from all participants. Their ages ranged from 43 to 82 years. There were 8 females and 2 males. Of the females, 6 were daughters of a resident, one a daughter-in-law and one a wife. One interview was conducted with two sisters who considered themselves joint caregivers. Two interviews were conducted with men, one a son and the other a husband. All participants identified themselves as primary caregivers. Their relatives' length of stay in a nursing home varied from 5 to 16 months at the time of the interview. All care recipients were over 65 years of age, except one who

was middle-aged when nursing home placement occurred. Only one of the care recipients was unaffected by cognitive impairment resulting from conditions such as Alzheimer's disease and Parkinson's disease. Several caregivers described their relatives as having chronic conditions such as diabetes mellitus, cerebral vascular disease and gastrointestinal disease. One resident had experienced abuse.

Setting

Interviews were conducted at a time and in a location of the participant's choice where privacy and lack of interruption could be anticipated. The majority of the interviews were held in conference rooms at the long-term care institution. One was conducted at the participant's home.

Ethical Considerations

Approval for the study was granted by the Human Investigation Committee of Memorial University of Newfoundland (see Appendix B) and the ethics committee of the corporation governing the long-term care institution (see Appendix C). Consent was obtained in writing at the beginning of each interview after the purpose and procedure were reviewed and participants had an opportunity to ask questions (see Appendix D). Confidentiality and anonymity were assured by assigning a number to each interview and refraining from using participants' names in the tape recording, the transcripts or the written documents of the study. A letter of the alphabet was used to identify the participant in the transcript. The master list of participant's identifying information and the audiotapes were kept in a private place at the researcher's residence. Both will be

destroyed upon completion of the study. Participants were assured of their right to withdraw at any time. They were informed that no direct benefits were anticipated from their participation and that they could have access to study results upon request. When emotional distress developed during interviews, participants were encouraged to take a break and resume if they felt able to. All participants completed their interviews.

Data Collection

The primary sources of data were open-ended interviews with each participant lasting approximately 80 to 120 minutes. Demographic information was recorded at the beginning of each interview, then through the use of general guiding questions, caregivers were asked to describe how their relative had come to be in the nursing home and what the experience had been like for them (see Appendix E). The purpose and objectives of the study guided the development of the interview guide. Probing and clarifying comments from the interviewer, also described in the interview guide, were used to stimulate the caregiver's expression of thoughts and feelings about the adjustments required during the experience. Each interview was audiotaped and then transcribed verbatim.

A secondary source of data were the memos made by the interviewer during and after the interviews to document observations and reactions to the interview situation and content. These were recorded with the transcript of each interview and later, on index cards. Another source of data was the literature review, which was conducted to more fully develop emerging concepts and theory. In theory-generating research processes such as this study, the literature is viewed as an additional source of data and used to assist the discovery process (Chenitz & Swanson, 1986).

Data Analysis

A constant comparative method of analysis was used, beginning with the first interview and continuing as data from each subsequent interview were compared with preceding interview data. This continuous back and forth process was intended to facilitate integration of the data and identification of the patterns within it (Morse & Field, 1995; Streubert & Carpenter, 1995). The goal was to reduce the data to concepts related to the adjustment of primary family caregivers and to identify a basic social process that formed the core of an explanatory theory about the phenomenon (Benoliel, 1996; Glaser & Strauss, 1967).

The interview transcripts were reviewed line by line and key words and phrases isolated into first level codes. Memos of observations and thoughts of the interviewer were recorded in relevant sections of the coded transcripts. These first level codes and memos were grouped into related content categories. The conduct of each subsequent interview was informed by the analysis of those previous to it. This style of data collection is characteristic of the theoretical sampling commonly used in grounded theory research, by which the researcher decides what data to collect next according to previous analysis and the emerging theory (Glaser & Strauss, 1967).

Each new set of first level codes was compared, in matrix fashion, to similar and different codes and categories developed from previous interviews (Glaser & Strauss; Wuest et al., 2001). An initial grouping of categories related to properties and dimensions of the caregiver adjustment experience gradually emerged. Interviews and this analysis process continued until no new categories appeared in the data. This theoretical saturation

(Glaser & Strauss, 1967) was validated by dismantling the categories and transferring all codes and memos to file cards. These were then re-ordered into increasingly discreet categories. At this point, writing the story about what was happening at different stages of this linear and temporal caregiving experience assisted in grouping categories chronologically. Strauss and Corbin (1990) propose the value of conceptualizing a story to achieve integration of data and isolation of a core category. Through this re-conceptualization process, the phases, adjustments, dimensions, conditions and variations of the caregiver adjustment process were refined. In addition, a basic social process was discerned as the core variable explaining the adjustment behaviours of caregivers.

Relevant literature was reviewed and compared to the emerging theoretical construct of caregiver adjustment. The addition of this data to the analysis clarified similarities of the proposed process to the concepts of others and illuminated unique contributions of the study to current knowledge of the caregiver adjustment experience. Finally, an outline of caregiver adjustment was developed, along with a diagrammatic representation of the process to aid discussion of the results.

Credibility

Credibility in grounded theory studies is achieved through participant selection and the systematic analysis of coded data using constant comparison. This process yields theory derived directly from the richness of human experience described by participants in the study (Glaser & Strauss, 1967). Purposeful and theoretical sampling in the selection of participants and the continuation of interviews until saturation of data was achieved ensured the adequacy of the data (Morse & Field, 1995). The extensive

comparisons of developing categories and concepts with original interview data during the analytic process illuminated the boundaries and variation in the process, ensuring that the emerging theory fit the expressed experience of primary family caregivers. By this means, the interviewees who lived the experience supplied content validity and relevance to the concepts identified. As each phase, dimension and condition of the developing theory emerged, selective sampling of the verbatim data was used to validate its fit. The level of abstraction achieved and the ability to illuminate a basic social process with this grounded theory method enhanced the effectiveness of the proposed theory for explaining and predicting the caregiver adjustment process. According to Morse and Field, this level of conceptualization increases the theoretical generalizability. However, the study design limited the relevance of results to those having similar experiences in similar contexts, particularly primary family caregivers who have experienced nursing home admission of their relative.

Chapter 4: Findings

This chapter identifies the core variable that unified the adjustment process of primary family caregivers whose relatives were admitted to a nursing home, and describes the social process of caregiver adjustment in terms of the core variable and its phases. Adjustments required in each phase and their unique dimensions are discussed. The underlying context of intervening conditions that existed throughout the social process of caregiver adjustment is included. An overview of the caregiver adjustment process is provided, followed by a detailed discussion of findings related to each adjustment phase. A summary of findings concludes the chapter.

The Caregiver Adjustment Process: Fulfilling the Commitment

Fulfilling the commitment was the name given to the basic social process that characterized the caregiver's journey from the onset of caregiving for their relative at home, through to their ongoing role after the relative's admission to the nursing home. This core variable rationalized the actions and reactions of caregivers in each phase of the caregiving experience. It was the definitive factor in whether intervening conditions served to sustain or constrain the caregiver. Ultimately, it explained the dedication and tenacity of caregivers in a role that dominated years of their lives.

Fulfilling the commitment was a linear process comprised of three phases: home caregiving, admission caregiving and nursing home caregiving (see Figure 1).

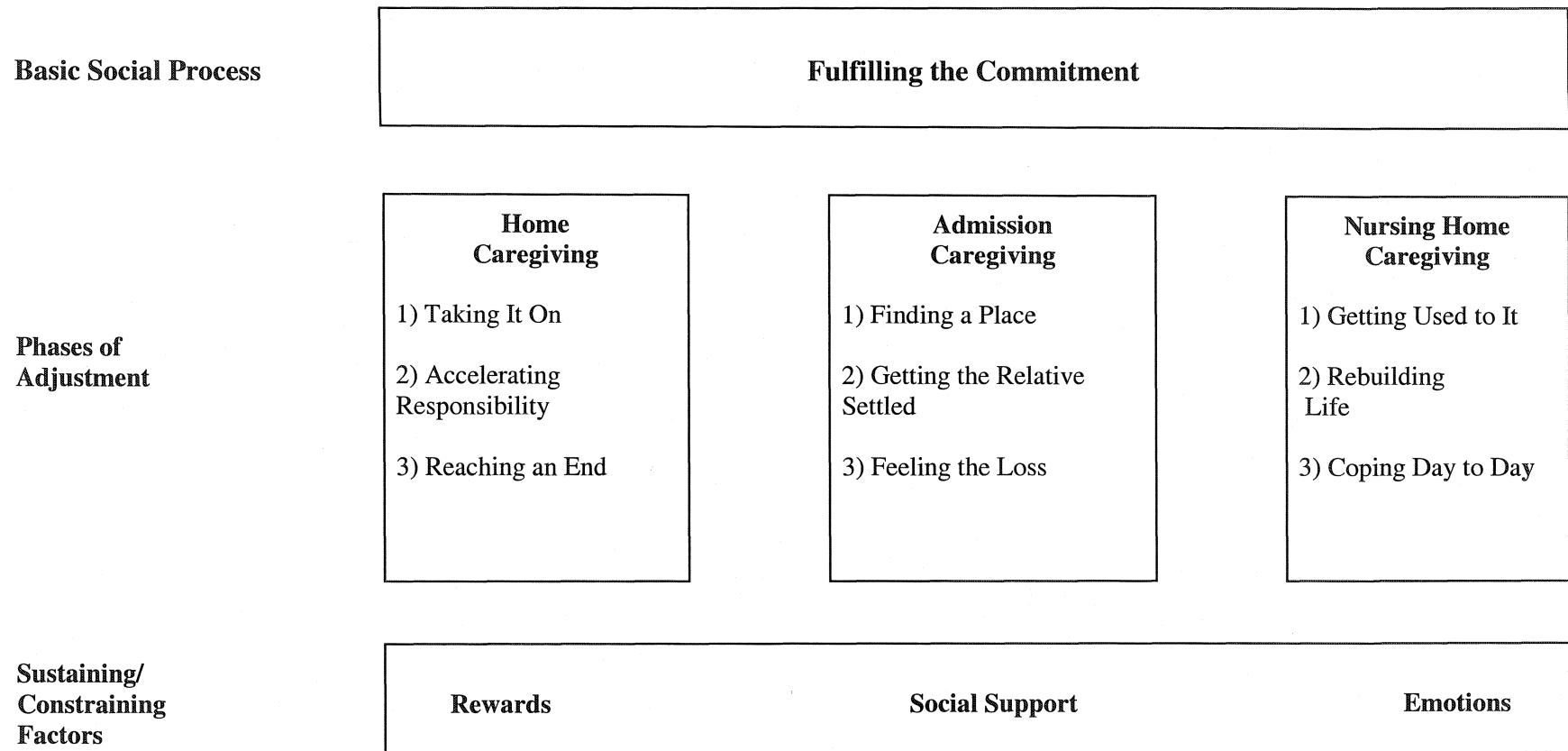


Figure 1. *The Adjustment Process of Primary Family Caregivers of Nursing Home Residents*

During the home caregiving phase, *taking it on*, *accelerating responsibility* and *reaching an end* explained the adjustments required by changing care needs as the relative's health declined. When taking it on, caregivers rationalized making the commitment and made the adjustments necessary to become caregivers. Accelerating responsibility adjustments were sudden or gradual as the care recipient's health deteriorated. Reaching an end signaled a turning point in the caregiver's ability to continue providing home care, the dimensions of which included a response of resistance or helplessness.

The adjustments of the second phase, admission caregiving, were *finding a place*, *getting the relative settled* and *feeling the loss*. The finding a place adjustment required the caregiver to choose a preferred location, while getting the relative settled included dimensions of facilitating comfort and appropriate care for the relative. During this phase, the final adjustment required caregivers to cope with the variety of acute emotions that were dimensions of feeling the loss of their relative.

The final phase of caregiving in the nursing home involved three adjustments: *getting used to it*, *rebuilding life* and *coping day to day*. The dimensions of getting used to it were accepting the situation, learning to continue the caregiving commitment in the new environment, and getting to know the staff. Rebuilding life required caregivers to find a balance between caregiving and their personal lives, such that they could refocus on their own health and personal interests. The final adjustment of the nursing home phase required the caregiver to find ways of coping day to day. The dimensions of this adjustment included keeping busy, taking their minds off the prevailing negative emotions, and living in the present.

Intervening conditions provided a context within which each adjustment was made throughout the caregiving experience. These conditions, *rewards*, *social support* and *emotions*, functioned to sustain or constrain the caregiver's passage from one phase to the next. Rewards, when perceived, were factors that provided role gratification. Social support was valued from family and secondarily, from health care professionals. Emotions challenged the adjustment process because they were heightened throughout the experience and predominantly negative. The caregiving process, including its phases, adjustments, dimensions, and constraining and sustaining factors, is outlined in Appendix F. Each phase is discussed in detail in the following section of the chapter.

Phase One: Home Caregiving

In describing the home care period, caregivers discussed the context within which they carried out their caregiving roles, including how they became primary caregivers and the characteristics, supports and stresses of home caregiving. They described the turning point reached when they were no longer able to provide adequate care at home and had to consider placement of their relative in a nursing home. This constituted a caregiving crisis because the need for action to diminish the burden of accelerating care requirements was constrained by the negative meanings placement had for caregivers. Their responses to the crisis demonstrated the internal conflict inherent in making the placement decision. The main adjustment processes of phase one, taking it on, accelerating responsibility and reaching an end are discussed in the following section.

Taking It On

The caregivers in the study all rationalized caregiving as a family responsibility for taking care of each other. As one caregiver said, "There's no alternative." They said this responsibility was derived from marital or filial duty, and the loving attachment they had to the care recipient. It carried with it a desire to meet the expectations of loved ones. Additional reasons for assuming the primary family caregiver role were availability and suitability.

Caregiving responsibility arose from the reciprocal nature of family relationships. Marital duty was described by a spouse who said, "I want to do the best I can for him," and another who said, "It just seems a natural thing [to do]." Filial duty was illustrated by a daughter who said, "She looked after us all our lives, now it's our turn." Caregivers also described responsibility arising from their affection for the relative, saying, "We were always very close." Family responsibility included a desire to meet the loved ones' expectations for care. One caregiver described her motivation as follows, "As long as I can . . . I would have her at home. She wasn't ready to go into a [nursing] home." Even after admission, one caregiver said of her dependent relative, "If he asked, I would have to . . . bring him home."

Participants identified availability compared to others in the family, either due to their personal circumstances or their proximity, as a rationale for becoming primary caregiver. One said, "I was retired, so I just made myself available." In two cases, family members moved home from outside the province to provide care. One of them said to her relative, "I'm able to do it. Would you like me to come home and stay with you?"

Proximity was identified as a rationale for caregiving by others, one of whom said, “She was living on the other side of our house.”

Suitability for the work as a reason for becoming primary caregivers was implicit in the comments of other caregivers. Among the respondents in the study, suitability for caregiving often seemed to be a gender issue. Frequently female relatives were considered most suitable. One female caregiver said, “I was the youngest girl and I was left with [the relative].” Another care recipient had a son living close by, but the caregiver said, “He wouldn’t stay with her.” One daughter explained her choice as caregiver by saying, “My sister . . . is not well . . . another sister died”, without mentioning the brother who lived in the same town as a possible candidate for the caregiving role. A male caregiver explained his role by saying, “I’m the only one in the family.”

Accelerating responsibility

Participants discussed how the relative’s care progressed from minimal to maximum support of daily living activities during the home care period. They identified their sources of support and the stresses of caregiving at home. Care requirements progressed slowly in most cases, but could change suddenly to maximum dependency.

Most participants experienced a gradual progression of their caregiving responsibility over a period of years. They started by providing assistance with instrumental activities of daily living such as home maintenance early in the experience, and progressed to total support for most activities including personal care by the end of the home care period. One caregiver described the early stages of caregiving, saying,

She was managing . . . using a walker, but we [she and her sisters] spent a lot of time with her. For almost a year, we had [home care] going in. . . . She fell and broke her hip We alternated sleeping at night and had [home care] during the day For three years we've really been caring for her.

Another caregiver described the early beginnings of his role by saying, "She used to come over and spend the winter months with us back in the early eighties." Others said the caregiving had been "coming on for a few years" or started "five or six years ago."

By the end of the home caregiving experience, most caregivers described responsibility for maximum support of their loved one. One caregiver said, "He couldn't be left alone . . . couldn't get out of bed on his own, couldn't go to the bathroom on his own. . . . I was up nighttime a lot." Another care recipient required extensive physical care and 24 hour supervision for dementia. Her caregiver described her responsibility as follows, "She has a colostomy. . . . She is in 'Pampers.' . . . I used to have to use a catheter four times a day to take water from her bladder. . . . Her short-term memory is very bad . . . I had to come down four or five times a night to check on her." In another situation in which dementia was a factor, a caregiver described her relative's needs by saying,

At home his mind was bad...always had to run after him He used to go out, used to say he was going to work. . . . I had to go get him in the car. . . . He wouldn't know where he was. . . . He didn't even know it was his home.

Two caregivers in the study described sudden dependence of the relative on the caregiver for total care. One said, "At home we provided very little nursing care. . . . Last

June she became ill . . . but up until that time she was looking after herself . . . her condition deteriorated fairly rapidly.” Another said, “She managed all right until this stroke.” In both of these situations, caregivers proceeded from minimal personal care responsibilities to a decision for placement in long-term care. As one noted, “It was obvious we couldn’t care for her at home.”

Caregivers who relocated to provide care in the relative’s home described themselves giving moderate to maximum personal care from the outset. One said,

I thought that when I came home to look after her, she was . . . going to her card games and everything. . . . Actually, I was only home a week when she went in hospital . . . and she had to have surgery . . . so from the time I came . . . four years ago, I was looking after her constantly in the house . . . 24 hours a day from the beginning.

Support during home care helped sustain caregivers in their roles. It was identified from three sources: family, community and physician. Caregivers talked about practical assistance, emotional support and validation received from immediate family and nearby siblings. Practical support was noted by caregivers with such comments as, “My husband’s gotten into cooking,” and “[Daughter-in-law] cooks the meals.” Another caregiver said, “Every time I had to call the ambulance, call the doctor, I always let my [sibling] know . . . [they] came [and] locked the house up.” One caregiver discussed the stress she felt without family support, saying, “It’s just that she needed 24-hour care and at home I didn’t have anyone else to help me, like no help at all.”

Caregivers felt validated and supported emotionally by family members. The value of the family’s agreement with the caregiver’s decisions was evident in comments such

as, “I talk to the family. . . . They understand . . . its all the difference,” and “[My children] feel I’m needed. . . . Its OK with them.” Emotional support from family was also important to caregivers who commented, “They were all . . . helping me just get through all of it”, and “There’s two of us [sisters] here . . . we cling together.”

Caregivers used community services such as home care, day care and respite care as a secondary source of support. Home care was a frequent option for the respondents in the study. They described their use of home care saying, “The summer before . . . I had full-time care during the week . . . 40 hours a week,” and “We had ‘Meals on Wheels’ and then we went to the home care program for a care worker to come in and help out . . . for about a year and a half.” Home care was used readily by most participants, but it was ultimately not enough support as care requirements mounted. This was noted by caregivers who said, “I had home care for nine hours a day, but then when she went home, I was alone,” and “It just got to the point where when she wasn’t there it was a problem.”

A day care centre was used in a limited way by two caregivers in the study. They described their use of day care as follows, “ He couldn’t be left alone, and . . . I got him to go over to the [day care centre] about six times” and, “If I wanted to go anywhere, wanted to go to the store, I had to go leave her at [the day care centre], you know.”

Some caregivers used respite care in a nursing home. One caregiver said, “I was having a difficult time at home with him so I had him booked for respite care. . . . He could stay for me to go on . . . holiday.” Another caregiver told her mother, “I’m going to put you down in the [nursing home for respite care] because . . . I need a break. I haven’t had a break in a year and a half.”

The family physician was a third source of support described by caregivers. They sought the advice of the physician when they felt stressed and reported that the physician often responded with a recommendation that the caregiver take a break by placing their relative in respite care. One caregiver said, “I went to see the family doctor and . . . he felt that I needed a break, so that’s when I put [the relative] in the [nursing] home for respite care.” Another caregiver described calling the physician when she felt very stressed. She said,

I had him booked for respite care but I had to call the doctor before. . . . The doctor came . . . and said, ‘My, you’re exhausted’ which I was, and I said . . . I have him booked for respite in March. . . . He said, ‘well, you can’t wait that long.’ . . . It was only a week when they called me from the hospital and said that he was being admitted.

The family of another caregiver urged her to call the physician to get something done about her stressful situation. She said, “They were saying, everybody knows that [the relative] needs more care, so that’s when we ended up getting an interview with the physician.”

Primary caregivers described escalating stress as the relative’s care requirements gradually progressed toward 24-hour dependence. Sources of stress were behaviours associated with dementia, worry about the relative’s safety, the strain of constant responsibility, and the physical demands of caregiving. These served as constraints in the caregivers’ ability to maintain home care.

The behaviours of care recipients with dementia were especially difficult. One caregiver said, “He was a demanding patient . . . [had] hallucinations.” Others were

stressed by wandering behaviour. One said, “He was getting up and getting out and we wouldn’t know.” The safety of relatives was an issue for other caregivers who said, “I always had to be checking on her . . . it was too big a worry,” and “She wanted her bedroom door closed . . . but I always left it open . . . so I could hear her. . . . I insisted that she don’t get out of bed because then I said, if you fall down and break something.”

The constant responsibility took its toll, as identified by some caregivers, “I couldn’t do what I wanted to do”; “With somebody that’s sick 24 hours a day, you’re never at ease” and, “It was just too much. . . . What was I going to do if I got sick?” Likewise, the physical demands of care created strain for caregivers, who said, “I got flu . . . lost weight . . . couldn’t cope”; “I got run down,” and “I got dizzy . . . I had problems breathing . . . it scared me. . . . I sort of neglected myself.”

Reaching An End

Primary caregivers described how their burden reached a turning point when the relative required constant care and supervision, particularly nighttime care which repeatedly interrupted the caregiver’s sleep. They described the increasing exhaustion that corresponded to increasing care demands. This brought them to a point where continued home caregiving was unsustainable. One caregiver said, “She was needing a lot more care than I was able to give.” Other caregivers talked of the exhaustion of nighttime care, saying, “I could cope daytime . . . but it was nighttime” and “We were up during the night with him and the next day . . . not getting any rest.” One summed up the dilemma of all caregivers, saying, “She needed 24 hour care which I couldn’t give at home.”

The turning point in home caregiving created by the exhaustion of prolonged 24-hour care, presented caregivers with a choice they were reluctant to make: continuing home care or seeking nursing home placement. One caregiver said, "It's not something that you would much want to do." They recognized that action was needed, that continued home caregiving would have potentially negative consequences for themselves and their relative, but they were constrained by their perception that nursing home admission would also have negative consequences. Their responses to the home caregiving crisis, resistance and helplessness, reflected the extent of their dilemma.

Some who sought short-term relief for their stress displayed resistance to the long-term implications of the situation. They consulted physicians and social workers seeking respite care, or chose options that delayed decision-making about long-term solutions. One caregiver who chose respite care said, "I couldn't bring myself to do it [decide about long-term care]. . . . I thought when I go back [after respite] he might have changed." When she finally made the decision about long-term admission and the health care professionals assured her it could be reversed, she said, "The decision wasn't written in stone . . . [that] made it easier to decide." Another caregiver chose a transfer to a 'transitional care' service when health care professionals advised her that long-term care was needed. She said, "No, I couldn't put her in care. . . . Put her on the [transitional care] floor for a while and see what happens." When the decision was imminent, she said, "My nerves got real bad. . . . I knew I couldn't keep going . . . [but] it seemed like I was letting her down." Resistance to taking steps toward long-term admission was expressed by another caregiver in the following way, "I was just kind of pushing it aside. . . . [The family] were saying . . . everybody knows it needs to be done. . . . I needed a lot of

pushing . . . [and] worried about how the rest [of her siblings] were going to feel about it. If I wasn't pushed . . . I'd still be there [providing home care]."

Helplessness in the face of accelerating care demands was the other reaction described by caregivers. Events tended to overtake this latter group whom often found home caregiving suddenly terminated by hospital admission of their relative. They then accepted nursing home placement that was recommended by a health care professional, as inevitable, feeling there was no alternative. Caregivers described their helplessness as follows, "It was obvious to us . . . and she knew it, too . . . the choice was almost made for us," and "I really didn't want to do it, but we had no choice . . . she was in hospital and they made the arrangements."

Participants also discussed intervening conditions which either sustained or constrained them in their decision-making, namely support of family and physician, the relative's acceptance of placement, their own sense of failure in their familial duty of care, and their sadness over the perceived loss of the relative to family life.

Family support was sought by caregivers to help sustain them through the decision-making crisis. One caregiver reported, "Me and my [children], we talked it over and figured it was a good place for her." Another noted, "I had support of two of my [siblings and] my husband said, do what you got to do." One caregiver's children and her sibling were a source of encouragement. She said, "My children, my [sibling] . . . were all telling me that . . . I can't do this [caregiving] now. . . . I really needed to do something . . . My [sibling] went with me." Lack of support was described in one family situation where siblings disagreed with caregivers about placement. The caregivers remained determined

that their decision was valid, saying, “If the rest of the family was going through what we were with him, they would know more about it.”

The physician’s validation of the need for placement was important to all caregivers as part of their decision-making process. Caregiver comments reflected the value of the physician’s support, such as, “It was obvious to him [physician] and us”; “Once we knew the doctor . . . could see things. . . . It wasn’t quite so hard.” Caregivers reported that at times the physician initiated the discussion of placement. One said, “She was in hospital and the doctor suggested that she was chronically ill and needed 24-hour care. . . . I wasn’t even thinking about . . . putting [the relative] somewhere.”

Anxiety about the dependent relative’s acceptance of placement was a constraint for caregivers, some of whom found ways to avoid direct responsibility for the process. One caregiver who used an assessment admission as an avoidance tactic said, “If I had said . . . you have got to go into a [nursing] home. . . . I would have felt more guilty.” Once the relative was in for assessment, she said, the decision “was taken out of our hands.” Another caregiver said, “We thought we were lucky . . . when they said a bed was available. . . . We were going to be gone [out of the province].” The caregiver’s sibling then took over the admission duties. Another sibling helped by being the one to broach the subject to the relative. Then, when the relative said, “Well, if . . . that’s what has to be,” it made the placement process easier than the caregiver had anticipated.

The caregivers’ sense of having failed in their familial duty of care was described as a constraint in making the placement decision. One said, “She used to always say to me, don’t ever put me in a [nursing] home . . . and I used to say, no . . . so I was on a real guilt trip. . . . It just seemed like I was letting her down.” Another asked herself, “Why didn’t I

try to keep her at home?” A third caregiver said, “Somebody will say, you can’t look after him at home? . . . This kind of gets to you.”

The caregivers’ reluctance to admit a relative to a nursing home was also related to their perception of placement as a loss to family life. They said, “It was a hard decision to make. . . . He wouldn’t be back home any more” and, “It’s hard because she lived with us for so long.” A spousal caregiver for whom placement came in mid-life said, “It’s really hard because your life changes. . . . You expect to be doing things together and . . . it’s all snatched away.”

Placement was also constrained for caregivers who felt that nursing home admission was a milestone signifying a final stage of life. It was seen as a last resort and a least desirable end to home caregiving, rather than a preferred choice for living. They said it meant “the end of the road,” and that, “life is coming to an end.” Some expressed the sentiment that nursing homes are “just places for people waiting to die” and said, “I hope I die rather than be admitted to a nursing home.” Thus, the decision to have a relative admitted to a nursing home was for many a necessary evil, not a positive solution to their caregiving crisis.

Phase Two: Admission Caregiving

Three adjustment phenomena marked the period surrounding admission of the caregivers’ relatives to a nursing home. First, caregivers had to find a suitable placement location and second, they had to get the relative settled into their new home. Third, caregivers had to live with their acute emotional reactions to placing their relative in care.

Finding A Place

Caregivers described making what choices they could to achieve a preferred environment for their relative. They selected the best physical surroundings possible, delaying the admission at times for better accommodation. Caregivers of those who required a protected environment for dementia care found they had the most limited choice.

Caregivers chose among facilities and preferred rooms within the facility of choice. They commented, “We looked at the other facilities. . . . The [nursing home] was the logical place”; “We waited until something came available here,” and “The family doctor suggested the [specific unit]. . . . I was totally against that. . . . The [nursing home] came up after, and we thought . . . that’s the better place.” Preferred rooms within a facility were also selected, as noted by one caregiver, “A room became available . . . one of those tiny little rooms downstairs. . . . We couldn’t accept that. . . . Three weeks later the room became available where she is now.” Caregiver’s choices were sometimes challenged by other family members, as noted by one caregiver, “One of her [children] was really upset . . . said we didn’t put her in a very nice place. . . . Then of course her [sibling] said . . . oh, don’t put her in [another nursing home] because it’s not nice there.” The caregiver responded that there are “not a lot of places, so . . . how can you please everybody?” Caregivers whose relative required a secure environment for dementia care had no choice but to go to the unit that was provided for that service. One caregiver seemed reassured by the security, saying, “At least we know he won’t get out here.”

Getting the Relative Settled

Caregivers described two dimensions of the settling-in process. These were facilitation of the relative's comfort and ensuring that appropriate care was being provided. They were sustained by evidence of the relative's acceptance of the new situation, the staff's positive response to their relative's needs and the relative's well-being. Deficiencies they saw in the institutional environment affected the initial adjustment of some caregivers.

Caregivers described the first aspect of getting the relative settled as an effort to achieve their relative's comfort in the physical surroundings and in interactions with other residents. Lobbying for improvements to the room and its furnishings was the focus in some situations. One caregiver said, "The room wasn't that nice . . . [it] really needed to be painted. . . . I even offered to go in and paint the room." Once the room was painted, she expressed satisfaction, not just for the relative's sake, but also for her own responsibility to answer to the rest of the family. She said, "Now when the family say the room isn't nice, I couldn't agree with them." Another concern was the type of bed. The caregiver said her relative "wanted an electric bed. . . . I kept after them until I got that."

Caregivers also took action to deal with situations in which they felt other residents' behaviour was potentially detrimental to their relative's safety or contentment. Changing the room so as to find a more compatible roommate was one initiative. One caregiver who felt the roommate's behaviour would be detrimental to her relative's well-being said, "I didn't want [her relative] in a room with this lady . . . put her in this environment, she's back in the old [home] environment again." Another caregiver intervened because the volume of the roommate's television disturbed her relative. She said, "I was upset because I knew my [relative] wasn't content in the room with that lady and I spoke to one

of the nurses.” After the relative was happily situated in another room, she said, “I felt better . . . that helped me a lot, just knowing that she’s settled and she’s content.” The relative’s contentment had a positive effect on the caregiver’s adjustment. In another situation, a neighbouring resident who wandered into other rooms was seen as a threat to the caregiver’s relative. She said, “It was not a good situation [for her relative] . . . so I mentioned it to the staff.” She was satisfied by the staff’s appreciation of her concern and their search for other accommodation for the person who was wandering.

Ensuring appropriate care for their relative was second focus of the caregiver’s attention in the early days after admission. They described a responsibility as primary caregivers to communicate the relative’s care needs to staff and to monitor the care provided. They identified uncertainty about what care they could expect and didn’t take appropriate care for granted. One caregiver said, “I used to say to the nurses . . . will you check her . . . make sure that she is not out of bed? . . . I wasn’t sure they would.”

Another caregiver monitored her relative’s signs of diabetic control. She said,

I had come in . . . around meal times and . . . her sugars must have been down. . . . She wasn’t able to eat because she was starting to get so shaky. I went and talked to them a few times about it . . . and they realized what was going on. . . . She needed to be watched more.

After the staff moved the relative to a place where she could be supervised during meals, the caregiver was satisfied. She noted, “She’s kind of settled right down now . . . and that’s why I’m thinking they watch her more.” The caregiver whose relative had suffered abuse made efforts to inform the nursing staff of the relative’s special needs. She said,

If [a particular family member] went into the room, you could see the difference in [her relative] when [the family member had] come out . . . so I said to the nurse . . . I want [the relative] watched this evening, and sure enough there was a big change in [the relative] . . . I knew because we'd been through it, but they don't understand. I'm not telling them how to do their job. I try to explain the environment [the relative] came from, that [the relative] needs them there.

She was gratified when one nurse said she stayed with her relative while the other family member was visiting and recognized her relative's need for support. She related that, "The nurse said, your [relative] looked up and held my hand and said, you staying here?"

Some caregivers found there were inadequacies in the institutional environment with which they had to reconcile themselves. These included lack of privacy, lack of specialized medical care, and inconsistencies in individualized dietary services. One caregiver concluded, "A lot of things you just learn to accept . . . adjust."

Privacy issues were related to having to share rooms. Some families felt their relatives' quality of life suffered from unwanted intrusion of other residents and families. One caregiver said, "There's two people in a small room . . . when they have company it just gets too crowded." Another caregiver whose relative was uncomfortable with the sociable attention of the roommate's [male visitor] said, "If she had a private room, I think she would be more comfortable." Other concerns voiced by caregivers were related to anticipated needs for privacy during critical family periods, particularly end of life situations. When asked if there was anything at the nursing home that troubled them, one caregiver said, "If she dies here, she's going to die in a room with somebody else and their company coming and going. . . . That is terrible."

Other inadequacies in services were concerns of caregivers, namely inconsistencies in meeting individual needs, and lack of on-site specialized medical care. A caregiver expressed frustration with menu irregularities, saying,

She's supposed to be on pureed [foods] . . . a lot of times that doesn't get through to the kitchen, [and] on her diet slips they have 'dislikes fish' and so many days the tray will come down and take the cover off and its fish. . . Then you realize the number of meals here, you know, you can understand it.

Lastly, medical services were a concern of another caregiver who said, "It bothers me here . . . that they have to get an ambulance if they have to see a specialist or anything."

Feeling the Loss

The emotions caregivers commonly described during the period surrounding admission of their relative to long-term care were loneliness, sadness, relief and for some, guilt. They were sustained in their adjustment to living with these emotions by rationalizing that their relative was safer, and that no one could keep up 24-hour care at home. Lack of acceptance by the relative and fear of other's attitudes about their placement decision negatively affected the adjustment in some circumstances.

Grieving caregivers described acute loneliness over the loss of the relative from their home life. One caregiver said, "It was really bad at first because I was alone You go home to an empty house." The emptiness of home without the relative was expressed by another caregiver, saying, "It was really lonely . . . first when you look over to her part [of the house] and she's not there . . . almost like when the children . . . went back to university. . . . We'd say everything is so empty." Others talked about the loss of

the person from their lives, saying, “I miss having her around,” and “[It’s] worse than losing a partner by death because they’re there, but they’re not there.”

Caregivers also felt great sadness that their loved one’s life had come to this final stage. At first some cried easily when visiting. They recounted, “First, when she went in there, before I’d go downstairs [to her room]. . . . I’d go in a room and cry ” and another said, “When she first came . . . I used to leave here [with] tears in my eyes.” Others verbalized their sadness saying, “It’s sad to see people go like that.” Their sadness was related to their helplessness to change the situation. Caregivers said, “It’s not your fault and you cannot fix it,” and “She’ll never see home again. . . . That makes me feel bad, but there’s nothing I can do about it.”

Caregivers found their feelings of grief were balanced by a sense of relief as the burden of care was eased, and as their relative showed signs of acceptance of the new living arrangement. Lessened physical strain was one aspect of relief experienced by caregivers. One said, “I have osteo[arthritis] and I had problems with my back and my shoulders. . . . Now I haven’t got to do things, only if I can do it.” More caregivers described a degree of relief from stress and worry. One said, “The burden is not nearly the same . . . 50% of it is gone,” and “I got part of my life back. . . . I’m not under stress all the time.” Another caregiver said, “At least we know that during the night he won’t get up and get away. . . . We haven’t got no worry . . . not like when [he] was home.”

Caregivers also identified increased freedom to do things other than caregiving, but qualified their freedom as partial. One caregiver said, “In theory it has freed us up somewhat. We’re not quite as tied down as we were before.” Those sentiments were echoed by another caregiver who said, “I’m still concerned . . . [but] if we want to do

something . . . it's easier knowing that she's not left alone." Still another caregiver said the responsibility had eased off, and explained this by saying, "If anything much is going on . . . they will call." Thus, after admission, as one caregiver said, they were "free to a point," rather than totally relieved of the responsibility for their relative.

The sense of relief was heightened for some caregivers by signs that their relative was accepting the new living arrangement. One said, "She kind of settled in . . . wasn't complaining . . . I thought she's definitely going to complain. . . . It worked out easier." Another caregiver said, "It would have been very upsetting . . . if she had wanted to come back home." Lack of acceptance by the relative diminished the relief initially for one caregiver. She said, "[Her relative] used to keep saying 'by the water' . . . her way of saying 'I want to go home.' . . . Hardest of all at first was when you leave, she coming to the door trying to get out, looking at you as if to say 'why are you doing this to me?'"

Some caregivers were burdened by a sense of guilt in addition to the feelings of loss they experienced. They described guilt for failing to maintain the relative at home. One caregiver said, "I wasn't willing to give up my life and my family's life for my [relative] but you feel guilty. . . . Everybody's got guilt because . . . she looked after us all our lives, now its our turn." Another said, "I used to feel guilt . . . well, just guilt that she was there." Being healthy when the spouse was not was a source of guilt for the participant for whom placement came in mid-life. This caregiver said,

I feel guilty because . . . I'm well and want to do things. . . . Some of my guilt is because I'm freer. . . . I'm not supposed to be enjoying myself and I guess that's the crux of the matter. . . . You wonder if people are saying, well [the caregiver] has [the relative] put in the [nursing] home and [is going] out [and] around [socially].

Lastly, some caregivers' guilt was related to worry about what the relative might think of them for their role in the placement process. One caregiver who felt she could justify not feeling guilty because she had done all she could for her relative at home was nonetheless worried about her relative's opinion, saying, "I don't think she's blaming me because she's here." Another caregiver was disturbed, saying, "I wonder how he feels . . . what he thinks. . . . Have I abandoned him?"

Phase Three: Nursing Home Caregiving

Respondents described three major caregiver adjustment processes during the weeks and months after the admission of their relative to a nursing home. These were: getting used to their caregiving role in the new environment, finding ways to live full and healthy lives that included caregiving, and learning to cope with day-to-day life. They accomplished these adjustments despite the constraints of living with persistent negative emotions. Factors that facilitated caregivers' adjustment during this period were the personal rewards of caregiving and the support of family.

Getting Used To It

Caregivers described three dimensions in the process of getting accustomed to caregiving in the nursing home. These included learning to accept the situation over time, developing ways to continue caregiving, and developing an effective and satisfying relationship with staff.

Several caregivers described acceptance of their situation as a simple factor of time. One caregiver at 7 months after admission said, "I'm used to her here now. . . . I guess you get used to it. . . . It just takes a lot of time." Others also found it easier as time

passed, one at 9 months post-admission said, "He's been gone a good while. . . . We're getting used to it." One caregiver at 8 months after admission acknowledged continued difficulty getting used to her situation, but said, "It was harder in the beginning. . . . I think it will get better as time goes on. I suppose it will."

Most caregivers accepted their circumstances with the resignation that they were powerless to change them. Some had more difficulty coming to terms with their situation than others. The caregiver for whom the spouse's placement came in mid-life said, "You have to accept what you can't change . . . so I probably will get to that stage," and later went on to say, "You know [it] in your mind, but its trying to get it in your heart. . . . It's difficult. . . . You expect your life to be different." Caregivers of older relatives seemed more able to accept their circumstances, although they did it with resignation and regret. One said, "I accept things as they are. . . . I don't know as much more can be done," and another said, "I kind of just resigned myself to the idea that it's the best thing." One caregiver identified her three steps to acceptance. She said,

It takes a year for the family to really accept. First, you got to accept that you put her in. Second, you got to accept you're not her family any more. The nurses are her family. Third is walking out. That's the three things you got to go through.

Some caregivers were philosophical about their situation, saying, "It's going to happen to all of us someday," and "After a while you realize that life goes on . . . and you have to, too."

Continuing the caregiver role was identified by participants as having two main foci. These were developing a visiting routine that satisfied the needs of caregiver and care recipient, and developing meaningful caregiving activities.

Visiting by the caregiver in the beginning stages after admission was frequent. Many called or visited several times a day, reassuring themselves of the relative's well-being. Caregivers said, "First when she went there, I would call every day and a couple of times a day," and "There's rarely a day I don't get over." Keeping up with what was happening was the purpose of daily visits for caregivers who said, "I always keep abreast of what's going on," and "When you're not there you don't know what really goes on." Over time, caregivers settled into a regular pattern that remained fairly frequent, varying from several hours daily to at least weekly.

Caregivers said the routine of their visits facilitated their adjustment by helping them get used to the new situation, satisfying their need and their relative's need for contact. One spouse who visited for most of every day said, "You feel like you'd be able to do something different but . . . you'd have to give up [daily visits]. I couldn't do that," and "If I didn't come in . . . she'd forget." Another caregiver who visited twice a day said, "It becomes a way of life. . . . You just get into a routine." Another daily visitor said, "If I don't go, I feel guilty." Other caregivers visited several times a week. One said, "I like to come and visit him two or three times a week . . . to see him . . . helps." Another caregiver who traveled from out of town said, "I come down on Monday and Friday now. . . . [Her relative] would like me to be here every day but that's a bit too much." The lowest visiting frequency was once per week, also by an out-of-town caregiver who

compensated for less frequent visits by staying longer. She said, “I try to go and spend the day, not just pop in and out.”

The second means of continuing the caregiving role was through finding satisfying ways to provide care. In addition to visiting regularly, primary caregivers augmented the staff’s care by variously feeding, doing hair and skin care, providing grooming accessories, clothing and ‘extras.’ One caregiver said, “The things we’ve done are because we want to do it.” In addition to feeding her relative twice a day, she said, “We cream her legs and her feet and do her hair. . . . You just feel you’re doing something.” Other caregivers said, “The main thing is to try to make her as comfortable as possible” and, “If I wasn’t here to help her, I don’t think she would eat very much.” Maintaining family relationships motivated another caregiver who described her role as her relative’s caregiver by saying, “When [another family member] was in hospital . . . I made a point of going over to bring [the relative] down to spend time with him [and] I always make a point to give a gift [at Christmas] from [the relative] to [the other family member].” Special occasions were important for another caregiver who, in spite of invitations from others, said, “I wouldn’t go too far away from her. . . I really wanted to spend Christmas Day with [her].”

Caregivers voiced a sense of obligation to continue their care of the relative and a conviction that they were best prepared among family members to fill this role in the nursing home. One said, “I am really her main caregiver because anything she needs, I always have to take care of. . . nobody else does. I don’t mind, I feel I know what she needs more than anyone else.” Another caregiver described her commitment and caregiving activities by saying, “[We keep her] dressed the way she should have been

dressed all her life . . . she has always done without for us . . . now its our turn to do for her.”

Developing a trusting and effective relationship with staff was a third dimension in the caregiver's achievement of comfort in the situation. Caregivers made efforts to get to know staff, develop a relationship and effective communication strategies. They were sustained in their efforts when they perceived that the relative's needs were being met, the staff were developing good relationships with their relative, they concurred with the nursing care plan and felt that communication with staff was reciprocal. The large volume of staff limited their adjustment efforts, as did communication problems.

Generally, caregivers held staff in positive regard, saying, “They seemed like a good bunch . . . do anything for you” and, “I think people over there are pretty dedicated.” However, participants revealed that comfortable relationships developed more easily for some than for others. One caregiver said, “I got no problems. . . . They're great,” while another said, “Some it's easier to talk to. . . . I'm not one that's really open getting to talk to people, so it might take a little while.” Caregivers identified the negative impacts of getting to know a large volume of staff with rotating schedules, saying, “There's not even the same ones when you come in. . . . There are always different shifts,” and “[They] keep leaving, then you see them again after 2 or 3 weeks.” The latter caregiver said its “easier to talk to people you know” and, at 5 months post-admission, he was “getting more familiar.”

Conditions that facilitated trust between staff and caregivers enhanced the primary caregiver's adjustment. Caregivers described the staff's positive response to their

relative's needs, the staff's development of a caring relationship with the relative, and their own concurrence with the staff's plan of care as facilitating their comfort with staff.

Meeting the relative's needs as perceived by the caregiver was a positive means by which staff demonstrated trustworthiness. One caregiver noted that because her relative had not fallen since admission, "I think the nurses are probably keeping an eye on her. At first I wasn't sure if they would or not, but I think they do." Another caregiver whose relative had been having problems with low blood sugar, and to whom the staff had responded appropriately, seemed to generalize that positive experience to other situations. She assumed, "If she wanted help and she had to buzz for them . . . they would come."

Caregivers were encouraged by positive relationships between staff and their relative. One caregiver said, "Staff are really good to him." Another said, "They're always very mindful." Strong relationships between staff and residents were equated with good care by one caregiver who said, "[She] is well liked . . . by all the nurses. . . . She gets along with them. She's getting good care." Consistency from staff in providing care enhanced trust for one caregiver, who said, "One [staff member] who's been there just about all the time . . . she's quite familiar with [her] because she sees her every day. The more staff know their patients I think the better . . . and the families, too."

A constraint in developing trust occurred for one caregiver when her female relative, who had dementia, had a disturbing encounter with a male staff member. She related that her relative had interpreted personal care as rape, and although she tried to rationalize what happened and downplay it, her relative continued to say that somebody did something to her. Despite discussing the incident with staff, the caregiver remained uneasy about it. She said, "It seemed like just the one time and I thought . . . she's just a

little old woman. Who's going to want to do anything crazy like that?" Her loss of trust proved very hard to regain even with conscious effort.

The caregiver's concurrence with the staff's plan of care is another factor identified as facilitating trust and caregiver adjustment. One caregiver said, "They think its good for her [to get up in a chair] . . . and I agree with them." Another caregiver demonstrated confidence in the staff's judgment when talking about how he took direction from the nurse, "The nurse said, come along [to his relative]. It's late. You go on . . . so that's what I had to do." Another caregiver appreciated the staff's understanding that her relative's inappropriate language, which she found embarrassing, was related to her condition. She said, "They obviously hear her but don't say anything." One caregiver was critical of care, and seemed distrustful when she commented, "You'd think they'd move him around [in his chair]." It disturbed her to see her relative sitting for long periods. She said, "I just have to . . . trust the system and hope he's being taken care of. . . . Sometimes that bothers me."

Some caregivers described deliberate actions taken to enhance their trust in staff. They talked about listening in on care being given, communicating with relatives of other residents about care, and maintaining a presence in the nursing home. One caregiver related how at the beginning of her relative's stay in long-term care, she "always came . . . at different times and they wouldn't know I was there. . . . I'd wait in the hall . . . and the way they handled her and talked to her . . . it was like one of us with her." She said, "Right from the beginning . . . [she] had a good feeling inside." Another caregiver told how she communicated with the family of her relative's roommate, and was gratified to learn that in their opinion, her relative was receiving good care. Lastly, another caregiver

ensured his relative's needs were met by staying in the nursing home for long periods regularly. He said, "Well, I was here most of the time. . . . If she wanted anything, she could tell me."

A final factor discussed by caregivers in developing effective relationships with staff was communication. They described using a variety of communication methods, ranging from regular personal contact and telephone calls to diary keeping. One caregiver described his direct communication method when he said, "I always touch base with whoever . . . have a chat." Others used telephone contact, one saying, "I will call if I don't get over." By contrast, another caregiver said, "I only speak to them about something if its something I really need to know about." One family used a diary and found it effective. That family caregiver said,

Everyone . . . writes down what she ate and what she was like that day. . . . Some of the nurses got into doing that, too. . . . We don't have to call in and say, well how did [she] do today. . . . We just walk in and there it is, written.

One caregiver, however, expressed frustration at lack of communication between staff about her care requests for her relative. She said, "I think the communication is put on her record . . . but its not followed through. . . . I feel the nurses are not trained to cope with the family."

Implicit in the establishment of satisfactory communication was an expectation by caregivers that it be reciprocal. Caregivers said they expected staff would notify them promptly of any problems or changes in their relative's condition. One caregiver said, "I put call-forwarding on so I can get calls . . . and they've got my cell number." Others'

expectations were described by another caregiver who said, “If something was wrong, they’re going to phone me.” Episodes when staff had not contacted the caregiver were a source of frustration. One said, “I’m her caregiver, so I should have been informed” when an incident happened with her relative. Another caregiver questioned staff when they moved her relative without notifying her. She said, “When I came in on Sunday, my [relative] was in that room. . . . I said, well, how come?”

Rebuilding Life

Caregivers described the adjustment of this phase as achieving balance between caregiving and other aspects of their lives. Dimensions of this process included balancing the relative’s needs and their own, re-establishing a healthy lifestyle, and pursuing interests outside of caregiving.

Striking a balance which suited them, between the relative’s needs and their own, was a step on the road to adjustment for caregivers. One caregiver who struggled with taking time for herself said, “I began to wonder if there was something wrong with me that I don’t want to be there all day long.” Other caregivers were in less conflict over their time commitment to caregiving. One caregiver said, “As long as my health and strength [remain], I’ll do it.” Pressure came from the children of one caregiver who said, “I think sometimes the kids think I’m too committed, that I should take some time off.” But she went on to say, “While she’s here, I’ll do this. . . . I don’t think there will be any change in our routine.” One caregiver had made concessions in caregiving to accommodate her personal needs. She said, “[My relative] would like me to be here every day . . . [but] I have things to do at home. . . . I need time for myself.”

After the stress that many caregivers experienced as they struggled with home care, the post-admission period became a time when they could re-establish their own health practices. One caregiver said, “Now I’m going to my family doctor . . . having all different tests. . . . I’m getting things looked after. . . . I’m feeling a lot better.” Others said they were “resting better.” One caregiver said, “I try to do something, go for a walk.” Physical fitness was a goal of another caregiver who said, “I’ve been going to the gym two or three mornings a week.” A second caregiver who regularly went to the gym, said, “I figure I’m the healthiest one in the family.”

Renewing acquaintances and resuming pleasurable activities were other avenues taken by caregivers as they integrated caregiving with former aspects of their lives. One caregiver said, “I go out to church . . . and meet people I went to school with.” Another said, “I gave up my music. . . . I took it up again just last month” and “I’m looking forward to skiing this year.” In the words of one caregiver, “You have to make a life as best you can.” A caregiver who had struggled with taking some time off from caregiving, said, “You realize we could do this for a long time. . . and not do things . . . not take a vacation.” She went on to say that with “prodding from my kids . . . and then my two [siblings] . . . I went [on vacation] for ten days. . . . After I came back, I thought, you know, [my relative] is fine and everybody managed.”

Coping With Day-To-Day Life

The main focus of caregivers as they adjusted to their new lifestyle was on living day to day. They faced each day constrained by persisting negative emotions and developed strategies for living in the present and keeping busy, which helped them focus on the tasks at hand. They also identified various aspects of their experience that

sustained them, namely the personal rewards of caregiving and the support of family. For caregivers, the future was on hold as they concentrated on the challenges of the present.

Persisting emotions of grief, loneliness, guilt and depression constrained the adjustment of some caregivers more than others. Grief over their family situation remained and resurfaced easily during the interview process, regardless of the time span from admission. Many respondents expressed their continued sadness and some were tearful, saying, "I don't cry anymore [when visiting]. . . . I'm crying now because I'm talking about it" and "This is silly [crying], I should be used to this by now."

Several caregivers expressed continued loneliness over the loss of their relative from family life. At 8 months, one respondent said, "It's a lonely life." At 12 months, another said, "Sometimes now I wake up at night and I think I hear her in her room."

Guilt persisted for a few caregivers. One caregiver at 8 months was still quite tortured by it, saying, "I still feel guilty and I know there's no reason for me to feel guilty. . . . I think I'm going to have to talk to somebody . . . try to come to terms with it." Another caregiver said that the relative was still asking at 12 months to be taken home at each visit. She said, "I still have that guilt."

Two caregivers identified periods of feeling 'down' at 10 and 12 months post-admission. One said, "It's a bit of a down time again. [She] has made the turn . . . then she rallies." The caregiver's mood went up and down with her relative's changes in condition. Another caregiver said, "Sometimes I do find myself, even right now, getting down."

Caregivers coped with daily life using a variety of strategies. They dwelt in the present rather than the future, kept themselves busy, and deliberately attempted to take

their mind off the emotional stresses of their situation. The majority of caregivers focused on a daily routine that sustained them. When asked about the future, they were reluctant to look ahead. One caregiver said the pattern of his life would remain “about the same.” Most said they would continue as they were for the length of time their relative remained with them, making comments such as, “While she’s here, I’ll do this.” Only one caregiver talked about future changes, as they related to the relative’s degenerative condition and its implications, saying, “When the time comes that [my relative] won’t know me . . . well, no good to stay all day.” Another caregiver consciously suspended decision-making about her future. She said, “When my [relative] is gone, that’s a decision I’m looking at.”

Several caregivers felt that keeping busy was the key to coping with their situation. One caregiver said, “I think it helps . . . to keep busy all the time.” Another said, “I can keep myself busy” referring to time occupied babysitting a grandchild. One other, who visited twice a day to feed meals and kept fit at the gym, said laughingly, “I figure I’ll need a hobby after I’m not doing this.”

Caregivers found value in deliberately thinking of other things and taking their minds off the situation with their relative. They accomplished this by distracting themselves with other activities. One caregiver said that getting a job “was the most important thing . . . getting my mind off it.” Another said, “Just get in a routine . . . [and] don’t think about it.” A third caregiver said, “My attention was going to other things . . . so I guess that probably did help.”

Caregivers found their ability to cope day to day enhanced by the rewards they received personally from caregiving, including the relative’s contented response. They looked for signs of the relative’s contentment as a measure of adjustment. If the relative

was happy, they were happy. If the reverse were the case, it added an extra challenge to the caregiver's adjustment. One caregiver who had been stressed by her relative's desire to leave when she was first in the nursing home said at 11 months, "To see her over there now, she's not stressed out, she's smiling all the time, I feel great knowing she's contented." Another caregiver said, at 12 months after admission, "Yesterday she was really happy." She noted that her relative's happiness made her own adjustment easier "because I knew she was more and more content." Another caregiver whose relative had dementia, was consoled by his relative's earlier understanding of the need for long-term care. He said, "I don't know if she's completely content over there . . . earlier when she could think things through, she knew she couldn't come back home." One other caregiver whose relative was discontent at 12 months, said, "I don't think she'll ever be content there. . . . It affects me but I just try not to dwell on it." She coped by continuing caregiving, keeping busy and trying to avoid thinking about her relative's unhappiness.

Other rewards for caregivers were small glimmers of recognition and signs of appreciation, which provided satisfaction and motivation to continue caregiving. One caregiver said, "At times she'll open her eyes right wide, like she just realized you're there." In a similar vein, a caregiver said, "When I went in, her eyes just still light up." Another said, "I think she likes to see me because she says . . . don't go yet." The ultimate reward for caregivers was exemplified in the comment of one caregiver who said, "So if my [relative] closed her eyes tomorrow, I did what I could."

Social support was also a significant sustaining factor as caregivers struggled to cope from day to day. A major source of support came from their families. Many expressed appreciation for the continuing presence of family members. They recognized

that all family members did not have the same understanding of the situation, and some were less supportive. They did, however, notice increased understanding over time and felt vindicated by it.

Support from the caregiver's nuclear family, that is, spouse and children, was present in all situations described by respondents. It was continuous from the beginning of the caregiving experience until the time of the interview, and included emotional and instrumental types of support. Varying levels of support were offered to caregivers from siblings. Most caregivers had at least one sibling who assisted with decision-making and provided emotional and practical support. In the post-admission phase of caregiving, siblings shared visiting duties. One caregiver said, "My [sibling] tries to get down on weekends [to visit]." Another caregiver said, "Now when I'm coming to the [nursing home], most days [a sibling] comes with me." Dissent about placement among siblings dissipated over time. At 11 months after admission, a caregiver whose siblings had been against placement, said, "I talk more to my family." She said, two of her siblings had been in to see their relative and said, "It's the proper place for [our relative], which was a big bonus for me." Another caregiver said her siblings "understand better now because they came to see him and he was confused."

Some of the caregivers whose extended families were not initially supportive, reported that most of them gradually came to accept the situation. Agreement about the need for placement was a source of support to caregivers. One caregiver reported that a distant relative initially said, "What did you do? . . . Your [relative] was good to you all these years, why did you take her away from [home]?" Months later the caregiver was relieved to have the same relative say, "She's just like the old [relative's name] back

again,” a sign to the caregiver that her relative recognized the positive effect of placement. Another caregiver noted with satisfaction that her distant siblings and extended family “wondered why she is here . . . [but] realize as time goes on that it was the right thing.”

Summary of Findings

The primary caregivers in this study, demonstrated a continuous commitment to providing for their dependent relative’s well-being throughout the three phases of the caregiving experience: home caregiving, admission caregiving and nursing home caregiving. Within each phase, they identified adjustment processes and sustaining and constraining factors that accounted for variations in the ease of their adjustment.

During the home caregiving phase, three processes were evident: taking on the caregiving role, accelerating responsibility, and reaching an end point. Availability and suitability were factors in the decision to become primary caregiver, but most importantly, it was a family responsibility for all respondents. Their passage through the experience varied with the progress of the relative’s deteriorating health. Caregivers were sustained by varying levels of family, community and professional support, and challenged by accelerating stresses. They all reached a turning point when the requirement for 24-hour care became unsustainable. Their resistance and helplessness in response to this crisis reflected their perception of the negative choices before them, that is, continued home caregiving or nursing home placement. Most were supported in their decision-making by family members and by the physician’s validation of the placement need. Their inability to continue at home forced caregivers to make the decision to have

the relative admitted to a nursing home, regardless of the negative connotations the move had for them. Nursing home admission signified a final stage of life and a loss to the family's life, and was experienced by caregivers as failure of the duty to provide care within the family. Anticipation of a negative reaction from the relative was an additional constraint in decision-making.

Once nursing home placement became inevitable, primary caregivers moved on to the second phase of their experience, caregiving in the period immediately surrounding admission. Adjustment processes in this phase involved finding a suitable location for the relative, getting the relative comfortably settled with appropriate care, and experiencing the perceived losses of placement. Constraints to adjustment during this phase were created by perceived inadequacies in the nursing home services and environment, uncertainties about available care, and the caregiver's emotional reactions to the end of home caregiving. As was the case during home caregiving, support from family members sustained caregivers during this trying phase of their experience. Many were also sustained by their relative's acceptance of nursing home placement.

After the caregiver was satisfied that the relative was adequately settled, the final phase of caregiving in the nursing home began. It was characterized by three adjustment activities: getting used to being caregiver in the nursing home; rebuilding a personal life that integrated caregiving with other activities; and learning to cope from day to day. Comfort for the caregiver in the nursing home was facilitated by the development of a visiting routine, meaningful care activities, and an effective relationship with staff. Many said these adjustments became easier with acceptance of their situation over time. A second adjustment was the gradual integration of caregiving responsibilities with the

other commitments and activities of the caregiver's life. Most caregivers were able to find a personally comfortable balance between the relative's needs and their own. They began to pursue other interests and social contacts, as well as healthier living, after having given priority to their relative's health during earlier phases of caregiving. A final adjustment was the challenge of learning to cope with day to day life. Caregivers lived in the present, leaving the future on hold while they continued their commitment to their relative's care. They were constrained to a degree by persisting grief over their loss and the relative's declining health, and found that focusing on the daily routines helped them get through it. They kept busy and kept their minds off their relative's situation as much as possible. As in other phases of the caregiving experience, they were sustained by family support. The personal rewards of caregiving were additional sources of support in this last phase of caregiving.

Fulfilling the caregiving commitment was the basic social process that emerged from the constant comparative analysis of interview data and linked the adjustment processes of each phase, explaining the variances in the caregiver's adjustment. Continuous commitment was evident from the often-insidious beginning of the caregiving experience through the stresses of home caregiving and the crisis of nursing home placement. Participants said it would continue until the natural end of the experience. Their caregiving was sustained by personal rewards and supportive relationships, and persisted despite the constraints created by the prevailing negative emotions that took a toll on each caregiver.

Chapter 5: Discussion

In this chapter the adjustment processes involved in fulfilling the family caregiving commitment to a relative who moves to a nursing home, as revealed in the current study, are related to reviewed literature. Several areas of the reviewed caregiving literature were found to be relevant. Middle-range theory development studies which provided explanations of the home caregiving and placement phases of the caregiving process contributed to development of the process defined in the current study, as did other studies of family experiences with placement of a relative in a nursing home, and of family roles and relationships in nursing homes. Additionally, literature about the caregiver's relationship to the care recipient, social support needs of caregivers, and emotional responses to caregiving contributed to understanding of some of the factors involved in the caregiver's ability to fulfill the caregiving commitment. There was considerable concurrence between the experiences of study participants and those described in the literature. However, the family caregiving process from its inception at home through the nursing home experience had not frequently been studied in its entirety. More information about the basic social processes, their dimensions, and the factors which influence the family caregiver's progress through the role adjustments of the experience would be helpful to health care providers. The findings of the current grounded theory study have contributed to existing knowledge of the nature and dimensions of the family caregiving process from its onset at home through the nursing home phase, and have identified factors that sustain and constrain family caregivers in the fulfillment of their role.

Grounded theory studies are conducted for the purpose of developing middle-range theories that explain human behaviour in various social situations (Chenitz & Swanson, 1986). The

personal meanings attributed to social interaction form the basis for individual behaviour (Morse & Field, 1995). Thus, a grounded theory approach suited the purpose of this study, which sought to explain the adjustment behaviours of primary family caregivers whose relatives were admitted to a nursing home. In addition, this investigation was intended to illuminate basic social processes involved in the evolution of the caregiver role and identify a core variable that could account for variations in adjustment behaviour among caregivers. The core variable identified was fulfilling the commitment.

In the remainder of the chapter, new insights about the adjustment process described by primary family caregivers as they fulfilled their commitment to their relative are discussed and related to reviewed literature.

New Insights

The primary family caregiving process was revealed as a series of role adjustments through three distinct phases of the caregiving experience, from the onset at home through the admission period to the continuation of the caregiving role in the nursing home. Schumacher (1995) characterized family caregiving as a series of transitions. Therefore, the middle range transition theory described by Meleis et al. (2000), and Schumacher et al. (1999), was examined for its relevance to the caregiving process described in the current study.

Most striking of the insights gained from primary family caregivers was the resolute commitment they demonstrated in fulfilling their responsibility to the relative. Other insights included the contribution of personal rewards and supportive relationships to the caregiver's success. Lastly, new insights were gained about coping strategies used by caregivers in meeting the ongoing challenge of negative emotions provoked by the experience. These insights and the

primary family caregiving process discerned from the current investigation are discussed in further detail and compared to relevant literature in the remaining pages of the chapter.

The Primary Family Caregiving Process

The study was proposed to identify the adjustment process of primary family caregivers after nursing home admission of their relative. However, it became evident during the interviews that the caregiver's adjustment was heavily influenced by the meanings and experiences of home caregiving and placement. An awareness developed that viewing the caregiving role from its onset could lead to a better understanding of the context within which nursing home caregiving adjustments occurred.

Thus, primary family caregiving was identified in the current study as a three-phase process which had an identifiable beginning in the home, a critical mid-point at placement, and a third phase with a foreseeable end in the nursing home. It progressed in linear and temporal fashion from home caregiving, to the caregiving required at admission, and on to the final nursing home caregiving phase. Progress in each phase was determined by the care recipient's changing health needs and the caregiver's resources for managing them. Within each phase, there were three role adjustments for caregivers. The adjustments of home caregiving were taking it on, accelerating responsibility, and reaching an end. Admission period adjustments were finding a place, getting the relative settled, and feeling the loss. In the nursing home phase, the caregiving adjustments were getting used to it, rebuilding life, and coping day to day. The dimensions of each and the factors which interacted to constrain or sustain caregivers, notably personal rewards, family support and negative emotions, accounted for variations in the caregiver's ability to fulfill their commitment to the relative.

Similarities have been found between the process identified in this study and those described by several others who have explored family caregiving as a process. Wilson (1989) focused primarily on the home caregiving process, while others centered their studies on the placement period (Dellasega & Nolan, 1997; Lundh et al., 2000; Penrod & Dellasega, 2001). Various aspects of each of these prior studies were compared to the current findings.

In the home caregiving period, the first adjustment identified in the current study was taking it on. The caregivers, who were children or spouses of the care recipient, saw their role as a family responsibility. Similarly, Wilson (1989), identified moral duty as a rationale for family caregiving. Her participants commonly took on the role as a last resort when there were no alternatives, whereas the caregivers in the current study described their motivation more positively. They attributed their decision to a loving relationship and to factors such as their availability and suitability compared to other family members.

The second adjustment of caregiving in the current study, was related to accelerating responsibility for care. Increasing care needs caused stress for caregivers when their resources were inadequate to meet current demands. Penrod and Dellasega (2001), described similar caregiver experiences in the first two stages of their process, called upsetting the status quo and deeming the situation inadequate. At this stage, the positive impact of stress-relieving professional intervention, which bolstered resources and provided caregiving respite, was noted in both studies.

The third adjustment phase of home caregiving in the current study, reaching an end, was characterized as a turning point in which caregivers reached a crisis of being unable to continue providing adequate care to their relative and were forced to consider other options. Caregivers in the study met the pending need to make a decision about placement of the relative in a nursing

home with resistance and a sense of helplessness. Giving up home care symbolized failure as a caregiver and the approaching end of the loved one's life. Many characteristics of this phase were similar to the experience of caregivers in corresponding phases of other studies (Dellasega & Nolan, 1997; Lundh et al. 2000; Penrod & Dellasega, 2001; Wilson, 1989).

Wilson (1989) talked of caregivers prolonging home care until they reached a breaking point, and characterized placement as the ultimate negative choice for which there was no alternative. In Wilson's turning it over stage, she emphasized giving up control and entrusting others as dimensions of the process. By contrast, caregivers in the current study discussed the placement decision more in terms of personal loss and failure. The meanings identified in both studies were in keeping with findings of Kellett (1999), whose hermeneutic analysis revealed five shared meanings of placement, including feelings of loss and failure as in the current study, and loss of control and a forced negative choice as identified in Wilson's study.

As in the current study, reaching the end was a stage identified by Dellasega and Nolan (1997). Compared to Wilson's (1989) study, Dellasega and Nolan noted that placement was not a universally negative experience, as it brought relief to many caregivers. A minority of caregivers in the current study also indicated that placement was the best or only solution, considering their relative's needs. These caregivers, although they expressed profound sadness, experienced less emotional turmoil than others in the study who felt guilty for failing to maintain home care.

The helplessness of the no-choice placement situation and the inevitability of the impending loss of the relative noted in the current study were echoed in the findings of Lundh et al. (2000). In their making the decision phase, those authors described caregivers' powerlessness and their feeling that they were letting the relative down, the same as several caregivers in the current study. In both studies, this often resulted in caregiver inaction, which lead to decision-

making about placement being initiated by others, namely health care professionals or other family members.

The second stage of the caregiving process in the current study was the admission period. The first role adjustment for primary family caregivers was the requirement of finding a place for the relative. Most caregivers chose a preferred environment among limited choices, sometimes delaying admission to wait for a better location. Lundh et al. (2000) described the same activity in their making the move phase. In addition, those authors reported that caregivers found the move less traumatic if the relative was in hospital, speculating that their separation had already begun. In the current study, several of the relatives were in hospital prior to admission to the nursing home, but participants did not indicate greater ease resulting from that type of transition.

The corresponding phase in a study by Penrod and Dellasega (2001) was called looking for a place. These authors noted the undesirable options of caregivers and reported that many felt pushed along by the system. These observations implied a sense of helplessness, as was expressed by several caregivers in the current study.

The second adjustment for caregivers during the admission period was getting the relative settled, during which they focused on facilitating comfort and appropriate care. As in the making the move phase of the experience reported by Lundh et al. (2000), caregivers first immersed themselves in the practicalities of getting the relative settled. Caregivers intervened to achieve suitable roommates and room furnishings, identified the relative's needs to nursing staff, and monitored care to reassure themselves of the relative's safety and well-being. Signs of the relative's adjustment and evidence of the staff's positive response to their relative's care needs eased their adjustment. Conversely, some caregivers' adjustment was constrained by worries

about roommate incompatibility; uncertainty about care provided; lack of positive responses from staff and institutional inadequacies, such as limited privacy and inconsistent service.

The most consistent similarities to these findings in other literature reports were found in the studies of Dellasega and Nolan (1997), and Lundh et al. (2000). Both reports spoke of caregivers' anxieties about quality of care. Lundh et al. reported caregivers having difficulty expressing their opinions to nursing staff about the relative's care requirements, many feeling ignored and wanting more influence over care. One participant in the current study complained of not receiving a positive response from staff when describing the relative's care requirements. However, most of the caregivers combined giving the relevant information to staff with monitoring activities, and were able to satisfy themselves that care was appropriate.

Participants in Dellasega and Nolan's (1997) study felt they needed more information about the care available. This finding was largely in contrast to the experience of participants in the current study, who seemed more interested in making sure staff knew what care was required and then monitoring staff to see that appropriate care was given. Like the participants in the current study, Dellasega and Nolan's caregivers used the care recipient's contentment as a gauge of the appropriateness of care and related that the relative's happiness was a positive factor in their own adjustment.

The third adjustment of the admission period in the current study, was feeling the loss. Caregivers experienced acute sadness, loneliness, and some relief of their burden at the time of placement. For a few, a sense of guilt was overwhelming. The emotional turmoil and ambivalence of this period was emphasized in all three studies that described the caregiver's adjustment (Dellasega & Nolan, 1997; Lundh et al., 2000; Penrod & Dellasega, 2001). In their making the move phase, Lundh et al. described caregivers being overwhelmed with negative

emotions and defined their ambivalence as resulting from contrasting feelings of increased freedom and great loneliness. Caregivers in the current study talked of having only partial freedom. All expressed significant sadness and loneliness at the loss of their relative from home.

In the current study, the guilt of caregivers was described as being primarily due to their failure as caregivers. Similarly, letting the relative down was a source of guilt described by caregivers in the study by Penrod and Dellasega (2001). For the respondents in Lundh et al.'s (2000) study, their guilt was expressed in self-accusation about their failure to maintain home care. A few participants in the current study echoed this sentiment, but more of the caregivers' comments in this study were efforts at self-justification.

The last period of adjustment for caregivers in the current study was during the nursing home stage of the process. The caregivers' first adjustment was getting used to it. This involved reaching a state of acceptance, finding ways to continue caregiving by developing a visiting pattern and meaningful care routines, and getting to know and trust staff.

Accepting the new situation took time and was accomplished by caregivers in the current study with resignation that no other course was possible. It was accelerated by a fatalistic attitude that life goes on and dictates one's course, and constrained for some by evidence of the relative's lack of acceptance, and their own persistent emotional turmoil and guilt. One caregiver in the study had difficulty accepting the fate that interrupted expectations of a future life into old age with the spouse. However, most participants in the study did reach a degree of peace with their circumstances. The only reference to this psychological dimension of adjustment found among the descriptions of caregiving process reviewed was in the study by Dellasega and Nolan (1997). These authors noted the difficulty many caregivers experienced in accepting their decision to place a relative in care, and identified rationalization of the move as their only alternative, and

recognition of the relative's contentment as factors which facilitated their acceptance of the situation.

Development of a new pattern of caregiving in the nursing home was commonly identified during this phase of adjustment in the current study and in those reviewed in the literature. Lundh et al. (2000) called this phase reorientation and stressed the caregivers' continued active involvement, as did Penrod and Dellasega (2001), in their corresponding phase called redefining the caregiver role. Caregiving changed form but did not cease, as was the experience related by caregivers in the current study.

Getting to know and trust staff, a dimension of getting used to it in the current study, was not identified specifically as an adjustment for caregivers in other references. Lundh et al. (2000), talked of caregivers at admission feeling ignored by staff, but did not indicate evidence of a relationship developing over the course of the nursing home period. Ryan and Scullion (2000a), in their qualitative study of staff and families in Ireland, explored perceptions of family roles in nursing homes. They noted that families trusted technical care to nurses but felt themselves better able to provide social and emotional care. In contrast, several caregivers in the current study were reassured in their trust of nursing staff by evidence of emotional bonds developing between their relative and the staff. Although a few caregivers in the current study felt constrained by the large volume of staff they encountered, and one by communication breakdown, most were able to establish effective communication strategies and a sense of trust that their relatives were getting appropriate care. They were sustained in this adjustment by the relative's positive adjustment, concurrence with the nursing care plan, and the experience of reciprocal communication.

In the current study, the caregivers' second adjustment in the nursing home period was an effort to rebuild their lives after the all-consuming experience of home caregiving. They sought to achieve a balance between the relative's needs and their own, to regain their own health, and to renew social and recreational interests. These activities during the nursing home period were commonly identified in other study reports. Lundh et al. (2000) described a reorientation phase when caregivers renewed social contacts, resumed normal life and rediscovered their self-esteem and self-worth after the emotional turmoil of placement. Dellasega and Nolan (1997) talked of a new beginning in which caregivers began to take better care of themselves and were able to take a holiday. This rebuilding life phase in which responsibility for the relative's well-being is maintained but is balanced by other personal priorities seems a common sign of positive adjustment among caregivers. In fact, Lundh et al. felt unsuccessful adjustment was evident when caregivers were unable to move beyond their day to day dedication to the relative in the nursing home and felt life was effectively over for them as well as their relative.

Coping from day to day was the last adjustment identified among caregivers in the current study. They coped by focusing on the present, deliberately keeping busy and taking their minds off the sadness of their relative's situation and its inevitable outcome. While most achieved a satisfying sense of balance in their personal lives, they continued to maintain frequent contact and caregiving activity with their relative. Their focus was on getting through each day. They developed a routine and avoided contemplation of the future. Other reviewed sources that have defined family caregiving processes have not reported coping strategies of caregivers. However, an investigation of chronic grief among caregivers by Lindgren et al. (1999) described looking to the future as a threatening experience for caregivers because of the anticipated losses it entailed. Additionally, in their description of a middle range theory of chronic sorrow, Eakes, et al. (1998)

described keeping active and taking one day at a time as positive strategies for coping with the ongoing sadness of caregiving.

Throughout the caregiving experience, caregivers in the current study were sustained by personal rewards and family support. No studies were found which described caregiver rewards as sustaining factors for role commitment. However, Wilson (1989) did note the value of family support during the taking it on stage of family caregiving. Other reviewed studies of caregiving process did not specifically identify family support as facilitating the caregiver's role. In contrast, Penrod and Dellasega (2001) identified a prevailing sense of isolation among caregivers in their study, whereas most participants in the current study expressed appreciation of the validation and emotional support they received from family members. Dellasega and Nolan (1997) mentioned the value of spiritual support during the new beginning stage of caregiving, and others made recommendations for professional support (Lundh et al., 2000; Penrod & Dellasega, 2001). However, despite these recommendations, Lundh et al. maintained that the support needed by caregivers has been a neglected area of investigation. Knowing more about the value of personal rewards and family support, as identified by participants in the current study, would be a useful first step toward a better understanding of factors which sustain the caregiver role.

Family Caregiving As A Series Of Transitions

Schumacher et al. (1999) have defined transitions as passages from one stage, state, subject or place to another. These are usually precipitated by marker events that create profound change and require new patterns of response. As such, the family caregiving role can be seen as having multiple transitions from its acquisition stage throughout the many adjustments required as the

care recipient's health deteriorates. With reference to the transition theory described by Meleis et al. (2000) and Schumacher et al., the current study contributes to knowledge about the critical events and sequential patterns of caregiving transitions, conditions of transition which affect progress, patterns of response that effect role change, and indicators of successful outcomes of transition. Each of these transition theory dimensions will be discussed in relation to findings of the current study.

Each adjustment in the three phases of caregiving in the current study marked a critical transition in the caregiving process, the successful navigation of which was necessary to move forward. The experience flowed sequentially from the taking it on phase through accelerating responsibility to the crisis of reaching an end at home. Then in the admission phase, caregivers went through finding a place and getting the relative settled, while feeling the loss. In the last phase in the nursing home, three transitions were required: getting used to it, rebuilding life and coping day to day. The pace at which caregivers moved through these phases was variable.

According to Schumacher et al. (1999), conditions in the situation affect movement through transitions by facilitating or inhibiting progress. Facilitating conditions are customarily personal, community and societal resources (Meleis et al., 2000). In the current study, personal resources such as a sense of duty, and personal rewards such as satisfaction gained from the relative's positive response, provided motivation and facilitated progress, as did support of family and health care professionals who constitute community level resources in Meleis et al.'s theory. Society level resources applied to the caregiving situation would include expectations of the culture that family members, specifically women, become caregivers, as well as the increasing emphasis on home care by government policy makers (McKeever, 1996; Montgomery, 1999). Predominant inhibitors of caregiver adjustment in the current study were

negative meanings and emotions associated with placement, and the impending loss of the relative from the family.

Patterns of response designed to effect role change, as described in the transition theory of Meleis et al. (2000), can be identified among the dimensions of each adjustment phase in the current study. An example is the psychological rationalization required to take on the primary caregiver role, justify admission of the relative to the nursing home, and cope with day to day life throughout the nursing home period. The physical and social changes required to make role transitions are other examples. These occurred at home as care requirements changed and new skills and resources were needed, and during the admission period when finding suitable accommodation and developing new relationships with staff were necessary to ensure adequate care for the relative. They were evident in the post-admission period in the nursing home when, in order to continue meeting the caregiving commitment, the caregiver had to find new ways to provide and monitor care, and to develop new patterns for day-to-day life.

Meleis et al. (2000) identified Indicators of successful outcomes of transition as mastery of skills and behaviours required in the new situation, and reintegration of identity. During the taking it on stage of the current study, these competencies and identity changes were acquired smoothly by most participants when adequate personal resources and support were present. Caregivers experienced inadequate resources to continue caregiving as care demands increased, threatening their sense of mastery and identity, and forming a basis for the crisis of the reaching an end phase. Physician support for decision-making was an added resource that assisted caregivers and their families to get through this so-called marker event (Meleis et al.). In the admission period, the sense of mastery and identity were slowly regained, augmented by the caregiver's early successes ensuring the relative's well-being in the new environment. Acute

emotional turmoil threatened to limit the caregivers' ability to mobilize personal resources when they were coping with the getting the relative settled transition. In the nursing home phase, mastery and identity were restored more fully as caregivers redefined their roles and achieved a new sense of balance in their lives. The connectedness described by Meleis et al. and Schumacher et al. (1999), as a process indicator of successful transition, could be seen in the current study in the caregivers' achievement of satisfying relationships with the relative, family and staff. This accomplishment by caregivers was a significant facilitating factor in achieving satisfaction with their new role in the nursing home. From the perspective of transition theory, such role satisfaction would be a measure of subjective well-being and thus, successful role transition.

The Commitment Of Primary Family Caregivers

Care recipients in the current study had highly committed caregivers, in contrast to the "myth of abandonment" of older relatives that prevailed during the growth of the nuclear family in the middle years of the last century (Brody, 1985; Penrod & Dellasega, 2001; Ross et al., 2002). The temporal perspective of the caregiving process gained in this study highlighted the enduring commitment of primary family caregivers. From this longer view of the caregiver role, four distinguishing features became clear. First was the value attached to the family duty of care; second, the strength of the bond between the caregiver and care recipient; third, the predominance of women relatives in caregiving roles; and fourth, the tenacity of primary family caregivers despite excessive physical and emotional burden. A review of relevant literature provided further insight into these aspects of family caregiving.

Caregivers in the current study took on their roles primarily because they felt it was a family responsibility. Literature was found that supported the value of the caregiving function to the integrity and continuing development of families in our society (Friedman et al., 2003; Greenberger & Litwin, 2003). The latter authors said, "Fulfillment of the caregiving role is considered a natural, necessary and meaningful part of family obligation and part of the value system" (p. 339). The sense of caregiving commitment was present in children as well as marital partners in the current study.

Filial duty is said to arise from the reciprocal nature of the parent/child relationship (Brody, 1985). Brody attributed the commitment of children to their parent's care to a sense of obligation to return the care they received from the parent. Kelley et al. (1999) identified ongoing commitment to caregiving as a desire to be faithful to a family duty. This duty was expressed by several caregiving children in the current study who commented that it was now their turn to provide care for their parent. There was no dissonance about commitment among the child caregivers in the current study. Their faithfulness was indicated by their stated intention to continue caregiving in the nursing home as long as their relative remained alive.

Spousal duty reflects a traditional view of lifelong marital commitment. Ross et al. (1997) reported that wives' regular visits to their spouses in nursing homes arose from a sense of duty, devotion and obligation. Their commitment was similar to that of the elderly spouse in the current study who still spent many hours every day in the nursing home after 16 months. By contrast, the middle-aged spouse in the study at 8 months post-placement felt more conflict between duty to the spouse and a desire for freedom. This caregiver felt guilty if not visiting every day but reported spending less time in the nursing home as time passed. A minority in the

Ross et al. study was reported as having a similar experience, but reference was not made in their study to any age difference among spouses with varying commitment.

Caregivers in the current study described a loving attachment to their relative as a rationale for their commitment. The intense and enduring emotional bond between caregivers and care recipients has been identified frequently (Penrod & Dellasega, 2001; Ross et al., 2002). Friedman et al. (2003) in a discussion of role theory, described the reciprocity of roles, noting that because one role is always complemented by another, a strong bond develops between two people with interrelated roles. Those authors believed that in caregiver/care recipient relationships, reciprocal affection functions to maintain the caregiver's commitment. In her description of caregiving role acquisition, Schumacher (1995) also identified a two-way relationship of shared attachment and obligation. Friedmann et al. (1999) saw emotional bonding was seen by as the key to satisfactory caregiving. Further, emotional involvement contributed to the personal motivation of caregivers in the view of Duncan and Morgan (1994). They described the caregiving commitment as caring about the person, in addition to caring for the person. Maintaining the bond with the relative was offered as a rationale for continued commitment by Kellett (1996) and Lundh et al. (1999). Kellett also identified motivation for some caregivers as arising from a fear of being forgotten. One caregiver in the current study expressed this latter sentiment. That caregiver had fears that the relative who had dementia would forget without the caregiver's daily visits.

The predominance of women in caregiving roles was evident in the current study and is supported as a phenomenon in the literature (Brody, 1985; Friedmann et al., 1999; Kelley et al., 1999). Their greater involvement with caregiving has been explained as the traditional role of women in families. Women are described as the health leaders, nurturers and caregivers, and the

ones charged with preserving family relationships (Friedman et al., 2003). In the current study, several caregivers described their efforts to maintain connections between the care recipient and other family members. Because women have been socialized as caregivers, Brody et al. (1990), in reporting the emotional effects of institutionalization of a relative on caregiving sons and daughters, said that daughters have higher expectations of themselves and often suffer more negative emotional effects than sons. Certainly, in the current study, the male caregivers expressed continued sadness about the fate of their loved ones, but did not display the more turbulent emotions of some of the women who cried during their interviews as much as 12 months after placement. Three women caregivers in the study also suffered from lingering guilt about placement, whereas the men seemed more reconciled to placement as the logical or best choice for care, given the relative's needs. Thus, although the feminist movement has influenced society for almost half a century, the essential role of family nurturer and caregiver would seem to remain securely in the domain of women.

Lastly, the tenacity of primary family caregivers despite notable burden was obvious in this study. The majority lived with 24-hour care responsibility for months or years, and all pledged to continue a lifestyle that gave prominence to their caregiving commitment for the duration of the nursing home period. In their study of caregivers, Greenberger and Litwin (2003) reported the coexistence of burden and competent caregiving, given adequate personal resources and social support. Their findings contributed to understanding the behaviour of the majority of caregivers in the current study who continued their commitment, often in circumstances of extreme stress at home, and maintained a frequent regular presence in the nursing home despite the emotional burden they carried. Greenberger and Litwin's study also contributed to understanding caregiving behaviour from a transition theory perspective. It enhanced knowledge of the

resources needed to facilitate role mastery, a factor in successful transition throughout caregiving.

Rewards Of Family Caregiving

Fulfilling the commitment was sustained in part by the personal rewards of caregiving. Caregivers in the current study made reference to facets of their role that were rewarding. These were the relative's positive response to the caregiver, satisfaction with their contribution to the relative's contentment and well-being, and success in achieving a sense of balance in their lives, which allowed them to continue their caregiving commitment.

Many of the dependent relatives in the current study were unable to express their gratitude, but even the smallest response that showed the care recipient's awareness and pleasure in the caregiver's presence was rewarding to the caregiver. Several authors have identified continuation of the relationship with the care recipient as a rationale for caregiving commitment (Lundh et al., 2000; Ross et al., 1997). However, only one reference for the particular dynamic of responsiveness in caregiver/care recipient relationships was found in reviewed literature. Friedman et al. (2003) described the value of reciprocal appreciation for preserving the bond between caregiver and care recipient. In light of this, the results of Ross et al. are of interest. Those authors found that wives whose institutionalized husbands had cognitive impairment were more inclined to focus on other aspects of their lives than visiting, compared to those whose husbands were cognitively well, but physically impaired. By contrast, although all but one care recipient in the current study had some degree of dementia, its presence wasn't identified as a factor in the frequency of caregiver visits. One exception was a caregiver who speculated that visiting duration might decline when the care recipient no longer recognized the caregiver.

Viewing visiting behaviour from a responsiveness/reward perspective could contribute to a better understanding of the dynamics that facilitate continued caregiving commitment.

Caregivers in the current study were rewarded in their role by evidence of the relative's well-being. Ross et al. (1997) noted that caregiving spouses who were able to make their partner happy felt useful. Conversely, they were less satisfied with visiting when the partner was not content. The contentment of the relative was a clearly expressed goal of most caregivers in the current study, and was associated with their own role satisfaction. They viewed their ability to facilitate the relative's sense of well-being as a sign of their success as caregivers. The fact that caregivers defined personal success by the achievement of the relative's contentment and well-being in a situation where the relative's health and well-being would predictably deteriorate, constituted a central paradox of the caregiving role with older persons.

Mastering the caregiving role and balancing its demands with other aspects of their lives was an achievement caregivers spoke of with satisfaction in the current study. Friedmann et al. (2003), identified the importance of successful role performance in achieving satisfaction. Also, role mastery and reformulation of identity were listed as indicators of successful role transition in the middle-range theory of Meleis et al. (2000). In the current study, achieving success in balancing caregiving and other life roles was viewed as a personal achievement that facilitated continued role performance.

Supportive Relationships

Family caregivers relied heavily on social support, primarily informal support from family members, and secondarily, formal support from health care professionals. The significance of social support for health and well-being was verified by its adoption in 1984 by the World Health

Organization as a major health promotion strategy (Stewart & Tilden, 1995). While instrumental support was valuable to caregivers in many practical ways in the current study, they talked most about the importance of emotional support and validation in sustaining them through the adjustments of the caregiving experience. Some related the added stresses they encountered from lack of the family's understanding and support of their caregiving decisions. A number of literature references to caregiver support added to the insights gained from caregivers in the current study.

Study participants related positive and negative examples of support from family members. It was also evident in the study that, while the majority of caregivers used some home care or other community support, a few did not. They all acknowledged the supportive value of professional validation of the need to place their relative. The investigation of Wuest et al. (2001) into connected and disconnected social support of caregivers identified factors that may have contributed to variations in support attained by caregivers in the current study. Wuest et al. described the critical significance of the caregiver's perception of helpfulness of available support as a factor in its use. They also reported that many women caregivers are reluctant to relinquish responsibility for caregiving to others. Clearly, the caregivers in the current study found various kinds of support from close family members, and validation of their placement decision by the physician helpful as they pursued their role. It may be that their varying use of community resources such as home care, day care and respite care was related to perception of these supports as helpful or non-helpful, and/or to a reluctance to share caregiving responsibility. Further investigation of such questions could contribute to the ability of health care providers to better support caregivers.

Family support was valued by study participants throughout the three phases of the caregiving experience. Wilson (1989) stressed the importance of family support to caregivers of a relative with Alzheimer's dementia in her theory of family caregiving. She said family support helped caregivers exercise an unburdening strategy during the taking it on stage of caregiving. Unburdening to others helped caregivers come to terms with the reality of their situation. Sharing the burden was also an important function of social support in the view of Kelley et al. (1999). These authors identified social support from family members as a modifier of stress for caregivers. Several caregivers in the current study talked about the value of having a family member to whom they could talk and who understood their situation, saying it made all the difference.

Family support was also important for the placement decision, according to Ryan and Scullion (2000b). In their qualitative study of 10 caregivers, the agreement of family members was an important support for caregivers, many of whom felt alone with the decision-making responsibility. The value of decision-making support was also identified in the work of Neufeld and Harrison (2003), who reported conflicts over care decisions as one of the main types of negative interactions that contributed to non-support of the caregiver. The distress created by disagreement over the placement decision, and conversely, the relief of family agreement, were evident in the stories of caregivers in the current study.

Formal social support from health care professionals was appreciated during particular periods of the caregiving experience in the current study. All caregivers reported the physician's validation of the placement decision. The value of this professional support was reiterated in many literature references (Kellett, 1999; Lundh et al., 2000; Penrod & Dellasega, 2001; Ryan & Scullion, 2000b). Lundh et al. noted that the placement decision was often expert driven, which

coincided with the experience of some participants in the current study. Those authors went on to say that the professional's validation legitimized the caregiver's decision. Such a sanction reduced the stigma of placement according to Ryan and Scullion, and was important for successful caregiver transition in the early post-placement phase, in the view of Kellett (1999).

Supportive relationships between staff and caregivers in the current study were evident in comments about the nursing home period, although most caregivers did not articulate their relationship with staff in terms of personal support. They talked more about making sure staff knew what care their relative required and finding ways, through monitoring and communication to reassure themselves of their relative's well-being. However, the ability to communicate their needs effectively to staff and be reassured of their relative's well-being implied development of a relationship that provided support for their caregiving role. Much of the reviewed literature extolled the need for shared care and partnerships between family caregivers and staff (Duncan & Morgan, 1994; Janzen, 2001; Kellett, 1999; Ryan & Scullion, 2000b). Little desire for this type of relationship was evident in the views of participants in the current study, short of their expressed wish for adequate communication about the relative's condition. Further investigation of the caregiver's preferences and perceptions of effective relationships with staff could add clarity for health care professionals who must build relationships with many family caregivers.

An expectation for reciprocal communication was implicit among caregivers' reported experience in the current study. Several were reassured by their belief that staff would notify them of any problems. The stress of communication difficulties was evident among a few who had problems relating to the high numbers of staff and for one who was distressed by perceived lack of communication among staff about the relative's care needs. In their study of family caregivers and nursing home staff, Ryan and Scullion (2000a) identified an imperative for

reciprocal communication. Janzen (2001) also identified two-way communication between staff and family caregivers as essential for caregiver effectiveness in the nursing home. Janzen stressed the staff's responsibility to support family caregivers. She suggested one mechanism for support could be the development of specific communication strategies between a family caregiver and staff. Negotiation of a workable relationship between staff and caregiver was a strategy suggested also by Walker and Dewar (2001) as a means of removing barriers to caregiver involvement in the nursing home. The current findings and reviewed literature emphasized the supportive value of a negotiated relationship between staff and caregivers for facilitating effective communication.

The value of social support to caregivers is underscored by the findings of Greenberger and Litwin (2003), who identified indicators for caregiver facilitation of care. Among their observations was the positive correlation that existed between social support and caregiver competence. This relationship, when viewed in the context of the current study, could explain the contribution of social support to the caregiver's ability to fulfill the caregiving commitment.

Coping With Negative Emotions

The overwhelmingly negative and prolonged emotions experienced by caregivers in the current study, as a result of the significance of the placement decision and the relative's declining health, seemed to be universal considering the uniformity of descriptions found in the reviewed literature. Caregivers have been reported to experience ambivalent and turbulent emotions, such as relief and guilt, sadness, loneliness, loss and failure (Dellasega & Nolan, 1997; Kellett, 1999; Lundh et al., 2000; Nolan & Dellasega, 1999; Nolan et al. 1996; Ryan & Scullion, 2000b). Lundh

et al. declared that caregivers were never free of negative emotions. Rather, in the view of Ryan and Scullion (2000b), emotional distress was present long after placement.

Lindgren et al. (1999) characterized the prolonged grief of caregivers whose relatives had dementia as a reaction to loss of the future. Their study of caregivers showed that so-called non-death grief persisted throughout the caregiving experience. In keeping with these findings, many participants in the current study expressed loss of the future with their relative as a source of grief. They also talked about their sadness after placement due to loss of the relative from their daily lives. Lindgren et al. reported that caregivers' negative emotions of anger and guilt were inversely related to satisfaction with their relationship with the care recipient, and speculated that for caregivers, the grief that accompanies the losses of dementia may be related to loss of hope for future repair of an unsatisfactory relationship. In the current study, the participant who had the most debilitating guilt was a spouse who lamented losing a future with the marital partner. In contrast to Lindgren et al.'s proposed rationale for guilt, the marriage relationship in the current study was described as good. The source of guilt and grief was explained as the freedom of the caregiver's good health compared to the total loss of freedom of the debilitated partner. Further exploration of the interconnections between guilt and grief in caregiver relationships could help health care providers to develop interventions to facilitate caregiver role adjustments.

Two caregivers in the current study said they felt depressed at times, more than 10 months after admission. Depressive symptoms have been described as common in the grief reactions of caregivers (Lindgren et al., 1999). Ross et al. (1997) measured depressive symptomatology in wives who had visited husbands in long-term care for nine months. They reported that 54% showed signs of guilt, sadness and depression. Depression was lower in those whose focus had been broadened to include other life activities, and higher in those whose focus remained

primarily on caregiving. Caregivers who reported periods of depression in the current study had widely varying degrees of involvement with their relatives. One visited twice daily to perform caregiving tasks, while another caregiver visited only once per week.

In the view of Eakes et al. (1998), the pervasive sadness reported by caregivers in the current study could be attributed to the ongoing gradual loss of the loved one and the disparity experienced between the idealized future and the present reality. They developed a nursing theory of chronic sorrow, suggesting that such sorrow should be considered normal in situations like that of caregivers of older relatives. They proposed the theory as having utility for understanding responses of caregivers to the management crises of caregiving and ongoing losses. It was their opinion that viewing chronic sorrow as normal could provide a stimulus for nurses to develop strategies to assist caregivers to cope with this anticipated phenomenon.

The resilience of caregivers in the current study in finding ways to cope with the prolonged emotional stress of caregiving was remarkable. Minimal references were found in the literature about ways caregivers cope with the enduring negative emotions of the caregiving experience. Brody et al. (1990) postulated that continued caregiving helps allay guilt. Other sources reported that caregivers found ways to justify the guilt-producing placement decision, such as needing to provide a safer environment for the relative (Dellasega & Nolan, 1997; Kellett, 1999; Ryan & Scullion, 2000b). This latter rationale was evident among caregivers in the current study who rationalized that increased safety was justification for their placement decision.

During the placement crisis, Lundh et al. (2000) reported that caregivers immersed themselves in the practicalities of the move to help overcome negative emotions. Wilson (1989) described a taking care of business strategy used by caregivers, saying the focus on pragmatic tasks created a sense of achievement and satisfaction for caregivers at an otherwise stressful

time. In the current study, concentrated activity was noted among caregivers during the getting the relative settled period of high emotion that accompanied admission.

Eakes et al. (1998) also referred to keeping grief and guilt at bay by using the strategy of coping day to day, as identified by caregivers in the current study. They identified a one day at a time attitude as a cognitive coping method used to manage chronic sorrow. The value of a focus on the present, with a routine that kept them busy and allowed them to take their minds off the negative emotions, was described by caregivers in the current study as facilitating their ability to fulfill their commitment over the long course of the caregiving experience. Maintaining involvement in personal interests and activities and seeking respite opportunities, as caregivers in the current study did, were described by Eakes et al. as action strategies designed to help caregivers gain control over their lives when living with chronic sorrow.

Summary

Discussion of the current study's findings in relation to reviewed literature has demonstrated many similarities to other research. It has also shown that the current study provided new insights into the family caregiving process at home and in the nursing home.

The current study extended the description of the nature and dimensions of the family caregiving process from the taking it on phase at home to the caregiver's experience a year or more into the nursing home phase. This fuller view added depth to the understanding of the meanings and emotions that sustained or constrained the caregiver's progress. The study contributed to a broader understanding of the sources of caregiver commitment and the personal rewards and supportive relationships, particularly with family members, which sustained the caregiver. The constraints imposed by negative emotions, as had been documented in earlier

studies, were evident from participants in the current study. The concepts of non-death grief (Lindgren et al., 1999) and chronic sorrow (Eakes et al., 1998) enhanced understanding of the emotional landscape of caregiving. Resources used by caregivers for coping with prolonged grief and guilt were illuminated by their identification of daily coping strategies, rewards and supports. The value of the living in the present philosophy was corroborated by the findings of Eakes et al. as a positive response to the chronic sorrow of caregivers. The determination of caregivers to overcome emotional constraints and continue caregiving was testimony to their commitment to their loved one and the significance they attributed to their caregiving role.

Finally, viewing the caregiving experience from a transition theory perspective enhanced understanding of the marker events in the caregiving process, and of conditions and resources needed to produce successful transition outcomes. The use of transition theory holds promise for more fully describing the caregiving process. It offers potential assistance in the development of interventions to support caregivers toward successful role transition, thus enabling them to fulfill their caregiving commitment.

Chapter 6: Limitations and Implications

In this final chapter, limitations of the study and implications for policy development and nursing practice, education and research will be discussed.

Limitations

A number of limitations to the generalizability of this study are due to the grounded theory method, which was chosen to address the objectives, and the specific demographics of the family caregiver participants.

The study is primarily limited by the small purposive sample used to investigate the family caregiver adjustment phenomenon. Although the in-depth interviews and constant comparative analysis of the grounded theory method yielded rich data grounded in the experience of participant caregivers, and permitted identification of a basic social process and its dimensions, the results are limited in generalizability beyond the demographic characteristics of participants chosen for study. The participants were all living within a 50-kilometer radius of a regional population center in Newfoundland. Thus, there may be context variations among families in other cultures and ethnic groups whose family structures and values may differ. It was noted, however, that substantial similarity existed among caregivers' experiences reported from other studies in North America, Europe, the Middle East and Australia (Dellasega & Nolan, 1997; Duncan & Morgan, 1994; Greenberger & Litwin, 2003; Kellett, 1999; Kelley et al., 1999; Lundh et al., 2000; Neufeld & Harrison, 2003; Penrod & Dellasega, 2001; Ross et al., 1997; Ross et al., 2002; Ryan & Scullion, 2000b; Wilson, 1989).

Family caregiving experiences other than those resulting in nursing home admission could provide variations not demonstrated in the current study. Participants in the study were voluntary which limited the investigation to those willing to share their experience. The experience of others less willing to come forward may differ. Additionally, these participants willingly became primary family caregivers. As such, the adjustment processes and commitment they exhibited may differ from other family members who may have assumed caregiving responsibility less willingly.

Sampling was limited to the target phenomenon defined for investigation, that is, the experience of primary family caregivers. Theoretical sampling of those who interacted with primary caregivers during their experience, such as other family members and health care professionals, may have added a different perspective on the process. Interviews were conducted between 5 and 16 months into the nursing home phase of caregiving when participants were still immersed in their role. Their phase of adjustment at the time of the interview may have influenced the views and emotions they expressed. Lastly, the position of the researcher, who is employed as a manager within the facility, although having no direct responsibility for the care of participants' relatives, may have altered the dynamics of the interview in undetermined positive or negative ways. These methodological limitations restrict the application of study findings to primary family caregivers in a similar situation and cultural context.

Implications for Policy Development

In this study, caregiving occurred primarily within the family. The rationales given by the participants for taking on the caregiving role pointed to the sense of obligation that existed within their families to care for their own. Also, the predominance of women caregivers in the

study was indicative of the continued role of women in families in our society (McKeever, 1996; Montgomery, 1999). These results reflected current societal assumptions of a moral responsibility within families for care of older members, and also of caregiving as the natural domain of women in families (Montgomery). As a consequence, women's home-based caregiving has not been conceptualized as work or as a focus for health care services (McKeever). Apart from modest funding for home care support, little program development related to family caregiving is visible. The rapidly aging population and the current emphasis on decreasing institutional health care costs make it imperative that a focus on supporting the family caregiver be developed at the policy level. Wuest et al. (2001) urged nurses to lobby for changes in policy that would increase the availability of supportive nursing interventions for family caregivers.

In the current study, the caregiver's ability to continue with home care as the relative required increasingly higher levels of personal care, was limited by inadequate personal and community resources. Caregivers felt themselves to be unavailable, unsuitable or unable to meet demands for extensive personal care, or they could not acquire enough home support from community agencies to make continuing care at home feasible. Without 24-hour support when needs for care existed around the clock, the most committed of family caregivers could not continue indefinitely.

These findings illustrated weaknesses in current government policies that emphasize family home care, but fail to support it in two major ways. First, family care at home is viewed as cost-efficient for the health care system, but in the opinion of Montgomery (1999), its effectiveness has received little attention. She cites the fallacy of an underlying assumption that families have the appropriate knowledge and skills to care for their older relatives, and identifies an alarming

neglect of quality care issues in home care. Family caregivers in the current study had little prior caregiving experience with older relatives and were stressed by their inadequacies in providing appropriate care. They might have benefited from a better knowledge base of caregiving skills and coping strategies. Nurses could develop education and support programs for family caregivers with adequate support from government policy and funding initiatives.

Secondly, the level of subsidized home care was inadequate for many family caregivers who would have preferred to continue providing care in the home. Nursing home placement was a last resort for the participants in the current study and for the majority, it was precipitated by inadequate home care support. The most recent federal recommendations for home care spending in Canada, contained in the Romanow and Kirby reports, were directed to post-acute, short-term home care (Fisher, 2003). The need for maintenance home care for chronically disabled older Canadians was not addressed. New initiatives in Newfoundland and Labrador await the outcome of the government's current review of long-term care services and programs being undertaken as part of the province's strategic health plan (Government of Newfoundland and Labrador, 2002). In both arenas there remains an expectation that families should assume responsibility for care of older relatives in the home, with little acknowledgment of the home support required to make that goal achievable.

An American study of the economics of home care found that professional nursing services were required to sustain home care (Green, Ondrich & Laditka, 1998). Those authors reported that even with the higher cost of nursing services that increased sustainability of home care, a cost neutral service – if not a cost saving service – was achieved. However, a Canadian study found that appropriately resourced home care, including various professional services for persons otherwise eligible for nursing home levels of care, was more costly than nursing home care

(Gilbert, 1992). Additionally, Gilbert doubted the availability of adequate resources to maintain nursing home levels of care in the community. Thus, although increasing the availability of home care support could be a response to needs perceived by the participants of the current study, achieving sustainability of home care may require more than supplementing the current types of home care. Appropriate home care resources may require the development of more professional intervention models and programs.

Additionally, in accordance with the experience of most participants in the current study, social values and policy leave women primarily responsible for family caregiving, perpetuating gender inequities and potentially constraining them from fulfilling other roles in the family and society (McKeever, 1996). The social costs of this model of family care for older relatives require more examination. Availability of more subsidized support and professional intervention could make extended home care more feasible, by permitting family caregivers to fulfill their commitment to caring for their relatives at home as many prefer, while permitting them to maintain their own well-being and meet other life commitments. Social costs of family care, if not economic costs, could be minimized with less institutionalization of older persons. Registered nurses could play a significant role in the development of home care policy and programming to meet family caregivers' needs for physical, emotional and educational support.

Implications for Nursing Practice

The findings of the current study expanded the available knowledge base about the family caregiving process and have implications for nursing practice in community and long-term care settings. The meaning and primacy of the caregivers' commitment to their relative and their ongoing caregiving role was clearly portrayed. It was reflected in the crisis precipitated by the

placement decision and the prevailing negative emotions experienced by caregivers related to the loved one's circumstances. Insights gained into sustaining factors during the adjustment process, such as personal rewards and coping strategies, will expand nurses' understanding of the caregivers' needs and resources. Recognizing the importance of validation and emotional and practical support to caregivers will provide nurses with a rationale for developing nursing interventions to enhance the caregivers' ability to fulfill their commitment throughout the caregiving experience.

Community Nursing Implications

The community nurse could fill two roles that would support family caregiving: direct support of the primary family caregiver at home, and a liaison role with nursing staff in the nursing home.

The struggle identified by caregivers in the current study, as they tried to maintain home care and cope with the crisis of the placement decision, illustrated an opportunity for enhanced support from health care professionals. Participants sought assistance during crises primarily from their physicians and their immediate family. They did not identify community health nurses as a resource, but would potentially benefit from programming within community nursing in which the caregiver was the focus of anticipatory interventions. Family caregivers' inability to access resources may result from lack of a connection with a nurse who could assess their needs and facilitate support (Wuest et al. 2001). Nursing interventions to sustain the caregiver's ability to provide appropriate care could include education in caregiving skills and accessing family and community resources; development of social support via peer support systems; and facilitation of short-term relief of caregiving stress through access to community services, such as day care and

respite care. Crisis management assistance from community nurses could ease the placement transition. Nurses could facilitate and support decision-making by validating the need and providing information about care and services available in the nursing home. They could also assist with placement access and planning for the move and provide emotional support throughout this critical turning point in caregiving. Program development and promotional initiatives to heighten awareness among family caregivers of the support available from community nurses would be required.

Participants in the current study had negative feelings and uncertainties about nursing home placement and felt compelled to educate nursing staff about their loved one's needs. Family caregivers have been described as feeling they have unique and expert knowledge of their relatives' needs, and distrusting the adequacy of nursing knowledge (Ryan & Scullion, 2000a; Wuest et al., 2001). The community nurse who has knowledge of the home caregiving experience, could function in an advocacy role by acting as a liaison with nurses in the nursing home where the relative is to be admitted. When admission to a nursing home is planned, the community nurse could provide valuable information to nurses about the needs of the new resident and the caregiver. Such foreknowledge could help nursing home nurses to provide better support for the caregiver through the turbulent emotional period of admission, enhance continuity of care, and increase the confidence of the caregiver that their relative's needs would be met in the new environment.

Long-Term Care Nursing Implications

Caregivers in the current study demonstrated uncertainties and negative emotions of placement and efforts to re-align their role in the nursing home. Supporting the adjustment of

primary family caregivers in the unknown world of the nursing home is an important role for long-term care nurses. Nurses at all levels of the organization could contribute to the success of primary family caregivers in fulfilling their commitment to their loved one in the nursing home.

Nurses in management could establish a vision and philosophy that makes primary family caregivers not just members of the team, but a focus of supportive care themselves. Policies and procedures could be developed which legitimize the primary family caregiver's involvement in the life of their relative in the nursing home and in the interdisciplinary care team. Procedures and job descriptions could also provide support for the nurses' role in caring for the family caregiver. With levels of dementia in the population continuing to climb, caregivers have increasingly become the decision-makers for nursing home residents, as was evident among participants of the current study. Protocols that facilitate and support that role are necessary today in all long-term care settings. Information and support services for caregivers, such as admission orientation, transition programs and family support groups could be initiated by nursing leaders working with interdisciplinary teams.

Caregivers in the current study had problems getting to know large numbers of staff and establishing adequate communication about the relative's condition. This problem could be minimized by nursing management's choice of a model of care. A suitable model could facilitate resident assignments for nursing staff that are consistent over a period of time, thus reducing the turnover of staff relating to the family and resident. Models such as case management, modular nursing, and other primary assignment methods, hold promise for improved consistency and accountability in long-term care settings. Assignment patterns which allow family members to get to know the relative's care providers quickly would facilitate the caregiver's adjustment during the admission period and in the getting used to it phase which follows.

Registered nurses in direct care roles have many opportunities to support the adjustment of primary family caregivers in the nursing home. The nurse who understands the dimensions of the adjustment process could begin with easing the caregiver's transition at admission and continue with phase-specific support throughout the adjustments of getting used to it, rebuilding life, and coping day to day.

During the admission period, caregivers in the current study were concerned about the relative's safety and felt a need to specify the relative's care requirements to nursing staff. Nurses could support the caregiver's adjustment by providing information about available care and services, and by proactively eliciting the caregiver's expertise and preferences when they assess the new resident's needs and develop a plan of care. Supporting the validity of the caregiver's placement decision and emotional responses to it could be another significant nursing intervention during the admission period. Also, the nurse could promote the caregiver's adjustment by providing accurate information about the relative's condition throughout the nursing home period. After the immediate admission phase, nurses could facilitate the adjustment process by seeking to clarify and support the caregiver's preferred caregiving role. The current study revealed the importance of the resident's adjustment to the caregiver's successful transition. Recognizing this, the nurse could regularly offer information about the relative's responses to the staff and other residents in the new environment.

Another major adjustment identified in the current study that could be supported by nurses was the caregivers' efforts to refocus their lives and achieve a healthy balance between caregiving and other activities. Because nurses are a knowledgeable health resource and are readily available to caregivers, they are in a position to support these adjustment activities. They could validate the importance of caregivers looking after their own well-being and encourage

attention to outside interests, recognizing that a healthy well-adjusted caregiver will be better able to provide necessary support to the resident (Davis & Buckwalter, 2001).

Additionally, nurses could assess individual caregivers' coping strategies and factors that sustain them, such as personal rewards and sources of support. In the current study, caregivers focused on getting through life on a day-to-day basis. They identified the strategies of keeping busy and living in the present as helping them avoid negative emotions and enabling them to get through the experience. Also, they avoided thinking about a future without their relative. Positive responses from the care recipient provided reinforcement for their caregiving efforts, as did understanding and support from family members. Knowing these strategies, nurses could intervene to support positive coping and sustain the caregiving role. Anticipatory support for future caregiver role transitions with the inevitable decline in the loved one's health could be another supportive intervention from nurses. By building a relationship of trust in the present, nurses could establish open communication that acknowledged ongoing grief and supported the caregiver's ability to anticipate and cope with future changes. The nurse could also recognize that other members of the interdisciplinary team can play significant roles in supporting caregivers, and facilitate timely referrals and interventions.

Implications for Nursing Education

The strength of commitment shown by primary family caregivers in the current study underscored the value attributed in our society to looking after each other within families. Caregiving has traditionally been a woman's role in families, and despite the growth of non-traditional family structures and the entry of women to the workforce, nurturing and caregiving remain predominantly in the sphere of women (McKeever, 1996; Montgomery, 1999). The

current aging of the population and promotion of family home care by society and governments make it critical that all nurses learn more about the pivotal role of primary caregivers, particularly with elderly family members. A focus on the primary family caregiver role in family and gerontological nursing education could be an important first step in developing that knowledge base within the nursing profession.

Family nursing education could include the dimensions and dynamics of the caregiving role. Caregiving roles in different developmental stages of family life and the effects of caregiving demands that fall outside the expected norms could be better understood by nurses. A case in point was the caregiver in the current study who was required to assume spousal care in mid-life. The loss of their anticipated years together as a couple in retirement caused the caregiver to feel resentful toward the spouse who needed care and support and also guilty for her wish for a freer life than caregiving offered. A better understanding of the mutuality of caregiver and care recipient roles and the extraordinary bond that develops between the two could be helpful to all nurses who work with families in our aging society.

Gerontological nursing concepts that highlight the care of older people within the context of the family could include more about the role of the family caregiver in maintaining health and independence in later years. Nurses could learn that to serve the older generation well, they must also consider the family as clients and more particularly, the self-selected or designated primary family caregiver. Findings in the current study revealed that whether in community or long-term care settings, caregivers were in need of support that enabled continuation of their role. Education programs could include all aspects of the caregiving experience, including information about the caregiver's duty of care, the crisis that may be precipitated by placement, and the caregiver's probable sense of continuing responsibility for care in the nursing home. Nurses

could also learn about factors that sustain and constrain caregivers so that they may provide better support. The implications for nurses' relationships with and accountability to family caregivers in the care of their relatives could be explored in gerontological nursing education. Resident care in nursing homes is no longer viewed as solely the responsibility of health care providers (Specht et al., 2000). Skills such as facilitation, collaboration, negotiation and conflict resolution could be taught, so that nurses could enhance their ability to develop and maintain effective working relationships with primary family caregivers.

Implications for Nursing Research

This study identified a basic social process of fulfilling the commitment and a beginning substantive theory to explain the adjustment process of primary family caregivers whose relatives are admitted to a nursing home. Extension of the research to non-traditional families, other cultural and ethnic populations, and to other variations of the phenomenon, such as those who continue to provide care at home and those who care for non-elderly disabled relatives, would contribute to the development of a middle-range theory explaining the family caregiving process.

Longitudinal research could be undertaken to explore the family caregiving episode from onset to relinquishment of the role. Interviews in the current study were conducted during the nursing home phase of caregiving. Other researchers have studied phases of caregiving at home, at placement or in the nursing home. It would create a more comprehensive understanding of the caregiver's experience if interviews were repeated with the same caregivers at different stages of the process. No reports were found in the reviewed literature about the effects of death of the care recipient on the primary caregiver nor on the adjustment required to relinquish the long-held

caregiving role. Follow-up interviews of primary family caregivers after the relative has died and the caregiving role has ended would enhance knowledge of a final transition in the caregiving process that has received little attention to date. Participants in the current study demonstrated the primacy of the caregiving role in their lives. Exploration of their transition to a life without their loved one and without the caregiving role would increase understanding among nurses who could intervene to provide support. Persistent grief among caregivers throughout the caregiving experience was evident in the current study. A better understanding of how the grief is resolved when their anticipated loss occurs could assist nurses to develop facilitative interventions that could be offered to caregivers during the nursing home period and in follow-up support afterward.

Further research is warranted into the sustaining factors and constraints identified by caregivers in the current study. Among the sustaining factors, the value of the care recipient's responsiveness as motivation for the primary family caregiver could be investigated. In this study, responsiveness of the relative to the caregiver was identified as a sustaining factor, often despite the relative's significant cognitive impairment. However, in their study of visiting patterns among wives with institutionalized husbands, Ross et al. (1997) found that wives visited less often when spouses had dementia and were less able to interact than cognitively intact spouses. This apparent discrepancy in the role of responsive interaction between caregiver and care recipient in sustaining caregiver attachment could be further explored.

Among the constraints identified in the current study, prolonged grief and guilt were common. Before nurses can develop effective interventions, much remains to be discovered about the dimensions of caregiver guilt, the sense of failure that accompanies it, and possible mechanisms for resolving it. Chronic grief or sorrow as a steady state among primary family

caregivers of living elderly relatives also warrants further exploration to enable better understanding of this phenomenon and the coping strategies used to alleviate its debilitating effects.

Coping strategies, such as a focus on the present, keeping busy and keeping one's mind off the caregiving situation, as identified by participants in the current study, have received little attention in caregiver literature. Further investigation is needed to determine the effectiveness of various strategies in facilitating caregiver role adjustment and maintenance. In particular, it would be important to understand more about the effectiveness of the living in the present or one day at a time strategy. Lundh et al. (2000) described it as a sign of unsuccessful adjustment that prevented caregivers from moving on with their lives. However, caregivers in the current study used it as a positive means of coping. They deliberately kept their minds off the enduring sadness so they could get through each day. Eakes et al (1998) described so-called action strategies, such as living one day at a time, as being commonly used by persons experiencing chronic sorrow. Clarification of the value of this and other coping strategies could be very helpful to nurses who could support the caregivers' use of those found most effective.

Lastly, the finding in the current study that caregivers identified continued responsibility for the relative's care in the nursing home, but did not articulate a need for a strong relationship with nursing home staff, requires further exploration. The majority of reviewed literature professed the value of nurses' supportive relationships with caregivers (Dellasega & Nolan, 1997; Duncan & Morgan, 1994; Kelley et al., 1999; Penrod & Dellasega, 2001). Current philosophies of long-term care extol the value of partnerships with families of nursing home residents. Partnerships imply working together toward a common goal. However, participants in the current study determined for themselves what level of participation they preferred and

monitored the care provided by others. While concurrence with the nursing care plan was important to them, they did not identify a desire for joint decision-making processes with nurses, nor did they describe seeking personal support from nurses. In addition to the provision of care they perceived to be appropriate, their main expectation of nursing staff was for adequate communication about the relative's condition. Future studies could explore relationships between caregivers and nurses more fully to determine what is most effective for reaching their common goal, the best quality of life for the resident. Also, the perceived value to the caregiver of personal support from nurses could be investigated more fully.

The considerable similarity among reviewed studies of family caregiving, particularly about placement experiences, could now provide a sufficient knowledge base to support intervention studies. Testing various interventions could identify those that meet with the most success in promoting caregiver adjustment. The nursing transition theory of Meleis et al. (2000) could provide a useful framework. Use of the process and outcome indicators for successful role transition, such as connectedness, role mastery and integration of identity, could provide measures of successful outcomes for studies of caregiver adjustment.

Summary

The purpose of this study was to determine the adjustment process of primary family caregivers whose relatives were admitted to a nursing home. A grounded theory approach was used and interviews conducted with 10 self-identified primary family caregivers from a population center in Newfoundland. Analysis using the constant comparative method was undertaken. It revealed a basic social process of fulfilling the commitment, and three adjustment processes in each of three phases of the caregiving experience. These were: taking it on,

accelerating responsibility and reaching an end in the home caregiving period; finding a place, getting the relative settled and feeling the loss in the immediate admission period; and getting used to it, rebuilding life and coping day to day during the nursing home period of caregiving. The dimensions of each adjustment were identified, as well as factors that sustained and constrained caregivers in their roles. A discussion followed of the findings and their contribution to existing knowledge as it was represented in reviewed literature. Lastly, the limitations of the study were identified and implications for future policy development, nursing practice, education and research were proposed.

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Appendix A: Letter to Participants of Resident Care Services

(Letterhead: Western Health Care Corporation
Long Term Care Corner Brook
Phyllis Griffin, Director of Resident Care Services)

September , 2000.

Next of Kin Name
Next of Kin Address

Dear :

I am writing to you on behalf of Euna Ferguson who is a nurse manager in two units of Long Term Care Corner Brook. She is also a graduate student in the Memorial University of Newfoundland School of Nursing who is preparing to start the research required for her Master of Nursing degree. As her proposed study involves family members of residents in nursing homes, she has been granted permission by the administration of Long Term Care Corner Brook and Western Health Care Corporation to make contact with you as the next of kin of a resident who has been admitted within the last year.

In the 12 years that Euna has been working in long term care, she has been involved with many families during the admission period, and has observed many different emotional reactions. As a nurse, she feels a need to know more about what families go through in their adjustment to this new family situation. It is her hope that with greater understanding, she and her colleagues will be better able to provide support to families during what is often a stressful period of family life. Those of us who work in long term care believe that developing good relationships with families makes a positive difference to the adjustment of residents and to their quality of life in the nursing home.

In order to learn more about the experience of families when their relatives are admitted, I am asking those family members who describe themselves as the person most responsible for their relative's care and well-being, to consider participating in a confidential interview with Euna in the near future. It would last approximately one hour and take place in a private place of the person's choice. The family caregiver's name and the name and location of his or her relative in Long Term Care Corner Brook would not be identified in the study. The study will be supervised by Dr. Sandra LeFort and Professor Karen Webber of the School of Nursing at Memorial University of Newfoundland. Euna will be pleased to share results of the study with interested participants.

If the primary caregiver in your family is interested in more information about the study, please call Euna at (709) 639-9247, Extension 245. If she is not there, you may leave a message and she will return your call promptly. After five o'clock, she may also be reached at her home number, (709) 634-1353.

Euna looks forward to hearing from you or a member of your family, and wishes to thank you in advance for considering your family's participation in her study.

Sincerely

Phyllis Griffin

Appendix B: Human Investigations Committee Approval Letter

Appendix C: Regional Ethics Committee Approval Letter

Appendix D: Consent to Participate in Biomedical Research

FACULTY OF MEDICINE - MEMORIAL UNIVERSITY OF NEWFOUNDLAND
AND
HEALTH CARE CORPORATION OF ST. JOHN'S
Consent To Participate In Bio-medical Research

TITLE: Family Caregiver Adjustment After Nursing Home Admission of a Relative

INVESTIGATOR: Euna E. Ferguson, R.N., B.N.

You have been asked to participate in a research study. Participation in this study is entirely voluntary. You may decide not to participate or may withdraw from the study at any time.

Information obtained from you or about you or your relative in the nursing home during this study, which could identify you, will be kept confidential by the investigator. The investigator will be available during the study at all times should you have any problems or questions about the study.

The purpose of this study is to identify the process of adjustment that family members experience when they place a relative, whose care has been their responsibility, in a nursing home. The information obtained from the study may be used to help nurses who work in long term care settings to understand and support families at the time of admission and within the first year.

You are asked to participate in an interview which will last for about one hour. You will be asked to talk about the experiences you've had getting used to having your relative in the nursing home. The interview will be audio-taped and then transcribed at a later time. You may be contacted a second time for a short period, if the investigator wishes further explanation.

Your name and your relative's name will not appear in the study report, and the tapes will be erased after the study is complete.

I will be interviewing members of a number of families, and expect the study to last about one year. You may have a report of the study after that time if you wish.

There are no discomforts or risks expected as a result of this study, and interviews will be conducted at your convenience. You may stop the interview at any time for any reason. Arrangements can be made for you to speak to a long term care social worker if you wish. No direct benefits are expected from your participation. However, other families in future may benefit from the support of nurses who understand more of what they are going through.

Your signature indicates your consent to participate, and that you understand the information provided about the study. In no way does signing this consent waive your legal rights, nor release the investigator and involved agencies from their legal and professional responsibilities.

Participant's Initials _____ Page 1

Appendix E: Interview Guide

Introductory information for participant

- review purpose of the study
- reinforce confidentiality and anonymity methods to be used
- identify time frame and reassure of the right to stop at any time
- remind that results will be made available on request
- solicit questions prior to starting
- have consent signed

Demographic data

Participant Identification Number: _____

Age: _____

Sex: _____

Relationship to the

Resident: _____

Relative's length of residency in long term care: _____

Medical Diagnosis of the Resident: _____

Guiding questions

Questions below are intended to be used as needed to stimulate the flow of the participant's story of the placement experience. All or none may be used in an individual interview.

Open-ended sample questions.

1. Tell me what its like for you now that you have placed your relative in the nursing home.
2. How do you feel about your situation/ your relative's situation now?
3. How are you managing day to day?
4. Have you noticed changes in your life/ your relationship with your relative since he/she moved to the nursing home? If so, how do you feel about them? Were some positive/helpful/difficult? What was it that made them so?
5. What is it like to deal with the staff at the nursing home/ with other family members?
6. What is it like coming to see your relative? How does it compare to when you first started coming to the nursing home?
7. How do you feel you've adjusted to this new situation in your family?
8. Ideally, how would you like your life with your family to be?
9. What do you think nursing staff did, or should do to make it easier for you to have your relative living in the nursing home?

Clarifying/probing questions.

1. Can you tell me more about that?
2. Can you describe that another way?
3. Is there anything else about that situation that concerned/challenged/pleased you?
4. Is there anything you want to talk about that I haven't asked?

**Appendix F: Fulfilling the Commitment, The Adjustment Process of Primary Family Caregivers
of Nursing Home Residents**

Fulfilling the Commitment: the Adjustment Process of Primary Family Caregivers of Nursing Home Residents

Phase One: Home Caregiving

<i>Adjustments</i>	<i>Dimensions</i>	<i>Sustaining factors</i>	<i>Constraints</i>
1. Taking It On	rationale: family responsibility availability suitability	duty to care loving relationship family support	
2. Accelerating Responsibility	gradual progression of responsibility for care sudden dependence for care	support: family community-home care, day care, respite physician	stresses: safety re dementia behaviours, burden re constant responsibility, physical strain, absence of family support
3. Reaching an End	turning point: impossibility of continuing with 24 hour care- exhaustion, lack of sleep, stresses responding to crisis: resistance to placement decision helplessness re inevitability of placement	support for decision-making: close family physician validation	fear of relative's reaction: refusal of placement negative meanings: failure of care loss end of life last resort

Phase Two: Admission Caregiving

<i>Adjustments</i>	<i>Dimensions</i>	<i>Sustaining factors</i>	<i>Constraints</i>
1. Finding a Place	choosing a preferred environment: facility, room	family participation and agreement	family disagreement
2. Getting the Relative Settled	facilitating comfort: room, furnishings, roommate facilitating appropriate care: identifying needs to staff, monitoring care	relative's acceptance relative's well-being positive response from staff	roommate incompatibility: conflict, perceived threats to safety, contentment uncertainty of care lack of response from staff institutional inadequacies: limited privacy, limited onsite medical care, inconsistencies in service lack of acceptance from relative in care
3. Feeling the Loss	loneliness: relative gone from home sadness: end stage of life relief: decreased burden, increased freedom guilt: failure of reciprocal duty	increased safety for relative: staff will call if problem lack of complaint from relative in care rationalization: caregiver did all he/she could at home (nobody can do 24 hour care), gave priority to own family life	fear of attitudes of others: re increased freedom

Phase Three: Nursing Home Caregiving

Adjustments

1. Getting Used to It

Dimensions

acceptance:
resignation
passage of time

continuing the care:
visiting pattern
meaningful care -personal
care, shopping, treats/extras,
family connections,
maintaining comfort and
contentment

getting to know staff:
developing trust- listening,
watching care, feedback from
other families, direct contact
with staff, being there
communication strategies-
in person, telephone calls,
diary keeping,
variations in contact frequency

Sustaining factors

fatalistic attitude:
happens to us all
life goes on

routine of care: don't think
about it
family participation: with
visiting and caregiving
personal satisfaction:
fulfilling duty, one best
prepared for caregiving

perception of needs met: by
staff
positive staff/resident
relationship
concurrence with care plan
reciprocal communication:
from staff

Constraints

**lack of acceptance by care
recipient**
unmet expectations of life:
mid-life placement
conflicting desires:
freedom vs. duty of care

**relative dissatisfied with
contact:** re visiting frequency
**infrequent visits of other
family:** grandchildren,
siblings

large volume of staff: rotating
assignments and shifts
**negative experience of
relative**

**lack of communication re
problems, changes**

Adjustments

2. Rebuilding Life

Dimensions

finding a balance: relative's
needs and personal needs
focus on personal health:
medical attention, exercise
pursuing other interests:
social, church, sports, music,
taking vacation

Sustaining Factors

personal satisfaction with
caregiving
relative's adjustment and
continued well-being

enjoyment
family encouragement

Constraints

family pressure to decrease
caregiving time

worry about relative's well-
being if absent

3. Coping Day to Day

living in the present
keeping busy
keeping mind off it

rewards of caregiving:
positive response of relative,
fulfillment of duty
family support: practical
help, participation, acceptance

persistent negative emotions:
grief, loneliness, guilt



