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FAMILY MEMBERS CARING FOR RELATIVES WITH ALZHEIMER DISEASE IN LONG-TERM CARE FACILITIES

by

Wonita M. Janzen ©

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Doctor of Philosophy

in

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The undersigned certify they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled FAMILY MEMBERS CARING FOR RELATIVES WITH ALZHEIMER DISEASE IN LONG-TERM CARE FACILITIES submitted by WONITA M. JANZEN in partial fulfillment of the requirements for the degree of DOCTOR OF PHILOSOPHY in REHABILIATION SCIENCE.

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ABSTRACT

The purpose of this study was to describe the role of family members caring for their relatives within a new residential care setting, an Alzheimer Care Centre (ACC), during the first eighteen months after admission of the relative. The three areas under investigation were involvement in care tasks, perceptions of formal care, and feelings about their relative's situation. The design included a comparison of the family members whose relatives are residing in special care units (SCUs) operated within traditional nursing home environments.

Results of the longitudinal analyses indicated that family members of ACC residents visited regularly, were involved in a variety of care tasks, were satisfied with the care provided at the facility, experienced few hassles in their interactions with the formal care providers, felt mild burden in caregiving, and experienced some guilt related to the situation. These measures remained fairly stable over the first eighteen months post-admission of the ill relative. Results of the comparison analysis between the two long-term care settings indicated that family members' involvement in care, perceptions of formal care, and feelings about their relative's situation were very similar. Noted exceptions were that the residential care family members were more satisfied with their relative's environment and experienced more burden than the SCU family members. Data from both groups of family members were used to examine the inter-relationships among involvement, perceptions and feelings in order to further describe family caregiving within the long-term care settings. Overall, results indicated that there were few interrelationships among the three concepts.

It was concluded that family members continue to provide care to their relatives within the long-term care facility, establishing a role for themselves within the formal care system. Their involvement in care, perceptions of formal care and feelings about their relative's situation remain fairly stable over time and are similar between residential care and SCU care settings. In general, the results of this study support the fact that family members do not "abandon" their relatives to the long-term care system and that different types of facilities are appropriate for different levels of care required by residents with Alzheimer Disease.

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Finally, I would like to thank my husband for his constant support and encouragement and my son, whose arrival prodded me to complete this project.

Family Involvement in Care Study

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April 3, 1995

Wonita Janzen, Msc.
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Dear Ms. Janzen,

You are granted permission to use the enclosed Family Perceptions of Care Tool (FPCT) which you requested. Its description is also enclosed.

Sincerely,

Meridean Maas

Meridean Maas, RN, PhD, FAAN
Professor

Enclosure

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Introduction

Alzheimer Disease (AD) is a major cause of disability among older people. The estimated prevalence of AD in Canada is 5.1% in persons over 65 years of age, ranging from 1% in those 65 to 74 years, to 26% among those aged 85 and over (Canadian Study of Health and Aging, 1994). AD is primarily characterized by deterioration of memory and cognitive functioning (Kaplan & Sadock, 1991). It is also characterized by a gradual loss of daily functioning, such as toileting, bathing and dressing (Auer, Sclan, Yaffee & Reisberg, 1994; Eisendorfer, et al., 1992) and is commonly manifested in a variety of symptoms, including wandering, agitation, apathy, hoarding and rummaging (Cohen-Mansfield, 1986; Deutsch & Rovner, 1991; Gilley, 1993; Patterson & Bolger, 1994).

Although many of these older adults are being cared for at home by family members, as the disease progresses family members often choose to move their ill relative into a long-term care facility. It is estimated that 50% of older adults with AD reside in long-term care facilities in Canada (Canadian Study of Health and Aging, 1994). There have been many studies published regarding the roles, responsibilities and reactions of family members in caring for community-residing relatives with AD, but there is limited research regarding family members following the admission of their relatives with AD into long-term care (Duncan & Morgan, 1994; Maas, Buckwalter, & Kelley, 1991; Montgomery, 1994). A decade ago George and Maddox (1989) wrote:

> Given the strong evidence that family members play a major role in the decision to place impaired older adults in nursing homes, it is ironic that the involvement and effects of family members subsequent to institutionalization have received so little attention (p. 133).

Although more research in this area has been published in the past decade, little is still known about family members' involvement in care for their relative, their perceptions of the care provided by the staff at the facility and their feelings about their relative's situation. Even less is known about family caregiving across time as the relative with AD continues to deteriorate within the confines of a long-term care facility or if family caregiving differs across types of long-term care settings. Therefore, the general purpose of this study was to examine family involvement in care, perceptions of formal care and feelings about their relative's situation over time within a residential care setting and to compare these measures with the involvement, perceptions and feelings of family members whose relatives are residing in special care units (SCUs) operated within traditional nursing home environments.

Relevance

Why would it be important to address the involvement, perceptions and feelings of family members after admission of the relative with AD? After all, the family does not move into the facility and the staff take over most of the daily, hands-on caregiving. It is important from a family systems perspective. Briefly, systems theory posits that even though a family is made of individuals, all are inter-related and what affects one member of a family affects the other members – they do not function in isolation. Therefore, the move of the relative with AD also affects the other members of the family, particularly the primary family caregiver. The lives of the family become intertwined with the staff at the facility. The roles of the family members within the family system change as well. Role theory posits that that *social role* is a definition of behavioral patterns, rights and responsibilities expected from occupying a specific position within a social structure. When the relative with AD was diagnosed or exhibiting symptoms while still living in the community, the roles of the family members likely changed to accommodate the changes in the ill relative. For example, if the ill relative used to do all the financial management of the household, another family member would have taken over that responsibility to keep the household operating adequately. When the relative is moved into a long-term care facility, the family roles and responsibilities again change, in relation to both the ill relative and the staff who now become part of the social structure. For example, the hands-on caregiving tasks of toileting and bathing that the family members used to do, become part of the staff responsibilities. With these two theories of human behavior and relationships in mind, examination of the involvement, perceptions and feelings of family members in relation to their role within the long-term care system can provide an important perspective of the picture of long-term care for persons with AD. Evaluation of these three concepts may have relevance for all those involved in the long-term care system.

First, family involvement in care, perceptions of formal care, and feelings about their relative's situation constitute measurements of the quality of long-term care for residents (Hawes & Kane, 1991; Montgomery, 1994). Because family members usually make the decision to place their relative with AD into a long-term care facility and are regular visitors to the facility, they are clients and their assessment of care should be of utmost importance to the formal long-term care providers (Montgomery, 1994; Wakefield, Buckwalter & Collins, 1997). Such information could assist government officials, facility administrators and staff in developing policies and allocating funding to long-term care services, in creating partnerships with family members, in forming support programs for families and residents, and in evaluating quality of care.

Second, the involvement of family members in the care of a relative with AD is essential to the resident's well-being. Research shows that family contacts are associated with greater emotional well-being in non-demented nursing home residents (Farber, Brod, & Feinbloom, 1991; Greene & Monahan, 1982), and the same may hold true for those with AD and related dementias. In addition:

> [Family involvement] encourages staff to respect the people for whom they are providing care by reminding them of previous roles played by residents. It is beneficial to residents since it serves as a tie with their own past and also provides some link with the world beyond the nursing home. Understanding the roles played by family members and by nursing home staff is important to bettering the relationship between them, ultimately improving the quality of life for institutionalized older people (Dempsey & Pruchno, 1993, p. 144).

Information regarding family involvement and perceptions may assist administrators and staff in promoting collaborative relationships with family members, in developing programs to support the family and residents, and in providing quality care to residents.

Third, family involvement in care may be essential to the family member's well-being. Although improvements in institutional care have been made over the past century, our society still holds negative attitudes toward admitting an older relative into a long-term care facility (Matthiesen, 1989). Many family members struggle with guilt and grief regarding the move and generally view it as a last resort (Johnson & Werner, 1982; Matthiesen, 1989). Continued family involvement in care may be one way of dealing with the guilt and grief and it allows the family members to monitor the care their relative receives (Bowers, 1988; Duncan & Morgan, 1994; Matthiesen, 1989). When an ill relative is admitted to a long-term care facility, he or she remains part of a family and allowing family members a role within the long-term care facility may be one way of maintaining family relationships and fulfilling family obligations (Smith & Bengston, 1979). In addition, providing care to an ill relative can have positive effects for family members such as feelings of satisfaction, reduced guilt, or being able to fulfill a commitment (Kinney & Stephens, 1989; Pruchno, Peters, Kleban & Burant, 1994). Information regarding family involvement in care, perceptions of formal care, and feelings about their relative's situation may assist administrators and staff in developing programs to support the family and residents, to improve relationships between family and staff, and to improve the quality of life for family members. It may also assist family members in establishing their role within the long-term care structure.

Background to the Study

Developments in Long-Term Care for People with Alzheimer Disease and Related Dementias

For the past two decades there has been a growing belief that special units or facilities should be established for people who suffer from AD and related dementias and that these special units or facilities are more beneficial for the residents and their families than traditional nursing homes or extended care facilities. This belief partly stems from the underlying models of health care that influence how care is implemented. Long-term care has traditionally fallen under the medical model of care. Briefly, the medical model emphasizes the cure and management of disease and the key relationship is between the physician and patient (Jesion & Rudin, 1983). An assumption is made that the patient is physically ill (Smith & Eggleston, 1989). This model works well in acute care settings, but may not be appropriate for long-term care settings where residents need services because of frailty or infirmity that affects their activities of daily living, while their actual medical problem may be slight (Smith & Eggleston, 1989). Some believe that a social model of care would be more appropriate for residents within long-term care facilities and, in fact, many such facilities work under a combination of the medical and social models (Jesion & Rudin, 1983; Smith & Eggleston, 1989). Briefly, the social model of care emphasizes resident quality of life, focusing on the psycho-social as well as medical needs of the resident and the main relationships are among the health care team, resident and family members of the resident (Jesion & Rudin, 1983). The social model of care may be particularly useful for the care of residents with AD and related dementias. For example, the older adult with AD who is cognitively impaired but whose physical functioning is relatively intact, may need assistance with dressing, meal preparation or using the telephone, but has little need for medical intervention.

Buckwalter (1991) maintained that special care units (SCUs) were established because most traditional nursing homes, functioning under the medical model, were not equipped with the environmental structures or the support and services required to care for cognitively impaired elderly. Although there was some opposition to the idea of segregating the cognitively impaired, many administrators, staff, families and researchers advocated the benefits of separation, such as less disruption for cognitively intact residents, improved safety for the residents with dementia and greater family satisfaction with separation (see Buckwalter for a discussion of this topic). Buckwalter's review of the literature produced five characteristics of SCUs which differentiated them from traditional nursing homes: (1) staff selection and training specific to caring for residents with AD; (2) activity programming specifically designed for cognitively impaired residents; (3) activities and programs designed for the families of the residents; (4) physical environment and décor to address the needs of residents with AD, such as a locked unit and separation from the main nursing home; and (5) admission criteria which specifies cognitive impairment of residents.

Studies of the benefits of SCUs have shown mixed results. Some studies have shown improvements or more positive results in terms of resident behavior, staff satisfaction, family satisfaction and reduced use of restraints with residents in SCUs compared to traditional nursing homes or patients on a waiting list for SCU admittance (Cleary, Clamon, Price & Shullaw, 1988; Kovach & Stearns, 1994; Wells & Jorm, 1987) while others have shown no change or effect on the residents (Holmes, et al., 1994; Wells & Jorm, 1987). In a review of the literature, Sloane, Lindeman, Phillips, Moritz and Koch (1995) maintained that the effectiveness of SCUs remains unproven.

Despite the characteristics outlined above and the lack of evidence regarding outcomes, there continues to be a wide variety of SCUs in operation. There are very few regulations regarding the development and operation of SCUs, making evaluation and comparisons of SCUs difficult and opening doors for fraudulent claims of "special care" (Berg, et al., 1991; Sloane, et al., 1995). Yet, in the United States the number of facilities with SCUs more than tripled between 1987 and 1996, with 22 percent of all long-term care facilities having a special care unit, wing or program (Leon, Cheng & Alvarez, 1997). Examining the trends in SCUs over a five-year period, Leon et al. remarked:

> Rather than self-contained, physically separated and distinct units, where the care is directed toward meeting the particular needs of individuals with dementia, SCUs are now conceived as a merging of features ranging from highly tangible elements such as modified physical environments to less tangible components such as specialized staff training. Investigators now conceive of SCUs as a continuum of care rather than a single tangible intervention (p. 50).

Further along this continuum of care and oriented toward a social model of service delivery are advocates who would have residents delay entrance into an institutional SCU and reside in a residential-style facility (Cohen & Day, 1993). The main argument behind a more residential-style setting is the therapeutic value of the environment on resident health and quality of life (Cohen & Weisman, 1991; Lawton & Nahemow, 1973). According to the environmental docility hypothesis by Lawton and Nahemow (1973), residents with reduced capabilities due to AD are more vulnerable to the effects of the environment on their behavior and even small changes in the environment can have substantial impact on resident outcomes. Under this premise is the view that environments should be designed and operated to enhance the abilities of the residents, to keep residents in a home-like, familiar environment and to promote both privacy and social contacts for residents. Although some SCUs have used this philosophy for their development, advocates for residential care facilities maintain that SCUs have not differed enough from traditional nursing homes. Residential care facilities have been established in Europe, the United States and Canada with research, mostly from Europe at this time, showing some positive results for the residents and families. Examples of the positive influence of the residential care environment include greater resident participation in activities and more social contacts after residents moved from a hospital to a residential care home (Knapp, et al., 1994); less dependency, less depression, fewer language difficulties, and greater mobility when residential care residents were compared to institutionalized residents (Ritchie, et al., 1992); and improved communication, improved self-care and less social disturbance when residents were moved into residential care centres (Sixsmith, Stilwell, & Copeland, 1993). The benefits of the environment seem to be greater for residents in the early to middle stages of dementia than those in the later stages (Annerstedt, 1997; Sixsmith, et al., 1993), suggesting that more traditional care may still be needed in the later stages of the disease.

Cohen and Day (1993) describe a number of residential centres for residents with dementia and list four general attributes of the environment: 1) a non-institutional image – to create a more home-like setting; 2) a negotiable environment – to create a "barrier-free," accessible environment which responds to the demands of dementia; 3) things from past – to use familiar objects which can exercise long-term memory and remaining capabilities; and 4) sensory stimulation without stress – to amplify the message and dampen extraneous stimuli. These attributes help to contribute to the deinstitutionalization of long-term care for residents with dementia:

> Increasingly, the model of the home or residential setting has been substituted as a more humane, potentially more cost effective, and more therapeutic alternative to the institutional model. The creation of a "homelike" environment is a primary strategy for deinstitutionalization." (p. 183).

The physical element is not the only aspect of the environment to consider. Cohen and Weisman (1991) also describe the organizational and social environments. The organizational environment refers to the policies, programs, and services offered by the facility and the social environment refers to the fellow residents, staff, family and friends with whom residents have interactions. In keeping with a "home-like" theme, most residential care centres provide opportunities for residents to participate in activities of daily living, such as meal preparation, laundry, cleaning, or gardening, as well as more structured activities such as sing-alongs, exercise classes, or crafts. An important aspect of the social environment is resident contact with family and friends. Two assumptions underlying the planning and operation of residential centres are that a "good" physical design can increase visiting and that visiting is desirable for both residents and family members. Therefore, two goals of residential care centres are to create spaces for visiting within the facility other than the resident's room, crowded lounges, or long corridors and to involve family members and friends in activities and resident care (Cohen & Day, 1993).

Although there has been widespread development of SCUs and residential care centres across Canada and the United States, there have been no standards established for the design and operation of such centres and there has been little research conducted on the exact benefits of such units and facilities (Buckwalter, 1991; Leon, et al., 1997; Ohta & Ohta, 1988). The three most obvious groups to experience any possible benefits from changes in long-term care for persons with AD are the residents, the families of the residents and the staff, and these groups should be the target of research into this area.

A New Residential Care Facility in Edmonton

Falling in line with the view that residential care for persons with dementia is a good alternative to traditional nursing homes and SCUs, The Capital Care Group of Edmonton, Alberta, initiated the development of a residential-style Alzheimer Care Centre (ACC). This organization already operates five large long-term care centres in Edmonton which provide regular nursing home and auxiliary hospital programs, as well as specialized dementia care on SCUs at four of the centres. The Capital Care Group is a publicly owned operator of long-term care programs and services. "Although proud of its expertise in providing care to individuals with dementia, the organization identified internally that there must be better models of care available that would enhance the provision of dementia care" (Tiedemann, Milke, Warren, Regehr & Mitchell, in press).

The residential care facility built by The Capital Care Group was designed similarly to Woodside Place, a residential facility in Oakmount, Pennsylvania, U.S.A. This facility consists of three "houses" adjoined by large common areas. Each house has bedrooms for 12 individuals and common dining and kitchen areas. Its unique physical layout and innovative programs are designed to meet the special needs of individuals in the middle stages of Alzheimer Disease. It opened in August 1995 with the gradual assessment and admittance of residents. Table 1 lists the admission criteria for the ACC.

There are three main program objectives of the ACC. The first objective is to enhance the quality of life of persons living within the ACC, maintaining their abilities and slowing their rate of decline for as long as possible. The second objective of the program is to enhance the quality of life for family members of persons served by the ACC, helping them to cope with their circumstances and care for themselves. The third objective is to enhance the quality of workday life by increasing staff job satisfaction and by helping them appreciate the importance of their role as well as the importance of caring for themselves.

In order to more fully understand the benefits of the ACC as an alternative care setting for persons in the middle stages of Alzheimer Disease, employees of The Capital Care Group collaborated with researchers from the University of Alberta to conduct a program evaluation of the new residential care facility. The evaluation design, based on a longitudinal comparison of the ACC and SCUs, enabled the research team to examine the effects of differences over time and between settings on the residents, family members and staff. The two main advantages of this type of comparison were: 1) both the ACC and the SCUs are operated by the same organization so that some policies and protocols are similar and 2) the fact that both settings are managed by the same organization facilitated research efforts and minimized difficulties in engaging participants (Warren, et al., 1998). The three facility objectives listed above provided the framework for the evaluation. This document contains one piece of that evaluation, the assessment of the involvement in care, perceptions of formal care and feelings about their relative's situation of the family members. More information about the entire evaluation can be found in the summary report (Warren, et al. 1998) and the technical report (Warren, in press) developed by the research team.

Table 1: Admission Criteria for the Alzheimer Care Centre.

- The client must have a physician diagnosis of probable Alzheimer Disease with moderate confusion and/or with some memory difficulties.
- The client's needs cannot be met in the community as determined by the continuing care assessment process.
- The client must be assessed in a geriatric assessment clinic to provide ACC staff with a specialized data base from which to develop an individualized care plan.
- The client must be able to participate in activities to some degree, and benefit from the special environment and programs.
- The client must be able to communicate with others to some degree, including the use of gestures.
- The client's medical status must be stable.
- The client must be able to ambulate with minimal assistance and/or use of cane or walker.
- The client may require assistance/supervision with meals, but must be able to participate in the process.
- The client may require some assistance/supervision with activities of daily living, as long as needs can be met with the assistance of one caregiver.
- The client must be cooperative with infection management procedures.
- The client must not require more than 30 minutes of intervention in a 24 hour period to manage behavior. Acceptable behaviors include: wandering, hoarding, rummaging, predictable aggressive behavior with low potential injury to self or other, inappropriate sexual behavior considered on a case by case basis.
- The client must be willing to not smoke in the centre.
- The client's family must be in agreement with the program philosophy and be agreeable to the client being discharged to another suitable location when he/she no longer meets the criteria of the centre. In cases where conflict between family members is present, a legal guardian will be required.

From Warren, Janzen, McKim & Liu, in press.

CHAPTER 2

Literature Review

Admitting an ill relative into a long-term care facility is a difficult decision for family members. Family members may spend months agonizing over the decision and, when the move is finally made, they may experience stress and guilt as well as a period of adjustment while they redefine and adapt their caregiving roles (Buckwalter & Hall, 1987; Linsk, Miller, Pflaum, & Ortigara-Vicik, 1988; Matthiesen, 1989; Stephens, Ogrocki, & Kinney, 1991). Although family involvement or programming is a goal of many long-term care facilities, the specifics of how family members are to be involved are often unclear (Holmes, et al., 1994; Shuttlesworth, Rubin, & Duffy, 1982), and the level of family involvement and satisfaction with the care provided vary greatly from facility to facility (Buckwalter, 1991). In Canada, family members may have a choice as to whether or not their relative with AD is admitted into a traditional nursing home, an SCU, or a residential care facility depending on the admission policy, bed availability, and geographic location of the facilities.

Contact with family is an important component in the lives of residents in long-term care facilities (Buckwalter & Hall, 1987; Cohen & Day, 1993). In studies of family visition to long-term care facilities, Greene and Monahan (1982) found that greater frequency of family visits was related to greater psychosocial well-being in the resident (as represented by measures of confusion, agitation, depression, regression, verbal hostility, and physical hostility) while Farber et al. (1991) found that higher quality of relationship between the resident and family member was associated with greater emotional well-being (as represented by measures of depression, life satisfaction and hopelessness). George and Maddox (1989) emphasized that family members are the primary link with life outside the facility for most residents.

In recognition of the importance of family, most SCUs and residential settings have some form of philosophy or policy to include family within the setting. Some examples of family programming include having staff encourage family involvement in activities and care, providing support groups or counselling for family members or having regular meetings between staff and family. Unfortunately, in a study examining the philosophy of care of twenty SCUs in the United States, Zimmerman et al. (1997) found that *supporting the family* and *creating a familiar environment* were not high priorities for SCU administrators. Such findings may be partly responsible for the emphasis on family visiting and creating a familiar environment promoted by residential centres.

Family Involvement in Care

Empirical and anecdotal information indicates that family members continue to be involved in the provision of care to their ill relatives after admission into a long-term care facility. Much of the emphasis in research studies has been on family visitation. Studies have shown that family members are frequent visitors to nursing homes, averaging 6 to 16 visits per month (Campbell & Linc, 1996; Laitinen & Isola, 1996; York & Caslyn, 1977; Zarit & Whitlatch, 1993). Results of a Canadian study with 214 family members of residents of special care homes indicated that 80% of family members visited at least once a week (Keefe & Blain, 1995). In a another study focusing on family visitation patterns in Canada, Keefe and Fancey (1997) found that 43% of a sample of 329 adult children with a parent over 65 years of age living in a long-term care facility visited their parent at least weekly. Another 19% visited once a month. The majority of these adult children (88%) spent their time visiting with their parent within the facility. A study from Finland reported that nearly two-thirds of the family visitors to a nursing home spent less than one hour per visit at the home, while approximately one-third spent an average of 1-2 hours per visit at the nursing home (Laitinen & Isola, 1996).

In a survey of visitors to a traditional nursing home, Campbell and Linc (1996) found that family members reported more barriers to visiting when the resident presented with mental deterioration. Keefe and Blain (1995) found that family members reported less enjoyment during visits with increases in the resident's level of confusion. Although visiting may be stressful or not satisfying when the resident has a cognitive deterioration, family members continue to visit regularly (Kammer, 1994; York & Calsyn, 1977). In fact, Dempsey and Pruchno (1993) found that family members of residents with mental deterioration were as equally involved in visiting and care tasks as were family members of cognitively intact residents. The above results would indicate that family members spend time interacting with their relatives within the walls of a long-term care facility, regardless of the cognitive status of the resident.

Many family members want to remain involved in their relative's care. Hansen, Patterson and Wilson (1988) described a family involvement program on a dementia unit created specifically in response to requests from family members for more direct involvement on the unit. Hatch and Franken (1984) reported that nearly half of 106 adult children of nursing home residents (approximately one-third of residents with cognitive deterioration) indicated a desire for staff to provide them with instruction in care for their relative.

Dempsey and Pruchno (1993) and Keefe and Blain (1995) surveyed family members of residents in long-term care and found that more frequent visiting was significantly related to greater involvement in care. What kinds of care do family members provide when they visit their ill relatives? The 424 adult children of residents in 175 different long-term care facilities in Dempsey and Pruchno's study were asked to identify the care tasks performed primarily by family and those performed primarily by staff from a list of 28 tasks. Family members were responsible for managing money, shopping, putting plants and extras in the resident's room, writing letters for the resident, marking the resident's clothing with name, giving permission for an operation, and managing spending money. According to the family members, there were a number of tasks that they shared with the staff, including walking with the resident, laundering clothes, emotional support, deciding on outings and choosing a doctor.

The 214 family members of residents in 14 long-term care facilities in Keefe and Blain's (1995) study, where nearly two-thirds of the residents presented with dementia, showed that family members reported highest involvement in social activities, such as sitting and talking with the resident, going for walks or drives, eating with the resident, or taking part in formal activities organized by the facility. Although involvement was less frequent than for social activities, family members also took part in many instrumental or care activities, such as sewing, sorting drawers, dealing with laundry, tidying, or shopping for the resident.

Other studies show similar results. Moss and Kurland (1979) found that family members with relatives in an American nursing home were involved in special activities, such as personal care, laundry, cleaning the room, going for walks, and cheering up their relatives. More recently, Linsk et al. (1988) examined a program designed to recognize and integrate family involvement with residents with AD in a nursing home setting. They found that family members chose to be involved in socializing and relationship-based activities more often than personal care or structured task-oriented activities.

In a Canadian study examining six SCUs for persons with dementia, a sample of 39 family members (mostly adult children and spouses) were asked open-ended questions regarding the types of activities they performed for their relatives (Gutman & Killam, 1989). More than one-third of the family members were involved in activities surrounding meals (e.g. feeding resident, taking resident to dining room, or encouraging resident to eat) and socializing (e.g. talking, visiting or sitting with resident). Approximately one-quarter of the family members were involved in activities related to the resident's clothing (e.g. checking for needed repairs or cleaning, bringing new clothes, or sorting laundry), grooming the resident (e.g. shaving, washing hair, or manicuring nails), walking with the resident, and bringing flowers for the resident.

The involvement of family members may be related to perceptions of the long-term care facility and staff. In a qualitative study of family involvement with older relatives in hospital, geriatric care and nursing home care, family members reported a number of facility factors which promoted and inhibited their involvement (Laitinen & Isola, 1996). Characteristics of nurses, such as humanity, skills, empathy, trust and friendliness, and good communication between the staff and family encouraged family members to be involved in care. Environmental factors such as privacy, lack of bureaucracy, and flexible visiting hours also encouraged involvement. However, family members also felt hindered in their involvement by negative attitudes of the nurses, lack of communication between the staff and family, not enough staff and the nurses' traditional ways of interacting with family caregivers. Environmental factors such as bureaucracy, lack of privacy and infections also inhibited family involvement.

In summary, all of the studies reviewed regarding family involvement in care supported the fact that many family members remain involved in the care of their ill relatives after admission into a long-term care facility. The literature also provides some insight into the regularity of visiting and the types of care tasks in which family members participate. However, there are some limitations to the current literature. Many of the studies did not differentiate between family members of the cognitively intact and the cognitively impaired residents (e.g. Dempsey & Pruchno; Hatch & Franken, 1984; Keefe & Blain, 1995; Keefe & Fancey, 1997). It is possible that the types of care tasks for cognitively impaired residents in which family members are involved may differ from those for cognitively intact residents because the cognitively impaired have different needs. Those studies which focused on family members of cognitively impaired residents tended to have smaller sample sizes which can reduce the power of significance testing and limit generalizability of the study results (e.g. Gutman & Killam, 1989; Linsk, et al., 1988; Moss & Kurland, 1979). Although there is information regarding the types of activities with which family members are involved, no comparisons of family involvement over time or between different long-term care settings were found. It may be that family involvement changes as the abilities of the resident change over time or as the family members adjust to the changes that long-term care admission makes in their lives. It is also possible that involvement is influenced by the type of long-term care setting, particularly the policies and philosophies associated with different settings. The present study attempted to address some of these limitations by focusing on family members of cognitively impaired residents, by using a longitudinal design, and by comparing family involvement between two types of care settings.

Family Perceptions of Formal Care

Within the whole experience of moving a relative into a long-term care facility and adjusting their caregiving roles, it is inevitable that family members form an opinion about the formal care provided by staff at the facility. Although the situation can be very stressful, researchers indicate that family members are generally satisfied with the care provided to their relatives in long-term care centres (Braun & Rose, 1987; Cleary, et al., 1988; Gutman & Killam, 1989; Laitinen, 1994; Maas, Buckwalter & Kelley, 1991; Maas, Buckwalter, Kelley & Stolley, 1991; Malmberg & Zarit, 1993; Ritchie & Ledésert, 1992). Even though family members were generally satisfied with the care, many of these research studies also indicated that they do express certain areas of dissatisfaction or needs for improvement.

One American study examined family members' perceptions of care for residents with AD living in traditional nursing homes and found that family members were highly satisfied with the care provided (Maas, Buckwalter, & Kelley, 1991; Maas, Buckwalter, Kelley & Stolley, 1991). However, they were more satisfied with overall care and care provided by non-nurse professionals than they were with physical care and the amount of resources available to care for the resident. Family members were most dissatisfied with not being asked to participate in care, lack of available resources and staff to provide care, and the insufficient number and variety of activities for the residents with Alzheimer's disease Using multiple assessments over a 12-month period, these authors found no statistically significant changes in satisfaction over time, although there was a trend for lower satisfaction as time progressed.

Results of Keefe and Blain's (1995) study, where nearly two-thirds of the residents presented with dementia, indicated that family members were generally satisfied with the nursing homes and the reasons given for their satisfaction included good care given by staff, friendly and caring characteristics of the staff, and the cleanliness of the facility. Although a high satisfaction rating was given, 13% of the 214 family members reported that the care was not always good and 107 of them provided other points of dissatisfaction, such as poor food, poor housekeeping, problems with personal care of the residents and with privacy, and lack of stimulation. Keefe and Blain also reported that family member satisfaction was associated with the extent to which they were made to feel at home, to which they were contacted by staff for information and to which they were involved in decisions regarding their relative, but not associated with frequency of visits to the nursing home.

A few studies examined family perceptions of care in SCUs for persons with dementia or Alzheimer Disease. In the Canadian study by Gutman and Killam (1989), the researchers found that although family members were generally satisfied with the facility, staff, care and programs in six SCUs, they offered suggestions for improvement in the areas of personal care (e.g. baths and clothes), staff relations with the ill relative and family members, and activities for the ill relatives. In an American study, Cleary et al. (1988) found family members to be very satisfied with a reduced stimulation unit for their relatives with Alzheimer Disease. Family members have also indicated satisfaction with the care at residential centres. Malmberg and Zarit (1993) evaluated a Swedish residential care facility for people with dementia. They found that family members were very satisfied with the facility and staff and that their main concern was how well the staff could manage the workload over time.

Another aspect of perceptions of care may be the number of hassles experienced by family members and their concern about the hassles experienced. Stephens et al. (1991) examined sources of stress for family members with relatives in a long-term care facility. These authors found that family members experienced a variety of hassles related to the nursing home environment, such as travelling to and from the facility, reminding the staff to do things for the resident and needing to tell the staff how to care for the resident. The greater the number of hassles experienced, the poorer the psychosocial well-being (i.e. anxiety, depression, activity restriction and negative relations) of the family member. Thus, the family's continued involvement with the resident living in a long-term care facility not only affects the quality of life for the resident (Demsey & Pruchno, 1993), but can impact the family member's psychosocial well-being as well.

Many of the above studies indicated strengths and weaknesses of various long-term care settings, but only a few studies comparing settings have been published. In France, Ritchie and Ledésert (1992) examined family perceptions of stress associated with a long-stay hospital and a *cantou* (residential care facility). Ninety-nine family members from the *cantous* and 158 from long-stay hospitals completed the survey and all family members had relatives diagnosed with senile dementia according to the DSM-III criteria. They found that family members indicated high overall satisfaction with care, although a large proportion of the family members reported specific problems. The main areas of dissatisfaction were with the provision of activities for the ill relatives, interactions with staff, and physical comfort of their ill relative. Family members of ill elderly in the *cantou* indicated higher satisfaction and slightly less stress than family members of ill elderly in the long-stay hospital.

Closer to home, Wakefield et al. (1997) assessed family satisfaction with three types of facilities for persons with dementia in the United States: nursing homes, SCUs, and group homes. They found that family members rated the SCUs and group homes similarly, while the nursing homes scored consistently lower on all satisfaction ratings. Family members with relatives in both the SCUs and groups homes listed the staff's love/concern/respect for the resident as the best aspect of care while the nursing home family members listed the food as the best aspect. Both SCU and group home family members listed staff quality as the worst aspect of care, while the nursing home family members ranked overall quality as the worst aspect of care. These authors speculated that the high rating of SCUs may have been due to high quality care, more selective admission criteria, the promotion of family involvement, or having had their relative in fewer different facilities prior to the SCU placement compared to the nursing home group.

Braun and Rose (1987) completed a comparison study of family members of ill residents (including dementia) in nursing homes and in geriatric foster family care in the United States. Their results indicated that family members had similar evaluations of the two types of settings, except that family members of foster family residents were more likely to perceive that their relative liked the activities, had special friendships, had enough privacy, and had improved during the first six months after admission. These authors concluded that the two settings of care provided comparable services.

In summary, the studies reviewed regarding family perceptions of formal care indicated that most family members are satisfied with the care provided to their relatives living in long-term care facilities. Although they are generally satisfied, more in-depth questions showed that they may be more pleased with some aspects of care than others and they do experience hassles associated with their role within the long-term care facility. However, there are some limitations to the current literature. Little is known about changes in perceptions over time as the resident with AD continues to deteriorate within the long-term care setting. It is possible that family satisfaction ratings may change, particularly if the staff are unable to adjust their care to accommodate the increasing needs of the residents. Only one longitudinal study was found which, with a very small sample, showed a trend for lower satisfaction over a one-year period (Maas, Buckwalter, Keeley & Stolley, 1991). Some differences in perceptions across care settings was noted, indicating greater satisfaction with facilities specifically designed for persons with dementia or more home-like environments. However, given the wide variety of facilities available where residents with dementia may reside, more comparative studies are needed to present a clearer picture of family satisfaction across types of facilities. For example, perceptions of care may be influenced by the characteristics of the administration, staff or environment of the different types of settings. The current study attempts to address some of the short-comings of the literature by using a longitudinal design and by comparing two types of facilities.

Family Feelings about their Relative's Situation

Many family members caring for a relative in the community struggle with the decision to admit their relative into a long-term care facility. There may be a variety of feelings associated with that decision as well as with adjusting to caregiving within the structure of the facility. Two reactions to admission and feelings about the situation which have been discussed in the literature are burden and guilt.

Burden. There is an extensive amount of literature that describes the burden of caring for a relative with dementia at home, but considerably less addressing burden after long-term care admission of the ill relative. The general conclusion of studies which address this concept emphasized that family burden does not end upon admission of the relative into a facility, but rather changes in nature (Elmstahl, Ingvad & Annerstedt, 1998). For example, Pratt, Wright and Schmall (1987) found similar burden scores for 149 family members caring for a demented relative in the community and 91 whose relative was in a long-term care facility. However, family members with a relative in long-term care expressed greater distress over not having enough money to provide care, being unable to continue providing care, wishing they could leave the care to someone else, and feeling they should do more than family members with community-residing relatives. Pratt, Schmall, Wright and Hare (1987) found similar results in a second, similar study with a larger sample.

Elmstahl et al. (1998) assessed family burden when the relative was admitted into residential care. For the 64 family members who participated in this study, overall burden was similar before and after placement, but was lower after the relative with dementia had been living in the facility for one year. Although not statistically significant, Monahan (1995) also found a trend for lower family burden associated with a greater length of time that the relative with dementia had been in a long-term care facility. These authors emphasized that burden was not eliminated over time. Pratt, Schmall, et al. (1987) suggested that burden remained after long-term care admission because of the continued stress of seeing a loved-one deteriorate, the maintained level of commitment and involvement, and new concerns related to the long-term care facility and its care structure. In fact, two studies have found associations between greater resident impairment and higher family burden after long-term care admission (Elmstahl, et al., 1998; Harper & Lund, 1990). It may be concluded from these studies that while there may be a decrease in family burden over time post-admission, those family members whose relatives are more impaired may experience greater burden at later times than family members whose relatives are less impaired. A study by Riddick, Cohen-Mansfield, Fleshner and Kraft (1992) showed a significant decrease in family burden after long-term care admission of the demented relative. However, the retrospective nature of their study may have biased the results toward a greater change in perceived burden than what actually existed.

Guilt. Some feelings of guilt have been associated with making the decision to admit the relative into a long-term care facility. With a small convenience sample of ten family members, Meacham and Brandriet (1997) found family guilt to be associated with the decision to institutionalize but not with the actual move, while the actual move of the relative caused the family to re-evaluate their decision. Johnson and Werner (1982) found that a greater number of people involved in the decision was related to less guilt felt by family members. The feelings of guilt were particularly lessened when the relative needing care and other family members were involved in the decision.

Family feelings of guilt frequently remain post-admission of the relative. Results of qualitative interviews with 32 daughters of mothers residing in a nursing home indicated a consistent theme of "unresolved guilt" (Matthiesen, 1989). The feelings of guilt were evident whether the mother had been living in the nursing home for 6 months or 11 years. However, many of the daughters felt that the guilt was easier to deal with when their mother had a cognitive impairment because their mothers were less aware of the situation. Similar results were found in an earlier study by Johnson and Werner (1982). Although overall guilt was low in this study, results indicated that family members expressed less guilt when the resident had a problem of "misidentifying people" (a sign of cognitive impairment). Another study, which dealt with admission of residents to a nursing home built specifically for dementia sufferers, found that after the decision had been made to move their relative into a facility family members whose relative was admitted compared to those whose relative was placed on a waiting list did not differ in their feelings of guilt (Wells & Jorm, 1987). However, guilt was somewhat reduced three months after the pre-test of the study, for both groups. Although the authors did not comment on this finding, it is possible that over time family members adjust or accept their decision which results in reduced guilt. In general, many family members expressed frustration, resentment and guilt concerning their visits to long-term care facilities whether or not the resident had a cognitive impairment (York & Caslyn, 1977).

In summary, the studies reviewed regarding family feelings about their relative's situation indicated that many family members experience both burden and guilt after admission of an ill relative into a long term care facility. However, there are some limits to the current state of knowledge. A number of studies compared the family members of relatives within a facility to those whose relatives resided in the community, but there were no comparisons across types of facilities. If burden is influenced by facility factors, as suggested by Pratt, Wright and Schmall (1987), family members at different types of facilities may experience different levels of burden. The few studies found which examined feelings across time or which correlated burden and guilt with time since admission of the resident seem to indicate that feelings of burden and guilt may decrease over time. However, if burden is also related to decreasing abilities of the resident, as suggested by Elmstahl et al. (1998) and Harper and Lund (1990), then it may increase again as the resident deteriorates. More research is needed to determine any patterns of change in family burden or guilt. The present study attempts to address some of the limitations in the literature by comparing families from two types of settings for residents with dementia and by using a longitudinal design up to 18 months post-admission of the resident.

Relationships Among Involvement, Perceptions and Feelings

Theorists and researchers have suggested a link between appraisals/attitudes and behaviors (for example, see Fishbein & Ajzen, 1975 or Mischel, 1973) that provides a basis for examining the relationships between family involvement in care and perceptions of care. Typically, the correlation between attitudes and behaviors is not strong and is influenced by other factors, such as the opportunity or the ideal situation in which to perform the behavior, subjective norms, and knowledge about the topic (see Matlin, 1999 for a discussion of this topic). However, when examining the correlation between family involvement and perceptions, these other factors discussed by Matlin may be favorable. For example, family members with a relative in a long-term care facility may have the opportunity to perform the caregiving behavior. Also, they are knowledgeable about the topic of caregiving, having been caregivers themselves, and having experience with the care provided by staff to their relative. The literature has provided some insight into the nature of the relationship between family involvement in care and perceptions of formal care.

Kammer (1994) studied family involvement as a way of coping with admission of a relative into a long-term care facility and found that family perceptions of care were related to their involvement in care. In this study, emotional responses by 89 family members were used to indicate their perception of care as measured by the Emotion Appraisal of Nursing Home Placement Tool. Four subscales related to four perceptions: 1) threat, which included emotions such as worried, fearful, anxious, apprehensive; 2) harm, which included emotions such as angry, sad, disappointed, guilty, disgusted, hurt, and demeaned; 3) challenging, which included emotions such as confident, hopeful, eager and enthusiastic; and 4) benefit, which included emotions such as exhilarated, pleased, happy, and relieved. Results indicated that the frequency of family visits increased when family members rated long-term care residence as highly threatening or harmful for their relative, and family visits decreased when family rated long-term care residence as beneficial or challenging. Kammer (1994) suggested that family members who felt more confident and comfortable with the formal provision of care did not feel the need to monitor the care as closely and thus decreased their visits. Findings from the above study suggest that family members are more involved when they perceive that the quality of care is compromised or they are not satisfied with the care.

An Australian study of 31 family members with a relative in a nursing home tested the relationship between involvement and perceptions. Toye, Percival and Blackmore (1996) found no relationship between inviting greater family involvement (asking them to take part in a collaborative care program) and increased satisfaction with nursing home care. In this study, only four family members actually agreed to increase their involvement. Although the groups were too small to perform statistical tests, the researchers reported a trend for the family members who increased their involvement to have consistently lower satisfaction scores than those who chose not to participate in the program. These researchers suggested that it may have been the family members who were least satisfied to begin with who took advantage of the opportunity to increase their involvement.

A more specific relationship between involvement and perceptions was found in Stephens' et al. (1991) study about sources of stress for family members of institutionalized dementia residents. For 66 family members whose relative had been residing in a nursing home an average of two years, there was a moderate but significant positive correlation between the number of weekly visits to the nursing home and the number of hassles experienced by family members with regard to interactions between the staff and family. More research is needed to clarify the relationship between perceptions and involvement.

The literature provides more information about the relationships between feelings and involvement and between feelings and perceptions. Both burden and guilt have been associated with involvement in care and perceptions of care. Although a small sample size may have precluded statistical significance, Monahan (1995) found a trend for family members with higher burden scores to also have lower perceptions of the quality of formal care and greater visiting frequency to the long-term care facility. Riddick et al. (1992) developed a model to explain caregiver adaptations to having a relative with dementia admitted to a nursing home that showed a negative correlation between caregiver burden and satisfaction with the nursing home. Grau, Teresi, Burton and Chandler (1995) found that family caregivers of relatives in a nursing home (approximately two-thirds of residents rated as confused) who had higher burden and guilt scores also had lower perceptions of the care provided at the facility. In a study examining attachment between adult children and institutionalized parents, Pruchno et al. (1994) found that greater involvement in care was associated with children feeling less guilty.

In summary, the literature review regarding the inter-relationships among involvement, perceptions and feelings indicated that there may be some connections among these concepts for family members caring for relatives living in long-term care facilities. Studies showed that greater involvement was related to lower perceptions of formal care (lower satisfaction but more hassles), that greater involvement in care was related to greater burden but less guilt, and that greater satisfaction was related to less burden and guilt. This study sought to confirm some of these relationships for family members of residents with Alzheimer Disease.

Summary

The literature indicated that there were different ways to define and measure involvement, perceptions and feelings. Involvement generally included both visiting and participation in caregiving tasks. Perceptions usually focused on satisfaction with formal care, but also included hassles experienced in the family's relationships with the long-term care staff. Feelings tended to focus on the burden and guilt experienced by family members with regard to the move of their relative into a long-term care facility. Although the relationships among these three concepts was rarely the focus of reported research, a number of studies mentioned connections among involvement, perceptions and feelings.

Many of the research studies reviewed described family involvement in care, perceptions of formal care, or feelings about their relative's situation at one point in time within one long-term care facility. Although such studies are important to the evaluation of long-term care quality and our understanding of family care to the ill elderly, the next step is for longitudinal studies of one setting of care or comparison studies across different settings (Sloane, et al., 1995). This study addresses both of these "next steps."

CHAPTER 3

Study Objectives

The present study focused on family members caring for relatives with AD in long-term care facilities. There were three main objectives: 1) family caregiving over time, 2) family caregiving between settings, and 3) relationships among involvement, perceptions and feelings. Due to the fact that this was a program evaluation, it was not theory-driven and hypotheses were not tested. Rather, a variety of questions directed the methodology and data analyses to meet the objectives of the study.

Objective 1: Family Caregiving Over Time

The first objective was to complete a longitudinal study of how family members provide care for relatives at the ACC. The opening of the new facility presented an opportunity to follow a cohort of family members who were experiencing a similar situation, i.e. moving their relative into a new setting of care, and all experienced a similar care environment. Multiple measures of family involvement, perceptions, and feelings were taken during the first 18 months after admission of the relative with AD into the facility in order to identify the responses of family members to this new setting and to examine any changes over time as patterns of caregiving were established within the facility.

A: Family involvement in care. The purpose of this part of Objective 1 was to provide a description of family involvement in care and to examine any changes in involvement over time. Five dimensions were chosen to represent the concept of family involvement: 1) the average number of visits to the facility per month, 2) the average length of time spent at the facility per visit, 3) the number of tasks involved with at the facility, 4) the frequency of involvement with tasks at the facility, and 5) the desired level of involvement in tasks at the facility. This section focused on the question: Does family involvement in care change over time at the ACC?

B: Family perceptions of formal care. The purpose of this part of Objective 1 was to describe family perceptions of the care provided by staff at the facility and to compare these perceptions over time. Three dimensions were chosen to represent the concept of perceptions of care: 1) family satisfaction with the care provided at the facility, 2) number of hassles experienced by family members, and 3) family rating of hassles associated with facility. This section focused on the question: Do family perceptions of formal care change over time at the ACC?

C: Family feelings about their relative's situation. The purpose of this part of Objective 1 was to describe the feelings of the family members regarding caring for their relative with AD within the facility and to examine any changes over time. Two characteristics were chosen to represent family feelings about their relative's situation: subjective burden and perceived guilt. This section focused on the question: Do family feelings about their relative's situation change over time at the ACC?

Objective 2: Family Caregiving Between Settings

The second objective was to complete a cross-sectional comparison of how family members care for their relatives within two types of settings: residential care at the ACC and the SCUs operated within traditional nursing homes in Edmonton.

A: Family involvement in care. The purpose of this part of Objective 2 was to provide a description of family involvement in care and to examine any differences in care between the settings. The same five dimensions as described in Objective 1 were chosen to represent the concept of family involvement. This section focused on the question: Does family involvement in care differ between two long-term care settings?

B: Family perceptions of formal care. The purpose of this part of Objective 2 was to describe family perceptions of care provided by the facility and to compare these perceptions between the two settings. The same three dimensions were chosen to represent the concept of perceptions of care as listed in Objective 1. This section focused on the question: Do family perceptions of formal care differ between the two long-term care settings?

C: Family feelings about their relative's situation. The purpose of this part of Objective 2 was to describe the feelings of family members regarding their relative's situation within the facility and to compare these feelings between settings. The same two concepts as described in Objective 1, subjective burden and perceived guilt, were assessed in both groups of family members. This section focused on the question: Do family member feelings about their relative's situation differ between the two long-term care settings?

Objective 3: Relationships Among Involvement, Perceptions and Feelings

The third objective was to complete an examination of the relationships among family involvement in care, perceptions of formal care and feelings about their relative's situation after long-term care admission. The literature provided some indication that there are relationships among these concepts and the purpose of this objective was to explore these inter-relationships for this sample of family members. Therefore, three questions directed this section of the study: 1) Is there a relationship between family involvement in care and family perceptions of formal care?, 2) Is there a relationship between family involvement in care and feelings about their relative's situation?, and 3) Is there a relationship between family perceptions of formal care and family feelings about their relative's situation?

CHAPTER 4

Methodology

Participants

"Family member" for this study was defined as the person who takes responsibility for the resident with Alzheimer Disease living at the facility (usually listed as next-of-kin in the resident's chart), who was involved in the resident's care before admission and who is related to the resident through blood or marriage. Although it would have been preferable to invite all family members involved in the care of individual residents to participate, this would have required considerably more time for data collection and substantially increased the costs of the study. Therefore, one family member for each resident was asked to participate in the study.

The study was explained to the family members by an employee of The Capital Care Group, and a signed consent form was obtained prior to data collection (Appendix A). All results are based on the behaviors and opinions of one family member per resident. The Ethics Committee of the Faculty of Rehabilitation Medicine, University of Alberta approved the study prior to recruiting participants.

Participants were recruited from the ACC and three SCUs operated by The Capital Care Group (see Appendix B for a description of the facilities). All residents from the ACC were considered eligible for the study and their family members were invited to participate. Family members of SCU residents who met the criteria for inclusion in the study were also asked to participate. Resident inclusion criteria included a diagnosis of AD (as determined by a geriatrician or physician), being ambulatory, residing at the facility for more than two months, and not presenting any concomitant conditions which affect cognitive status, such as Parkinson's, cerebral vascular accident, post-myocardial infarct, or transient ischemic attacks. Prior to data collection, The Capital Care Group evaluators believed that the residents in both settings would be similar on salient characteristics, although the SCU residents were likely to have more physical problems than the ACC residents. Initially, matching the residents on salient characteristics (such as level of impairment or length of time residing in the centre) was considered in order to compare family members who were experiencing similar caregiving situations. However, after reviewing the charts to determine the number of eligible residents for the study, matching was not considered feasible due to the threat of attrition in this population and the small number of eligible residents and family members at the facilities. Alternatively, data was obtained for several resident and family characteristics to assess group comparability later in the study. Resident characteristics included previous living arrangements of the resident (community or other facility), length of time residing in the facility, age and gender. A description of functional status of the residents as assessed by The Capital Care Group can be found in Appendix C. Family member characteristics included age, gender, relationship to the resident, ethnicity, education, marital status, perceived health, employment status and distances residing and working from the facilities.

Residents from the traditional nursing homes were not included in this study for two main reasons: 1) very few residents in the middle stages of AD were residing on the traditional nursing home units because The Capital Care Group had SCU facilities available for them, and 2) The Capital Care Group evaluators believed that any residents with AD who resided on the traditional nursing home units would have significant physical problems and concomitant conditions and would not meet the study's inclusion criteria.

Data Collection

When a signed consent form had been obtained, family members were contacted by the researcher responsible for interviewing the families in order to schedule a meeting. Data was collected through interviews with family members using a standard interview schedule which included individual questions and scales. The interview schedule had been pre-tested on 6 family members with a relative residing in a long-term care facility. (The purpose of the pre-test was to determine the approximate length of the interview and to obtain feedback from the caregivers as to the appropriateness of the questions to their situations and whether they thought that any additional questions should be added to the interview. No changes were made to the interview schedule as a result of the feedback given from the pre-test family members.) The researcher met with family members in a location other than the facility in order to reduce response bias among those who might be inhibited by the presence of staff when answering questions at the facilities. This location was usually the family member's home, but some family members chose to meet at the researcher's office, their own workplace, or a restaurant. The same researcher, who had previous experience interviewing family caregivers, conducted all interviews. On average, interviews lasted 1.5 hours, ranging from approximately 45 minutes to 2.5 hours.

Family Caregiving Over Time

To collect data for the first objective, family members from the ACC were interviewed three times: 6, 12 and 18 months after admission of their relative into the ACC. Eighteen months was chosen as the end point because previous research with residential care residents suggested that loss of sample size accelerates after 18 months (Silverman, 1995).

Family Caregiving Between Settings

To collect data for the second objective, family members from the SCUs completed the same interview schedule as the ACC family members. Originally, the intent of the study was to collect data longitudinally from the SCU family members and compare the data to the ACC family members at each of the three time periods. However, once the study had begun it became readily apparent that this longitudinal comparison would be tenuous for a variety of reasons. First, the

ACC and SCU family members were at different stages in the continuum of caring for their relatives. Analysis of resident data collected during the first family interview time period indicated that the residents at the SCUs were significantly more impaired than the ACC residents (Appendix C). Resident impairment has been shown to influence family involvement in care, perceptions of formal care and feelings about their relative's situation (Dempsey & Pruchno, 1993; Elmstahl, et al., 1998; Harper & Lund, 1990) and may have influenced any longitudinal comparisons between the groups.

Second, the two groups of family members had different amounts of time to establish their roles within the facilities. The SCU residents had been living at the SCUs for a significantly more months (M = 21.13) than the ACC residents (M = 5.26), t(74) = -5.65, p. = .00. Previous literature indicated that some measures of involvement, perceptions and feelings may be influenced by the length of time that the resident have been living in the facility (Elmstahl, et al., 1998; Grau, et al., 1995; Keefe & Blain, 1995). Analysis of data collected at the first interview confirmed that length of time living at the facility was significantly related to the number of tasks involved with and the satisfaction with care provided (Table 38 in Appendix D, column 2), suggesting some influence on family member involvement and perceptions. Although not significant at the $p \leq .05$ level, there was a trend for length of time living at the facility to be negatively correlated with the frequency of involvement in tasks.

Third, the attrition rate was high for the SCU group. By the second interview, nearly one-third of the participants had left the study. This trend was expected to continue through to the third interview. In consideration of the previous two points and the high attrition rate, a decision was made to not conduct a third interview with the SCU family members.

Consequently, a decision was also made to conduct only one cross-sectional analysis using the second interview of the ACC family members (at one year post-admission, n = 33) and the first interview of the SCU family members (n = 38). This dealt with all three problems noted above. First, the additional six months given to the ACC residents allowed for the continued deterioration of the residents with AD, reducing the gap in resident impairment between the two types of settings and allowing for greater comparability of the family members' caregiving situations. Second, the average number of months that the resident had been living at the facility was closer (ACC=12.47; SCUs=21.78) using the second ACC interview rather than the first, providing the ACC family members with more opportunity to establish their role within the facility. Third, by comparing the second ACC interview to the first SCU interview, the SCU attrition rate was no longer a problem.

It should be noted that comparing the third interview of the ACC family members to the first interview of the SCU family members in order to further reduce the problems noted above was considered. This course of action was rejected because the number of ACC family members left in the study by the third interview (n = 20) was considerably smaller than at the second interview (n = 33). Smaller groups and vastly unequal group sizes reduce the power of the statistical analyses to detect differences between the groups (Cohen, 1977). Using the length of time the resident had been living at the facility as a covariate was also considered. This would have removed the variance associated with the covariate from the error variance and adjusted for prior differences between groups by adjusting the dependent variables as if all subjects scored the same on the covariate (Tabachnick & Fidell, 1989). Another bi-variate correlation analysis using the second interview ACC data and the first interview SCU data was completed (Table 38 in Appendix D, column 3). Results showed that the length of time living at the facility was no longer significantly correlated with any of the involvement, perceptions, or feelings measures (although the correlation with satisfaction with the care provided reached near significance) and the use of a covariate was rejected because it was no longer an issue after the residents had been living at the facilities for one year or longer.

Relationships Among Involvement, Perceptions and Feelings

The data used for the analyses in Objective 2 (ACC second interview and SCU first interview) were used to examine the relationships among family involvement in care, perceptions of formal care, and feelings about their relative's situation. Although no theoretical or literature-based results were found to indicate that the relationships among involvement, perceptions and feelings would differ by type of setting, the two groups were analyzed separately.

Measures

The interview schedule included demographic items, scales and single questions regarding family involvement in care and family perceptions of formal care and two scales to measure family feelings about their relative's situation (see Appendix E for the entire interview schedule). Items not directly related to the objectives of the study were included in the interview schedule in order to more fully describe family caregiving within the long-term care facilities. Some of these items were included at the request of The Capital Care Group.

Family members were asked to answer the questions based on their behavior, feelings, and opinions in the past six months. The use of self-report data can be valid and reliable in research regarding both global and situation-specific constructs (Dolan & White, 1988; Moskowitz, 1986). The measures are described below.

Describing the Sample

The interview schedule included several single-item questions regarding the age and gender of the family member, familial relationship of the family member to the resident, ethnicity, level of education, marital status, self-rated health, employment status, and distances residing and working from the facility. Items regarding the resident included age and gender, reasons for seeking long-term care admission, length of time the resident had been residing in the facility and whether or not the resident had been admitted to a facility prior to the current one. There were also a few questions regarding the visiting of other family members and a scale which focused on the family member's perception of the resident's freedom of choice in daily activities (The Perceived Latitude of Choice Scale by Hulicka, Morganti & Cataldo, 1975). These measures were used to describe both family members and residents.

Family Involvement Measures

1. *Average number of visits to the facility.* Family members were asked to estimate on average how frequently they visited the facility. Responses were calculated on a monthly basis (4 x weekly visits for family members who provided this information in terms of visits per week). Family members were asked to estimate their visits instead of keeping a sign-in log at the centres because The Capital Care Group administrators felt that a sign-in log would not fit with the philosophy of ACC. The philosophy of ACC holds that family members are free to come and go at will, as they would if they were visiting the resident's private home.

2. *Average length of visits.* Family members were asked to estimate the average length of time they spent at the facility per visit. This measure was calculated as the number of hours per visit. Again, family members were asked to estimate the time they spent at the facility rather than keeping a sign-in/sign-out log for the reason mentioned above.

3. *Number of tasks involved with.* Family members were asked to indicate the tasks they performed from a list of 39 tasks in which family members of long-term care residents may participate, with two options to list other tasks. Because no standardized tool for this concept could be found in the literature, the list was derived from studies which indicated family involvement in a variety of tasks in long-term care facilities (Gutman & Killam, 1989; Laitinen, 1993; Linsk, et al., 1988; Moss & Kurland, 1979; Shuttlesworth, et al., 1982) and checked by The Capital Care Group staff for appropriateness. To provide more detail into the types of tasks performed by family members, two members of The Capital Care Group and the interviewer independently categorized the tasks as either social/recreational or personal care/guardian. Where two of the three raters agreed, the task was placed into a given category. There are 20 tasks in the social/recreational category and 19 tasks in the personal care/guardian category (Appendix E, Part 5). Family members were asked whether or not they had ever been involved in the tasks since the admission of their relative into the facility or since the previous interview (for the second and third interviews). This measure was calculated as the number of tasks in which family members indicate involvement, with possible scores ranging from 0 to 39. Higher numbers indicate participation in a greater variety of tasks.

4. *Frequency of involvement in tasks.* Family members were asked to indicate the frequency with which they were involved in tasks from the list of 39 tasks described above (#3). Family members were asked to estimate how often they completed the tasks on a 5-pt rating scale (1 = less than once per month, 2 = 1 to 3 times per month, 3 = once per week, 4 = 2 to 4

times per week, 5 = 5 or more times per week). The frequency of involvement in tasks measure is an average of the frequency of involvement across the tasks and possible scores range from 1 to 5. Higher values indicate greater frequency of involvement.

5. *Desired level of involvement in tasks.* Family members were asked to indicate how well their actual level of involvement in the 39 tasks listed above (#3) coincided with their desired level on a 3-point scale: -1= would like less involvement, 0= would like the same involvement, and +1= would like more involvement. The satisfaction measure is an average of the responses to each item. Possible scores range from –1 to +1. Positive values indicate a desire for more involvement while negative values indicate a desire for less involvement.

Family Perceptions Measures

1. *Family satisfaction with care provided.* The Family Perceptions of Care Tool was used to assess family members' satisfaction with the conditions of care at the facilities (Maas & Buckwalter, 1989). This 51-item tool was designed to measure satisfaction with 4 areas of care for the elderly with Alzheimer Disease living in long-term care facilities. Responses are scored on a 7-point rating scale from strongly disagree to strongly agree. Maas, Buckwalter, Kelly and Stolley (1991) published psychometric data for the scale based on a repeated measures pilot study with 15 family members. They reported the Cronbach's alpha coefficients for the four subscales as: the resident's environment (.77 to .87); physical nursing care (.91 to .93); relationships among residents, staff and families (.74 to .92); and overall care (.87 to .96). For the total scale, Cronbach's alpha coefficients ranged from .92 to .97. Test-retest reliability after 10 days ranged from .78 to .90. Content validity was established by a panel of gerontological nurses and social workers who reviewed the tool. The authors stated that no comparable measure was available for construct validation. This measure was designed to be self-administered, so the family members in the present study were asked to complete this section of the interview schedule themselves. Responses to the items were averaged for a total score ranging from 1 to 7. Higher scores indicate greater satisfaction.

In addition to the above scale, family members were asked four general questions regarding their overall satisfaction with the facility, staff and care provided which were rated on a 5-point rating scale. These questions included: 1) Are you satisfied with the opportunities provided by the centre for you to be involved in the care of your relative? 2) In general, are you satisfied with the programs/activities provided by the centre for residents? 3) Are you satisfied with the staff at the centre? and 4) Overall, how satisfied are you with the centre as the place for your relative to live? Family members were given the opportunity to give suggestions for improvements in the provision of care given to their Alzheimer relatives and to comment about aspects of the facility with which they were particularly pleased. Higher scores indicate greater satisfaction (Results for these questions are reported in Appendix H).

2. *Number of hassles experienced by family members.* The Caregiving Hassles Scale: Nursing Home Hassles (Stephens, et al., 1991) was used to assess family hassles associated with their relative residing in a long-term facility. This 27-item scale is scored in two parts: Part 1 asks for a yes/no response indicating whether the incident has happened, and Part 2 asks the family members to rate the degree of hassle associated with the incident on a 4-pt Likert scale. The reliability coefficient for this scale was reported as .85. The developers of this scale divided it into three subscales with the following alpha coefficients: a) caregiver-staff hassles .70, b) resident-staff hassles .82, and c) practical/logistic hassles .61. For the present study, the word "hassles" was changed to "issues" or "concerns" at the request of The Capital Care Group because hassles was deemed to have a negative connotation. Responses to whether or not the hassles or issues occurred were summed for a *total number of hassles experienced* score with possible scores ranging 0 to 27. The responses to the degree of hassle or concern were averaged for an *average rating of hassles experienced* with possible scores ranging from 1 to 4. Higher scores indicate greater hassles experienced and greater concern about the hassles.

Family Feelings Measures

1. *Subjective burden.* The Burden Interview (Zarit, Reever & Bach-Pederson, 1980; Zarit and Zarit, 1982) was used to assess family member subjective burden. This 22-item scale asks family members to rate how often they experience certain feelings about the impact of their ill relative's disabilities on their life, on a 5-point continuum from "never" to "nearly always". Internal consistency has been reported to vary between .88 (Hassinger in Zarit & Zarit, 1987) and .91 (Gallagher et al. in Zarit & Zarit, 1987). Test-retest reliability has been reported at .71 (Gallagher et al. in Zarit & Zarit, 1987). Validity has been estimated by Derogatis, Lipman, Covi, Richels and Uhlenhuth (1970), by correlating the scale's total score with a single global rating of burden (r = .71) and with the Brief Symptom Inventory (r = .41). Although initially designed to be used with caregivers whose relatives were residing at home, it has been used with caregivers after the admission of their relative into a long-term care facility (Grau, et al., 1995; Harper & Lund, 1990; Monahan, 1995). For the present study, a category of "not applicable" was added and scored as "0" so that family members could indicate that an item did not apply to their situation. Responses to the items were summed for a total score ranging 0 to 88, with higher scores indicating greater burden.

2. *Perceived guilt.* The Guilt Scale (Wells & Jorm, 1987) was used to assess the guilt felt by family members relating to their caregiving role and long-term care admission of their relative. This scale has three items rated on a 4-point Likert scale (0=not at all, 1=a little, 2=a lot, 3=almost unbearably). The items included: 1) Recently I have felt very guilty regarding my decision to admit my relative into a continuing care facility; 2) I keep thinking I should be doing more for my relative; and 3) I worry about whether my relative is cared for well enough. Internal consistency was reported at .70 for a sample of 26 family caregivers. Other psychometric data were not available for

this scale. For the present study, responses to the items were summed for a total guilt score ranging 0 to 12. Higher scores indicated greater feelings of guilt.

Data Analysis

Data collected in the interview schedules were entered into a statistical computer program spreadsheet, SPSS 8.0 (SPSS, 1997), for data analysis. Descriptive statistics, such as frequencies, measures of central tendency, variability, and range, and univariate statistics, such as t-tests or F-tests, were used to describe the sample and to describe the involvement, perceptions and feelings of the family members who participated in the study. Although some of the measures used in this study produced data at the ordinal level, researchers in the behavioral sciences frequently use such data in as interval level, as was done in this study. Results of comparisons were considered significant at an alpha criterion of .05. It should be noted that multiple testing of variables between groups can increase the chance of a Type I error (i.e. rejecting a true null hypothesis) and is usually compensated for by lowering the alpha criterion to .01. However, in this study statistical results which met the .05 alpha criterion were always reported, but caution in interpretation was mentioned.

Repeated measures multivariate analysis of variance (MANOVA) was used to analyze the longitudinal data from the ACC. Measures for the three hypotheses summed to ten dependent variables. Stevens (1996) recommended computing separate MANOVAs for subgroups of dependent variables when the MANOVA technique is used to examine differences among a large number of dependent variables and when there is a rationale for analyzing them separately. In this case, the ten variables comprise three concepts: involvement in care, perceptions of formal care, and feelings about their relative's situation. Therefore, three separate analyses were conducted with TIME as the within-subjects factor. The results were considered significant at an alpha criterion of .05. All post-hoc analyzes were conducted using the Bonferroni correction method, unless otherwise stated.

MANOVA was used to analyze the data for the comparison between the ACC (second interview) and the SCUs (first interview). As with the longitudinal data, three separate MANOVAs were conducted for the involvement, perceptions and feelings data, with SETTING as the between-subjects factor. Results were considered significant at an alpha criterion of .05.

Ideally, structural equation modeling would have been used to examine the interrelationships among the involvement, perceptions and feelings variables for the third objective of the study. However, due to the small sample size and the large number of variables, this could not be conducted with confidence. Therefore, a bi-variate correlation matrix was produced, showing the correlations at both the .05 and .01 alpha levels.

One issue evident in this study is that of statistical power. "*The power of a statistical test of a null hypothesis is the probability that it will lead to the rejection of the null hypothesis*, i.e. the probability that it will result in the conclusion that the phenomenon exists" (Cohen, 1977, p. 4). Power depends on three parameters: the significance criterion, the sample size, and the effect size. Briefly, the more stringent the alpha criterion, the less power the statistical test will have to reject a false null hypothesis; the larger the sample size, the greater the power of the statistical test; and the larger the effect size (i.e. the degree to which the phenomenon is present in the population), the greater the power. In the present study, the small sample size is most pertinent to the data analysis and reporting of results (Appendix F). The sample size (the number of family members) was limited due to the number of residents housed at the ACC, the number of residents who met the criteria for inclusion in the study at the SCUs, and the loss of sample size over time. Although the sample size was limited, and likely affected the power of the statistical tests to detect a difference where a difference existed, the descriptive statistics were used to complement the multivariate findings and aid in any conclusions drawn from the analyses. In order to compensate for the small sample size and increase power, an alpha criterion of .05 was used instead of the more stringent .01.

Limitations

The purpose of this study was to describe family members caring for relatives with AD living in long-term care facilities through a longitudinal evaluation of a new residential care facility and a cross-sectional comparison between the residential facility and existing SCUs. To the best of the investigator's knowledge, this study is the first of its kind in Canada. However, there are some limitations associated with the design and methodology this study. First, since this was a convenience sample and a volunteer sample, the family members associated with the participating facilities may not be representative of family members of residents with Alzheimer Disease in other such facilities. Also, any conclusions drawn from the results of the study are limited to long-term care facilities operated by The Capital Care Group and may not apply to similar facilities operated by other organizations. Also in terms of the sample, the majority of participants were Caucasian, of European or North American descent, and the findings may not apply to family members from other ethnic origins, such as Asian or African.

Second, the ACC residents were found to differ significantly in functional status from the SCU residents (Appendix C). It seems likely that the family members associated with the two groups of residents are from two different populations, or at least, from the same population at different stages in the progression of the disease. Although the two groups of family members can be compared, any differences found cannot be solely attributed to the type of care program implemented. For example, it may be possible that the SCU family members would perceive the SCU care differently if their relatives were functioning at a higher level. Unfortunately, the constraints to sample selection and study design described earlier in this chapter did not allow for a matched sample with a longitudinal comparison. However, it should be noted that ACC and SCU family members were similar on their demographic characteristics, such as age, gender, and employment, indicating that similar types of family members have relatives in both facilities and allowing for a more valid comparison of the two groups. The residents at the SCUs had been living in these facilities significantly longer than the residents at the ACC. However, length of time the resident had been living at the facility was not significantly correlated with the involvement, perceptions or feelings measures, suggesting that it is not an important factor when examining these concepts after the residents had been living at the facility for longer than one year and likely had little bearing on any of the results.

Third, the sample size for the present study was small, due to the constraints of the number of beds available at ACC, attrition over the study period, and the number of eligible residents at the SCUs. The resulting power of the statistical analyses to detect differences where differences exist was low. Therefore, the results of this study should be interpreted with caution. However, noticeable trends were reported to compensate for the lack of power due to the small sample size. The large drop in sample size was not anticipated, as previous studies have shown that residents tend to remain about 18 months in such a residential setting (Silverman, 1995). Attrition was largely due to residents being transferred out of the facility or being deceased.

Fourth, there may have been some biases present in comparing the new ACC and existing SCUs. Sloane et al. (1995) suggested that the quasi-experimental nature of such studies, with non-random selection of subjects opens the study to many forms of bias. For example, unit size bias refers to the fact that small units may be more effective than larger units. There was a unit size difference in the present study because the ACC is an independent building with a total of 36 residents while the SCUs are all part of larger nursing homes which house a large number of residents. In addition, only family members of residents who met the study criteria were selected for participation in the study, omitting other family members who visit the SCUs. However, in this study there was little difference in the effectiveness (i.e. family satisfaction) of the two groups, suggesting that this bias may not have been an issue.

Another example of bias is that of unit age bias which refers to the fact that systematic differences between residents, family and staff are a result of the newness of a facility. Newer facilities tend to have higher functioning residents and may have better staff-resident ratios, although they may also have greater staff turnover rates and staff with less experience. Sloane et al. (1995) commented that the effects of unit age bias are unpredictable. In the present study, the ACC residents were functioning at significantly higher levels than the SCU residents (Appendix C) but the staff turnover rates and knowledge of AD for both types of facilities were similar (Andiel, 1999). The newness of the facility may have affected the family members' satisfaction with the environment. The ACC family members were significantly more satisfied with the environment and with programs and activities than the SCU family members. The results may have been different if the SCUs had also been new facilities.

CHAPTER 5

Results

Sample Description

Sample Size

In total, 76 family members agreed to participate in the study. At the beginning of the study, one family member from the ACC declined to participate, leaving 35 family members to complete the first interview. Three additional family members completed a first interview as they replaced those who had left the study, providing a total of 38 family members who completed a first interview. A total of 20 family members were left in the study by the third interview. Table 2 shows sample size across time and reasons for losing participants. At the SCUs, 38 family members agreed to take part in the study.

Table 2: Sample Size Over Time.

Interview 1	Interview 2	Interview 3
ACC sample 38	33 • 2 residents transferred • 2 residents deceased • 1 family declined further participation	20 • 6 residents transferred • 2 residents deceased • 1 family unavailable • 4 family excluded (incomplete data)
SCU sample 38	26 • 2 residents deceased • 6 family unavailable or could not be reached • 3 family declined further participation • 1 no longer a caregiver	(A third interview was not conducted with the SCU family members for reasons explained in Chapter 4.)

For the purposes of this study, the SCU family members were treated as a homogeneous group. The numbers of participants from each SCU was too small to include them separately in any of the multivariate analyses used to address the main objectives of the study (i.e. SCU A = 13, SCU B = 18, SCU C = 7). One-way analysis of variance was used to compare the three groups on the primary study variables. Results indicated that the family members were similar on the majority of variables. Overall, any differences were considered minor and the data for the three SCUs were grouped for all further analyses.

Sample Demographics

Tables 3a and 3b provide numerical descriptions of the family members who participated in the study from both settings of care. The average age was in the mid-fifties for both groups of family members and in the early 80's for their relatives. Approximately two-thirds of family members were female and more than three-quarters were married, in both groups. A large number of family members interviewed in both groups were adult children of the residents. Both groups of family members considered themselves in good to excellent health. Both ACC and SCU family members were primarily Caucasian, of Canadian or European descent, and highly educated. The distance of the family members' homes from the facilities appears to be quite different between the two groups, but the ACC average is affected by two family members who lived outside of the Edmonton area. Excluding these two from the sample showed that the average distance from home to the ACC was 16.27 km (Min. = 2.5, Max. = 80) compared to the 12.25 km of the SCU family members. The two groups had spent approximately the same amount of time caregiving prior to admission, but the SCU family members had been caregiving for a longer period of time since the admission of their relative into the facility.

Independent samples t-test analyses and Chi-square analyses indicated that there was only one statistically significant difference between the two groups of family members. The SCU family members had experienced a greater length of time since admission of the resident into the facility than the ACC family members, $\underline{t}(74) = -5.65$, $\underline{p} = .00$.

Table 3a: Sample Characteristics (Means[a] of Continuous Variables).

Characteristics	ACC $\underline{n} = 38$	SCUs $\underline{n} = 38$
Age of Family Member (years)	56.34 (35 - 79)	57.42 (32 - 85)
Age of Resident (years)	81.39 (67 - 93)	80.39 (63 - 94)
Distance of Family Member's Home from Facility (km)	46.99 (2.5 - 850)	12.25 (0.5 - 97)
Distance of Family Members' Workplace from Facility, if applicable (km)	28.06 (1 - 350)	23.22 (0.5 - 142)
Time caregiving prior to admission of resident (years)	3.57 (0 - 12)	3.01 (0 - 10)
Time since admission of resident into facility (months)	5.26 (3 - 7)	21.13 (3 - 71)

[a] The minimum and maximum scores are shown in parentheses.

Table 3b: Sample Characteristics (Frequencies of Categorical Variables).

Characteristics	ACC n = 38	SCUs n = 38
Gender of family member (female)	24	25
Gender of resident (female)	33	24
Relationship to resident with AD		
Spouse	6	10
Daughter	18	13
Son	11	8
Daughter-in-law	1	4
Other relative	2	3
Self-rated health		
Excellent	10	10
Very good	15	10
Good	9	17
Fair	4	1
Poor	0	0
Marital status (married[a])	30	32
Employment status (employed[b])	23	18
Education level		
< 12 years	11	10
High school graduate	3	7
Trade/technical school	6	6
College/university education	18	15
Maternal origins		
Canada/United States	16	19
British Isles	10	10
Western Europe	3	2
Eastern Europe	8	7
Asia	1	0
Paternal origins		
Canada/United States	14	18
British Isles	9	9
Western Europe	4	4
Eastern Europe	9	6
Asia	1	1
Other	1	0

[a] "Married" included married and living-as-married; "not married" included widowed, separated, divorced and never married.

[b] "Employed" included full-time, part-time and self-employed; "not employed' included unemployed, retired, and homemakers.

Admission of the Resident

Family members were asked why they chose to move their relative into a long-term care facility. As shown in Figure 1, the reasons most often chosen by family members had to do with the behavioral and functional problems associated with the disease. Family members were frequently influenced by the suggestion of another person, usually a physician, who prompted them to move their relative.

Some significant differences existed between reasons chosen by the SCU and ACC family members. The SCU family members more frequently expressed their relative's behavior problems, incontinence, and inability to recognize familiar people as reasons for seeking admission than did the ACC family members, $ts(74) = -2.62, -3.13$, and -2.29, respectively, $ps < .05$. (Appendix G provides a comparison of family members with and without prior long-term care experience.)

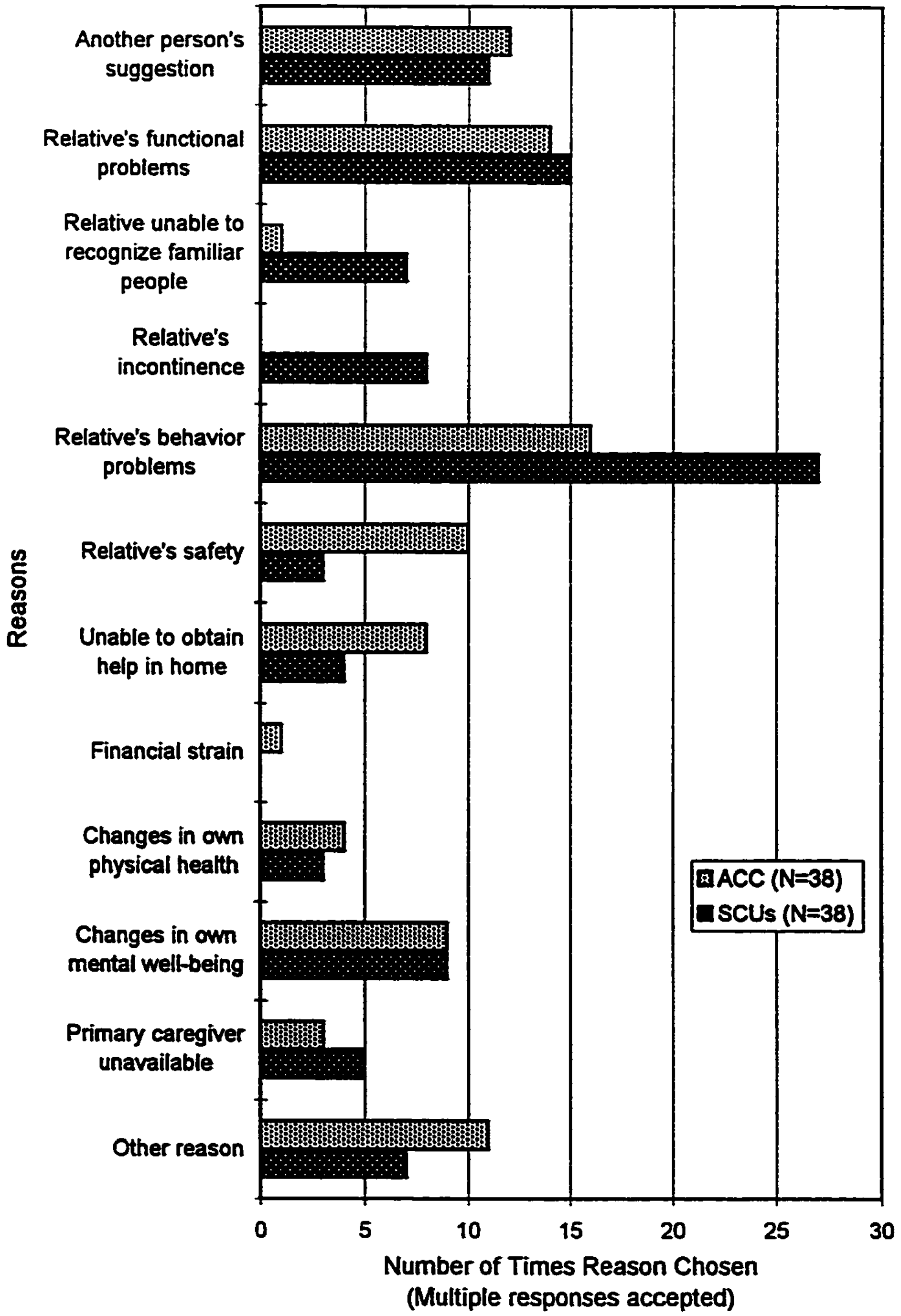
Other Family

Although the present study focused on the involvement of one family member, their views on the involvement of other family members was included in the questionnaire in order to describe the potential help the main family member may have had with caregiving. The main family member (who completed the interview) was asked to list other family members who visited the resident and/or were in involved in providing care. On average, eight other family members visited the ACC residents while an average of six family members visited the SCU residents (excluding the family member who completed the interview). The vast majority of these visitors were the adult children of the resident. These other family members generally visited less frequently than the main family member, with an estimated average of 1.7 visits per month to the ACC and 1.4 visits per month to the SCUs.

The main family member was asked to compare the involvement of other family members to themselves on a scale from 1 = much less involved to 5 = much more involved. Overall, other family members were perceived as being less involved than the family member who completed the interview, with an average rating of 1.4 for ACC families and 1.6 for SCU families.

Finally, the main family member was asked to rate how supported they felt by the involvement of other family members on a scale from 1 = not supported to 10 = very supported. On average, ACC family members rated supportiveness at 6.5 (SD = 3) while SCU family members rated it at 5.9 (SD = 3). Supportiveness ranged from 1 to 10 for both groups, indicating a wide spread in feelings of support, and there was not a significant difference between the two groups of family members.

Figure 1: Family Reasons for Seeking Long-Term Care Admission



Objective 1: Family Caregiving Over Time

Family Involvement Over Time

The purpose of this part of Objective 1 was to describe involvement in care and to examine any changes in involvement over time within the ACC. Table 4 shows the means and standard deviations for the five involvement variables. Of the 38 family members who completed a first interview, 20 remained in the study to complete a third interview. Therefore, all longitudinal analyses used a sample size of 20 where data were available.

Table 4: Means and Standard Deviations of Involvement Measures Over Time at the ACC (n = 20).

Measures (Range of possible scores)	Interview 1	Interview 2	Interview 3
Average visits per month (0-28)	6.75 (5.59)	6.64 (6.60)	6.23 (6.42)
Average length of visits (hours)	1.28 (0.69)	1.05 (0.70)	1.40 (1.02)
Number of tasks involved with (0-41)	21.25 (3.97)	20.65 (4.50)	21.65 (5.21)
Average frequency of involvement in tasks (1-5)	1.98 (0.43)	1.97 (0.45)	1.82 (0.33)
Desired level of involvement in tasks (-1 to 1)	0.09 (0.13)	0.06 (0.13)	0.07 (0.15)

A comparison of sample characteristics (i.e. those listed in Tables 3a and 3b) between the 20 family members who remained in the study and the 18 who did not showed no significant differences between the two groups except for age of the resident. The 20 family members who remained in the study had relatives who were older (M = 83.85, SD = 7.90) than those who did not (M = 78.67, SD = 6.04), $t(36) = 2.25$, $p = .03$.

Addressing the question. The question was: Does family involvement in care change over time at the ACC? Repeated measures MANOVA was used to answer this question, with all five variables shown in Table 4 representing the concept of involvement. The MANOVA Wilks' criterion indicated that there was not a significant main effect for TIME $F(10, 68) = 1.10$, $p = .37$. This result suggested that family involvement did not change much over the 18-month period. The observed power for this analysis was .18. This low power is likely due to the small sample size. Although the power of the analysis was too low to detect small effects within the sample, an overview of the means and standard deviations shown in Table 4 seems to support the finding. There were no obvious trends across time for the variables, except a very slight decrease for the average visits per month. To supplement the information pertaining directly to the question, other statistics were used to further describe how family members are involved in care at the ACC over time.

Describing visiting. On average, family members visited 6-7 times per month (Table 4). Based on information provided in the interviews, most family members visited both weekdays and weekends and weekend visiting seemed to increase by the third interview (Table 5).

Table 5: Time of Week Family Members Usually Visit the ACC (n = 20).

	Number of Family Members		
Time of Week	Interview 1	Interview 2	Interview 3
Weekdays	4	4	2
Weekends	7	7	10
Both	9	9	8

Most family members visited in the afternoon only, or the afternoon/evening times (Table 6). This pattern remained fairly stable over time, although there was some increase and decrease movement for family members who visited at anytime of the day.

Table 6: Time of Day Family Members Usually Visit the ACC (n = 20).

	Number of Family Members		
Time of Day	Interview 1	Interview 2	Interview 3
Morning	0	1	1
Afternoon	9	8	10
Evening	2	2	2
Morning and/or afternoon	0	1	1
Morning and/or evening	1	0	0
Afternoon and/or evening	7	3	5
Anytime	1	5	1

While at ACC, family members spent most of their time in the dining and kitchen areas of the facility, the resident's room, and other sitting or common areas (e.g. by the fireplace), as shown in Table 7. There was an increase and decrease pattern in the time spent in the yard and garden areas, likely influenced by the time of year of the interview (e.g. winter versus summer). There was also a trend for family members to spend more time in the foyer and hallway areas with the residents as time progressed and to spend more time in the sitting and common areas by the third interview.

The most common reasons for visiting reported by family members included to enhance the well-being of the resident and to check up on the resident's situation (Table 8). Feelings of love for the resident and family obligation were also mentioned frequently. There was a trend for family members to list checking on their relative's situation less frequently as time progressed and to list for their own or their relative's well-being more frequently after the first interview.

Table 7: Location of Visits by Family Members to the ACC (n = 20).

Location of Visits	Number of Family Members[a]		
	Interview 1	Interview 2	Interview 3
Kitchen and dining rooms	10	10	11
Resident's room	10	10	11
Sitting and common areas	8	8	11
Television room or lounge	5	2	4
Foyer and hallways	3	5	8
Yard and garden areas	1	7	0
Games room	1	1	1
Music room	1	0	0

[a] Family members were asked to list the three areas where they spent the most time.

Table 8: Reasons for Visiting of Family Members to the ACC (n = 20).

Reason for Visiting	Number of Family Members[a]		
	Interview 1	Interview 2	Interview 3
Love for resident	9	5	5
Family obligation	6	5	6
To check resident's situation	12	9	7
To provide caregiving to resident	3	3	5
To take resident on outing from facility	1	2	1
For own well-being or enjoyment	1	5	4
For resident's well-being or enjoyment	8	12	11
"Because he's/she's my ______." (e.g. wife, mother)	0	2	2
Other[b]	1	2	5

[a] Family members were asked to list three reasons for visiting.

[b] Other includes: so resident does not forget family member, to check on pet, because has time, because visited resident before moving to facility.

Describing tasks. Family members were involved in a variety of tasks, which they performed with or for their relative. Table 9 shows the means and standard deviations for the two categories of tasks in which family members were involved. Repeated measures MANOVA indicated that involvement remained fairly stable over time for the social/recreational category. There was a significant increase in involvement in the number of types of personal care/guardian tasks from Interview 2 to Interview 3, F(2, 18) = 4.08, p = .03. There was also a trend for the number of personal care/guardian tasks to decrease from Interview 1 to Interview 2. Within each interview, family members were involved in significantly more types of social/recreational tasks than personal care/guardian tasks, ts(19) = 6.19, 7.58, and 7.01, respectively, ps ≤ .00.

Table 9: Means and Standard Deviations of Involvement in Number of Tasks at the ACC (n = 20).

Involvement in Tasks (Possible range of scores)	Interview 1	Interview 2	Interview 3
Social & recreational tasks (0 to 20)	12.35 (1.93)	12.35 (1.98)	12.30 (2.56)
Personal care/guardian tasks (0 to 19)	8.80 (2.73)	8.05 (2.98)	9.10 (3.01)

Describing frequency of involvement in tasks. Family members were asked how frequently they took part in the tasks with which they were involved. Table 10 shows the means and standard deviations for the two categories of tasks. Repeated measures MANOVA showed that frequency of involvement for the social/recreational category was less at Interview 3 than at Interviews 1 and 2, F(2, 18) = 4.74, p = .02. There was no statistically significant difference in involvement in personal care/guardian tasks over time. Within each interview, family members were more frequently involved in social/recreational tasks than personal care/guardian tasks, ts(19) = 5.99, 5.84, and 4.65, respectively, ps ≤ .00.

Table 10: Means and Standard Deviations of Frequency of Involvement in Tasks at the ACC (n = 20).

Involvement in Tasks Possible scores ranged 1 to 5	Interview 1	Interview 2	Interview 3
Social & recreational tasks	2.17 (0.49)	2.20 (0.58)	1.95 (0.40)
Personal care/guardian tasks	1.67 (0.40)	1.60 (0.40)	1.63 (0.35)

Describing desired level of involvement in tasks. Family members were asked whether they desired more, less, or the same involvement in the list of 39 tasks. Table 11 shows the means and standard deviations for the two categories of tasks. Repeated measures MANOVA showed no significant changes over time within either category. Within each interview, family members desired significantly more involvement in social/recreational tasks than in personal care/guardian tasks, ts(19) = 5.49, 4.64, and 4.06, respectively, ps ≤ .00. However, it should be noted that most family members preferred their involvement to remain the same.

Table 11: Means and Standard Deviations of Desired Level of Involvement in Tasks at the ACC (n = 20).

Involvement in Tasks Possible scores ranged -1 to +1	Interview 1	Interview 2	Interview 3
Social & recreational tasks	0.16 (0.40)	0.14 (0.18)	0.13 (0.21)
Personal care/guardian tasks	0.01 (0.13)	-0.02 (0.11)	0.00 (0.12)

Family Perceptions of Formal Care Over Time

The purpose of this part of Objective 1 was to describe family perceptions of formal care and to examine any changes in perceptions over time. Table 12 shows the means and standard deviations for the three perceptions variables. As with family involvement, the data for the 20 family members who remained in the study to complete a third interview were used where available.

Table 12: Means and Standard Deviations of Perceptions Measures Over Time at the ACC (n = 19[a]).

Measures (Range of possible scores)	Interview 1	Interview 2	Interview 3
Satisfaction with the care provided (1-7)	5.99 (0.59)	5.85 (0.85)	5.98 (0.70)
Number of hassles experienced (0-28)	4.75 (2.69)	4.30 (2.66)	4.55 (2.80)
Average rating of hassles experienced (1-4)	1.42 (0.60)	1.44 (0.57)	1.48 (0.66)

[a] One participant was excluded due to missing data.

Addressing the question. The question was: Do family perceptions of formal care change over time at the ACC? Repeated measures MANOVA was used to answer the question, using the three variables listed in Table 12 to represent the concept of perceptions. A total of 19 participants were used in the perceptions analysis (one was excluded due to missing data). The Wilks' criterion showed that there was not a significant main effect for TIME $F(6, 68) = 0.90$, $p=.502$. That is, family members' perceptions of care did not significantly change over the course of the study. The observed power for this analysis was .33. Again, the ability of the analysis to detect a difference where a difference exists is low, likely due to the small sample size. However, an overview of the means shown in Table 12 revealed that satisfaction and the rating of hassles were quite similar across all three time periods. There was a trend for the family members to list fewer hassles after Interview 1. To supplement the information pertaining directly to the question, other statistics were used to more fully describe family perceptions of formal care.

Describing satisfaction. Overall family members were satisfied with the formal care provided at the ACC and remained satisfied over the three interviews. Means and standard deviations for the four subscales of the Family Perceptions of Care Tool (Maas & Buckwalter, 1989) are shown in Table 13. Repeated measures MANOVA indicated that there were no significant changes over time in any of the subscales. A review of the means would suggest that there was little change. Analyses within each time period showed a significant difference between the family members' satisfaction with the environment and their overall satisfaction, $F(3, 17) = 7.28$, $p = .00$ at Interview 3. Although not statistically significant at Interviews 1 and 2, the means listed in Table 13 indicate that family members were most pleased with the environment of the ACC and least satisfied with the overall care of their relatives. (Appendix H provides a detailed description of the family members' general satisfaction with care.)

Table 13: Means and Standard Deviations for the Subscales of the Family Perceptions of Care Tool at the ACC ($n = 20$).

Satisfaction with... Possible scores ranged 1-7	Interview 1	Interview 2	Interview 3
The resident's environment	6.27 (0.62)	6.06 (0.88)	6.19 (0.65)
The physical nursing/staff care	5.89 (1.44)	5.95 (1.07)	6.09 (0.95)
The relationships among residents, staff and family members	6.04 (0.64)	5.76 (0.81)	6.00 (0.72)
The over all care	5.80 (0.71)	5.67 (0.99)	5.69 (0.93)

Describing hassles. Table 14 shows the average number of hassles experienced by family members for the three subscales of the Caregiving Hassles Scale: Nursing Home Hassles (Stephens, et al., 1991). Family members indicated whether or not a particular hassle occurred in the past six months (yes/no), but did not report how frequently it had occurred. ("Number of hassles" refers to the number of types of hassles, not the total occurrence of hassles experienced.) Repeated measures MANOVA showed that there were no significant changes over time for any of the subscales, although there was a trend for hassles related to interactions between the resident and staff to increase and some increase and decrease movement of the other two subscales. Within each interview period, family members experienced significantly more hassles associated with the practical/logistic aspects of care than with interactions between the family and staff and interactions between the resident and staff, Fs(2, 18) = 19.28, 20.02, and 9.36, respectively, ps ≤ .01

Table 14: Means and Standard Deviations for the Subscales Indicating the Number of Hassles Experienced at the ACC (n = 20).

Hassles associated with... (Range of possible scores)	Interview 1	Interview 2	Interview 3
Interactions between family and staff (0-8)	0.95 (0.99)	0.70 (1.17)	0.95 (1.40)
Interactions between the resident and staff (0-12)	0.95 (0.95)	1.00 (1.17)	1.40 (1.19)
Practical/logistic aspects of caregiving (0-8)	2.85 (1.42)	1.40 (1.19)	2.20 (1.06)

Family members were asked to rate the amount of concern a hassle produced for them. Table 15 shows the average ratings of hassles experienced by family members for the three subscales of the Caregiving Hassles Scale: Nursing Home Hassles (Stephens, et al., 1991). Family members only completed a rating for the hassles they experienced, and not for hassles which they did not experience. Therefore, family members who experienced no hassles were omitted from the analyses, leading to variation in the sample sizes for the calculations. Repeated measures MANOVA showed that there were no significant changes in the subscales over time by ACC family members. It should be noted that the ns for each subscale were low and varied, providing little power for the analysis. An overview of the means indicated that they were quite similar for interactions between the resident and staff and for the practical/logistic aspects of caregiving. There appears to be more concern with the hassles associated with interactions between the family and staff from Interview 1 to Interview 2.

Comparisons of the subscales within each interview period were also conducted. Within Interview 3, family members were significantly less concerned about hassles associated with the practical/logistic aspects of care than about interactions between family and staff and between residents and staff, F(2, 5) = 8.98, p = .02. Although not always statistically significant, there was a pattern for family members to rate hassles associated with interactions between the family and staff as most concerning while hassles related to the practical/logistic aspects of caregiving as least concerning.

Table 15: Means and Standard Deviations for the Subscales Indicating the Rating of Hassles Experienced at the ACC.

Hassles associated with... Possible scores range 1-4	Interview 1	n	Interview 2	n	Interview 3	n
Interactions between family and staff	1.86 (1.03)	11	2.43 (1.17)	7	2.23 (0.80)	8
Interactions between the resident and staff	1.71 (0.84)	12	1.75 (0.97)	12	1.73 (0.74)	15
Practical/logistic aspects of caregiving	1.27 (0.43)	19	1.23 (0.29)	20	1.25 (0.57)	19

Family Feelings About Their Relative's Situation Over Time

The purpose of this part of Objective 1 was to describe the feelings of family members regarding their relative's situation within the long-term care facility and to examine any changes over time. Table 16 shows the means and standard deviations for the two variables chosen to represent feelings about their relative's situation. As with the other two parts of Objective 1, the data for the 20 family members who remained in the study to complete a third interview were used where available.

Table 16: Means and Standard Deviations for the Feelings Measures Over Time at the ACC (n = 20).

Measures (Range of possible scores)	Interview 1	Interview 2	Interview 3
Subjective burden (0-88)	17.45 (9.58)	20.40 (12.53)	18.60 (14.13)
Perceived guilt (0-12)	2.50 (1.79)	1.65 (1.23)	1.30 (0.98)

Addressing the question. The question was: Do family feelings about their relative's situation change over time at the ACC? Repeated measures MANOVA was used to answer the question, with the burden and guilt scores used to represent the concept of feelings. The Wilks' criterion showed that there was a significant main effect for TIME F(4, 72) = 5.10, p = .001. The observed power for this analysis was .96. The tests of within subjects contrasts indicated that the change was in feelings of guilt, which decreased over time. Bonferroni post hoc tests for perceived guilt indicated a significant difference between Interviews 1 and 3. Burden scores remained relatively stable over time.

Objective 2: Family Caregiving Between Settings

Family Involvement in Care

The purpose of this part of Objective 2 was to describe family involvement in care and to examine any differences in involvement between two long-term care settings for residents with AD. All comparisons between settings of care used ACC Interview 2 data (n = 33) and the SCU Interview 1 data (n = 38). Table 17 shows the means and standard deviations for the five involvement variables.

Table 17: Means and Standard Deviations of the Involvement Measures in Both Settings.

Measures (Range of possible scores)	ACC n = 33	SCUs n = 38
Average visits per month (0-28)	7.37 (6.67)	7.37 (6.91)
Average length of visits (hours)	1.20 (0.71)	1.35 (1.23)
Number of tasks involved with (0-41)	20.85 (4.67)	18.42 (4.90)
Average frequency of involvement in tasks (1-5)	1.95 (0.45)	2.04 (0.55)
Desired level of involvement in tasks (-1 to 1)	0.03 (0.13)	0.04 (0.13)

Addressing the question. The question for this part of Objective 2 was: Does family involvement in care differ between the two long-term care settings? MANOVA was used to answer this question and the results of the Wilks' criterion indicated that there was no significant main effect for SETTING F(5, 65) = 1.77, p = .13. That is, family involvement was similar for both groups of family members. The observed power for this analyses was .57. The power for this analysis was low and larger sample sizes may have produced different results. However, an examination of means listed in Table 17 indicated that the two groups scored similarly on all of the measures, except for the number of tasks involved with at the facility, supporting the results of the analysis. Although not significant at the multivariate level, the univariate test of between-subjects effects indicated that ACC family members were involved in a greater number of types of total tasks than the SCU family members, $F(1,69) = 4.52$, $p = .04$. To supplement the information pertaining directly to the question, other statistics were used to more fully describe family involvement in the two settings.

Describing visiting. On average, family members in both settings visited seven times per month (Table 17). Based on information provided in the ACC Interview 2, nearly half of the family members visited both weekends and weekdays while approximately one-third visited weekends only (Table 18). This is in contrast to the SCU family members where more family members visited weekdays only and fewer on the weekends.

Table 18: Time of Week Family Members Usually Visit the Long-term Care Settings.

Time of Week	Percentage of Family Members[a]	
	ACC $n = 33$	SCUs $n = 38$
Weekdays	18	26
Weekends	36	16
Both	46	58

[a] Percentages may not add to 100 due to rounding.

The afternoons was the most popular time for both groups of family members to visit their relatives (Table 19). A greater percentage of SCU family members visited during the morning only and the morning/afternoon time periods, while more ACC family members visited during the afternoon/evening or at anytime.

Table 20 shows the location of visiting within the facilities. More than one-third of ACC family members reported that they spent time in the dining and kitchen areas of the facility, the resident's room, other sitting or common areas and the yard. Approximately one-third of the SCU family members reported that they spent time in the foyer and hallways and the atrium or courtyard areas of the facilities, while just over one-quarter spent time visiting the resident in the dining and kitchen areas of the facility, the resident's room, and the television room or lounge. In the SCUs, some of the areas where family visited were outside of the SCU wing, in other areas of the nursing home.

While a direct comparison with the SCUs was not possible because the facilities have different floor plans and visiting spaces, there were some obvious differences between the two groups in terms of the type of visiting spaces utilized. For example, a greater percentage of ACC family members visited in the kitchen and dining areas than the SCU family members. There were also trends for the ACC family members to spend more time visiting in the resident's room and to spend more time in the sitting/common areas of the centre than the SCU family members.

Table 19: Time of Day Family Members Usually Visit the Long-term Care Settings.

Time of Day	Percentage of Family Members[a]	
	ACC n = 33	SCUs n = 38
Morning	6	21
Afternoon	42	40
Evening	6	3
Morning and/or afternoon	3	11
Morning and/or evening	0	3
Afternoon and/or evening	21	13
Anytime	21	11

[a] Percentages may not add to 100 due to rounding.

Table 20: Location of Visits by Family Members to Both Settings.

Location of Visits	Percentage of Family Members[a]	
	ACC n = 33	SCUs n = 38
Kitchen and dining rooms	64	26
Resident's room	55	26
Sitting and common areas	39	16
Television room or lounge	15	26
Foyer and hallways	27	37
Yard and garden areas (outdoor)	33	16
Atrium and courtyard areas (indoor)	N/A	34
Games room	3	3
Balcony	N/A	8
Off the unit or ward	N/A	8

[a] Family members were asked to list the three areas where they spent the most time.

The most common reasons for visiting reported by both groups of family members were for the resident's well-being and enjoyment and to check on the resident's situation (Table 21). The ACC family members expressed feelings of love for the resident, "Because he's/she's my _____", and other reasons more frequently than the SCU family members, while the SCU family members mentioned their own well-being and enjoyment and to provide caregiving more frequently than the ACC family members.

Table 21: Reasons for Visiting of Family Members to Both Settings.

Reason for Visiting	Percentage of Family Members[a]	
	ACC n = 33	SCUs n = 38
Love for resident	33	26
Family obligation	24	26
To check resident's situation	46	53
To provide caregiving to resident	15	21
To take resident on outing from facility	9	3
For own well-being or enjoyment	18	40
For resident's well-being or enjoyment	64	40
"Because he's/she's my _____." (e.g. wife, mother)	12	5
Other[b]	12	3

[a] Family members were asked to list three reasons for visiting.

[b] Other includes: so resident does not forget family member, to take another visitor, because family member was caregiving prior to admission, because they are the only family living in Canada.

Describing the number of tasks involved with. Family members at both settings were asked to indicate whether or not they were involved with the 39 tasks listed in the interview schedule. The total number of tasks involved with was divided into two categories (Table 22). A closer examination of this data using MANOVA indicated that the two groups significantly differed, $F(2, 68) = 6.66$, $p = .00$. This difference was for the social/recreational tasks. Although not statistically significant, a similar pattern of greater involvement in the number of personal care/guardian tasks by the ACC family members was also evident. Within each type of setting, paired samples t-tests showed that both ACC and SCU family members were involved in a greater number of social/recreational tasks than personal care/guardian tasks, $t(32) = 7.72$, $p = .00$ and $t(38) = 5.11$, $p = .00$.

Table 22: Means and Standard Deviations of Number of Tasks Involved With at Both Settings.

Measures (Range of possible scores)	ACC n = 33	SCUs n = 38
Social/recreational tasks (0 to 20)	12.74 (2.45)	10.34 (2.91)
Personal care/guardian tasks (0 to 19)	9.26 (2.84)	7.95 (2.78)

Describing frequency of involvement in tasks. Family members were asked how frequently they took part in the tasks with which they were involved. Examination of the two categories of tasks listed in Table 23 using MANOVA indicated no statistically significant differences. The means, however, show a pattern of slightly greater frequency of involvement for the ACC family members. Within each setting, paired samples t-tests indicated that both ACC and SCU family members were more frequently involved in social/recreational tasks than personal care/guardian tasks, $t(32) = 7.95$, $p = .00$ and $t(37) = 7.25$, $p = .00$.

Table 23: Means and Standard Deviations of Frequency of Involvement at Both Settings.

Measures Possible scores ranged 1 to 5	ACC n = 33	SCUs n = 38
Social/recreational tasks	0.73 (0.11)	0.65 (0.16)
Personal care/guardian tasks	0.53 (0.18)	0.48 (0.17)

Describing desired level of involvement in tasks. Family members were asked whether they desired more, less or the same involvement in the list of 39 tasks. For the categories of tasks listed in Table 24, MANOVA results showed no statistically significant differences between the settings and a review of the means showed that they were similar. Within each group, paired samples t-tests indicated that both ACC and SCU family members desired greater involvement in social/recreational tasks than personal care/guardian tasks, $t(32) = 5.37$, $p = .00$ and $t(37) = 3.78$, $p = .00$. In general, it should be noted that with the means very close to zero, most family members preferred their involvement to remain similar to their current level.

Table 24: Means and Standard Deviations of Desired Level of Involvement at Both Settings.

Measures Possible scores ranged –1 to +1	ACC n = 33	SCUs n = 38
Social/recreational tasks	0.09 (0.07)	0.10 (0.20)
Personal care/guardian tasks	-0.04 (0.12)	-0.01 (0.12)

Family Perceptions of Formal Care

The purpose of this part of Objective 2 was to describe family perceptions of formal care and examine any differences between settings. Table 25 shows the means and standard deviations for the three perceptions variables. As with the first part of Objective 2, data for this part was used from the second interview of the ACC family members and the first interview of the SCU family members, where available.

Addressing the question. The question for this part of Objective 2 was: Do family perceptions of formal care differ between the two long-term care settings? MANOVA was used to answer this question and the Wilks' lamda showed that there was no significant main effect for SETTING $F(3,67) = 1.66$, $p = .18$. In other words, the two groups were similar on perceptions of care. The observed power for the analysis was fairly low, .42. Due to the low power, the univariate tests were also considered. The tests of between-subjects effects indicated that the variances for satisfaction with the care provided reached near significance, $F(1) = 3.72$, $p = .06$, indicating a possible difference between the two groups on this measure. To supplement the information pertaining directly to the question, other statistics were used to more fully describe family perceptions of formal care at the two settings.

Table 25: Means and Standard Deviations of the Perceptions Measures in Both Settings.

Measures (Range of possible scores)	ACC n = 33	SCUs n = 38
Satisfaction with the care provided (1-7)	5.71 (0.83)	5.35 (0.86)
Number of hassles experienced (0-28)	4.91 (3.06)	5.40 (3.17)
Average rating of hassles experienced (1-4)	1.57 (0.59)	1.58 (0.50)

Describing satisfaction. The four areas of care shown in Table 26 are the four subscales of the Family Perceptions of Care Tool (Maas & Buckwalter, 1989). The MANOVA Wilks' Lambda for SETTING was significant, F(4, 66) = 12.12, p = .00. The tests of between-subjects effects indicated that ACC family members expressed significantly greater satisfaction with the physical environment of their relative's home than the SCU family members.

Repeated measures MANOVAs showed that there were also some differences within each of the settings. For the ACC family members, satisfaction with the environment was greater than that of overall care, F(3, 30) = 4.37, p = .01. In contrast, SCU family members were less satisfied with the environment than the other three aspects of care, F(3, 35) = 13.68, p = .00. They were also more satisfied with the physical nursing/staff care than with the relationship among residents, staff and family and with overall care. (Appendix H provides a detailed description of the family members' general satisfaction with care.)

Table 26: Means and Standard Deviations for the Subscales of the Family Perceptions of Care Tool in Both Settings.

Satisfaction with... Possible scores ranged 1-7	ACC n = 33	SCUs n = 38
The resident's environment	5.90 (0.83)	5.08 (0.93)
The physical nursing/staff care	5.75 (1.10)	5.76 (1.13)
The relationships among residents, staff and family members	5.70 (0.83)	5.44 (0.88)
The overall care	5.54 (0.95)	5.28 (0.87)

Describing hassles. Overall, Table 25 showed that family members experienced few hassles and did not express much concern about the hassles experienced. Table 27 shows the means and standard deviations for the subscales of the Caregiving Hassles Scale: Nursing Home Hassles (Stephens, et al., 1991). ("Number of hassles" refers to the number of types of hassles, not the total occurrence of hassles experienced.)

MANOVA showed no statistically significant differences between the two groups of family members on any of the three subscales. However, an overview of the means shows some trends for the ACC family members to experience more hassles associated with the practical/logistic aspects of caregiving.

There were some differences within each group as well. Repeated measures MANOVAs showed that the ACC family members experienced more hassles with the practical/logistic aspects of caregiving than with the interactions between family and staff or between residents and staff, F(2, 31) = 18.27, p = .00. For the SCU family members, each of the three subscales were significantly different from the others, F(2, 36) = 32.39, p = .00.

Table 27: Means and Standard Deviations for the Subscales Indicating the Number of Hassles Experienced in Both Settings.

Hassles associated with... (Range of possible scores)	ACC n = 33	SCUs n = 38
Interactions between family and staff (0-8)	0.95 (0.99)	0.70 (1.17)
Interactions between the resident and staff (0-12)	0.95 (0.95)	1.00 (1.17)
Practical/logistic aspects of caregiving (0-8)	2.85 (1.42)	1.40 (1.19)

Table 28 lists the rating of concern for the three subscales of the Caregiving Hassles Scale: Nursing Home Hassles (Stephens, et al., 1991). (The family members only rated hassles which they experienced so the sample sizes for each subscale varied.) Results of MANOVA indicated no statistically significant differences. Once again, small sample sizes may have precluded statistical significance. However, the means listed in Table 28 appear similar, showing support for the findings.

Repeated measures MANOVAs within each group showed some differences between subscales. ACC family members were significantly less concerned about the hassles associated with the practical/logistic aspects of caregiving than with the hassles associated with the interactions between family and staff and between residents and staff, F(2, 11) = 5.65, p = .02. The same contrasts were found for the SCU family members, F(2, 18) = 8.40, p = .00.

Table 28: Means and Standard Deviations for the Subscales Indicating the Rating of Hassles Experienced in Both Settings.

Hassles associated with... (Range of possible scores)	ACC	n	SCUs	n
Interactions between family and staff (0-8)	2.28 (0.88)	16	2.31 (0.86)	21
Interactions between the resident and staff (0-12)	1.91 (0.95)	23	1.78 (0.81)	30
Practical/logistic aspects of caregiving (0-8)	1.35 (0.49)	32	1.36 (0.56)	38

Family Feelings about Their Relative's Situation

The purpose of this part of Objective 2 was to describe the feelings of family members regarding their relative's situation within the long-term care facility and to examine any differences between the two settings. Table 29 shows the means and standard deviations for the two variables chosen to represent family feelings about their relative's situation. As with previous parts of Objective 2, the data from the second ACC interview and the first SCU interview were used for the comparison, where available.

Addressing the question. The question was: Do family member feelings about their relative's situation differ between the two long-term care settings? MANOVA was used to answer this question, with burden and guilt scores used to represent the concept of feelings. The Wilks' criterion for SETTING was significant, $F(2, 67) = 96.11$, $p = 00$. The observed power for this analysis was .94.

The tests of between-subjects effects indicated that the difference was in the measure of burden, with the SCU family members feeling less burdened than the ACC family members. The two groups of family members rated their perceived guilt similarly.

Table 29: Means and Standard Deviations for the Feelings Measures in Both Settings.

Measures (Range of possible scores)	ACC $n = 32$	SCUs $n = 38$
Subjective burden (0-88)[a]	21.78 (12.95)	12.47 (8.50)
Perceived guilt (0-12)[b]	1.66 (1.41)	1.55 (1.25)

[a,b] Higher scores indicate greater burden and greater guilt.

Objective 3: Relationships Among Involvement, Perceptions and Feelings

The purpose of Objective 3 was to examine the relationships among family involvement in care, perceptions of formal care and feelings about their relative's situation after long-term care admission of the relative with AD. Although no theoretical or research evidence was found in the literature to indicate that there would be a difference between the two groups of family members based on the type of facility, the relationships among involvement, perceptions and feelings were examined separately for each group. The same groups used for the comparison analyses in Objective 2 were used for Objective 3.

Addressing the question. Three questions directed the examination of data for this objective. The first question was: Is there a relationship between family involvement in care and family perceptions of formal care? Results of the bi-variate correlation matrices showed that involvement and perceptions were not highly inter-related for either group of family members (Tables 30 and 31). There was one statistically significant, positive relationship between the number of tasks involved with and the number of hassles experienced for the ACC group and one between the number of visits per month and the family member's satisfaction with the care provided for the SCU group.

Table 30: Correlations Among Involvement and Perceptions Measures for the ACC Family Members (n = 33).

Involvement	Perceptions		
	Satisfaction with the care provided	Number of hassles experienced	Average rating of hassles experienced
Average visits per month	.10	.10	-.11
Average length of visits	-.10	.24	.05
Number of tasks involved with	-.13	.36*	.31
Average frequency of involvement in tasks	-.04	.26	-.01
Desired level of involvement in tasks	.05	-.26	-.09

* $p \leq .05$ ** $p \leq .01$

Table 31: Correlations Among Involvement and Perceptions Measures for the SCU Family Members (n = 38).

Involvement	Perceptions		
	Satisfaction with the care provided	Number of hassles experienced	Average rating of hassles experienced
Average visits per month	.35*	-.13	.16
Average length of visits	.16	-.07	-.03
Number of tasks involved with	.27	.04	.11
Average frequency of involvement in tasks	.28	-.13	.15
Desired level of involvement in tasks	.09	-.13	-.17

* $p \leq .05$ ** $p \leq .01$

The second question was: Is there a relationship between family involvement in care and feelings about their relative's situation? Similarly, the results of the bi-variate correlation matrices for both groups of family members indicated that involvement and feelings were not highly related (Tables 32 and 33). There were two statistically significant, positive relationships between the average number of tasks involved with and both feelings measures for the ACC family members.

There was one significant, positive relationship between the frequency of involvement in tasks and subjective burden for the SCU family members.

Table 32: Correlations Among Involvement and Feelings Measures for the ACC Family Members (n = 33).

Involvement	Feelings	
	Subjective burden	Perceived guilt
Average visits per month	.04	.04
Average length of visits	.32	.12
Number of tasks involved with	.52**	.36*
Average frequency of involvement in tasks	.29	.24
Desired level of involvement in tasks	-.25	.06

* p ≤ .05 ** p ≤ .01

Table 33: Correlations Among Involvement and Feelings Measures for the SCU Family Members (n = 38).

Involvement	Feelings	
	Subjective burden	Perceived guilt
Average visits per month	-.28	-.19
Average length of visits	-.16	-.02
Number of tasks involved with	-.19	-.18
Average frequency of involvement in tasks	-.32*	-.18
Desired level of involvement in tasks	-.13	.19

* p ≤ .05 ** p ≤ .01

The third question was: Is there a relationship between family perceptions of formal care and family feelings about their relative's situation? The bi-variate correlation matrices produced for each group showed mixed results (Tables 34 and 35). The results for the ACC family members showed that perceptions and feelings were highly inter-related. Greater burden and guilt were associated with less overall satisfaction with formal care and with a greater number of hassles experienced and higher rating of concern about the hassles experienced. However, the results of the SCU family members indicated little association between the concepts. There was only one significant, positive relationship between the number of hassles experienced and subjective burden.

Table 34: Correlations Among Perceptions and Feelings Measures for the ACC Family Members (n = 33).

Involvement	Feelings	
	Subjective burden	Perceived guilt
Satisfaction with the care provided	-.51**	-.63**
Number of hassles experienced	.59**	.69**
Average rating of hassles experienced	.53**	.74**

* p ≤ .05 ** p ≤ .01

Table 35: Correlations Among Perceptions and Feelings Measures for the SCU Family Members (n = 38).

Involvement	Feelings	
	Subjective burden	Perceived guilt
Satisfaction with the care provided	-.27	-.28
Number of hassles experienced	.44**	.24
Average rating of hassles experienced	.18	.13

* p ≤ .05 ** p ≤ .01

CHAPTER 6

Discussion

The purpose of this study was to describe involvement in care, perceptions of formal care and feelings about their relative's situation for family members of relatives with AD living in a long-term care facility. Family involvement, perceptions and feelings were assessed over time at the new Alzheimer Care Centre (ACC) residential care facility and then a cross-sectional comparison was made between data collected from family members at ACC and three special care units (SCUs) operated within traditional nursing home settings. The cross-sectional comparison was made to assess whether the type of care setting differed by family involvement in care, perceptions of formal care or feelings about their relative's situation. The results reflect the behaviors and opinions of one family member per resident who took part in the study, and not the entire family.

Overall, the results are consistent with the literature in this field in that family members remain involved in the care of their relative, they tend to be satisfied with the formal care provided to their relatives, and they experience some feelings of burden and guilt after admission of their relative into a long-term care facility.

Family Involvement Over Time at the ACC

The first objective of the study was to complete a longitudinal evaluation of how family members provide care for relatives at the ACC. The first question pertaining to this objective was: Does family involvement in care change over time at the ACC? The concept of involvement in care was represented by five measures: frequency of visits, duration of visits, number of tasks performed by family members, frequency of involvement in tasks, and desired level of involvement in tasks. The multivariate statistical analysis indicated that family involvement in care remained relatively stable over the first 18-months after admission of the resident into the ACC.

Visiting. With regard to the frequency and duration of visits, the results confirm what we already know from the literature, that family members visit on a regular basis (Keefe & Fancey, 1997; Kammer, 1994; Laitinen & Isola, 1996; York & Caslyn, 1977). These results also provide new information because of the prospective nature of the study design, that visiting does not decrease over time. No studies which tracked visiting patterns over time were found in the literature. It is likely that visiting would get more difficult as the resident with AD deteriorates and one may assume that family visits to the facility would decrease. In fact, the assessment by The Capital Care Group showed that the residents' functional abilities did deteriorate over the three assessment periods (Appendix C). However, family visiting remained steady. There was a wide variety in visiting patterns with some family members visiting once per month while others visited almost daily.

One of the goals in the design of residential care facilities is to create spaces for visiting other than the resident's room, crowded lounges or long corridors of more traditional long-term care facilities (Cohen & Day, 1993). From the information collected in this study, the resident's room is still a popular place for visiting, likely due to its privacy. Approximately one-quarter of the family members reported spending time in the television room (a common feature of what is commonly called the "lounge") and, over time, more family members reported visiting in the hallways. Although the physical design of these three areas in the ACC differ from more traditional facilities, they are readily utilized for visiting.

Tasks. While visiting, or at other times away from the facility, family members were involved in a variety of caregiving tasks, although they tended to take part in a greater number of social/recreational tasks than personal care/guardian tasks. This is likely due to the fact that the staff at the centres have taken over many of the personal care responsibilities for the residents (Dempsey & Pruchno, 1993). Also, family members likely see less of their relative after admission than they did before admission, particularly if their relative had been living with them prior to admission. The time they now spend together may be more of a social visit than a "caregiving" visit (Linsk, et al., 1988). However, family members do continue involvement in some personal care activities, either complementing the care provided by staff, or providing extra care which the staff may not have time to perform. In fact, the number of types of personal care/guardian tasks in which family members participated increased over time, likely in response to the decreasing abilities of the residents.

Although the number of personal care/guardian tasks increased, the frequency of involvement (the number of times the task was performed) did not. Rather, the frequency of involvement in social/recreational tasks had decreased by 18 months. This may have been in response to the deteriorating abilities of the residents, making participation in social/recreation activities more difficult. It may also have been a trade-off with the personal care/ guardian tasks, which increased by 18-months post-admission. Throughout the study, family members reported greater frequency of involvement in social/recreational tasks than personal care/guardian tasks and family members appeared satisfied with this level of involvement. Their desired level of involvement did not change over time and most family members indicated that they preferred their involvement to remain the same. The family members who did desire a change in their involvement tended to want more involvement in social/recreational tasks but not in personal care/guardian tasks.

Family Perceptions Over Time at the ACC

The second question pertaining to the first objective was : Do family perceptions of formal care change over time at the ACC? The concept of perceptions of formal care was represented by three measures: satisfaction with care, the number of hassles experienced and the rating of concern regarding the hassles experienced. Multivariate statistical analysis indicated that family perceptions of care did not change over the 18-month period following admission of the resident into the ACC.

Satisfaction. ACC family members were generally very satisfied with the care provided to their relatives. Previous research had indicated that family members tend to express satisfaction with the care that their relative is receiving from long-term care facility staff (Gutman & Killam, 1989; Maas, Buckwalter & Kelly, 1991; Malmberg and Zarit, 1993). There may be a number of reasons for this high satisfaction rating. First, the quality of care provided at the ACC may be very high and meets the expectations of family members, leading to high satisfaction ratings. Second, the transfer of the daily caregiving duties from the family members to the staff relieves some of the strain and stress from family members, leading to positive views of the formal care provided to their relatives. However, results regarding feelings about their relative's situation showed that family members still felt some burden in providing care for their relative, perhaps relating to their continued visiting and involvement in tasks or their new role within the facility (Pratt, Wright & Schmall, 1987). Third, family members may be hesitant to complain or make negative comments about aspects of the care with which they are not pleased because they do not want to jeopardize their relative's standing at the facility or for fear of staff retaliation through their relative (Wakefield, et al., 1997). Fourth, survey and interview techniques in research lend themselves to positive bias in that participants tend to give socially acceptable, positive or affirmative responses to questions regarding satisfaction. However, the interviewer attempted to reduce this bias by emphasizing the fact that all responses were confidential and by conducting the interviews in a place other than the facility. Family members in this study were pleased with all the aspects of care provided to their relatives at the facility (i.e. the environment, physical care provided by staff, relationships among the resident, staff and family, and overall care).

Hassles. Family members experienced few hassles in their interactions with staff and the facility. Throughout the study, family members experienced more hassles related to the practical and logistic aspects of providing continued care to their relative (e.g. travelling to and from the facility) than hassles related to interactions among people, but these were rated low on degree of concern. Although not always statistically significant, there was a trend for family members at each interview to rate hassles associated with interactions between family and staff as the most problematic and hassles related to the practical or logistic aspects of care as least problematic. For example, during the interviews, some family members commented that the hassle listed, "giving up other activities to visit my relative", would occur but they did not consider it a problem; it was part of the whole caregiving situation. On the other hand, if a hassle was related to their interaction with the staff or their relative's care (e.g. relative was left ungroomed or untidy) they were quite concerned. These results indicated that the degree of hassle experienced was greater when it involved the relationships among family, residents and staff, than when it involved the family member's own role in providing care. The staff are key people in the lives of family members and family members have strong opinions about them.

Family Feelings Over Time at ACC

The question pertaining to this part of Objective 1 was: Do family feelings about their relative's situation change over time at the ACC? The concept of feelings about their relative's situation was represented by two measures: subjective burden and perceived guilt. Multivariate statistical analysis showed that feelings of burden did not change over time whereas feelings of guilt decreased over the 18-month period post-admission of the resident into the ACC.

Burden. Throughout the study, family members experienced mild burden related to caring for their relative within the long-term care facility (as rated by Zarit & Zarit, 1987). It was possible that the small sample precluded any statistical significance, but a review of the means did not indicate a pattern or trend. This result differs from the only other prospective study of family burden post-admission of a relative with dementia found in the literature. Elmstahl et al. (1998) found a decrease in general burden after one year, but also found that some dimensions of burden remained unchanged or even increased. However it is difficult to compare the results of the present study with Elmstahl et al. because two different measures of burden were used and the one used in the present study was not divided into dimensions of burden.

Guilt. At the beginning of the study, family guilt was fairly low and was reduced over time. Wells and Jorm (1987) followed family members for three months post-admission and also found a reduction in guilt. The present study followed the family members for eighteen months and confirmed that guilt decreased over time although some feelings of guilt remained. Guilt may have been low because family members were highly satisfied with the care their relatives were receiving, or they may have already come to terms with the decision to admit their relative and the actual move.

Comparing the Involvement of ACC and SCU Family Members

The second objective of the study was to complete a cross-sectional comparison of how family members care for their relatives within two types of settings: residential care at the ACC and SCUs operated within traditional nursing homes. The first question pertaining to this objective was: Dies family involvement in care differ between two long-term care settings? As with the longitudinal comparison, the concept of involvement in care for the two setting comparison was represented by five measures: frequency of visits, duration of visits, number of tasks performed by family members, frequency of involvement in tasks, and desired level of involvement in tasks. The multivariate statistical analysis indicated that family involvement was similar for the ACC and SCU family members.

Visiting. On average, the ACC and SCU family members visited the same number of times per month (i.e. seven) and for nearly the same length of time. It appears that family members visit their relatives regularly regardless of the type of setting. The two groups of family members tended to be more similar than different in terms of visiting patterns and reasons for visiting. Both groups of family members spent time in the resident's rooms, the television room/lounge and hallways, indicating that these visiting areas are utilized regardless of the type of facility (i.e. residential care or SCU). The SCU family members spent time visiting off the unit, in the atrium or courtyard areas of the nursing homes, an option not available to the ACC family members because the ACC building stands independently from any other building.

Tasks. For both groups, family members were involved in more types of social/recreational tasks and more frequently in social/recreational tasks than personal care/guardian tasks. This is likely due to the fact that the staff in both settings perform many of the personal care tasks once performed by family members while the resident was living in the community. Family involvement in the number of personal care/guardian tasks and the frequency of involvement was similar for both groups. However, the ACC family members were involved in a greater variety of social/recreational tasks and more frequently involved in these tasks than the SCU family members. This difference may have been due to differences in the amount of social/recreational programming provided by the facilities. For example, ACC offered more programs and activities for residents and family than the SCUs (Andiel, 1999). It may also have been due to the abilities of the residents. For example, the SCU residents were reported as more impaired in their functioning than the ACC residents, perhaps reducing their ability to take part in social or recreational activities (Appendix C).

With regard to their desired level of involvement in tasks, there were no statistically significant differences between the groups, although both groups of family members desired greater involvement in social/recreational tasks than personal care/guardian tasks. As with the longitudinal results, most family members were satisfied with their current level of involvement.

Comparing the Perceptions of ACC and SCU Family Members

The question pertaining to this part of Objective 2 was: Do family perceptions of formal care differ between the two long-term care settings? As with the longitudinal analysis, the concept of perceptions of formal care was represented by three measures: satisfaction with care, the number of hassles experienced, and the rating of concern regarding the hassles experienced. Multivariate statistical analyses indicated that family perceptions of care did not differ between the two settings.

Satisfaction. Both groups of family members reported high satisfaction levels with their respective settings, although there was a trend for the ACC family members to be a little more satisfied than the SCU family members. More in-depth analysis indicated that the difference lay in their satisfaction with the environment. ACC family members were more pleased with their relative's physical environment than were the SCU family members. This result points to the most obvious difference between the two settings - the environment. The ACC is designed to be more home-like, with furnishings found in a home, individual bedrooms, carpeted floors, and accessible kitchens and it is a newly built facility. This seemed to be appealing to the family members. The SCUs, on the other hand, are all part of older, larger traditional nursing homes, with hospital-like atmospheres of tiled floors, a combination of individual and shared bedrooms, and central nursing stations.

Even with the environmental differences noted above, the satisfaction ratings for both long-term care settings were high, suggesting that the care provided by the staff meets the expectations of the family members at both settings. This is in agreement with other findings in the literature which point to high ratings of satisfaction by family members (Gutman & Killam, 1989; Maas, Buckwalter & Kelley, 1991; Malmberg & Zarit, 1993). The findings are also in agreement with the results of Ritchie and Ledersert's (1992) comparative evaluation of traditional long-stay hospitals and residential facilities in France and Braun and Rose's (1987) comparative evaluation of nursing homes and geriatric foster family care. Family members tend to be more satisfied with more home-like environments.

Hassles. There were no significant differences in the number of types of hassles experienced or the ratings of the hassles between the two groups. It may be that family members of relatives with AD living in long-term care facilities experience similar hassles relating to staff or their role in providing care regardless of whether the facility is a residential care facility or a special care unit. Family members experienced few hassles overall which indicates positive relationships among the family, residents and staff at both settings of care.

Despite obvious differences in the physical environment, perceived differences in resident choice and freedom, and the slightly differing foci of the philosophy of care statements, the two settings are specifically designed for residents with cognitive impairments and are operated by the same organization. They seem to be more similar than different in their operation. This observation corresponds to the findings by Wakefield et al. (1997) who found that family satisfaction for SCUs and group homes was similar and both were more satisfactory to family members than traditional nursing homes.

Comparing the Feelings of ACC and SCU Family Members

The question pertaining to this part of Objective 2 was: Do family member feelings about their relative's situation differ between the two long-term care settings? As with the longitudinal analysis, the concept of feelings about their relative's situation was represented by two measures: subjective burden and perceived guilt. The multivariate statistical analysis showed that the two groups significantly differed in their feelings of burden, but were similar in their feelings of guilt.

Burden. Both groups of family members experienced mild burden (as rated by Zarit & Zarit, 1987). However, the ACC family members experienced more burden overall than the SCU family members. These results would support the literature which points to a decrease in burden as the time from admission increases (Elmstahl, et al., 1998; Monahan, 1995) because the SCU family members had relatives who had been living on the SCUs for a much greater length of time than the ACC residents had been living at ACC. This result would also contradict the literature which posits an increase in burden as the relative with AD deteriorates (Elmstahl, et al., 1998; Harper & Lund, 1990). The SCU residents were significantly more impaired than the ACC residents (Appendix C) yet the SCU family members felt less burdened than the ACC family members. There may be another factor affecting burden which was not considered in the analysis, such as staff expectations for the family. If the expectations for family involvement at the ACC was greater than that at the SCUs, family members may have felt more burdened in trying to meet the expectations. However, examination of expectations was beyond the scope of the present study.

Guilt. Both groups of family members experienced low levels of guilt. Although some guilt is expected due to the societal views of non-family care of the ill elderly and family obligations, the literature (Wells & Jorm, 1987) and the findings from the longitudinal analysis of this study would suggest that guilt decreases over time. One would expect the SCU family members to have less guilt because their relatives had been living at the facilities longer than the relatives of the ACC family members. However, this was not the case. Given that the feelings of guilt were low for both groups, this finding may better be supported by the findings of Mattheisen (1989) and Johnson and Werner (1982) which showed that some guilt remained regardless of the length of time which had passed since admission of the relative and that guilt tends to be low when the ill relative has a cognitive impairment.

The Relationships Among Involvement, Perceptions and Feelings

The third objective for the study was to complete an examination of the relationships among family involvement in care, perceptions of formal care and feelings about their relative's situation after long-term care admission. In addition to evaluating involvement, perceptions, and feelings over time and between settings, an examination of the inter-relationships among these concepts may assist in our understanding of family members caring for relatives with AD living in long-term care facilities. It may also help the staff and administration in their efforts to co-exist as caregivers with family members. For example, if higher family satisfaction were related to lower involvement (Kammer, 1994), then staff could work together with family members with high involvement to help them "let go" of some of their caregiving duties and work on building relationships with family members which involved trust and respect.

Overall, results indicated that family involvement in care and perceptions of care were not highly inter-related. Only one correlation for each group was statistically significant and they showed a fairly low-moderate strength of relationship. For the ACC family members, involvement in a greater number of tasks was related to a greater number of hassles experienced. This relationship was supported by Stephen et al. (1991) who found that greater visiting was related to greater hassles. These relationships may be a result of family members' desire to maintain a key role a caregivers for their relatives and possible disagreements over roles between the family and staff. For the SCU family members, greater frequency of visits was related to higher satisfaction with care. This appears to be in contradiction to the results of Kammer (1994) and Toye et al. (1996) who found lower satisfaction related to greater involvement. It may be that family members in this study felt comfortable with the staff and the long-term care setting which corresponded with more visiting. However, the general lack of statistically significant inter-relationships between these two concepts would indicate that perceptions and involvement are not inter-related.

Overall, the results indicated family involvement in care and feelings about their relative's situation were not highly inter-related. For the ACC family members, there were two statistically significant correlations with low-moderate strength of relationship: higher burden and higher guilt were associated with involvement in a greater number of tasks. For the SCU family members, higher burden was associated with greater frequency of involvement in tasks. The finding for burden is in agreement with Monahan (1995) who also found higher burden associated with greater involvement. Family members who continue to be highly involved in caregiving activities (either number of activities or frequency of involvement) continue to experience the burden related to these activities. Pratt, Wright and Schmall (1987) suggested that burden was related to continued involvement and commitment to the impaired relative. These results do not support the findings of Pruchno et al. (1994) where greater involvement in care was related to less guilt. It may be that those who feel more guilty, remain involved in tasks in an effort to cope with their guilt. However, the general lack of statistically significant inter-relationships between these two concepts would indicate that feelings and involvement are not inter-related.

The relationships among perceptions of formal care and feelings about their relative's situation showed interesting results. For the ACC group, these two concepts were significantly and moderately to highly inter-related. Obviously, the measures for perceptions and feelings both concerned the subjective evaluation of the family members and would be expected to be related. However, the same did not hold true for the SCU group, where the only significant correlation was between the number of hassles experienced and subjective burden. The ACC findings are supported by previous studies found in the literature which showed lower satisfaction related to higher negative feelings (Grau, et al., 1995; Monahan, 1995; Riddick, et al., 1992) and more hassles experienced related to lower psycho-social well-being (Stephens, et al., 1991). Why the SCU group differed from this is unknown. It is possible that a third factor my be influencing the relationship between the two concepts, such as the level of impairment of the resident, length of time the relative has been residing at the facility, or facility factors, such as staff or environment. However, examination of mediating variables was beyond the scope of the present study.

Conclusions and Future Considerations

The present study has provided information regarding family involvement in care, perceptions of formal care and feelings about their relative's situation at a new residential care facility. The information presented in this study provides further insight into family caregiving post-admission of a relative which has not been widely explored within the previous literature.

The longitudinal examination of family caregiving provides support for refuting the myth that family members abandon their relatives to the long-term care system. Both involvement and perceptions remained fairly stable over time suggesting that family members contribute to the care of the residents, and are pleased with the care provided by staff. Family feelings of burden and guilt were also present throughout the study, although guilt decreased over time, suggesting that the responsibilities of visiting, providing care, watching the resident deteriorate and interacting with staff and administration continue to affect the feelings of the family members (Pratt, Wright & Schmall, 1987). This would imply that the "strain" and burden associated with caregiving, which are a focus of research examining community family caregiving, continue to be issues for family members after the relative has moved to a facility. Concern about meeting the needs of the family members should be a goal for long-term care administrators and staff and services should be extended beyond the resident to the family. Facility administrators may want to include items in their policies and procedures which address the role and involvement of the family within the facility in order to promote good working relationships between the family and staff (Janzen, in press).

The cross-sectional results of this study also provide new information about family caregiving within different settings, which has been relatively unexplored in the previous literature. In this study, very few differences were found between the involvement, perceptions and feelings of family members at the ACC and SCUs. This would suggest that the quality of care provided to residents at these facilities is similar. The advantage of this comparison was that both types of facilities were operated by the same organization, making differences in policies and procedures relating to the family minimal. Any differences in family involvement, perceptions or feelings would be less influenced by the organizational environment than by differences in the social and physical environments (Cohen & Weisman, 1991). The most significant findings were the differences in the family members evaluations of the facility's environment, the resident's choice in daily activities (Appendix C) and their own subjective burden. This suggests that the main difference between the residential care facility and the SCUs is not one of quality of care, but rather of aesthetics and resident autonomy. The ACC is a new facility and designed to be more homelike, which appealed to many family members. Greater choice for ACC residents may be due to the fact that they were functioning at a higher level than SCU residents or that more activities were provided for them to participate in (Andiel, 1999). The SCU residents may not have been able to make choices regarding their activities, grooming, etc., leaving the staff to make choices for them. It is also possible that the staff training at the ACC placed a greater emphasis on resident freedom of choice. The higher burden of the ACC family members compared to the SCU family members was unexpected, but may point to a difference in the newness of the experience. Two-thirds of the ACC family members had not experienced their relative living in a long-term care facility prior to the study and were fairly new to the whole situation. The SCU family members had relatives who had been living in the facilities for a longer period of time and may have been more familiar with the whole long-term care situation. The higher burden may have had to do with expectations as well. The ACC was promoted as a new and, perhaps, better alternative for long-term care than the existing settings and family involvement was encouraged by staff and the administration. The expectations placed upon family members may have been related to higher burden. However, examination of the relationship between expectations and burden was beyond the scope of this study.

Overall, the lack of differences between the two settings would suggest that the care provided to residents at the SCU facilities is not "worse" than that at the residential care facility. There appears to be a place for both types of facilities within the long-term care continuum (Cohen & Day, 1993) to address the needs of the residents as their functional abilities continue to deteriorate through the progression of the disease. There are characteristics about the environment of residential facilities which appeal to family members and they desire such places for their relatives to live when their relatives can no longer live at home. However, given the selective admission and discharge criteria of the ACC, there must be a place for residents to go who do not meet the criteria or are discharged from the ACC. The SCUs provide such a place.

The results of this study provide some information about the relationships among involvement, perceptions and feelings which have generally been alluded to in the previous literature. Such information could be useful in understanding family caregiving after long-term care admission of a relative. Family involvement in care and their perceptions of care were shown to be fairly independent of each other. This provides interesting information on the role that family members take after their relative has been admitted into a long-term care facility. Family involvement is likely due to the preferences of the family members in terms of how often they visit and the tasks in which they choose to participate. Other factors such as work or family responsibilities, the closeness of the relationship with the resident, or the number of family members involved in care may have a greater impact on involvement than their perceptions of care. However, examination of the contribution of these factors to involvement was beyond the scope of the present study. In addition, family members seemed satisfied with care regardless of whether they visited frequently or not.

Likewise, family involvement in care and feelings about their relatives' situation were not highly inter-related. An interesting difference between the ACC and SCU family members appeared in the examination of the relationship between perceptions of formal care and feelings about their relatives' situation. These concepts were highly inter-related for the ACC group, but not the SCU group, suggesting that there may be mediating factors affecting this relationship. Such factors may include the functional abilities of the resident, or supports or services provided to family members. However, examination of possible mediating factors was beyond the scope of this study. The previous literature provided some information regarding these inter-relationships, but more research is needed to clarify how these concepts relate to each other and the effects of other factors on involvement, perceptions, and feelings.

Future research may wish to expand upon the findings of this study and, perhaps, address some of the limitations of the present study. Longitudinal studies with larger sample sizes and greater statistical power are needed to confirm or refute the results of the present study. For example, such results may confirm the stability of family involvement post-admission. Future studies may want to consider reducing some of the possible biases present in this study by comparing facilities which are relatively similar in size, facilities which are similar in terms of unit age, and by comparing the family members of residents who are more similar in functional status and length of time residing in the facility. It would be interesting to include traditional nursing homes in the comparison in addition to SCUs and residential care facilities. Although all three types of facilities were available in the urban location of this study, many rural towns do not provide the same options for care. The involvement, perceptions, and feelings of family members may differ under such circumstances. Future studies may also include a range of other factors which may affect involvement, perceptions, or feelings, such as the strength of the relationship between the family member and resident, a comparison of the facility policies regarding family involvement (particularly if facilities are operated by different organizations), or the expectations of staff and family regarding family involvement.

In conclusion, this study has provided information about the involvement, perceptions, and feelings of family members with relatives residing in long-term care facilities. The results are positive in that family members continue to visit regularly and participate in a number of caregiving tasks. In addition, family members are generally satisfied with the care provided by staff in the facilities and experience few hassles in relating to the staff or providing input into their relative's care. Regardless of time and type of setting, family members experience some burden and guilt regarding the care of their relatives within the facility.

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APPENDICES

Appendix A: Consent Form

TITLE: Family Involvement in and Perceptions of Care

INVESTIGATORS:

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Mr. B. McKim, Program Planner, Capital Health Authority. Phone: 495-5000
Dr. Lili Liu, Professor, Occupational Therapy, University of Alberta. Phone: 492-5108
Ms. Wonita Janzen, Doctoral Student. Phone: 492-0374

PURPOSE:

The purpose of this project is to learn how family members view the care which their relative receives and how family members are involved in the care of a relative with Alzheimer Disease. You will be interviewed at a time convenient for you by a researcher who will ask you questions about your experience with continuing care. The interviews will last approximately one to two hours and may be audiotaped. One interview will take place immediately, and then you will be interviewed twice more : about 6 months and 12 months later.

Your participation is completely voluntary. Although we would like you to answer as many questions as fully as possible, you are free at any time to refuse to answer any questions you choose or to withdraw from the study with no consequences to you or to your relative. Your information will help us to understand more about family caregiving and feelings about care at the Centre.

You are free to ask the interviewer, Wonita Janzen, questions about the study any time - both during the interview or at 492-0374.

CONSENT:

I, ______________________ voluntarily agree to take part in the above named project. I understand that all the information given will be treated confidentially. My name will not appear on any of the completed questionnaires - only a code number. Audio tapes will be identified with a code number and these tapes will be destroyed as soon as the material is copied out, checked by the interviewer and no longer needed. My name will not be given in any report arising from the research since all the information will talk about groups not individuals.

______________________	______________________
Signature of Family Member	Date
______________________	______________________
Signature of Interviewer	Date
______________________	______________________
Signature of Principle Investigator	Date
______________________	______________________
Signature of Project Coordinator	Date

Appendix B: Description of the Facilities

1) The ACC measures 24,750 square feet. This was the first residential facility built by The Capital Care Group and was modeled after Woodside Place, in Oakmont, Pennsylvania. It is a specially designed cluster environment with three "houses", several common central areas, and a secure outside yard with gardens and wandering paths. The footprint of the building is like an italic letter "*E*". The three houses, each accommodating 12 residents, form the three arms of the letter "*E*" with common spaces forming the upright of the letter. The common spaces include an entertainment centre, music room, craft room, horticulture room, hair salon, family dining room and a "great room". Each house has ten private (single) rooms and one semi-private (double) room, a home-like kitchen and a living room/dining room. The residents have access to an enclosed garden area. The administration offices are separated from the residence by locked doors. A maximum of 36 residents can live at the centre.

The ACC has 14 full-time staff and 18 part-time staff. Day staff include: 1 manager, 1 licensed practical nurse (LPN), and 8 resident companions. Evening staff include: 1 LPN and 3 resident companions. Night staff include: 1 LPN and 2 resident companions.

2) SCU A is located in one wing of a long-term care facility owned and operated by The Capital Care Group. It is divided into two sections, Main A and Main B, with a total area of 23,234 square feet. Each section has a central dining area and three lounges. The bedrooms are all singles or doubles with a toilet and sink. Tub and shower rooms are more centrally located. The residents have access to an outdoor garden area. A maximum of 51 residents can live on the unit.

The SCU has eleven full-time staff and 31 part-time staff. Day staff for each section include: 1 nurse manager, 1 LPN, 2 nursing attendants (NAs), 1 rehabilitation attendent/nursing attendant (RANA) and 1 registered nurse (RN). Evening staff for each section include: 1 LPN, 2 NAs, and 1 RN. Night staff for both sections together include: 1 LPN, 2 NAs.

3) SCU B is located in one wing of a long-term care facility owned and operated by The Capital Care Group. The total area of the SCU is 17,671 square feet. The nurses station is located centrally. The dining area is surrounded by a balcony which overlooks an indoor atrium. There are two lounges. The bedrooms are singles, doubles and quadruples with a toilet and sink. The tub/shower area is located behind the nurses station. A maximum of 50 residents can live on the unit.

The SCU has eleven full-time staff and 32 part-time staff. Day staff include: 2 residents care managers, 2 LPNs, and 6 NAs. Evening staff include: 1 RN, 2 LPNs, and 3 NAs. Night staff include: 1 LPN and 1 NA.

4) SCU C is one wing of a long-term care facility owned and operated by The Capital Care Group. The dining area and nurses station are located at one end of the unit. There are two lounges. The bedrooms are singles and doubles with a toilet and sink. The doubles share the toilet and sink area. The tub/shower room is located centrally. A maximum of 32 residents can live on the unit.

The SCU has six full-time staff and 16 part-time staff. Day staff include: 1 resident care manager, 1 LPN, and 3 NAs. Evening staff include: 1 LPN and 2 NAs. Night staff include: 1 NA.
NOTE: SCU C was closed due to renovations by the end of this study.

Appendix C: Resident Functional Abilities and Freedom of Choice

Functional Abilities

Data regarding the functional abilities of the residents was collected by The Capital Care Group. Although not directly related to objectives of the present study, this information was included in order to enhance the description of the family members' caregiving situations and to provide possible explanations for the study findings.

Data collection. Data on resident functional ability was collected by a nurse employee of The Capital Care Group in order to describe the abilities of the residents at the ACC over time and to compare the residents from the two types of settings. This data was available to The Capital Care Group staff and administration. All residents at the ACC were assessed, while the residents from the SCUs who met the study criteria (listed in Chapter 4) were assessed[1]. Both groups of residents were assessed three times, at 6, 12 and 18 months post-admission of the ACC residents. The following measures were used to assess resident functional status:

1. *Physical Status*

A combination of the Functional Assessment Measure (FAM) and the Functional Independence Measure (FIM) was used to measure ADL. This combined tool is often referred to as the FAM+FIM (Hall, Hamilton, Gordon & Zasler, 1993). Its items measure aspects of self-care, sphincter control, mobility, communication, psychosocial adjustment and cognitive function. Items are scored on a better-than or worse-than relationship between adjacent categories. The numbers on the 7-point ordinal scale do not necessarily represent equal distances between any comparable point. This tool was already in use within the The Capital Care Group organization at the start of this study. The Capital Care Group nurse interviewed other staff regarding the physical ability of the residents. Possible total scores ranged from 30 to 210 with higher scores indicating better functioning.

2. *Cognitive Status*

The Mini-Mental State Exam (MMSE) was used to assess cogntive status (Folstein, Folstein, & McHugh, 1975). It is a 30 item scale which takes approximately 5-10 minutes to complete and measures basic language skills, orientation, registration and recall of items and calculation ability. The Capital Care Group nurse trained other staff at all the facilities to administer the MMSE. Either the nurse or another staff member assessed the resident directly. Possible total scores ranged from 0 to 30, with higher scores indicating better functioning.

3. *Behavioural Status*

The Multidimensional Observation Scale for Elderly Subjects (MOSES) was used to measure psychosocial functioning among residents (Helmes, Csapo & Short, 1987). It is 40 items

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[1] The n of the residents does not match the n of family members because some family members declined participation and some residents met the study criteria but did not have family.

long, assesses 5 areas of functioning including self-care, disorientation, depressed/anxious mood, irritable behaviour and withdrawn behaviour. The Capital Care Group nurse interviewed other staff regarding resident behavioural functioning. Possible total scores ranged from 40 to 160, with lower scores indicating better functioning.

4. *Emotional Status (Depression)*

The Cornell Scale for Depression in Dementia (Alexopoulos, Abrams, Young & Shamoian, 1988) was used to assess emotional status. It is a 19-item instrument designed to rate depressive symptoms in a person with dementia within the week prior to assessment. The Capital Care Group nurse interviewed other staff regarding the emotional status of the residents. Possible total scores ranged from 0 to 38, with lower scores indicating better functioning.

Results. Repeated measures MANOVA was used to assess ACC resident functioning over time (Table 36). The Wilks' criterion for averaged multivariate tests of significance indicated a main effect for TIME, $F(8, 74) = 4.92$, $p = .00$. Post-hoc comparisons showed a significant decrease in the FIM+FAM scores from Assessment 1 to Assessment 3 and from Assessment 2 to Assessment 3. MMSE scores decreased significantly from Assessment 1 to Assessment 2. MOSES scores increased significantly from Assessment 1 to Assessment 2 and Assessment 1 to Assessment 3. The Cornell scores did not significantly change over time.

Repeated measures MANOVA with the SCU data (Table 37) showed similar results. The Wilks' criterion for the averaged multivariate tests of significance indicated a main effect for TIME, $F(8, 94) = 5.90$, $p = .00$. Post-hoc tests indicated significant decreases in the scores for the FIM+FAM across all assessment periods. A significant decrease was also found between Assessment 1 and Assessment 3 of the MMSE. The MOSES and Cornell scores did not significantly change over time.

Table 36: ACC Functional Status Means at Each Assessment.

Status Measure	Assessment 1^a n = 36	Assessment 2^a n = 31	Assessment 3^a n = 23
FIM+FAM	120.89 (36-161)	120.65 (58-62)	114.61 (35-148)
MMSE	12.69 (0-23)	13.00 (0-25)	13.24 (0-24)
MOSES^b	76.06 (48-115)	74.13 (45-123)	80.00 (51-124)
Cornell^b	5.44 (0-12)	3.74 (0-16)	6.52 (0-26)

[a] Range of scores given in parentheses.
[b] Higher scores = lower functioning

The MANOVA Wilks' criterion for SETTING, F(4, 42) = 15.93, p = .00, was also significant. Tests of between-subjects effects for the averaged transformed variables indicated that the SCU residents were functioning at a significantly lower level than the ACC residents on the FIM+FAM, MMSE, and MOSES, but not the Cornell.

Table 37: SCUs Functional Status Means at Each Assessment.

Status Measure	Assessment 1[a] n = 44	Assessment 2[a] n = 39	Assessment 3[a] n = 26
FIM+FAM	77.59 (40-131)	70.26 (40-122)	64.69 (35-127)
MMSE	3.82 (0-19)	3.28 (0-17)	3.12 (0-18)
MOSES[b]	96.98 (66-120)	100.54 (62-132)	99.00 (68-130)
Cornell[b]	4.34 (0-11)	4.52 (0-15)	5.50 (1-13)

[a] Range of scores given in parentheses.
[b] Higher scores = lower functioning

Resident Choice

One of the values of the social model of service delivery adopted by the ACC administration and staff is that of resident freedom. The Perceived Latitude of Choice Scale (Hulicka, Morganti & Cataldo, 1975) was included in interview in order to evaluate resident freedom of choice in daily activities. Another reason for including this scale was to enhance explanations of findings regarding family member perceptions of formal care and feelings about their relative's situation, both which may be affected by the family member's perceptions about resident freedom. For example, family members may feel less guilty about moving their relative into the long-term care facility if they perceive that their relative has choice and independence.

Data for Interview 1 showed that the ACC family members scored an average of 88.39 (SD = 11.67) on the Perceived Latitude of Choice Scale while the SCU family members scored an average of 69.57 (SD = 16.65). Results of an independent samples t-test indicated that the two groups significantly differed on their perceptions of resident choice, t(64) = -7.71, p = .00. This difference in resident choice may have been affected by the abilities of the residents. ACC residents were functioning at a higher level than the SCU residents and may have been more able to make choices. It may also be influenced by the opportunities for choice provided to the residents by the staff in the two settings. The ACC staff training program and influence of the "home-like" setting may have contributed to more opportunities for resident choice than in the SCUs. In fact, a review of the philosophy of care statements provided by The Capital Care Group showed that they focus on different groups: the ACC statement focuses on the residents while the SCU statement focuses on the staff (Appendix I). This may have influenced whether staff give residents more or less choice in daily activities and contributed to perceived differences in resident choice by family members.

Appendix D: Correlations of Variables with Length of Time in Centre

Table 38: Correlations of Family Involvement, Perceptions and Feelings Measures with Length of Time in Centre.

Measure	ACC and SCU Interview 1 n = 76	ACC Interview 2 and SCU Interview 1 n = 71
	Length of time resident in centre	Length of time resident in centre
Average visits per month	-0.12	-0.08
Average length of visits	-0.12	-0.12
Number of tasks involved with	-0.23*	-0.13
Average frequency of involvement in tasks	-0.22	-0.20
Desired level of involvement in tasks	-0.14	-0.13
Satisfaction with the care provided	-0.31**	-0.23
Number of hassles experienced	0.13	0.14
Average rating of hassles experienced	0.13	0.15
Subjective burden	-0.16	-0.14
Perceived guilt	-0.01	0.17

* p.≤.05. ** p.≤.01.

Appendix E: Interview Schedule[2]

EVALUATION PROGRAM - FAMILY INTERVIEW #1

Thank you for agreeing to complete this evaluation. Your opinions are important to us. Parts of this questionnaire will be completed together with the interviewer while other parts you will complete on your own. Please feel free to ask questions when they arise.

Family member I.D. ________ Interview # _________ Place of interview: ________

Date of interview: __________ Centre I.D. _________

Part 1: Personal Information

What is your age in years?	__________ years
What is your gender?	1 = Female 2 = Male
What is your relationship to the resident?	1= wife 2 = husband 3 = daughter 4 = son 5 = daughter-in-law 6 = other relative _______________ 7 = other non-relative _____________
What country did most of your family's relatives come from?	On your father's side _____________ On your mother's side ____________
How much education have you had?	1 = 9 years or less 2 = Partial high school 3 = High school graduate 4 = Trade or technical school 5 = Partial college/university 6 = College/university graduate 7 = Graduate/professional training

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[2] The interview schedule has been re-formatted to fit this document. Footnotes were added to clarify which questions belong to the scales mentioned in Chapter 4. The Capital Care Group used the term "continuing care centres" when referring to its facilities and this term was used in the interview as well.

What is your marital status?	1 = Single, never married 2 = Living as married 3 = Married 4 = Widowed 5 = Separated 6 = Divorced
In general, how would you rate your overall health right now?	1 = Excellent 2 = Very Good 3 = Good 4 = Fair 5 = Poor
What is your present employment status?	0 = Not employed: homemaker_____ unemployed _____ student _____ retired _____ 1 = Part-time employed 2 = Full-time employed 3 = Self-employed
What job have you done for most of your working life? Categorize as:	1 = Professional 2 = Managerial/administrative 3 = Clerical and sales 4 = Skilled labor 5 = Unskilled labor 6 = Farming, logging, fishing 7 = Other________________
How long have you been (employment status)?	____________________________________

Part 2: Alzheimer Relative and Admission into Continuing Care Centre

How old is your Alzheimer relative?	__________ years
What is your Alzheimer relative's gender?	1 = Female 2 = Male
How long were you caring for your relative before admission into the centre?	___________ months/years
Date of admission into the centre:	____________________________________
(Time between admission date and interview date:	____________ weeks)

What circumstances led to your decision to admit your Alzheimer relative into a continuing care centre?

Please rate 1=most influential, 2=second most influential and 3=third most influential:

___ = Another person's suggestion
___ = Changes in own physical health
___ = Changes in own mental well being
___ = Financial strain
___ = Behavioral problems
___ = Unable to obtain help in home
___ = Incontinence
___ = Unable to recognize familiar people
___ = Functional problems (e.g. eating)
___ = Other ____________________

Distance between your home and the centre: ____________ km

Distance between your workplace and centre: ____________ km (if applicable)

PART 3: Feelings about Caregiving[3]

The following is a list of statements which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way since your relative has been living in the centre: never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

Statement	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
1. Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed over your relative's behavior?	0	1	2	3	4
5. Do you feel angry when you are around your relative?	0	1	2	3	4
6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid what the future holds for your relative?	0	1	2	3	4
8. Do you feel your relative is dependent upon you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4

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[3] The Burden Interview (Zarit, et al., 1980; Zarit & Zarit, 1982).

Statement	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11. Do you feel that you don't have as much privacy as you would like, because of your relative?	0	1	2	3	4
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
13. Do you feel uncomfortable about having friends over, because of your relative?	0	1	2	3	4
14. Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?	0	1	2	3	4
15. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
18. Do you wish you could just leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4

	Not at all	A little	Moderately	Quite a bit	Extremely
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

How do you feel about each of the following statements? Please circle one number between 0 and 3.[4]

		Not at all	A little	A lot	Almost unbearably
1.	Recently I have felt very guilty regarding my decision to admit my relative into a continuing care centre.	0	1	2	3
2.	I keep thinking I should be doing more for my relative.	0	1	2	3
3.	I worry about whether my relative is cared for well enough.	0	1	2	3

PART 4: Visiting

On average, how frequently are you able to visit? ________________ (week/month)

On average, how long is each visit? ________________________ (minutes/hours)

What day(s) of the week do you usually visit? ______________________________

____

What time of day do you usually visit? ___________________________________

____

Where do you spend most of your time at the centre?

____

____

____

____

Why do you visit? (for what reasons?)

____

____

____

____

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[4] The Guilt Scale (Wells & Jorm, 1987).

We are interested in knowing how other family members and/or friends are involved in the care of your relative. Who else visits your relative? Please indicate:

1. their relationship to your Alzheimer relative (e.g. son, granddaughter, etc.),
2. where they live ,
3. how often they visit (per week or month), and
4. how involved they are in the care of your Alzheimer relative compared to you. Please choose from 1-5 to indicate their involvement compared to your involvement.

Relationship & City	How often?	Much less involved		About the same		Much more involved
		1	2	3	4	5
		1	2	3	4	5
		1	2	3	4	5
		1	2	3	4	5
		1	2	3	4	5
		1	2	3	4	5
		1	2	3	4	5
		1	2	3	4	5
			2	3	4	5
		1	2	3	4	5

What kinds of activities do other family members do when they visit your relative?

How supportive for you is the involvement of other family members?

Not supportive								Very supportive	
1	2	3	4	5	6	7	8	9	10

PART 5: Involvement in Tasks[5]

The following is a list of tasks with which family members are sometimes involved at a continuing care centre. Please circle the answer which best describes your involvement. First, indicate whether or not you have participated in any of the tasks since your relative has been living at the centre. You may not be involved in all the tasks because some of these tasks may not be needed by your relative or sometimes staff will complete the tasks.

Second, if you mark "Yes" to any of the tasks, also indicate how often you participate in the tasks by choosing one of the following: 1 = Less than once per month; 2 = 1 to 3 times per month; 3 = Once per week; 4 = 2 to 4 times per week; 5 = 5 or more times per week

Third, whether you marked "yes" or "no" to participating in the tasks, please indicate whether you are satisfied with your level of involvement in each of the tasks by choosing one of the following: 1 = Would like to be less involved; 2 = Would like involvement to remain the same; 3 = Would like to be more involved

TASK	Do you do this?	Less than once per month	1 to 3 times per month	Once per week	2 to 4 times per week	5 or more times per week	Less involved	Same involved	More involved
1. Talk/visit/sit with relative. (S)	Yes No	1	2	3	4	5	-1	0	+1
2. Care for relative's hands/feet and nails. (P)	Yes No	1	2	3	4	5	-1	0	+1
3. Launder relative's personal clothing. (P)	Yes No	1	2	3	4	5	-1	0	+1
4. Make relative's room attractive (e.g. plants, pictures, trinkets). (S)	Yes No	1	2	3	4	5	-1	0	+1
5. Write letters/cards for relative. (S)	Yes No	1	2	3	4	5	-1	0	+1
6. Make newspapers, books, or magazines available. (S)	Yes No	1	2	3	4	5	-1	0	+1

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[5] Compiled by Wonita Janzen (1996). Items marked with an (S) belong in the social/recreational category while items marked with a (P) belong in the personal care/guardian category.

TASK	Do you do this?	Less than once per month	1 to 3 times per month	Once per week	2 to 4 times per week	5 or more times per week	Less involved	Same involved	More involved
7. Take relative for drives or lunch away from centre. (S)	Yes No	1	2	3	4	5	-1	0	+1
8. Eat meals with relative at the centre. (S)	Yes No	1	2	3	4	5	-1	0	+1
9. Feed relative or encourage/prompt to eat. (P)	Yes No	1	2	3	4	5	-1	0	+1
10. Care for relative's hair (e.g. washing, cutting, arranging for haircare). (P)	Yes No	1	2	3	4	5	-1	0	+1
11. Walk inside/outside with relative. (S)	Yes No	1	2	3	4	5	-1	0	+1
12. Clean/tidy relative's room. (P)	Yes No	1	2	3	4	5	-1	0	+1
13. Shop/run errands for relative. (P)	Yes No	1	2	3	4	5	-1	0	+1
14. Check condition of glasses, dentures, hearing aides, etc. and repair if necessary. (P)	Yes No	1	2	3	4	5	-1	0	+1
15. Encourage relative's participation in activities. (S)	Yes No	1	2	3	4	5	-1	0	+1
16. Participate in structured activities with relative (e.g. board games, playing cards, crafts). (S)	Yes No	1	2	3	4	5	-1	0	+1
17. Bring others along to visit (e.g. grandchildren, friends, pets). (S)	Yes No	1	2	3	4	5	-1	0	+1

TASK	Do you do this?	Less than once per month	1 to 3 times per month	Once per week	2 to 4 times per week	5 or more times per week	Less involved	Same involved	More involved
18. Update relative on family activities (e.g. show photos). (S)	Yes No	1	2	3	4	5	-1	0	+1
19. Provide special foods (e.g. treats, extras). (S)	Yes No	1	2	3	4	5	-1	0	+1
20. Organize celebration or bring gifts for special days. (S)	Yes No	1	2	3	4	5	-1	0	+1
21. Exercise with relative. (P)	Yes No	1	2	3	4	5	-1	0	+1
22. Supply relative with personal spending money. (P)	Yes No	1	2	3	4	5	-1	0	+1
23. Adjust relative's personal radio and/or television. (S)	Yes No	1	2	3	4	5	-1	0	+1
24. Help with toileting or changing undergarments. (P)	Yes No	1	2	3	4	5	-1	0	+1
25. Cheering up relative. (S)	Yes No	1	2	3	4	5	-1	0	+1
26. Help with dressing/undressing. (P)	Yes No	1	2	3	4	5	-1	0	+1
27. Provide adequate supplies (e.g. tissues, toiletries, etc.) (P)	Yes No	1	2	3	4	5	-1	0	+1
28. Help with bathing. (P)	Yes No	1	2	3	4	5	-1	0	+1
29. Read to relative. (S)	Yes No	1	2	3	4	5	-1	0	+1
30. Give relative body or back massage. (P)	Yes No	1	2	3	4	5	-1	0	+1

TASK	Do you do this?	Less than once per month	1 to 3 times per month	Once per week	2 to 4 times per week	5 or more times per week	Less involved	Same involved	More involved
31. Provide for religious needs (e.g. take to church, arrange pastoral/clergy visits). (S)	Yes No	1	2	3	4	5	-1	0	+1
32. Help relative make telephone calls. (S)	Yes No	1	2	3	4	5	-1	0	+1
33. Keep clothing current (e.g. appropriate for season, replace worn out items). (P)	Yes No	1	2	3	4	5	-1	0	+1
34. Inquire about medications being taken. (P)	Yes No	1	2	3	4	5	-1	0	+1
35. Escort to doctor, dentist, etc. appointments. (P)	Yes No	1	2	3	4	5	-1	0	+1
36. File claims for benefits for relative (e.g. income tax). (P)	Yes No	1	2	3	4	5	-1	0	+1
37. Check relative's temperature (e.g. feel forehead). (P)	Yes No	1	2	3	4	5	-1	0	+1
38. Listen to music or sing with relative. (S)	Yes No	1	2	3	4	5	-1	0	+1
39. Cook/bake with relative. (S)	Yes No	1	2	3	4	5	-1	0	+1
40. Other: ____________	Yes No	1	2	3	4	5	-1	0	+1
41. Other: ____________	Yes No	1	2	3	4	5	-1	0	+1

PART 6: Family Evaluation of Care[6]

DIRECTIONS: Each of the statements below describes something about your relative's care or living environment. You are asked to indicate your own feeling about each statement in terms of the extent to which you agree or disagree. Highest agreement = 7 and highest disagreement = 1. Circle the number for each statement that best describes the extent to which you agree or disagree. A few of the questions have an option to choose not applicable (n/a) if the statement does not apply to your situation.

	Strongly Disagree						Strongly Agree
1. I feel reassured about my relative's care after I visit.	1	2	3	4	5	6	7
2. I could feel more welcomed by staff when I visit my relative.	1	2	3	4	5	6	7
3. Staff listen to the problems or concerns I have about my relative.	1	2	3	4	5	6	7
4. Staff are patient with my relative.	1	2	3	4	5	6	7
5. Staff are caring in the interactions with my relative.	1	2	3	4	5	6	7
6. Staff show affection through use of touch with my relative.	1	2	3	4	5	6	7
7. Staff tend to treat my relative as a child.	1	2	3	4	5	6	7
8. Staff provide for the privacy of my relative.	1	2	3	4	5	6	7
9. Staff appear to be knowledgeable about Alzheimer's disease.	1	2	3	4	5	6	7
10. Staff solicit my help in providing care for my relative.	1	2	3	4	5	6	7
11. Staff provide support to help me deal with my feelings about my relative's situation.	1	2	3	4	5	6	7

---

[6] The Family Perceptions of Care Tool (Maas, Buckwalter & Kelley, 1991; Maas, Buckwalter, Kelley & Stolley, 1991). An option of "n/a" was added for some items.

	Strongly Disagree						Strongly Agree	
12. Other residents at the centre get upset with my relative's behavior and sometimes treat him or her with unkindness.	1	2	3	4	5	6	7	
13. My relative is allowed to move about freely if she or he is physically able.	1	2	3	4	5	6	7	
14. My relative gets enough exercise.	1	2	3	4	5	6	7	
15. My relative should be encouraged to participate in more activities that help maintain abilities.	1	2	3	4	5	6	7	
16. Enough activities are provided for my relative.	1	2	3	4	5	6	7	
I AM SATISFIED WITH THE CARE MY RELATIVE RECEIVES:								
17. In general.	1	2	3	4	5	6	7	
18. From nursing staff.	1	2	3	4	5	6	7	n/a
19. From the physician.	1	2	3	4	5	6	7	n/a
20. From the social worker.	1	2	3	4	5	6	7	n/a
21. From the recreation staff.	1	2	3	4	5	6	7	n/a
22. From the dietician.	1	2	3	4	5	6	7	n/a
23. From physical therapy.	1	2	3	4	5	6	7	n/a
24. From occupational therapy.	1	2	3	4	5	6	7	n/a
25. From speech therapy.	1	2	3	4	5	6	7	n/a
I AM SATISFIED WITH THE FOLLOWING ASPECTS OF MY RELATIVE'S ENVIRONMENT:								
26. Cleanliness.	1	2	3	4	5	6	7	
27. Freedom from unpleasant odors.	1	2	3	4	5	6	7	
28. Noise level.	1	2	3	4	5	6	7	
29. Attractiveness of decor.	1	2	3	4	5	6	7	

	Strongly Disagree						Strongly Agree	
30. Safety for residents.	1	2	3	4	5	6	7	
31. Opportunity for physical exercise.	1	2	3	4	5	6	7	
32. Number of staff resources to provide care.	1	2	3	4	5	6	7	
33. Opportunities for my relative to enjoy the outdoors and other diversions.	1	2	3	4	5	6	7	
34. Adequate equipment resources to provide care.	1	2	3	4	5	6	7	
35. Protection of my relative's personal belongings.	1	2	3	4	5	6	7	
36. My role in providing my relative's care.	1	2	3	4	5	6	7	
MY RELATIVE'S CARE <u>COULD BE BETTER</u> IN REGARD TO:								
37. Grooming and hygiene.	1	2	3	4	5	6	7	
38. Medication used.	1	2	3	4	5	6	7	n/a
39. Use of restraints.	1	2	3	4	5	6	7	n/a
40. Sensory stimulation (e.g. artwork, music, colors, etc.).	1	2	3	4	5	6	7	
41. Use of self care abilities.	1	2	3	4	5	6	7	
42. Bowel and bladder function.	1	2	3	4	5	6	7	
43. Control of behavior.	1	2	3	4	5	6	7	
44. My input into the care provided.	1	2	3	4	5	6	7	
IN GENERAL:								
44. I always feel informed about my relative's condition.	1	2	3	4	5	6	7	
45. I feel that this living arrangement is the best that it could be for my relative.	1	2	3	4	5	6	7	

	Strongly Disagree						Strongly Agree
46. My relative's personal belongings are sometimes taken or used by other residents.	1	2	3	4	5	6	7
47. Staff sometimes talk too loudly to my relative.	1	2	3	4	5	6	7
48. Staff too often get angry and/or speak sharply to my relative.	1	2	3	4	5	6	7
49. Staff do the best they can but are often too busy to give my relative the attention he or she should have.	1	2	3	4	5	6	7
51. If more resources were available, staff could provide care that would be more beneficial for my relative.	1	2	3	4	5	6	7

PART 7: Caregiving Issues[7]

There can be issues that annoy or bother you; that make you upset or angry. Some issues occur on a fairly regular basis, and others are relatively rare. Some have only a slight effect, and others have a strong effect. These next few questions are things that can be issues in caring for a relative who resides in a continuing care centre. You will find that some of these things will have been a concern recently, whereas other have not.

For each item, please indicate whether this issue has happened and, if yes, how much of a concern was it? Please rate how much of a concern it was using the following scale: 1 = it wasn't; 2 = somewhat; 3 = quite a bit; 4 = a great deal

ISSUE	DID IT HAPPEN?		HOW MUCH OF A CONCERN WAS IT?			
	Yes	No	It wasn't	Somewhat	Quite a bit	A great deal
1. Staff member(s) being rude to you.	Y	N	1	2	3	4
2. Relative's complaints about staff members.	Y	N	1	2	3	4
3. Receiving phone calls at home or work from the centre.	Y	N	1	2	3	4
4. Needing to tell the staff how to care for your relative.	Y	N	1	2	3	4
5. Ways staff handle your relative's behavior problems.	Y	N	1	2	3	4
6. Giving up other activities to visit your relative.	Y	N	1	2	3	4
7. Having to remind staff to do things for your relative.	Y	N	1	2	3	4
8. Staff not taking personal interest in your relative.	Y	N	1	2	3	4
9. Scheduling appointments for your relative.	Y	N	1	2	3	4
10. Staff not treating your relative with dignity.	Y	N	1	2	3	4

---

[7] The Caregiving Hassles Scale: Nursing Home Hassles (Stephens, Ogrocki & Kinney, 1991). The word "hassles" was replaced with "issues" and "concerns".

ISSUE	DID IT HAPPEN?		HOW MUCH OF A CONCERN WAS IT?			
	Yes	No	It wasn't	Some-what	Quite a bit	A great deal
11. Feeling left out of decisions made about your relative.	Y	N	1	2	3	4
12. Staff leaving your relative un-groomed/untidy.	Y	N	1	2	3	4
13. Having to remain in constant contact with the centre.	Y	N	1	2	3	4
14. Staff complaining to you about your relative.	Y	N	1	2	3	4
15. Staff speaking about your relative as if he/she were not there.	Y	N	1	2	3	4
16. Not being able to leave the local area for short trips.	Y	N	1	2	3	4
17. Staff making you feel unwelcome.	Y	N	1	2	3	4
18. Staff ignoring your relative's requests.	Y	N	1	2	3	4
19. Staff's phone calls asking you to bring things for/to your relative.	Y	N	1	2	3	4
20. Difficulty interacting with your relative's physician.	Y	N	1	2	3	4
21. Staff not encouraging your relative to do things for self.	Y	N	1	2	3	4
22. Staff expecting you to be available at any time.	Y	N	1	2	3	4
23. Staff over-medicating your relative.	Y	N	1	2	3	4
24. Staff leaving your relative in pajamas all day.	Y	N	1	2	3	4
25. Extra expenses due to providing care for your relative.	Y	N	1	2	3	4
26. Staff being intolerant toward your relative.	Y	N	1	2	3	4
27. Staff not working with your relative on exercises/activities.	Y	N	1	2	3	4

PART 8: General Questions

From your observations, how much choice does your relative have in terms of the following activities[8]:

	Very little choice	Some choice	Free choice	
1. Who to sit with at meals.	1	2	3	n/a
2. What is served at meals.	1	2	3	n/a
3. What time to eat meals.	1	2	3	n/a
4. Who to have a snack or coffee with.	1	2	3	n/a
5. Where to have a snack or coffee.	1	2	3	n/a
6. What time to go to bed.	1	2	3	n/a
7. What time to get up.	1	2	3	n/a
8. When to have a bath.	1	2	3	n/a
9. Where to see visitors or friends.	1	2	3	n/a
10. When to see visitors or friends.	1	2	3	n/a
11. When to watch TV.	1	2	3	n/a
12. What TV programs to watch.	1	2	3	n/a
13. Where to spend free time.	1	2	3	n/a
14. With whom to spend free time.	1	2	3	n/a
15. Who to have for friends.	1	2	3	n/a
16. What clothes to wear.	1	2	3	n/a
17. What type of haircut to get.	1	2	3	n/a
18. What name to be called (first, last, nickname).	1	2	3	n/a
19. What hobbies to have.	1	2	3	n/a
20. What to spend money on.	1	2	3	n/a
21. Where to shop.	1	2	3	n/a
22. Whether to associate with other people or not.	1	2	3	n/a

---

[8] The Perceived Latitude of Choice Scale (Hulicka, et al., 1975).

	Very little choice	Some choice	Free choice	
23. Who to complain to.	1	2	3	n/a
24. Whether to offer suggestions to other people about how things are done.	1	2	3	n/a
25. Whether to attend a religious service.	1	2	3	n/a
26. What papers or books to read.	1	2	3	n/a
27. How much personal privacy is available.	1	2	3	n/a
28. Whether to work.	1	2	3	n/a
29. Where to work.	1	2	3	n/a
30. What type of work to do.	1	2	3	n/a
31. What personal possessions to have.	1	2	3	n/a
32. Who to live with.	1	2	3	n/a
33. Colors of wall, pictures, etc., in living quarters.	1	2	3	n/a
34. Whether to have a private room.	1	2	3	n/a
35. Whether to live at the same place or go elsewhere.	1	2	3	n/a
36. When to go out (leave living quarters for a few hours).	1	2	3	n/a
37. Whether to participate in certain activities (games, crafts, meetings, etc.)	1	2	3	n/a

Are you satisfied with the opportunities provided by the centre for you to be involved in the care of your relative?

Very dissatisfied Very satisfied
1 2 3 4 5

Please explain (i.e. how do they encourage you to be involved):

In general, are you satisfied with the programs/activities provided by the centre for residents?

Very dissatisfied Very satisfied
1 2 3 4 5

Please explain (i.e. most favorite activity, least favorite activity):

Are you satisfied with the staff at the centre?

Very dissatisfied Very satisfied
1 2 3 4 5

Please explain (i.e. what you like the most, what you like the least):

Overall, how satisfied are you with the centre as the place for your relative to live?

Very dissatisfied Very satisfied
1 2 3 4 5

Please explain (i.e. what do you particularly like or what would you like to see improved/changed):

Thank you for your time. We will send results of the evaluation to you upon completion of the evaluation program.

Appendix F: Sample Size Determination

The power of a statistical test is related to the sample size. The issue of power for the present study was discussed in Chapter 4. This sample size determination was included in order to provide an example of the sample size required for adequate power in such a study. The sample size was determined from power tables in Cohen's (1977) book that include the relationships among power, sample size and effect size. Sample size is usually determined for one analysis within a study, even though many analyses may be conducted. The analysis chosen for the sample size determination in this study was the comparison between the ACC and SCU family members. A table listed for the F tests on means in the analysis of variance and covariance with an alpha criterion of .05, a small effect size (.10 as described by Cohen), and two groups of subjects was used to determine the sample size (p. 311). Conventionally, a power level of .80 is chosen for the behavioral sciences (Cohen). It was determined that 350 subjects per group would have been needed in order for the power level to fall between .76 and .82. The actual sample size of this study was considerably smaller than this, for the reasons mentioned in Chapter 4.

Appendix G: Families With and Without Prior Long-Term Care Experience

Although each of the ACC and SCU groups of family members were treated as homogeneous for the purposes of this study, a description of their prior experiences was included to enhance the sample description. The ACC residents entered the facility at approximately the same time when the facility opened in the summer of 1995. The average length of time that the ACC residents had been living at the facility at the time of the first interview was 5.26 months (SD=1.08), ranging 3 to 7 months. Therefore, the family members were all dealing with similar staff and administration and any subsequent changes in staff and/or care policies. Twenty-eight of the residents moved from home while ten of the residents moved from another type of long-term care facility. The average length of time that the ten residents had been residing in another facility was 14 months (SD=11.6), ranging 1 to 30 months.

Three MANOVAs, for the involvement in care, perceptions of formal care, and feelings about their relative's situation measures were conducted on the two groups to assess any differences between family members with and without prior long-term care facility experience. The overall Fs for the MANOVAs were non-significant. However, due to the power issues discussed earlier, the results of the univariate tests were reported. The two groups of ACC family members differed on only two of the ten study variables. First, the average length of visits was shorter by approximately a half-hour for those ACC family members with prior long-term care experience (M = 0.93, SD = 0.50) than those without (M = 1.47. SD = 0.75), $\underline{F}(1) = 4.50$, $\underline{p} = .04$. Second, the family members with prior long-term care experience desired greater involvement in tasks (M = 0.11, SD = 0.15) than those without (M = 0.03, SD = 0.09), $\underline{F}(1) = 4.71$, $\underline{p} = .04$. These differences may be explained by the assumption that family members with prior long-term care experience were more familiar with their role within the facility while those without prior experience were adjusting to the changes taking place after the admission of the resident. Overall, results indicate that both groups of family members were fairly similar in their involvement, perceptions and feelings.

The SCU residents were admitted to the facilities as beds became available because the SCUs had been in operation for a number of years. The average length of time that the SCU residents had been living at the facilities was 21.13 months (SD = 17.28). Fourteen of the thirty-eight SCU residents had been in another facility prior to their current residence. These 14 residents had been living in another facility an average of 17.69 months (SD = 18.2), ranging 1 to 60 months. The SCU family members as a group may have experienced different administration, staff and possible changes in care policies during the time that their relative spent in the current long-term care facility.

Three MANOVAs, for the involvement in care, perceptions of formal care, and feelings about their relative's situation measures were conducted on the two groups to assess any differences between family members with and without prior long-term care facility experience. The overall Fs for the MANOVAs were non-significant. However, due to the power issues discussed earlier, the results of the univariate tests were reported. The two groups of SCU family members differed on only one of the ten study variables. The average number of visits per month was greater for those SCU family members without prior long-term care experience (M = 9.33, SD = 7.83) than those with experience (M = 4.00, SD = 2.82), $\underline{F}(1) = 5.98$, $\underline{p} = .02$. Overall, results indicate that both groups of family members were fairly similar in their involvement, perceptions and feelings.

The results of these analyses lend support to the results of the longitudinal analysis with the ACC family members which indicated that involvement, perceptions and feelings do not change much over time. Those family members who had been involved in the long-term care system for greater lengths of time showed similar involvement, perceptions and feelings to those whose relatives had been living in the facility for less time.

Appendix H: General Satisfaction with Care

In addition to the Family Perceptions of Care Tool (Maas & Buckwalter, 1989) used to assess satisfaction with care, four general satisfaction questions were asked of the participating family members. Although not part of the multivariate analyses, these measures provided additional information regarding the family members' satisfaction with four areas of care. These questions were similar to questions asked in the Woodside Place Evaluation (Silverman, 1995).

Over Time at the ACC

The means and standard deviations for the four general satisfaction questions are shown in Table 39.

Table 39: Means and Standard Deviations of General Satisfaction with Care at the ACC (N = 20).

Measure Possible scores ranged 1-5	Interview 1	Interview 2	Interview 3
Satisfied with opportunities provided by centre to be involved in resident's care	4.79[a] (0.42)	4.75 (0.55)	4.85 (0.37)
Satisfied with programs/ activities provided by centre for residents	4.30 (1.03)	4.50 (0.89)	4.60 (0.68)
Satisfied with staff at the centre	4.65 (0.59)	4.68 (0.58)	4.80 (0.41)
Overall, satisfied with the centre as a place for resident to live	4.95 (0.22)	4.95 (0.22)	4.90 (0.31)

[a] n = 19.

Family members had high ratings of satisfaction and repeated measures MANOVA showed no significant changes in general satisfaction over time. Within Interview 1, family members were more satisfied with the opportunities for involvement than with the programs/activities provided for residents and they were more satisfied with the centre as a place for their relative to live than with the programs/activities provided for residents and with the staff, F(3, 16) = 4.64, p = .02. Although not statistically significant at all interview times, there was a trend for family members to rate their satisfaction with the environment highest and their satisfaction with the programs/activities lowest. This was a similar finding to the subscales of the Family Perceptions of Care Tool discussed previously.

The family members were given an opportunity to make comments about each of these four questions. Comments provided by family members were very similar across the three interviews, so a description of Interview 1 comments only will be provided below (n = 20). With regard to the first general satisfaction question about opportunities for involvement, family members were asked whether and how staff encourage or discourage their involvement. The majority of family members said that staff encourage their involvement in their relative's care. Below is a summary of the comments:

- 14 family members commented that the ACC indirectly encourages involvement (e.g. send out calendar of events, post schedule of activities at the facility, facility has an "open-door" policy).
- 12 family members commented that the ACC directly encourages involvement (e.g. staff personally invite family members to events, thank family members for help, keep family informed about resident).
- 1 family member commented that the ACC staff and administration discouraged involvement (e.g. did not return phone calls, did not send newsletters or activity schedules).
- 3 family members commented that they had experienced neither encouragement or discouragement.

With regard to the second general question about satisfaction with the programs and activities provided for residents, family members were asked to list their most and least favorite activities, to make suggestions regarding activities, and could provide additional comments. The likes and dislikes reported showed a wide variation and were considered to be personal preferences of the family members. Below is a summary of the comments:

- 19 family members commented on particular activities that they liked or perceived that their relative liked to be involved with (e.g. sing-alongs, bowling, church service).
- 3 family members commented on particular activities which they disliked (e.g. bingo, dancing, games).
- 11 family members made suggestions for activities which they would like to see included in the schedule (e.g. slide shows, cookie-baking contest, entertainers).
- 5 of the 11 family members who made suggestions for activities commented that they would like to have the residents go on more outings (e.g. picnics, shopping, go to museum).
- 3 family members commented that some of the activities were too childish.
- 2 family members commented that the activities did not take into account the varying abilities of the residents (e.g. poor eyesight or hearing, different levels of cognitive ability).

With regard to the third general satisfaction question about the staff, family members were asked to comment on what they liked/disliked about the staff and to provide any additional comments regarding the staff. Most family members were very pleased with the staff. A summary of the comments follows:

- 20 family members provided comments on positive qualities of the staff or positive experiences they have had with the staff (e.g. friendly, caring, patient).

- 6 family members provided comments on negative qualities of some staff or negative experiences they have had with the staff (e.g. rude, disrespectful, talk negatively about residents).
- 4 family members commented on staffing issues (e.g. not enough staff, too many part-time staff, staff not available to speak with family).

With regard to the fourth general satisfaction question about the centre as a place to live, family members were asked to comment on what they liked about the environment, what they would like to see improved, or to provide any other comments about the facility. Most family members were very pleased with the environment of the ACC. Below is a summary of the responses:

- 20 family members commented on aspects of the environment which they particularly liked (e.g. clean, spacious, nice décor).
- 6 of the 20 family members specifically mentioned that they liked the homelike or family atmosphere of the facility.
- 4 of the 20 family members specifically mentioned that they liked the freedom allowed the residents.
- 10 family members provided suggestions for improvement to the environment (e.g. phones in the residents' rooms, larger closets in the rooms, a larger family dining room).
- 3 of the 10 family members who mentioned improvements specifically commented on improving the front door entrance system (e.g. hide the entrance, hide the code pad, place staff where they can see the entrance).

Comparing the ACC and SCU

The means and standard deviations for the four general satisfaction questions are shown in Table 40. Results of MANOVA showed a significant difference between the two groups of family members, SETTING $F(4, 60) = 3.54$, $p = .01$. Tests of between-subjects effects indicated that ACC family members were more satisfied than SCU family members with the programs and activities offered by the facility and with the facility as a place for their relative to live. Although not statistically significant, there was also a trend for ACC family members to be more satisfied with opportunities for involvement than the SCU family members.

Within each setting, repeated measures MANOVAs showed that ACC family members were more satisfied with the facility as a place for their relative to live than with each of the other three areas of satisfaction, $F(3, 27) = 4.33$, $p = .01$, while at the SCUs, family members were less satisfied with the programs and activities provided than with the staff and with the facility as a place for their relative to live, $F(3, 32) = 3.68$, $p = .02$.

Table 40: Means and Standard Deviations of General Satisfaction with Care in Both Settings.

Measure Possible scores ranged 1 to 5	ACC n = 32	SCUs n = 38
Satisfied with opportunities provided by centre to be involved in resident's care	4.66 (0.60)	4.37 (0.75)
Satisfied with programs/activities provided by centre for residents	4.48[a] (0.81)	4.06[b] (0.94)
Satisfied with staff at the centre	4.58[a] (0.62)	4.47 (0.69)
Overall, satisfied with the centre as a place for resident to live	4.88 (0.34)	4.67 (0.88)

[a] n = 31. [b] n = 35.

The family members were given an opportunity to make comments about each of these four questions. With regard to the first general satisfaction question about opportunities for involvement, family members were asked whether and how staff encourage/discourage their involvement. Below is a summary of the comments:

- 26 ACC and 27 SCU family members commented on how staff encourage their involvement (e.g. invite to activities, mail a schedule of events, thank them for their help).
- 1 ACC and 2 SCU family members commented that staff discourage their involvement (e.g. don't provide activities during weekend hours, don't return phone calls).
- 6 ACC and 9 SCU family members commented that staff neither encourage nor discourage involvement (e.g. involvement is up to the family member).

With regard to the second general question about satisfaction with the programs and activities provided for residents, family members were asked to list their most and least favorite activities, to make suggestions regarding actvities, and could provide additional comments. A summary of the responses is listed below:

- 25 ACC and 27 SCU family members listed activities which they liked or perceived their relative to like (e.g. tea parties, sing-along, baking).
- 13 ACC and 3 SCU family members listed activities which they disliked or perceived their relative disliked (e.g. games, housework, dancing).
- 16 ACC and 15 SCU family members gave suggestions for activities (e.g. travel-logs, music entertainers, gardening).
- 8 ACC and 7 SCU family members specifically mentioned that they would like the residents taken outside of the facility more frequently (e.g. picnics, shopping, bus tours).
- 2 ACC and 8 SCU family members commented that there were not enough activities available.

- 0 ACC and 8 SCU family members commented that they did not know much about what activities were available.

With regard to the third general question about the staff, family members were asked to comment on what they liked/disliked about the staff or to provide additional observations regarding the staff. A summary of the responses follows:

- 32 ACC and 37 SCU family members listed qualities which they liked about the staff (e.g. friendly, caring, loving).
- 9 ACC and 9 SCU family members commented on qualities which they disliked about some staff members (e.g. unkind, impatient, ignore family).
- 7 ACC and 8 SCU family members commented on staffing issues (e.g. staff are too busy, frequent changes in staff, too many part-time but not enough full-time staff).
- 5 ACC and 11 SCU family members specifically mentioned that more staff members were needed at the facilities.

With regard to the fourth satisfaction question about the centre as a place to live, family members were asked to comment on what they liked about the environment, what they would improve, or to provide any other comments about the facility. Many of the comments made were specific to the facilities and included a wide range of likes and suggested improvements. A summary of the responses follows:

- 33 ACC and 34 SCU family members listed characteristics which they liked about the facilities (e.g. clean, good food, atrium/garden).
- 17 ACC and 21 SCU family members made suggestions for improvements to the facilities (e.g. phones in residents' rooms, better cleaning, more privacy).
- 5 ACC family members specifically mentioned that the facility did not look like an institution or hospital while 10 SCU family members specifically mentioned improvements to the décor or to make the facility more "homelike."

Appendix I: Philosophy of Care Statements

The following philosophy of care statements are reproductions of the originals by The Capital Care Group. The statements for the ACC are first, with those for the SCUs following.

ALZHEIMER CARE CENTRE
PHILOSOPHY

- We believe that a flexible and secure home-like living environment provides the best quality of life for residents with Alzheimer Disease or related dementia.

- We believe that the special environment, programs and staff training of the Alzheimer Care Centre supports resident choice, independence, dignity and privacy through individualized care.

- We believe that client freedom should be promoted without physical restraints

- We believe that family members, friends and volunteers play a key role in the care of the resident. We will seek to involve them in all programs.

- We believe that staff are an important component of the program. Their training and support will be provided on a regular basis to help them serve the care needs of those with Alzheimer Disease or related dementia.

- We believe that the Alzheimer Care Centre should play a leadership role in the research and care of those with Alzheimer Disease or related dementia.

- We believe that the Alzheimer Care Centre has a responsibility to provide community service through outreach programs.

ALZHEIMER CARE CENTRE
VALUE STATEMENT

1. *We value the personality and previous lifestyle of the resident.*
   The resident participates as feasible in those activities which reflect their personality and previous lifestyle. The staff are familiar with the previous personality and lifestyle of each of the residents. This knowledge is reflected in the care they provide the residents.

2. *We value client independence and freedom, acknowledging that safety risks need to be managed.*
   There is rationale use of medications to manage behavior. Physical restraints are not used. The environment and the programs of the Centre are designed to minimize the risk of injury to the resident.

3. *We value the participation of family and friends in the life of the residents in the Centre.*
   Family and friends are satisfied with their involvement in the resident's life. Family and friends participate in many of the Centre activities and visit frequently.

4. *We value the participation of volunteers in the programs of the Centre.*
   There is a wide range of opportunities for volunteer participation in the Centre. The number of volunteers involved at the Centre is numerous and volunteer satisfaction is high.

5. *We value the unique contribution of each staff member to the program.*
   Programs are in place to provide support and education to staff. Staff find their work rewarding.

6. *We value the importance of reaching out into the community.*
   There is an outreach program which supports the caregiver in the community and assists those with Alzheimer Disease or related dementia to remain in the community for as long as possible.

7. *We value the contribution which research makes to the care of persons with Alzheimer Disease or related dementia.*
   The Centre offers a milieu which supports research regarding the care of persons with Alzheimer Disease or related dementia.

CAREGIVER PHILOSOPHY, KNOWLEDGE AND SKILLS

STATEMENT OF BELIEF	STAFF CHARACTERISTICS/ EXPECTATIONS
We believe that knowledge of the disease process involved in the cognitively impaired residents is essential, and that upgrading of knowledge and skills is the responsibility of each staff member.	Demonstrates an understanding of dementias, recognizes knowledge gaps and participates in ongoing education.
We believe in and are committed to the interdisciplinary team approach to care for the cognitively impaired resident.	Demonstrates commitment to the philosophy and role of the Special Care Unit. Understands other disciplines' area of expertise and utilizes this resource. Contributes to and adopts the total care plan.
We believe that flexibility and adaptability are essential when working with the cognitively impaired resident.	Educational training in dealing with persons with dementia. Demonstrates the ability to adapt to situations as they occur. Demonstrates the ability to change from familiar/scheduled work routines and try new ideas.
We believe that family members of the cognitively impaired resident are part of the team, and require individualized support, encouragement and education.	People oriented rather than task oriented point of view. Demonstrates and practices effective interpersonal skills.

STATEMENT OF BELIEF	STAFF CHARACTERISTICS/ EXPECTATIONS
We believe in the resident's right to dignity and self worth.	Demonstrates patience and the ability to be non-judgemental. Demonstrates ability to see the resident as an adult and as a unique individual.
We believe in the need to deal with the behaviour and emotions of the cognitively impaired resident in a calm, constructive and creative manner.	Demonstrates the ability to be patient, nonjudgemental and utilize a gentle, calm and supportive approach. Aware of and contributes to identified strategies to use in potentially stressful situations.
We believe that staff selection should be made on the basis of certain personal attributes.	Demonstrates leadership skills, a positive outlook, sense of humor, creative problem solving skills and good communication abilities.
We believe in consistent staffing to provide excellent in delivery of care.	Demonstrates a consistent approach, good assessment skills, planning and evaluation of programs.