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Family Caregiving in Formal Care Settings

by

Lisa M. Douziech ©

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

in

Family Studies

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The undersigned certify that they have read, and recommended to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled Family Caregiving in Formal Care Settings submitted by Lisa M. Douziech in partial fulfillment of the requirements for the degree of Master of Science in Family Studies.

N Keating

Norah Keating

Koop

Priscilla Koop

Janet Fast

Janet Fast

Date December 15, 1997

DEDICATION

To my loving mother.

ABSTRACT

The purpose of this study was to explore family involvement in elder care within formal care settings. We examined the proportion of family members participating, frequency of their involvement, and time spent providing care to their elders within eight care categories. Family members concentrated their involvement and time in enhancing well being, care management, financial management, transportation, and shopping. On average family members provided care thirty-two times per month, and spent twenty-four hours per month in caregiving. We then examined family caregiving across three models of care. Family members with elders in assisted living had more frequent activity in shopping, housework, and transportation. These families also spent significantly more time in housework, care management, and overall time. Family members with elders in adult family living spent significantly more time in skilled care and financial management. Results suggest that the care setting, client needs, and care polices impact family caregiving.

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CHAPTER 1

INTRODUCTION

The provision of health care for the today's elderly has become a key issue for policy makers. Expectations regarding responsibility for meeting seniors' health care needs have been changing, with responsibility for meeting these needs shifting away from the formal sector, and onto informal caregivers (Barusch, 1995; Keating, Fast, Connidis, Penning & Keefe, 1997). A new philosophy of involving family members in care and establishing partnerships between formal and informal caregivers is emerging. Within this philosophy there seems to be the assumption that families are not doing enough. and should be encouraged to do more. There are several reasons for encouraging greater family involvement in health care delivery. These reasons include reducing the cost of public health care, ensuring that families fulfill their caregiving responsibilities, and providing better quality care as a result of family involvement.

The Reasons

The recognition of the new role for informal caregivers as active participants in delivering health care coincides with a perceived cost crisis within Canada's health care system (Chappell, 1993). Shifting more responsibility onto informal caregivers appeals to policy makers as a means of reducing health care costs (Barusch, 1995; Chappell, 1993). Given the belief that the amount of public health care support required by the elderly is no longer affordable, more pressure will be put on informal caregivers, and particularly families, to provide care.

Families are believed to have a responsibility for meeting the health care needs of their elderly family members. If family members are made "partners" in care, they will be able to fulfill their caregiving obligations. Those supporting the partnerships paradigm assume that families have an filial obligation to be involved, and believe that families should be encouraged to do more for their elderly relatives (for example, National Advisory Council on Aging, 1990).

Developing caring partnerships in which there is a collaborative relationship between family members and formal staff is thought to result in the best care possible for seniors (Keating et al., 1997). Family members are now conceptualized as the ideal people to provide care (Schwenk, 1993). Keeping the family involved serves to maintain family ties and connectedness, and helps create a home-like atmosphere in formal care settings. Within the partnerships paradigm it is assumed that family involvement is essential if elders are going to receive the best care possible, and have their care needs met.

What's Really Going On?

On the surface, the partnerships paradigm seems to embrace our current values of supporting family involvement in the care of seniors. However, Keating et al. (1997) suggest that this partnerships paradigm has a subtext which is based on the belief that we can no longer afford the previously provided level of elder care. This move towards developing a "partnership" between families and staff in an effort to provide superior care to elders is actually a means of shifting more responsibility for care onto family members in order to contain public cost. The end product means that families are doing a lot more elder care and cost to the public health care system has been reduced.

Underlying the partnerships paradigm is the assumption that not only should families be involved, but they should be doing more to meet the health care needs of their elders. In response to this, one might inquire as to what families are currently doing to meet the health care needs of the elderly. A review of the caregiving literature reveals that families are extensively involved in the care of elderly residing in the community. It is families, and not formal caregivers that provide the majority of care to these seniors (Brody, 1981, 1995; DeFriese & Woomert, 1992). Even when formal support is available, families continue to provide the bulk of their elder's care. The research evidence also suggests that families are performing a wide range of caregiving tasks in an effort to keep their elderly relative living in the community.

Often families do all they can to keep their elder living in the community. It is only when the care demands go beyond the family's capabilities that the elder is relocated to a formal care setting. According to the subtext of the partnerships paradigm, family members of elders who reside in formal care are not contributing enough to their relative's care. Based on this philosophy, recommendations have been made to shift more responsibility for care onto family members. However, research evidence suggests that families do not abandon their relative after placement into formal care. Rather, families often wish to maintain some type of caregiving involvement.

The research literature on what families are doing for their elders in formal care settings is very limited. There is evidence that families provide care in a variety of areas, but this research is incomplete. Thus we know very little about family involvement in caregiving within formal settings. Yet, in an effort to cut health care costs, programs and recommendations are being put in place based on the assumption that families have an obligation to provide care and are not meeting this obligation. The problem is that we do not have a clear understanding of what caregiving families are currently providing in these settings. It is possible that families are currently doing all they can and that we may already have reached a threshold with respect to how much care families can provide (Keating et al., 1997).

It is premature for policy makers to shift greater responsibility for care of elderly onto families within formal settings without evidence of families' current caring involvement and capacity. Research needs to be done in order to determine what families are doing in formal settings and if they are able and willing to provide more care. Only after we have a complete understanding of family involvement in caregiving within formal care settings are we in a position to make policies which impact their level of caregiving responsibility.

Purpose of Study and Research Questions

The main purpose of this study is to explore the caregiving activities families are performing in formal care settings. The specific goals of this research project are: to document the caregiving activities families members perform for elderly residents in formal care settings; the frequency with which family members perform the caregiving activities; the amount of time families spend on caregiving activities; and the levels of family involvement in caregiving activities across three models of continuing care in Alberta.

CHAPTER 2

LITERATURE REVIEW

The aging of Canada's population has raised concerns about the degree to which the government will be able to provide formal health care services to seniors (Chappell, 1993). Given the federal and provincial deficits, and the move towards cutting costs in health care, the question of who will meet the health care needs of seniors becomes increasingly relevant.

The new policy paradigm of eldercare emerging seems to imply that family members are not doing enough, and that they need to assume more responsibility for eldercare (Keating et al., 1997). This paradigm and its components will be discussed, and examples of recommendations based on this paradigm will be presented.

Most of the research exploring family involvement in providing care to the elderly has focused on elderly persons who live in the community. This literature reveals that family members are extensively involved in a wide variety of tasks for their elderly relatives. This literature will be examined so as to give us some indication of the types of caregiving tasks that family members may be performing for their elders in formal care.

The research literature suggests that families tend to do all they can to keep their elderly relative living in the community, and move their family member into a formal care setting only as a last resort. Contrary to common beliefs of family abandonment of elderly in these formal settings, research evidence suggests that family members wish to maintain some type of caregiving role. Unfortunately, little research has been done to establish what caregiving activities families are actually performing in formal settings. There is evidence to suggest that families are involved in a variety of tasks, but a complete picture of family involvement in formal care setting still eludes us.

It is apparent that we need to know more about family involvement in eldercare activities within formal settings. It is inappropriate to suggest that families are not assuming enough responsibility for eldercare when we have virtually no information on what they are doing, how often they are performing tasks or how much time they devote to eldercare. Without this information, we are in no position to propose or implement eldercare policy that calls for greater involvement of family members.

The Partnerships Paradigm

Over the years, recommendations have been made for the development of collaborative partnerships between staff and family (For example, Bowers, 1988; Dempsey & Pruchno, 1993; Foster, 1991; NACA, 1992; Schwartz & Vogel, 1990; Silverstone, 1978). These recommendations are based on a philosophy which recognizes family members as partners in the delivery of health care to seniors residing in formal care settings.

Within the health care system today, a new policy paradigm of care for frail elderly is emerging. One of the main tenets of this paradigm is that caring partnerships will result in the best care for seniors. This caring partnership is conceptualized as a collaborative effort between informal and formal care providers. On the surface this paradigm appears to reflect the current view that care by family members is ideal, and that informal caregivers need to be supported in their efforts to provide care (Keating et al., 1997). However, Keating et al., (1997) suggest that this partnerships paradigm has a subtext which is based on the belief that "...the amount of public support previously provided to frail seniors is no longer affordable, and that more responsibility for eldercare must be carried out by informal caregivers..." (p.25). In essence, the partnerships paradigm that is developing today is really a means of reducing public health care costs by shifting more caregiving responsibility onto family members.

Moving Towards Partnerships

A review of the caregiving research literature reveals that ideas of caring partnerships started to surface many years ago. For example, Shuttlesworth, Rubin and Duffy (1982) discussed the importance of partnerships and stated that if an effective partnership is to be established, there must be a program in place which outlines the tasks in the caregiving process, along with who is expected to perform each task. Silverstone (1978) suggested that efforts by the professional and paraprofessional staff to involve concerned family members in the direct care of the resident reflect a team philosophy. Silverstone recommends the involvement of family in team efforts because it has two benefits. The first benefit is that working as a team serves to involve family members who have valuable information about the resident. The second benefit is that families can perpetuate intimate ties from the past. These two examples show how families were gaining recognition as care providers and how ideas about working with families rather than around them were emerging.

The idea of establishing a caring partnership between informal and formal care systems is far more common today. There are more recommendations, programs and policies being based on this 'partnerships' philosophy. Some have argued that partnerships are important because formal and informal caregivers possess complementary skills. It is assumed that both formal caregivers and family members will be more suited to performing certain tasks. Walker, Pratt, and Eddy (1995) suggest that interventions that conceptualize formal and informal caregivers as partners need to acknowledge the unique and vital skills that each possess. The formal care system might include resources such as power and expertise, whereas the informal system may have the resources of proximity, affection, long-term commitment, and intense knowledge of the elder (Walker et al., 1995). Dempsey and Pruchno (1993) also believe that families are important and can have a complementary caregiving relationship with formal caregivers. Formal care staff and the family are seen as providing coordinated care in which both staff and family perform certain tasks. Dempsey and Pruchno state that policies and practices can enhance this team approach in the delivery of services to institutionalized elderly in two ways. First, they suggest that tasks which must be performed by formal staff be clearly outlined and explained to family members. Second, they recommend that staff training should encourage staff to view the family members as caregivers who can assist in the carrying out of tasks. They see these practices as leading to an increase in the quality of care provided and give meaning to the role played by family members.

Health care policy and programs are focusing on the development of caregiving partnerships. The involvement of family members on an ongoing basis is seen as a way of helping to ensure that the needs of the elderly are met, resulting in better care. Numerous recommendations for the establishment of partnerships with family members have been made. For example, the National Advisory Council on Aging (NACA, 1990) recommended linking informal caregivers and the formal service network into partnerships. More specifically, it was recommended that: (1) formal service providers should consult with residents, and work with informal caregivers in planning and providing care services; (2) training to prepare and assist formal caregivers in working with informal caregivers would be in place; and (3) information and counseling should be provided to informal caregivers concerning the role and limitations of the formal service sector. NACA (1990) goes on to suggest that the formal and informal service sectors need to cooperate in an atmosphere of mutual respect and understanding.

Providing relevant information to families about the possibilities to take part in care planning, decision making and evaluating care is another type of recommendation that has been presented for establishing partnerships with families (Laitinen, 1992). Laitinen (1992) suggests that family members need to be made aware of the opportunities that exist for caregiving involvement, as well as the support from staff that is available to them. Stevens et al. (1993) also appear to believe in the partnerships philosophy as shown in their recommendations for increasing family involvement. They argue that families are important and should be included from the beginning in the care planning process so as to allow families to express their own needs and goals in the provision of care. These researchers go on to say that the family's desire for active involvement in caregiving tasks be assessed so that their roles and responsibilities for tasks can be clarified. Buckwalter and Hall (1987) also show their support for the partners paradigm by recommending that family members be made aware of how they can be involved in the care process. They argue that planning opportunities for task responsibilities by families can facilitate care for the resident, satisfaction with the facility, and family interaction (Buckwalter & Hall, 1987). Others have suggested that early direction and assistance to families who want to be involved in care are likely to reinforce family member's feeling of being valued and welcomed (Schwartz & Vogel, 1990). Recommendations on what formal care settings can do to decrease the uncertainty experienced by families regarding their role in the facility has also been suggested as a way of encouraging the development of caregiving partnerships (Sharp, 1990).

Within these recommendations, there appears to be support for a collaborative partnership between formal and informal care providers. A few have focused their recommendations on how to assist family members who wish to have some type of caregiving role. However, many of the recommendations appear to reflect the subtext of today's partnership paradigm, that of shifting more responsibility for eldercare onto family members. There seems to be the assumption that families could and should be doing more to meet the health care needs of their elderly relatives. The question that arises is 'what health care tasks are families currently providing to their frail seniors?', and 'should more responsibility be shifted onto them?'. Keating et al. (1997) point out that there is "...evidence that family members already provide extensive support to seniors and are becoming increasingly stressed because of their caregiving activities, suggesting that we may have already reached a threshold with respect to how much support informal caregivers can provide" (p.25). A closer examination of what caregiving services families are providing is needed before any statements can be made about their capacity to assume more responsibility in eldercare.

Families and Eldercare

Family Caregivers

The health care needs of frail elderly are met by formal and informal care providers. As the government reduces health care funding to the formal sector, more health care demands will be shifted onto informal caregivers (Keating et al., 1997). The majority of informal caregivers are family members. The assistance provided by family caregivers derives from normative or voluntary interpersonal relations, rather than from formal legal mandates or publicly mediated financing mechanisms (Litwin & Auslander, 1990; National Advisory Council on Aging, 1990). Family caregivers tend to have had a long-term relationship with the care recipient, and feel an obligation to provide care normally associated with being a family member. Unlike formal caregivers, family members are rarely paid for the care which they provide. A common assumption regarding formal and informal caregivers is that formal caregivers have specialized training in performing health care tasks, whereas family caregivers lack such training (NACA, 1990).

Given the subtext of today's partnerships paradigm, the focus of this literature review will be restricted to family members and their role in providing health care services to frail elderly persons.

Tasks Involved In Eldercare

Researchers have tended to conceptualize caregiving for the elderly as a set of caregiving tasks (Abel, 1990). However, there has been a lack of consensus regarding how to categorize these caregiving tasks (Stone, Cafferata, & Sangl, 1987). Given this lack of consensus, Keating, Fast, Oakes and Harlton (1996) conducted a research project which resulted in a definition of eldercare and a categorization of caregiving tasks that would be included under this definition. They defined eldercare as "a comprehensive set of tasks and services that maintain or enhance seniors' independence" (p. 5). The categories of tasks included in eldercare were: personal care, household maintenance and repair, household adaptations, shopping for goods, transportation, management of financial affairs, and care management. Other researchers have also included emotional support as an important component of caregiving. Baines, Evans and Neysmith (1992), argued that 'caring about' someone, an aspect of emotional support, is a valuable but often ignored aspect of care. When included in caregiving task inventories, families almost always identified emotional support as part of their caregiving role (Horowitz, 1985). Another category of caregiving is skilled care which includes technical tasks. Research suggests that technical tasks are generally performed by formal caregivers. However, with current cutbacks in health care, responsibility for performing technical tasks/skilled care are being shifted onto families. These categories cover the broad spectrum of health care services that are required by frail elderly. For the purpose of clarity, the caregiving categories of personal care, care management, enhancing well-being, housework, financial management, transportation, skilled care, and shopping will be used to guide the discussion of what caregiving tasks family members perform for elders who reside in the community and in formal care settings. These same task categories are used in this research project.

Family Caregiving to Elders Living in the Community

The majority of research examining family involvement in eldercare has focused on elders who reside in the community. In the absence of evidence about what goes on in formal care settings, having a clear understanding of what family members do for these elders might give us some indication of what tasks we might expect to find family members to be performing for elders in formal care settings

There is evidence that families provide considerable assistance to elderly persons living in the community. When elderly individuals are in need of care, it is frequently family members to whom they turn first (Cox, 1993; DeFriese & Woomert, 1992; Hooyman & Gonyea, 1995; Garant & Bolduc 1990). It has been estimated that nearly three quarters of the noninstitutionalized elderly population depend on informal caregivers for the assistance they require (DeFriese & Woomert, 1992, Soldo, 1984). Brody (1981, 1995) states that families provide over 80% of in-home care to elderly people, and that 10%

of the elderly who live at home would require nursing home placement if it were not for the support received from informal caregivers.

To help them meet the needs of their elders, some families use formal services to assist them in their caregiving tasks. Soldo (1984) found that 16% of dependent persons sampled received assistance from both formal and informal caregivers. Formal services were used to supplement the care given by family members (Kane & Kane, 1987). The issue of substitution of formal services for informal care among elderly living in the community has been an expressed concern by some. The argument is that formal services will encourage families to reduce or withdraw the amount of care that they provide (Tennstedt, Crawford, & McKinlay, 1993). The research, however, does not support this argument of substitution. Findings from several studies suggest that the use of formal care services does not lead to families' abandonment of their caregiving responsibilities (Edelman, & Hughes, 1990; Garant & Bolduc, 1990; Tennstedt et al., 1993). Tennstedt et al. (1993) found that the use of formal services occurred only under certain conditions and helped ensure continued community care. Service substitution occurred, for example, during a change in the caregiving arrangement, such as the loss or change of the primary caregiver. Substitution of formal services for informal care was temporary, and ended when a replacement informal caregiver was found. No evidence of a major trend toward service substitution, or of families voluntarily withdrawing their help in favor of formal service use was found (Tennstedt et al., 1993).

When formal services are available, families do not necessarily withdraw the care they provide to their elder. Rather, formal services complement an already well-established system of informal caregiving (Tennstedt & McKinlay , 1989). Despite the availability of a range of formal services, Tennstedt and McKinlay (1989) found that the average elderly person received five times more care from family members as compared to formal caregivers. In the location from which their sample was drawn, a variety of formal services was available to assist elders and informal caregivers. For their respondents, informal care remained the primary source of assistance.

In conclusion, it is apparent that family members assume the majority of the caregiving responsibility for elders residing in the community. Families appear to be doing all they can in an effort to meet their elder's needs. It is only when they are no longer able to fulfill these needs do family members seek formal assistance. Given the research evidence, it seems questionable as to whether more responsibility for eldercare should be shifted to family members.

The Last Resort - A Formal Care Setting

Over the years, researchers have documented families' efforts to delay institutionalization (Brody, 1969, 1995; Brody, Poulschock, & Massciocchi, 1978; Hooyman & Gonyea, 1995; Tobin, 1995; Townsend, 1965), sometimes going beyond their physical, economic, and emotional capabilities (Brody, 1969; Cox, 1993; Hall, 1980; Montgomery, 1982). The decision to admit a family member to a formal care setting does not generally occur suddenly. Rather, institutional placement is often preceded by gradually deteriorating physical and mental status of the elderly person and/or the caregiver (Foster, 1991). The need for care by the elder gradually increases to a point beyond the family's capabilities.

Arranging for an elderly relative to live in a formal care setting is the last resort taken after all other alternatives have been exhausted. Seeking formal care seems to be the final stage of a dynamic process involving consideration of the relevant resources and costs (Walker, 1991). The strong desire of families to maintain their elderly member in the community means that the institutionalization process may occur only when families reach a crisis stage in which they no longer have the resources and/or expertise to provide the needed care (Buckwalter & Hall, 1987). Most families tend to see placement as a way of preventing further declines in the physical or mental status of the caregiver or the elderly family member (Cox, 1993). The decision to seek formal care may occur when family members find that they are unable to provide adequate care, because of competing family or professional demands, or because they are unable to cope with caregiving demands (Garant & Bolduc, 1990).

Formal Care and the Myth of Abandonment

One of the most pervasive myths in our society is that of widespread institutionalization and subsequent abandonment of the elderly by their family members. This assumption that families are not involved with their elderly relatives in formal care settings has been termed "the myth of segregation of the aged" (Spark & Brody, 1970), the myth of alienation (Shanas, 1979) and, more commonly, the myth of abandonment (Smith & Bengston, 1979; Brody, 1978). Shanas (1979) referred to this myth as "the widely held belief in contemporary American society [that] old people are alienated from their children" (p.3). Treas (1977) states that "an oft-voiced sentiment holds that younger people no longer accord the parental generation the respect, love and help which are traditionally its due" (p.486). Children are viewed as ungrateful because they are seen as 'dumping' their parent into institutional care (Silverstone, 1978). It is often assumed that families have failed in their role as service providers (Smith & Bengston, 1979), and that the elderly in long-term care institutions have weaker family ties than elderly living in the community (Shanas, 1960). Overall, this myth surrounding the placement of elderly in formal care settings holds that these elderly persons are neglected, rejected, and abandoned by their family members (Shanas, 1979; Silverstone, 1978).

Twenty years ago, researchers found no basis for the widespread view that families were abdicating their responsibility to care for their elders. For example, Smith & Bengston (1979) found no families who fit the stereotype of a child abandoning an elderly parent. Interviews revealed no instances of discontinued involvement with elderly parents by their children. Based on interviews with elderly residents and their most involved family member, the authors concluded that many elderly persons in long-term care are close to and involved with their families. Similarly, in a separate study, families were found to continue family involvement with their elderly through visiting and telephone calls (York & Calsyn, 1977). Families did not separate themselves from their older relatives living in formal care settings, but continued to be involved with them.

Despite the empirical evidence from the 1970's, the myth of the neglectful family has persisted into the 1990's. Today this assumption of family abandonment is presented in more positive terms within the partnerships paradigm. As already mentioned, the subtext of this paradigm appears to be that family members should take on more responsibility for eldercare. It is assumed that family members are not fulfilling their caregiving duties for their elderly relatives.

Family Involvement In Formal Care Settings

Movement into a formal care setting does not necessarily signify the end of care given by families. Often families who are deeply involved in the caregiving process often feel a strong sense of continued responsibility after placement, and wish to maintain some caregiving function even though they are not able to maintain the older person in the community (Foster, 1991; George, 1984; Silverstone, 1978). Families may want to continue to be involved in caregiving because they can show their relative that they care (NACA, 1992), and to fulfill a sense of obligation (Walker, 1991). Brody, Dempsey, and Pruchno (1990) suggest that providing some help to an institutionalized parent may have positive effects for children. Being able to continue to be useful to the parent may fulfill feelings of filial responsibility and to some extent mitigate the sense of guilt many children experience (Brody et al., 1990).

After an elder has been placed into a formal care setting, staff assume responsibility for many of the tasks previously performed by family members. Given that the responsibility for performing all these tasks no longer falls solely on the family, and given that the research findings indicate that many families wish to continue involvement in care, the question that arises is what types of involvement in caregiving are families engaging in after placement of a relative. Information of what families are doing in formal care settings will allow us to develop a more accurate picture of what caregiving responsibilities families are assuming in these settings.

Research on family involvement in caregiving activities within formal care settings is limited. However, this research does suggest that families are involved in a variety of caregiving activities. For the purpose of clarity, these research findings will be presented according to the eldercare categories already discussed.

Personal Care

Research examining the caregiving activities families are performing in formal care settings has revealed that some family members continue to provide assistance with personal care. For example, Linsk et al. (1988) found that families assisted the resident with grooming. Research findings have also indicated that the most common personal care activities in which families assisted were dressing/undressing, and standing up/getting into bed (Laitinen, 1992). It was found that about 4% of families engaged in this activity on a daily basis. The other types of personal care activities that families were found to engage in included using the toilet, eating, drinking, washing, caring for hair, caring for teeth, caring for hands and nails, and caring for skin. In a study by Keefe and Fancey (1996), it was discovered that, during visits, approximately 21% of families reported giving personal care, and approximately 14% of families assisted with eating.

These studies suggest that families carry out a variety of tasks in meeting the personal care needs of their elderly family member. Even though these studies suggest that families are involved in performing a variety of personal care activities, we do not know how often they perform these different tasks, or how much time they spend doing them.

Care Management

The category of care management includes activities like making appointments, keeping an eye on things, and speaking up for an elderly family member. There is evidence to suggest that families engage in monitoring, a type of keeping an eye on things activity. In a study by Zarit and Whitlatch (1992), it was found that families engaged in monitoring, and that families interacted with staff to ensure that the care needs of their elderly family member were met. Monitoring of staff behavior by family members was also reported by Duncan and Morgan (1994). One of the ways that family members in this study monitored staff treatment of residents was by watching how their elderly family member reacted to different staff members. Families also watched the staff's treatment of other residents. When monitoring revealed problems in how staff treated their relative, it was discovered that families would take steps to get the staff to relate to their elder as a person. These studies suggest that families engage in a variety of activities in order to monitor the care that their elder is receiving.

Families have also been found to spend time teaching staff how to give personalized care (Bowers, 1988). These family members would give biographical information (information on preferences, needs and vulnerabilities), as well as show how the resident liked things done.

The research evidence on care management suggests that families were actively involved in keeping an eye on and improving the care that their elder received. Monitoring allowed families continually to assess care and identify problem areas. Research to date has not established how often families engage in monitoring activities, or how much time they devote to monitoring. More research needs to be done to assess what other types of care management activities families are engaging in.

Enhancing Well being

Providing emotional support, participating in leisure activities, and talking or listening are examples of activities that are included in the category of enhancing well-being. Laitinen (1992) found that families provided emotional support to their elders, although the specific activities involved in the provision of emotional support were not presented.

Families also have identified several interactive activities in which they engage during visits that are related to enhancing well-being. The most frequent type involved enhancing well-being through talking to the relative, holding hands, and touching (Linsk et al., 1988). In a study by Keefe and Fancey, (1996), families also reported that the most common activity in which they participated during visits was sitting and talking (approximately 80%). As well, Smith and Bengston (1977) found that families spent time in conversation and in reminiscing. This research suggests that families perform a variety of 'enhancing well-being' tasks during their visits.

Families may enhance their elder's well-being by engaging in social events or other leisure activities. Research evidence shows that about 32% of families go for walks with the elder (Keefe & Fancey, 1996). Going for drives was another reported leisure activity that about 25% of families engaged in. Approximately 15% of families participated in nursing home activities, and about 14% went on outings with their elder. Other leisure activities that families identified as being involved in included playing games, watching television, and reading to the resident (Keefe & Fancey, 1996). Linsk et al. (1988) also found that families participated in going for walks with their elderly family member. Families in these studies performed a variety of leisure and social activities to enhance the well being of their elderly family members.

Research has established that family members perform a variety of activities that enhance the well-being of their elder. Research to date has not examined how often families provide enhancing well-being types of activities, or how much time they spend performing these activities. This information is necessary if we are going to have an accurate picture of what families are doing in formal care settings.

Housework

Housework, such as food preparation, cleaning, and doing laundry is another area in which families may perform care services. Research on what families are doing in this category of caregiving has revealed that approximately 10% of families report involvement in tending to clothes and cleaning (Keefe & Fancey, 1996). In a study by Laitinen (1992), it was found that about 16% of families engaged in making the bed for their elderly family member. The research in this area is very limited, however these studies do suggest that families perform housework tasks for the elderly in formal care. It is clear that the information on the types of housework tasks families perform, how often they do these tasks, and how much time they spend doing them is not fully developed.

Financial Management

Families can assist their elderly by helping to manage their financial affairs. Research examining family involvement has revealed that families are involved in the management of financial and insurance matters for their elderly family member (Keefe & Fancey, 1996; Zarit & Whitlatch 1992). Unfortunately, there is little or no information on the specific activities involved in financial management, how often families have to attend to financial matters, or how much time it takes to deal with their elder's financial affairs.

Transportation

Research on family involvement has shown that families provide transportation services for their elders living in formal care settings (Keefe & Fancey, 1996). Because the research in this area is sparse, we do not know what types of transportation related services family members are performing for their elders living in formal care. Future research will need to explore how often families are providing this type of activity, and how much time they spend performing these tasks.

Skilled Care

The caregiving category of skilled care includes activities that are more 'technical' in nature. For example, managing the elder's physical health, helping with pain management, or watching for reactions to medication are included in this category. Providing technical services tends to require education on the correct performance of these types of activities. For this reason, we might anticipate that many technical tasks would be assumed by the formal care staff.

Even though skilled care is more technical in nature, families may choose to perform some of these activities. In one study, it was found that family caregivers did not relinquish all technical tasks to staff (Duncan & Morgan, 1994). Similarly, Linsk et al. (1988) found that family members carried out technical and emotional caregiving activities and expected staff to show similar concern about their elder's emotional state and physical well-being. Unfortunately, neither of these studies specifically outlined what families were doing. One research project has documented family involvement in specific skilled care activities. In this study it was found that 36% of families helped their elder exercise (Laitinen, 1992). More research might allow us to determine the specific types of skilled care tasks in which families are engaged, their frequency, and the amount of time required to carry out these tasks. Given the recent cutbacks in health care funding and the subtext of the partnership paradigm, we might find that families are reporting greater involvement in performing skilled care tasks than was the case in the past.

Shopping

Shopping has been identified as an activity that is included as a part of eldercare. Surprisingly, this activity did not come up in the research examining what family members were doing in formal care settings. The reasons for this are not known. However, it could be due to the fact that shopping is now becoming more of an issue as cutbacks in health care are occurring. We may see more responsibility put on families to supply their elders with things like toiletries or medical supplies whereas in the past, those needs were met by the formal care setting. Research needs to explore the range of shopping activities that families engage in, how often they provide these services, as well as how much time it takes to do these activities.

Conclusion

As is evident, the research examining family involvement in formal care settings is sparse and incomplete. Although the research clearly indicates involvement of family members in a range of caregiving activities for their elder living in formal care, we still do not have a complete understanding of family involvement in these settings. More work needs to be done to improve our understanding of what caregiving activities families are performing. We also have virtually no information on how often family members perform different care tasks, or how much time they spend performing these tasks. Once we have this information, then we can start to evaluate the appropriateness of the partnership paradigm.

Models of Innovative Continuing Care

There are a variety of formal care options open to elderly individuals who are no longer able to reside in the community. Different formal care programs provide a unique combination of services and cater to a particular type of clientele. The particular needs of the elder will dictate which formal care settings are most suited to serving them. Four innovative continuing care programs were used in this study. These programs differ in many respects including model of care (adult family living, assisted living, dementia care), size of program (2-50 people), services offered in the program, and resident population targeted. It is likely that family members will respond to the unique policies and eldercare demands that each of these programs have. Given these differences, we might anticipate finding some variation in the particular tasks categories that family members report involvement in across the three models of care. To date, no comparison of family involvement in eldercare tasks across different models of care has been undertaken.

Adult Family Living

Two of the sites used in this study were adult family living programs. South (1997) identified a set of characteristics which are commonly used to describe adult family living programs. These include: 1) shelter and personal care provided in a private residence; (2) the primary care provider lives in the home and is unrelated to clients; (3) a small number of adult clients reside in the home; (4) the care provider receives financial compensation in exchange for providing clients with a number of designated services; (5) additional services, supervision and monitoring are available by professional staff of the agency or organization that manages the program (Folkemer, Jensen, Lipson, Stauffer, & Fox-Grage, 1996; Kane, Illston, Kane, & Nyman, 1990; Sherman & Newman, 1988).

The specific services that are provided by the home operators can vary, although providing the basic services of room and board is considered compulsory (South, 1997). Other common services that are provided include housekeeping, assistance with medical and social services, assistance with daily living activities, medication, personal care, transportation, and shopping (Ladd & Hannum, 1992; Mor, Sherwood, & Gutkin, 1986).

Generally the clientele in adult family living programs are older adults with physical and/or mental disabilities (South, 1997). Placement in an adult family living home is related to an elder's values, attitudes and preferences. The individuals who choose these programs tend to value flexibility and home-like settings (Kane et al., 1990). For this reason, both of the adult family living programs in this study sought to provide a flexible home-like environment in which the needs of the client were met.

We might expect to find that family members of these individuals engage in more care management activity. These elders are living in homes in which the quality of care given by home operators can vary. For this reason, these families may feel a greater need to keep an eye on their relative than might families with elders in other care programs. A second activity that may contribute to greater care management by these families is speaking up for their relative. Elders living in these homes may feel reluctant to complain to home operators for fear that it might result in their removal from the home. We might also anticipate finding more transportation reported by these families because home operators are not able to provide this service. Families might have greater responsibility for driving their elder to appointments, running errands with them, and driving them to places.

Dementia Care

Individuals with Alzheimer disease have unique needs that must be recognized and met by the care facility. Alzheimer disease care programs respond to the specific symptoms and attributes of this disorder. Alzheimer care emphasizes the management of behavior that results from the progressive deterioration of a client's mental functioning (Dobbs & Rule, 1992). The types of services that are provided by these programs are intended to meet the needs of the individuals with Alzheimer disease, family members of these individuals, and staff who care for the client (South, 1997). Support services that are provided to clients include assistance with personal care, as well as full range of day and evening activities (Sand, Yeaworth, & McCabe, 1992). Some facilities also seek to have a home-like environment so as to have a setting that is consistent and familiar (Alzheimer's Association, 1992; Calkins, 1988).

The Alzheimer care facility used in this study had semi-private rooms. This facility provides twenty-four hour assistance and supervision to clients diagnosed with mid-stage Alzheimer disease. This care program also actively seeks to address the health, coping and educational needs of family members.

Given the cognitive ability of these clients, we might anticipate finding that their families are more involved in financial management than are families from other care programs. This dementia care center used in this study assumes much of the responsibility for housekeeping, personal care, and skilled care. For this reason we might find that families who have a relative in this setting are less involved in these types of care.

Assisted Living

Within the research literature, there is no common definition of assisted living. However, there are certain characteristics that have been used to describe assisted living, including: 1) the provision of shelter; 2) professionally managed personal and health care services to a client; 3) care provided within a group of residential settings; and 4) access to unscheduled care on a twenty-four hour basis (Kane & Wilson, 1993). The individuals that are served by assisted living programs tend to be in a transition stage in which they do not require twenty-four hour care, but they are not able to function completely independently.

A wide range of services is provided by assisted living facilities. Most provide a basic level of support services, such as accommodation, meals, and laundry services. As well, assistance with personal care, nursing assessment and health monitoring, and routine nursing tasks may be offered (Kaplan, 1995; Kane et al., 1990; Kane & Wilson, 1993; Wilson, 1993).

The guiding principle of assisted living programs is the optimization of the physical and mental independence of clients (Regnier, 1996). This is accomplished through a commitment to protecting the client's privacy, dignity, choice, individuality, and shared responsibility within a home-like environment (Concepts in Community Living, 1994; Kane et al., 1990; Regnier, 1991).

The assisted living facility used in this study has a philosophy which strives to promote control, dignity, independence, individuality, and privacy of clients, while at the same time facilitating aging in place (South, 1997). This facility seeks to provide accommodation and holistic care for the aged, infirm, disabled, and disadvantaged regardless of race or religion. Given this, clients have a wide range of health care needs that must to be met by the facility.

One of the features of this facility is that clients and their families contract for services. This contract is an agreement regarding who is responsible for providing certain types of care services. Clients and their families choose to pay for certain services, and provide other services themselves. For this reason, families may be performing more personal care and housekeeping than families in the other care models. Another feature of this facility is that clients have their own kitchen. This may result in greater shopping activity by family members in this program than in the other models of care.

Statement of the Problem

Extensive research has been done on informal caregivers who provide assistance to elderly living in the community. Families, and not the formal care system, provide the majority of long term care in the community. Within the community, families perform a wide variety of tasks in meeting the care needs of the elderly. Less is known about what caregiving activities families perform once their elder has moved into a formal care setting. Despite our lack of knowledge regarding family involvement in formal care settings, today's partnerships paradigm of eldercare is centered on placing more responsibility for meeting elder's health care needs on the shoulders of family members. The question that arises is how can we make any policies or recommendations regarding family involvement in eldercare within formal settings when we know very little about what they are doing?

Research Questions to be Tested

This new partnerships paradigm has the potential to strongly affect family members of elders who reside in formal care settings. It is assumed that these family members could be doing more. However, a review of the literature suggests that we do not have a clear understanding of what family members are presently doing in these settings. The purpose of the following research questions is to establish what family members are doing, how often they are doing different tasks, how much time they spend performing different tasks, and whether there are any differences in caregiving activity across different models of care.

1. What types of caregiving activities are family members reporting participation in?
2. How much time do family member spend performing different caregiving activities in a one month period?
3. How often do family members perform different caregiving tasks in a one month period?
4. How does participation of family members in different caregiving activities vary across the different models of care?

CHAPTER 3

METHODOLOGY

This research was part of a larger project being undertaken by the EPICC (Evaluation Programs of Innovative Continuing Care) program of applied research at the University of Alberta. EPICC was funded under the Seniors Independence Research Program, Health Canada. One of the objectives of the EPICC project was to describe the services provided by family members to seniors residing in continuing care programs. There were four innovative care programs in Alberta being evaluated in this study: Two adult family living programs, one assisted living program, and one residential dementia care facility.

The study reported here used information on participation, frequency and time that family members spent providing care to an elderly relative in formal care. This information was used to gain a better understanding of caregiving by families to relatives in formal settings. This chapter will begin with a discussion of sampling, followed by a description of the procedure used to recruit participants and obtain consent at each of the continuing care programs. Information on data collection methodologies will be presented, along with a discussion of how and why the method used in this study was chosen. This will be followed by a discussion of the interview protocol and procedures. The types of data analyses that were used to answer the research questions will also be described. This chapter will end with an examination of the ethical considerations of this research project.

Sample Selection

EPICC is a program of applied research which actively involves representatives from the different care programs. The methods and procedures used to recruit participants for this study were determined through a collaborative process between the EPICC research group and program representatives. The specific recruiting methods used for each care program were determined through discussions with each program representative. This was done to ensure that the best possible method for recruiting and obtaining consent was used for each program, given its unique characteristics.

In the adult family living program in Calgary, participants were contacted by a program representative. The study was described to clients either on admission, or on the first home visit by a program representative following admission. At that time, an information sheet and consent form was given to the client. A representative from this program also talked with family members on the day of admission. If families were absent on the day of admission, an information sheet and consent form were left at the home of the resident for the family to read on their next visit. If the program representative did not hear from the family members within two weeks, a follow-up telephone call was made to find out if family members were interested in participating in the research project.

In the adult family living program in Edmonton, clients and family members were contacted by a program representative. The study was described to clients during a regular visit to the resident's home by program staff. An information sheet on the EPICC project and a consent form were given to the clients. Letters were sent out to the next-of-kin of all clients in their program. Follow-up telephone calls were made by a program representative to those family members who did not respond to the letter. During this call, the study was described to them, and they were asked if they were interested in participating in the study. If they were, consent forms were mailed out, signed and returned.

At the assisted living facility, a separate study was being conducted concurrent with this project. There was a commitment to sharing of data from clients and family members to minimize intrusiveness for participants. Clients of this facility were approached by a representative from the other research project. During this meeting, both studies were described to the client, and an information sheet and joint consent form were given to them. (A joint consent form for both of the studies was used with residents and family members respectively.) For family members, an orientation meeting was held to inform them about the two research projects. Some family members signed a joint consent form after the orientation meeting. The remaining family members who had not signed a consent form during the orientation meeting were contacted by telephone by a research associate from the other project to find out if they were interested in participating in the two studies. For those who agreed to participate over the telephone, the consent form was signed during the first face-to-face contact with family members.

Clients residing in the dementia care center were unable to provide informed consent because of cognitive impairments. Instead, family members were asked to sign a joint consent form that provided consent for their participation, as well as the participation of their elderly relative in this study. For family members, two orientation meetings were held to provide information about this project. Some family members signed joint consent forms during these meetings. For the remaining families, follow up letters and joint consent forms were sent out by a research associate from the EPICC project. After three weeks, a research associate from the EPICC project contacted by telephone those family members who had not returned a signed consent form to see if they wanted to participate in the study.

Sampling

The population of respondents for this study were family members of elderly who resided in one of the four innovative continuing care programs which were part of the EPICC project. The sample that was used in this study comprised those family members that had been identified as providing care to their relative. Only those family members whose relative had been in the program for at least one month were eligible for participation. Participation was then restricted to those family members who had provided some type of care during the previous month. The sample for this study was then further restricted to those family members who were willing to participate in the study.

During the telephone interviews with these family members, participants were asked if there were any other family members who were providing care for their elder. If participants identified additional family members as being involved, they were asked to provide the names and telephone numbers of additional family caregivers. These "network calls" generated a second wave of participants. The rationale for contacting this second wave of family members was to get more information on what the family network is doing. This second wave of participants were contacted by telephone, informed about the study, and asked if they would be interested in providing information on the care services they provide to their elderly relative who resides in one of the innovative continuing care programs. Approximately 78% of respondents from the first and second identified other family members as being involved with their relative.

All family members who agreed to participate in this study were interviewed if they met two criteria: length of residency and active involvement. The study was limited to family members who had a relative who had resided in an innovative care program for at least one month. During the first month of residency, it is believe that family members are more involved with their elder because it is a time of settling in, meaning that their caregiving behavior during this first month is not typical. An initial screening question was done to ensure that this residency requirement was met. If the elder had not lived in the residence for at least one month, then the interview was set for a later date. Postponement of the interview occurred only once. The second criterion was that families had to have engaged in some type of caregiving activity with their elderly relative within the last month. The reason for this requirement was that the interview questions were structured around a one month period. A set of screening questions was presented that assessed involvement over the last month in eight different caregiving task categories. Since all participants reported some type of caregiving involvement over the previous month, no one was excluded because of this criterion.

The length of time needed to complete the structured interview with participants varied according to factors such as the number of activities the family member was involved in, and the respondent's ease in making frequency and time estimates. On average, the structured interview took approximately 26 minutes to complete.

Measures

In order to capture all of the different caregiving services that families provide to their elderly relatives in formal care, a set of aggregate task categories of care was used in this study. Within each of these aggregate task categories, there were a set of caregiving activities. For a complete listing of the aggregate task categories and the activities included under each category, see appendix A.

In order to answer the questions posed in this study, we needed to collect information on the proportion of family members participating in the different care activities, frequency of caregiving, and time spent providing care. We obtained information on proportions by asking people if they had engaged in the different activities during the previous month. Information on frequency was obtained by asking respondents how often they had provided an identified activity during the previous month. In order to get information on time use, we used a stylized method of data collection.

Time Use Data Collection Methodologies

There is a long tradition of collecting information on time use, and a variety of methodologies has been developed to collect this type of data. These methods include direct observation, the "beeper" method, 24-hour recall diary, and stylized estimate methods.

Each of these methodologies has certain advantages and disadvantages. Direct observation is considered the most accurate method for collecting time use data, but its use is limited due to its cost and level of intrusiveness (Paille, 1994).

The "beeper" method, in which participants record their activities when signaled by a beeper, can also be used to collect information on time use. Research has found that the beeper method is a good measure of activities done inside the home, but it is less accurate for those activities done outside the home because respondents tend to under report these activities (Juster & Stafford, 1991; Robinson, 1985). Paille (1994) points out that another potential drawback of this method is its risk of mechanical failure.

The twenty-four hour diary approach is considered the best method for collecting time use data when the objective is to get a portrait of daily life (Fast, Keating, & Eales, 1997). This method has been described as the superior approach overall by Juster and Stafford (1991). The twenty-four hour dairy is considered the best approach for collecting time use information on daily life for two reasons. First, the diary method has more reasonable costs compared to direct observation and beeper methods. The second reason is that the diary method tends to produce more accurate data on the typical day than the stylized method (Robinson, 1985; Juster & Stafford, 1991). Diaries are considered to have higher reliability, validity, flexibility and usability than the stylized estimate methods (Paille, 1994). One of the reasons that this method yields accurate data is that a shorter recall period is typically used than when data are being collected using a stylized method (Paille, 1994). Yet, the advantage of the short recall period can also be a weakness of this method. The difficulty is that this is not always a typical day for every activity, resulting in some activities being overestimated and others underestimated (Paille, 1994). Caregiving activities would be difficult to accurately capture with the twenty-four hour recall diary because many activities are infrequent or episodic (Fast et al., 1997). Sampling several days for each respondent would reduce this weakness (Paille, 1994), but it would also increase cost, intrusiveness, and require higher levels of respondent cooperation.

An important advantage of the stylized method is that the data allow for analysis at the individual level (Paille, 1994). For this method, respondents report activities performed over a longer period of time resulting in a better chance of capturing the full range of activity than does the diary. This feature is especially important when examining activity that occurs infrequently (Fast et al, 1997, Paille, 1994). "Analysis of [stylized] data promises to provide better insight than do the 24-hour dairy estimates into...the way participation in a particular type of activity is related to other activities, attitudes, or background characteristic. This is especially true for activities that are highly irregular and unlikely to be captured by a single-day diary" (Robinson, 1985, p. 45). Robinson (1985) points out that the 24-hour diary may be limiting when looking at a particular type of behavior because "the single-day diary [is] too short a time slice to provide anything beyond a frustrating glimpse of the long-range personal context of such behavior" (P.45). A second advantage of the stylized method is that it allows for reporting of "joint production". With many types of tasks, it is possible to perform more than one activity at a time. Activities that are likely to be more visible and obvious are more likely to be reported when using diary methods resulting in under-representation of less obvious secondary activities (Fast et al., 1997). Multiple activities that are being performed concurrently are more likely to be captured using stylized methods. Yet, some may interpret this strength as a weakness because it could result in double counting.

A drawback of the stylized method is that respondents are usually required to recall events that happened longer ago than those used in diaries. Fast et al. (1997) point out that the farther back you ask respondents to recall, the less accurate they are in estimates of time use. This has been identified as a main reason time use diaries are preferred over stylized method (Fast et al., 1997). Another weakness of this method is that respondents tend to overestimate their time use in some activities, and underestimate time use in other activities, resulting in unreliable time estimates. (Herzog et al., 1989; Juster & Stafford, 1991; Paille, 1994).

Rationale for Stylized Estimates

There are a variety of research questions that could be informed by time use information. The type of time use data collection methodology used should be determined by the objectives of the study. The twenty-four hour diary has often been identified as the preferred method for collecting time use data, especially when examining a typical day. But there are some circumstances in which examining a typical day would not be very informative (Fast et al, 1997). In this study we are interested in acquiring a better understanding of what family members are doing in formal care settings. One of the main objectives is to collect detailed information on time spent performing a range of caregiving tasks. Caregiving is one of those activities for which the diary method may not be most appropriate because some caregiving activities by family members tend to happen relatively infrequently or episodically. Caregiving tasks would likely be under-reported in single day diary data (Fast et al., 1997). Another consideration when examining family caregiving is that "caregiving episodes may also be very short, too short when taken individually to warrant being coded as a separate activity.... But taken together, they may add significantly to demands on the caregivers time" (p.5 , Fast et al., 1997). The stylized estimate method would have more "success" at capturing these short activities.

Fast et al. (1997) point out that little formal evaluation has been carried out to determine which time use methodology would be most appropriate when obtaining estimates of time spent on infrequent and/or irregular activities. For this reason it is difficult to determine which method is most appropriate for collecting information on time spent performing caregiving tasks by family members. However, given that the types of activities that we examined are likely to be infrequent or episodic, the twenty-four hour diary would not be appropriate. The stylized method may result in overestimation of time spent on some activities, but it allows us to capture caregiving involvement of family members in a variety of activities.

Development of the Stylized Estimates Interview Protocol

Since all of the clients were residing in one of the formal care settings sampled, it was assumed that family members' involvement was going to be very episodic. For this reason, and based on the type of data that we wanted to collect, it was decided that a stylized estimates method adapted from the 1996 General Social Survey (GSS) would be tested with family members. The stylized estimates method developed for the GSS was used to collect information on the proportion of people who were providing care to others, the frequency with which they provided care, and the amount of time spent providing care. Because the GSS collected the same types of information that we wanted, it was adapted for our purposes. The general wording for the stylized estimates interview protocol followed the same format that was used in the 1996 GSS.

The activities that were included in the stylized estimates interview, were derived from the Definition of Service Events list (See Appendix B). An initial list of activities was developed from a review of the literature. A work group of site representatives, researchers and graduate students took the initial list and developed definitions for each service activity. Other service activities were added as needed based on the work group's collective experiences. The comprehensiveness of the first draft of the list of service events was tested during the pilot of time use methods with formal service providers. Following completion of the pilot, and based on the observations of an EPICC research associate, existing definitions were expanded to include previously unidentified service activities, or new definitions were created.

The stylized estimates interview protocol was pilot tested with three women who provide care to relatives in a continuing care setting (Millwoods Assisted Living Center). The structured interview guide was revised based on feedback from the women and recommendations made by the EPICC research associate who conducted the interviews. Efforts were made to personalize the interview as much as possible by using the name of the elderly relative and by referring to the specific family relationship that the respondent had with the elder.

Interview Procedure

Stylized Estimates Interview Protocol

Family members who had provided consent were called and asked to participate in a telephone interview that discussed the caregiving activities they had engaged in for their elder over the last month. These individuals were informed about the types of questions they would be answering, and the approximate length of the interview. If family members were willing to participate, the questionnaire was either completed at that time, or a more convenient time was scheduled.

The interview began with an initial screening question asking if their elderly family member had lived at his/her place of residence for at least one month. If this was not the case, then an interview was set up for a later date after the one month period had elapsed. If participants met this criterion, then the interviewer proceeded. A list of aggregate task categories, along with examples of specific tasks that would be included in these categories, were read to respondents. (See Appendix A for list of aggregate task categories and activities included within each category. See Appendix C for the interview protocol) Family members were asked to indicate whether they had engaged in any of the activities within each of the aggregate task categories over the last month. For those aggregate categories in which families participated, more in-depth questions were asked. The detailed questions within each aggregate task category asked respondents if they had performed specific caregiving activities in the last month, how often in the last month they had performed an identified task, and on average, how much time it took to complete the task on each occasion.

After this section of questions had been completed, families were asked if there were any other caregiving services they provided for their elder that we had not asked them about. If other activities were identified, respondents were asked questions about how often they had performed that task over the last month, and on average how long the task took to complete. This structured interview ended by asking respondents if there were any other family members who were doing things for the same elderly relative. If other family members were identified, we asked respondents if they would be willing to give us the names and telephone numbers of these family members so that we could contact them to provide time use information.

Once this section of the structured interview was completed, we asked participants to complete a second questionnaire on their beliefs about who should be responsible for providing caregiving services to their relative. This questionnaire took about ten minutes to administer and was done by all participants. This questionnaire was completed for a different piece of the EPICC project, and was not used for this study.

Family members who had been identified by other respondents as being involved were contacted by telephone. The interviewer explained who they were, and how the respondent's name and telephone number had been obtained. The study was described to them and they were given a brief description of what their participation would involve. Respondents were then asked if they would be willing to participate. If the respondent agreed to participate, a convenient time to conduct the interview was scheduled. The same process and questions that were used with the first wave of participants were used with the second wave of participants.

Data Analysis

The first research question posed in this project was "what types of activities are family members participating in?" In order to examine the types of caregiving activities family members were involved in, frequency counts of yes/no responses were calculated for each caregiving activity as well as for the aggregate task categories. These proportions are reported.

The second research question was "how often do families engage in different tasks in a one month period?" Descriptive statistics were calculated and report the mean frequency that family members participated in each task and aggregate task category. Lastly, an overall frequency of performing all caregiving tasks for relatives in formal care was reported. This information gives us an indication of the average number of times per month that families provide care.

The third question posed in this study was "how much time do family members spend in the different caregiving tasks in a one month period? Descriptive statistics on time in caregiving were calculated and reported. Lastly, we wanted to find out how much time families spend in caregiving in a one month period. This average amount of time spent per month on all caregiving activities was calculated.

The last question posed in this study was "how does family involvement in caregiving vary across the different models of care?" It was hypothesized that there might be differences between the models because of the differences in philosophy, clientele, and setting. Calculations were done to determine how family involvement in caregiving varied across the different care models. The models of care were compared on proportions of family members providing care in the different caregiving categories, mean frequency with which family members provided care, and mean time families spent in caregiving activities.

The first set of calculations examined proportion of family caregivers involved in the different aggregate task categories across the models of care. Cross-tabulations on the proportion of family involvement for each model of care were reported. In order to determine if the differences in the proportion of family involvement between the models of care were significant, Pearson-chi square tests were performed.

Next, we wanted to determine if the average number of caregiving episodes per month varied across the models of care. In order to do this, the mean frequency of participation in the eight aggregate task categories for each model of care was reported. To determine the presence of differences, One-way Analysis of Variances (ANOVA) were performed. The Scheffe post-hoc test was done to provide evidence of where differences were. Results of this test provide information on which models of care were significantly different in mean number of episodes per month.

Lastly, we looked at differences in time spent in caregiving by family members across the different models of care. The mean amount of time family members spent in each of the aggregate task categories was reported. In order to determine if there were any statistically significant differences in time spent in each aggregate task category between the models of care, one-way ANOVAs were calculated. For those aggregate task categories that showed a statistically significant difference between models of care, the Scheffe post-hoc test was performed. These results provide information on what programs are significantly different in terms of amount of time spent in the aggregate task categories.

Ethical Considerations

This research project was reviewed and granted approval by the Human Ethics Review Committee in the Faculty of Agriculture, Forestry, and Home Economics. All participants in this study were provided with information on the project, and a consent form for their participation (see appendices D, E and F). Participants were given the name and number of a contact person in the EPICC project should they require any further information. Informed consent was obtained from both family members and clients. Participants were informed that their involvement was voluntary, and they had the right to withdraw at any time without consequence.

In order to maintain confidentiality of data and identities, all participants were assigned alphanumeric codes. The names of respondents and all of the data obtained in questionnaires and forms were stored in a locked filing cabinet at the University of Alberta.

CHAPTER 4

RESULTS

Sample Description

Due to the particular characteristics of the four innovative continuing care programs used in this study, there were differences in the sample size obtained from each site. A total of 19 family members was obtained from the two adult family living programs, 21 family members were obtained from the assisted living program, and an additional 39 family members were obtained from the dementia care center. This yielded a total sample size of 79 family members. Response rate for participation in the interview among family members contacted was 95.29%. An average, 1.6 family members were interviewed per client.

Demographic information was obtained from each respondent. The purpose of this information was to give us a glimpse into the type of family members that tend to provide care (See Table 1). The majority of our respondents were women (54 females, 25 males), which is consistent with the research literature (See Brody, 1981; Stone et al., 1987; Shanas, 1979b; Tennstedt & McKinlay, 1988). The age range of the family members was 26-75 years, with a mean age of 54.57 years (SD=11.04). Most of the respondents were from the second generation which was comprised mostly of daughters, sons and daughter-in-laws.

Table 1.

Number of Respondents by Generation and Relationship to Resident

Generation	Frequency (n)	Proportion (%)
Same Generation	6	7.6
Husband	2	2.5
Wife	1	1.3
Brother	2	2.5
Sister-in-Law	1	1.3
Second Generation	69	87.3
Son	15	19
Daughter	33	41.8
Son-in-Law	4	5.1
Daughter-in-Law	11	13.9
Nephew	2	2.5
Niece	4	5.1
Third Generation	4	5.1
Granddaughter	4	5.1

Most respondents were married and either retired or working full-time (See Table 2). Overall, respondents rated their health positively, with the majority reporting that their health was either excellent or good (Table 2).

Table 2.

Marital and Employment Status and Perceived Health

Variable	Frequency (n)	Proportion (%)
Marital Status		
Married/Common Law	67	84.8
Single	6	7.6
Widowed	3	3.8
Divorced/Separated	3	3.8
Employment Status		
Retired	26	32.9
Not Employed	14	17.7
Employed Part-Time	11	13.9
Employed Full-Time	28	35.4
Perceived Health		
Excellent	26	32.9
Good	44	55.7
Fair	9	11.4

The Research Questions

Question 1

The first research question posed in this research project was "What types of activities are family members participating in?" Frequency counts on yes/no responses to questions about involvement in the different aggregate task categories during the previous month revealed that there was family involvement in all of the task categories tested. Almost all of the family members sampled (96.2%) reported engaging in enhancing well-being tasks during the previous month. Approximately 59.5% of the family members sampled report participation in care management, 58.2% reported financial management, 54.4% provided transportation, and 49.9% did shopping. Fewer family members reported participation in skilled care (21.5%), housework (29.1%), and personal care (25.3%). (Table 3).

Frequency counts for reported participation in each of the caregiving activities within these aggregate task categories were also calculated (Table 3). Within the category of enhancing well being, the largest proportion of family members reported participation in "being there for the resident" (91.1%). Participation in leisure activities (70.9%) and helping the resident with remembering (60.8%) also had high rates of family participation. In the category of shopping, the greatest proportion of family member participation was in "shopping for other things" (48.1%). "Keeping an eye on things" was the activity in the care management category that had the highest proportion of family involvement (54.4%). Just over half of families reported helping their relative with financial affairs (58.2%). Both of the activities in the transportation category had a relatively high rate of family involvement: 41.8% of family members went to appointments/ran errands, and 46.8% drove their elder places. Fewer than 20% of respondents reported participation in any of the tasks listed under skilled care, housework, or personal care. The highest proportion of family involvement in skilled care was in watching the resident for reactions to medications (14%). The most common housework tasks were cleaning the resident's room (17.7%)

and taking care of the resident's clothes (16.5%). In the category of personal care, helping the resident go to the bathroom (13.9%) had the highest proportion of family involvement.

Table 3.

Task performance of Family Members

Caregiving Category with Specific Tasks	% doing	Mean episodes per month	Mean time per month (hrs)
Enhancing Well Being	**96.2**	**15.8**	**14.42**
Participated with resident in leisure activities	70.9	3.24	5.53
Helped with resident's spiritual/cultural practices	10.1	.24	.20
Helped resident keep in touch with family or friends	25.3	.62	.26
Were 'there' for the resident	91.1	7.75	7.02
Helped resident with remembering	60.8	4.13	1.41
Care Management	**59.5**	**5.72**	**1.28**
Make appointments/arrange services for resident	24.1	.46	.10
Keep an eye on things	54.4	4.75	1.01
Spoke up for resident	16.5	.51	.17
Financial Management	**58.2**	**1.19**	**.97**
Helped resident with financial affairs	58.2	1.19	.97
Transportation	**54.4**	**2.66**	**3.86**
Went with resident to appointments/ran errands	41.8	1.07	2.28
Drove resident places	46.8	1.59	1.58
Shopping	**49.4**	**1.41**	**1.17**
Special equipment	5.1	.09	.21
Medical supplies	8.9	.13	.04
Other things	48.1	1.20	.92
Housework	**29.1**	**1.31**	**1.24**
Prepare food for resident	8.9	.26	.27
Cleaned resident's room	17.7	.36	.28
Cleaned common areas	0	0	0
Did resident's laundry	13.9	.42	.55
Took care of resident's clothes	16.5	.28	.14

Table 3

Task Performance of Family Members (continued)

Caregiving Category with Specific Tasks	% doing	Mean episodes per month	Mean time per month (hrs)
Personal Care	**25.3**	**2.68**	**.60**
Helped resident get ready for the day	3.8	.44	.13
Helped resident get ready for bed	2.5	.14	.05
Helped resident shower/bath	1.3	.03	.01
Did resident's hair	7.6	.29	.18
Did resident's nails	6.3	.11	.01
Helped resident go to bathroom	13.9	1.11	.14
Assisted resident with mealtime	8.9	.29	.03
Helped resident with eating	5.1	.16	.06
Helped resident with medications	5.1	.11	.01
Skilled Care	**21.5**	**1.25**	**.45**
Helped manage resident's physical health	7.6	.39	.03
Helped ensure resident's behavior was appropriate/safe	5.1	.16	.32
Helped resident deal with pain	2.5	.22	.02
Watched resident for reaction to medications	13.9	.48	.07
Overall		**32.22**	**24.00**

Question 2

The second question raised in this research project was "How often did family members engage in different care tasks in the previous month?" The mean number of episodes per month was calculated for both the aggregate task categories and the individual caregiving activities (Table 3). Results indicate that family members engage in caregiving activity an average of 32 times per month. When looking at the individual activities, we find that family members engaged in enhancing well being tasks most frequently, averaging almost 16 episodes per month. Care management was the second most frequently engaged in activity. On average families provided this type of care almost six times per month. Families provided personal care an average of 2.7 times per month. Transportation provided an average of 2.6 episodes per month. The task categories of shopping, skilled care, housework, and financial management were performed between one and two times per month by family members.

Within the aggregate task category of enhancing well being, the most frequently engaged in activity by family members was "being there for the resident", averaging 7.75 times per month. This was followed by leisure activities (3.24) and helping the resident with remembering (4.13). Within the care management category, "keeping an eye on things" was the most frequent activity averaging approximately five times per month. In the personal care category, the activity with the highest frequency was helping the resident to the bathroom. On average, families did this about once a month. Family members engaged in managing financial affairs an average of 1.19 times per month. Families provided both types of transportation activities an average of once per month, this included going to appointments/running errands (1.07) and driving resident places (1.59). The most frequent type of shopping done by family members was shopping for other things. Families provided this service to their relatives an average of 1.2 times per month. All of the other caregiving activities had a mean frequency of less than one episode per month.

Question 3

The third question in this research project was "How much time did family members spend performing the different care tasks?" The mean amount of time for each caregiving activity and for each aggregate task category were calculated and are presented in Table 3. Family members spend an average of 24 hours providing care per month. Results indicate that family members spent the most time (an average of 14.4 hr/mo.) performing enhancing well being tasks. Transportation had the second highest average time at 3.86 hours per month. Family members spent an average of 1.17 hours per month shopping for their relative. Approximately 1.24 hours per month were spent in housework, and 1.28 hours per month in care management. Financial management, personal care and skilled care had a reported mean time of less than one hour.

Among the individual care activities, family members spent the most time (7.02 hrs/mo.) "being there for the resident". Participating in leisure activities (5.53 hrs/mo.) was also an area in which families devoted a large amount of time. Families spent approximately 2.2 hours per month going with their relative to appointments or errands. Almost 1.5 hours per month was spent by family members driving their relative places. Helping the resident with remembering was another area in which families spent time (1.41 hrs/mo.). There were several activities which family members spent approximately one hour each month providing, these include keeping an eye on things (1.01 hrs/mo.), helping with financial affairs (.97 hrs/mo.), and buying other things (.92 hrs/mo.). The only other activity in which families spent an average of at least twenty minutes per month was doing the resident's laundry (.55 hrs/mo.).

Question 4

The last question raised in this research project was "How does family involvement in caregiving vary across the different models of care?" Table 4 shows the proportion of family members participating in each task category for adult family living, dementia care, and assisted living. Results show that there were significant differences across models of care in the proportion of family members participating in the aggregate task categories of personal care (p=.003), care management (p=.01), housework (p=.02), and transportation (p=.02).

Table 4

Proportion of Family Members Performing Each Task Category per Month

Task Category	% All Programs	% Adult Family Living	% Dementia Care	% Assisted Living	X^2	P
Shopping	49.4	36.8	43.6	71.4	5.80	ns
Skilled Care	21.5	31.6	15.4	23.8	2.07	ns
Housework	29.1	15.8	23.1	52.4	7.83	.02
Care Management	59.5	78.9	43.6	71.4	8.32	.01
Financial Management	58.2	68.4	51.3	61.9	1.70	ns
Personal Care	25.3	21.1	12.8	52.4	11.54	.003
Transportation	54.4	68.4	38.5	71.4	7.96	.02
Enhancing Well Being	96.2	94.7	94.9	100.0	1.13	ns

Tests for differences across models of care in the mean number of episodes per month of engaging in each of the aggregate task categories were performed. ANOVA results are reported in Table 5, including the mean number of episodes of family participation in each task category for adult family living, dementia care, and assisted living, F-values and significance levels. Results indicate that there is a significant difference in the frequency with which family members engaged in housework tasks between assisted living and the other two models of care ($p<.01$). Family members of clients from the assisted living model of care reported significantly more episodes of housework than did family members of clients from either dementia care or adult family living. Family members of clients from assisted living also report more episodes of shopping than those family members of clients from adult family living ($p<.05$). Lastly, the findings show that assisted living clients' family members engaged in transportation significantly more often than family members of clients from dementia care ($p<.05$).

Table 5.

Mean Number of Episodes Family Members Perform Each Task Category Per Month

		Means (Ranges in Parenthesis)		
Task Category	**F**	**Adult Family Living**	**Dementia Care**	**Assisted Living**
All tasks	1.48	28.55 (2-65)	28.56 (1 -134)	42.29 (4-125)
Shopping	3.59*	.79[a] (0-4)	1.19 (0-12)	2.38[a] (0-8)
Skilled care	.32	1.68 (0-10)	1.24 (0-18)	.86 (0-11)
Housework	5.27**	.29[a] (0-2.5)	.95[b] (0-10)	2.91[a,b] (0-15)
Care Management	1.74	5.68 (0-21.5)	4.44 (0-30)	8.14 (0-26)
Financial Management	.47	1.47 (0-6)	1.08 (0-8)	1.14 (0-4)
Personal Care	.45	.95 (0-9)	3.08 (0-69)	3.52 (0-24)
Transportation	4.06*	3.29 (0-13)	1.21[a] (0-9)	4.81[a] (0-36)
Enhancing Well Being	.41	14.39 (0-46)	15.38 (0-90)	18.52 (1-52)

a = significant difference between 2 groups
b = significant difference between 2 groups
* = significant at .05 level
** = significant at .01 level

Lastly, the models of care were compared on the mean amount of time (hours) family members spent performing each aggregate task category per month. Table 6 shows ANOVA results. Results indicate that family members of clients from assisted living spent significantly more time doing housework than family members of clients from either adult family living or assisted living ($p<.01$). As well, family members of clients from assisted living spent significantly more time providing care management than did family members of clients in dementia care ($p<.01$). Adult family living clients' family members spent significantly more time assisting with financial affairs than did families with clients from the dementia care model ($p<.05$). Skilled care is another area in which family members of clients from the adult family living model spent significantly more time than family members of clients from either dementia care of from assisted living ($p<.05$). Lastly, a statistically significant difference was found between models of care for "all tasks". Family members of clients from assisted living spent significantly more time providing care to their relative than did family members who have a relative in dementia care.

Table 6

Mean Number of Hours Spent by Family Members Performing Each Task Category per Month

		Means	**(Ranges in**	**Parenthesis)**
Task Category	**F**	**Adult Family Living**	**Dementia Care**	**Assisted Living**
All tasks	4.41*	21.88 (2.52-68.33)	18.46[a] (1-72.77)	36.16[a] (3.67-146.08)
Shopping	2.86	.66 (0-3)	.83 (0-8)	2.25 (0-16)
Skilled care	4.36*	1.52[a,b] (0-13)	.12[a] (0-2)	.11[b] (0-1)
Housework	7.15**	.30[a] (0-3)	.57[b] (0-4.83)	3.34[a,b] (0-20)
Care Management	5.80**	1.53 (0-7)	.56[a] (0-5)	2.40[a] (0-12)
Financial Management	4.37*	1.81[a] (0-8)	.68[a] (0-5.33)	.74 (0-3)
Personal Care	.61	.12 (0-.88)	.78 (0-13.93)	.69 (0-6.92)
Transportation	3.08	4.76 (0-18)	1.04 (0-9)	8.29 (0-94.5)
Enhancing Well Being	1.78	11.17 (0-37)	13.89 (0-52)	18.35 (2-42.75)

a = significant difference between 2 groups
b = significant difference between 2 groups
* = significant at .05 level
** = significant at .01 level

CHAPTER 5

DISCUSSION

All over the world, governments have instituted policies and legislation requiring families to provide care to their elderly. Some governments have made it a criminal offense not to care for one's elderly relatives, while others have "encouraged" family involvement through financial incentives or by restructuring access to health care services for elders with families (Barusch, 1985). In Canada we have also seen more responsibility for care of the elderly being shifted onto family members through the philosophy of caring partnerships. Underlying this philosophy is the subtext that families are not providing the amount of care that they should for their elders (Keating et al, 1997). When we go into the research literature to examine family involvement in caregiving we find little research has been done on families within formal care settings. Yet there is a push to place more responsibility for care onto these families.

This research project was the first step in gaining a better understanding of family involvement in caregiving within formal care settings. Probably the most revealing findings of this project were that, on average, family members provided care thirty-two times per month, and spent an average of twenty-four hours each month delivering care. This means that involved family members provided care about seven times a week, and spend approximately six hours per week in caregiving. This time is almost equivalent to an extra work day each week. It is a tremendous amount of time to spend in care, especially if family members have other time commitments like a full-time job or a family of his/her own to care for.

Enhancing Well Being

In this study we found that family members tended to report involvement in caregiving tasks that were non-technical and/or emotional in nature. Previous studies have also documented this type of family caregiving within formal settings (Keefe & Fancey, 1996; Linsk et al., 1988; Smith & Bengston, 1979). Almost all of the family members in this study reported involvement in enhancing well being activities. The most common tasks in this category included being there, leisure activities, and helping with remembering. Interestingly, we also found that this caregiving category and these three tasks had the highest mean episodes per month, and the greatest mean time per month. Overall we found that enhancing well being was an extremely important activity that almost all involved family members provided. Being there, leisure activities, and helping with remembering were the activities that stood out in terms of proportion doing, mean episodes, and mean time per month. Typically families have been seen as the ones who are responsible for providing non-technical or emotional care whereas staff provide the technical and redundant types of care (Barabash, 1989; Schwartz & Vogel, 1990). Family involvement in enhancing well being activities seems to fit our traditional ideas of family members providing for the emotional needs of their elders.

Care Management

Care management is another category of care in which the tasks are relatively unskilled/non-technical in nature. Previous research has documented some family involvement in this area, but it has tended to focus on monitoring (Duncan & Morgan, 1994; Zarit & Whitlatch, 1992). Over half of the family members in this study reported involvement in this type of care. The majority of this involvement was in keeping an eye on things. Monitoring was the most frequent care management activity, and families devoted the most time to it. It appears that involved family members felt a need to ensure that their relative's needs were being recognized and met, and that the environment they were living in was safe. This finding suggests that families do not transfer total responsibility for the care of their elder to formal staff. Rather, families may feel a sense of responsibility for ensuring that their elder is getting the care needed, and thus monitor the care and environment provided by the facility. Results also indicate that families do speak up on their elder's behalf. Although this is not shown to be a frequent or time consuming activity, it does suggest that family members are not passive when their monitoring reveals a problem. It appears that when there is a concern family members take action by speaking up for their relative.

Financial Management

When elders are no longer able to manage their financial affairs it is often family members who assume responsibility for this task (Keefe & Fancey, 1996; Zarit & Whitlatch, 1992). More than half of the family members in this study reported helping their relative with financial affairs. This task was done about once per month for approximately one hour. Within a family it is typically one person who assumes responsibility for their elder's financial affairs. Because we sampled as many as seven individuals in one family, the frequency and time involved in financial management may be underestimated. This high level of family involvement is consistent with our ideas about who is typically responsible for assisting in the financial affairs of the elderly. It is the policy of the formal care programs involved in this study not to assume responsibility for their clients' financial affairs. Rather, when elder's are no longer able to manage their own financial affairs, it is typically a family member or some other appointed trustee who assumes this role.

Transportation

Transportation is a service that is not directly provided by any of the care programs involved in this study. In order to meet the transportation needs of elders, family members or an outside transportation service must provide this service. Similar to Keefe and Fancey (1996), we also found that more than half of the family members involved in this study provided transportation for their elders. This activity is divided into driving places and going to appointments/errands. Family members provide transportation about 2.5 times per month, and spend almost 4 hours providing this service.

Shopping

Within the caregiving literature, researchers have not examined family involvement in shopping. For this reason it is particularly interesting that approximately half of the family members in this study provided this type of care. The majority of the shopping was for non-medical things, indicating that medical type of needs are being met by the formal care facility. Family members shopped for other things like goodies, toiletries and clothing. On average, family members shopped for "other things" approximately once per month and spent an average of one hour in this activity.

Other Activities

There are some activities which family members appear to give up once their elder is moved into a formal care setting. Research shows that families perform housework for elders in the community (Keefe & Fancey, 1996), however our results indicate that most involved family members do not perform housework tasks for their elders in formal care. Similarly, families provide a lot of personal care for elders living in the community, especially if the elder resides in the family member's home (Keefe & Fancey, 1996). But once the elder is moved into a formal care setting, we find very low levels of participation, frequency and time in personal care tasks. It appears as though much of the responsibility for performing these relentless tasks is given up by family members and assumed by staff. Skilled care is another area in which we find low levels of family involvement. This finding may be due to staff performing those tasks that families previously provided when the elder was residing in the community. However, this low level of family involvement may also be partly due to elders requiring a level of care for which training is required.

Preliminary Summary

The findings from the first three questions posed in this study indicate that family involvement tends to be centered around those activities that are emotional and/or non-technical in nature. It appears that when an elderly relative enters formal care, family members continue to be extensively involve in caregiving. However, the manner in which these family members choose to be involved appears to change. When an elder is living in the community, families tend to be more involved in housework, personal care, and to some degree skilled care. However, when an elder enters a formal setting, much of the responsibility for these types of care is shifted onto formal care workers. This frees family members to do more emotional and/or non-technical types of care (Smith & Bengston, 1979). Involved family members continue, and may increase, their involvement in enhancing well being activities. We also find families engaging in care management through monitoring care and speaking up when a problem or concern arises. Families continue to be involved in financial management, although we might anticipate that the rate of participation in this domain increases once elders are moved into formal care because of the increased incidence of cognitive impairments. We also found high family involvement in transportation and shopping. Overall, the findings suggest that family members remain committed to their elders. They provide care on a frequent basis, and spend considerable amount of time in caregiving.

One last comment on family caregiving seems warranted. When we examine the care provided by families, it would seem that the types of care they provide complement what formal staff would be doing. Typically we think of staff as being responsible for things like personal care, housework, and skilled care, whereas family members are responsible for the emotional and non-technical needs of their elders. Although there may be no firm divisions between what staff and family members do, these findings suggest that families are providing the types of care that are typically expected. Future research might explore how caregiving patterns of family members change once an elder moves into formal care. This may help us to understand what caregiving priorities family members have, the caregiving choices they make, and how frequency and time spent in caregiving tasks change. We might also want to examine how caregiving tasks of family members and staff complement each other.

Caregiving Across Models of Care

Models of care can vary by the type of setting, the clientele they serve, and their care policies. Each of these characteristics has the potential to impact family caregiving within formal care. In this study three models of care were represented, these included assisted living, adult family living, and dementia care.

Enhancing Well Being

Our first step in examining how family involvement might vary by model of care was to compare the proportion of family member involvement in eight different task categories. We found that participation rates in enhancing well being were not significantly different across the models of care. This finding suggests that enhancing well being activities remain important despite differences in setting, clientele, and care policies.

Care Management

Interestingly family members of clients from dementia care had a lower level of participation in care management than family members of elders from either adult family living or assisted living. As already discussed, care management primarily involves keeping an eye on things, or monitoring care. The reasons for this low participation rate are unclear, however we might speculate that it has something to do with the type of clientele, staff and services provided at the dementia care facility. Family members may see staff in dementia care as being experts in caring for individuals with this type of illness. For this reason, family members may experience less need to monitor care than do families with relatives in adult family living or assisted living. It is also the policy of this program to keep families continually informed of changes in their relative's condition or treatment, thus potentially contributing to less monitoring. Lastly, this program brings in a lot of services like doctors, denturists, and optometrists which would result in clients requiring fewer monthly appointments and services.

In the adult family living model of care almost 80% of family members participated in care management during the previous month. Many family members of clients in adult family living may feel a need to keep an eye on things because there are no twenty-four hour care professionals available, nor are there co-workers present to monitor the home care operator. As well, clients in these programs may feel reluctant to complain or express concerns in fear that it might jeopardize there continued residence in that home. For this reason, family members may have to speak on their relative's behalf more often than family members of clients in the other models of care.

In the assisted living model of care, families also have a higher level of participation in care management than family members of clients in dementia care. We might speculate that these family members feel a greater need to monitor care because the staff - client ratio is 15:1. In the dementia care facility this ratio is 5:1 during the day and 9:1 in the evenings. Given that there are fewer staff members per client, assisted living families may fell that they have to spend more time keeping an eye on things in order to ensure that their elder is receiving the care that is needed.

Transportation

When we compared the models of care in the area of transportation, we found that more family members of clients from adult family living and assisted living were providing transportation services than dementia care families. Family members of clients from dementia care reported the lowest level of participation in transportation. The main reason for this difference may lie in the type of clientele these models of care service. Often clients in assisted living and adult family living do not suffer from cognitive impairments which restrict their movement from the facility. Individuals with Alzheimer's disease who reside in dementia care may become aggitated when they leave the familiar surroundings of the facility. For this reason many in-house social activities are organized, and numerous services are brought in for clients. The result is that clients in dementia care have lower transportation demands than clients from the other models of care. These result suggest that the type of clientele and the services that are offered within the models of care plan an important role on the transportation demands that are put on family members.

Housework and Personal Care

As already discussed, housework and personal care are two areas in which family involvement tends to be low. It was suggested that even though some family members continue to provide care in these two areas, it is primarily staff who provide these services. Interestingly, when we compared the models of care we found that family members of clients from assisted living had higher levels of participation in housework and personal care than did family members of clients from the other models of care. In the dementia care facility, family members were not explicitly encouraged to be involved in these types of care, rather families were encouraged to be involved in activities and other enhancing well being activities. In the adult family living model of care, families may feel somewhat reluctant to do housework or personal care because they re in another person's home. The high levels of involvement of family members of clients in assisted living my in part by due to the physical setting and the program's care policies. In this program clients have private living quarters. As a result, family members may feel more "free" to provide both housework and personal care. As well, this program has a philosophy of "shared responsibility". When residents enter the program a service plan is developed. This plan is based on what the client's needs are, and who will meet those needs. If the client has needs that go beyond what the facility provides, the client has the option of doing the task themselves, hiring someone, or enlisting the help of a family member. Typically family members are part of this care plan and they agree to provide a certain set of services for their elder. It may be through this service contract that family members are increasing their involvement in housekeeping and personal care. These results suggest that both the physical setting and the care policies present have an impact on participation rates of family members in housework and personal care.

Episodes of Care

In order to further explore the differences in family involvement in care across continuing care models, we examined mean episodes and mean time per month for each task category. A general pattern emerged among the significant differences in the episode data. Among those activities that had significant differences in frequency between models of care, family members of clients in assisted living consistently did those activities more often than family members of clients from either adult family living or dementia care.

There were three categories of care in which the mean number of episodes per month were significantly different across the programs, including housework, shopping and transportation. Results indicate that assisted living families perform housework significantly more often than families of clients from either adult family living or dementia care. As already touched on, the service contract in the assisted living program may be contributing to higher levels of family involvement in housework. If clients in assisted living require additional housework than what is provided, they may ask for assistance from family members. These clients also have personal living space which includes a bathroom and kitchenette. These physical features of the assisted living facility may also be creating additional need for family involvement in housekeeping which result in greater frequency of this category. Within dementia care and adult family living, housework is primarily performed by staff. Adult family living is unique in that the care setting is the home of the care operator. In this setting it might be awkward for family members to do housework even if they were willing to do so.

Shopping was the second type of care that families with clients in assisted living provided more often. Results indicate that these family members shop significantly more often than family members of clients in adult family living. One of the reasons for more shopping being performed by assisted living family members is that this service is not provided by the facility, nor is there any in house store from which clients can buy some of their things. These clients also have their own kitchenette which means that they would need to be supplied with groceries. In adult family living, the home operator prepares all the meals so there is no need to purchase groceries. As well, some home operators agree to pick up things for their clients when they are doing their own shopping. In such cases, clients reimburse the home operator for the items purchased. Family members may still be involved in shopping for things like clothing. Given the unique features of these programs, it is not surprising to find differences in the frequency of shopping between them.

Transportation was the last aggregate task category in which there were significant differences in frequency of care. Results indicate that family members of assisted living clients provided transportation significantly more often than family members of dementia care clients. As already touched on, clients from dementia care suffer from Alzheimer's disease making it difficult for them to leave their environment. These clients also have many services brought in for them. For these reasons, the frequency of transportation provided by family members is relatively low. Clients from assisted living may have more transportation demands and tend not to be restricted by cognitive impairments. Again we see how the type of clientele can have an impact on how families provide care.

Time

When we examined those task categories that had significant differences in mean time across models of care, we found that it was family members from assisted living or adult family living that were spending the most time in care. Overall we found that family members of assisted living clients were spending significantly more time providing care than families in dementia care. Some of the potential reasons for this difference have already been discussed. These were related to type of clientele, specific care policies, and the physical setting of each of the programs.

Not surprisingly, we found that assisted living families were spending more time in housework than families of clients from either dementia care or adult family living. We know these families are doing housework more often and that it may be related to the service contract and the private living quarters. Given this it makes sense that assisted living families would also be spending more time in housework than family members of clients from the other models of care.

Care management was another task category in which family members of clients from assisted living spent significantly more time than family members of clients from dementia care. As already mentioned, family members of clients in dementia care may spend less time in care management because they see staff as being experts in their elder's care. The physical setting has also been specially designed for the needs of persons with this disease, thus further contributing to family members engaging in less care management. The assisted living facility is a very different picture. Here we have residents with a variety of needs and staff who have received more general training. We also find the staff-client ratio to be less favorable in assisted living than in dementia care. Family members of clients in assisted living may perceive there to be a greater need to monitor care because staff are not seen as experts, nor are there as many staff members around to care for their relative.

There are two types of care in which assisted living family members were not spending more time. Our results indicate that family members of clients in adult family living spend significantly more time providing skilled care than do family member of either dementia care or assisted living. The physical setting and staff of adult family living may account for this difference. In adult family living programs, there are no skilled workers present in the households. For this reason family members may feel a greater need to be involved in skilled care activities. In assisted living and dementia care there are formal staff available to perform skill care services. Thus families from these models of care devote less time to tasks in skilled care.

Lastly, we found that families with elders in adult family living spent significantly more time in financial management than families of dementia care clients. This finding might be due in part to differences in policy regarding client finances between the models of care. In both of the adult family living programs, there were no programs in place to help family members manage the financial affairs of their elders. It was also the policy of these programs that when a client could no longer manage his/her own financial matters, a family member or some other designated individual would assume this role. Home operators and other employees of the adult family living program were not permitted to provide this service. Since many of the residents in adult family living do require some type of assistance in this area, family members are often very involved in financial management. The dementia care facility is unique in that it has a financial management program in place to assist family members. Clients have an in-house trust account from which they can regularly withdraw money for expenses. Each month the family replenishes this account. Families are also given options like paying rent by direct debit from their relative's bank account. It appears that the different policies regarding client's financial affairs have had an influence on the amount of time that family members spend in financial management.

Conclusion

The results of this study suggest that family members provide care on a frequent basis, and spend significant amounts of time in caregiving. Family members appear to concentrate much of their caregiving activity on the emotional and non-technical types of care, while leaving the redundant and more technical tasks to staff. We might speculate that the care provided by family members complements that done by staff. However, it is important to recognize that some family members chose to continue involvement in those areas of care that we typically think of as staff's responsibility. This would suggest that although families tend to provide certain types of complementary care, overlap in caregiving exists and there are no clear dividing lines between what staff and family members do.

When we examined caregiving across models of care we got a sense of how differences in clientele, physical setting, and policies impacted family involvement in care. Family members appeared to respond to the unique circumstances of the care facility and their elder's needs. This finding was probably most evident for family members of clients in assisted living. Here we could easily see how the characteristics of the program directly impacted participation rates, frequency, and time spent in the different care categories.

It is evident that family members are not abandoning their elders in formal care. Rather we find that family members remain committed to caring for their relatives. The subtext of today's partnerships paradigm suggests that families are not doing enough and they need to be encouraged to fulfill their filial responsibilities. However, the results of this study do not support this argument. Family members devote approximately six hours per week to their elder's care. This is in addition to the other time commitments they have like full-time employment, children, or other elderly relatives to care for. To accuse family members of not doing enough seems unwarranted. The results of this study suggest that we need to reconsider policies and programs that require or encourage greater family involvement in caregiving.

Future Research

This study provided some information on the caregiving activities of families within formal care settings. This was the first step in gaining a better understanding of what family caregiving looks like once an elder moves into formal care. However, more work is needed in order to arrive at a complete picture of family involvement within these settings. For example more research might be done to examine how family involvement in care varies depending on the "family" policies that exist within a care program. It would be interesting to examine a variety of programs in which there was a wide spectrum of "family" policies. For example, we might examine what caregiving tasks families perform in programs which require family involvement, in programs which only encourage family involvement, and in programs which have no formal policy regarding family involvement. We might also want to do research to examine family members' feelings about providing care. For example, what impact does caregiving have on their lives? It would be informative to know if families find caregiving overly burdensome or if they prefer a more active role, and how this varies by the type of "family" polices in place. By answering these and similar questions we will arrive at a better understanding of family caregiving within formal care, and be able to inform policy makers of the potential implications of eldercare policies affecting families.

Bibliography

Abel, E. (1990). Informal care for the disabled elderly: A critique of recent literature. Research on Aging, 12(2), 139-157.

Alzheimer's Association Patient and Family Services. (1992). Guidelines for dignity: Goals of specialized Alzheimer/dementia care in residential settings. Chicago: Author.

Baines, C., Evans, P., & Neysmith, S. (1992). Confronting women's caring: Challenges for practice and policy. Affilia, 7(1), 21-44.

Barabash, M. (1989). Evaluation of a structured orientation programme for families of institutionalized seniors: Final Report. Edmonton: Senior Citizens Secretariat.

Bowers, B.J. (1988). Family perceptions of care in a nursing home. The Gerontologist, 28(3), 361-368.

Brody, E.M. (1969) Follow-up study of applications and non-applications to a voluntary home. Gerontologist, 9(3), 187-196.

Brody, E.M. (1978). The aging of the family. The Annals of the American Academy of Political and Social Science, 438, 13-27.

Brody, E.M. (1981). "Women in the middle" and family help to older people. The Gerontologist, 21(5), 471-480.

Brody, E.M. (1995). Prospects for family caregiving: Response to change, continuity, and diversity. In R.A. Kane & J.D. Penrod (Eds.). Family caregiving in an aging society: Policy perspectives (pp. 15-28). Thousand Oaks: Sage Publications.

Brody, E.M., Dempsey, N.P., Pruchno, R.A. (1990). Mental health of sons and daughters of the institutionalized aged. The Gerontologist, 30(2), 212-219.

Brody, S., Poulschock, S.W., & Masciocchi, C. (1978). The family caring unit: A major consideration in the long term support system. Gerontologist, 18, 556-563.

Buckwalter, K.C., & Hall, G.R. (1987). Families of the institutionalized older adult: A neglected resource. In T.H. Brubaker (Ed.), Aging, health and family: Long-term care (pp. 176-196). Newbury Park, CA: Sage Publications.

Calkins, M.P. (1988). Design for dementia. Planning environments for the elderly and the confused. Owings Mills, MD: National Health Publishing.

Chappell, N.L. (1993). Implications of shifting health care policy for caregiving in Canada. Journal of Aging and Social Policy, 5(1/2), 39-55.

Concepts in Community Living. (1994). Principles of assisted living. Eugene, Oregon: Good Samaritan Assisted Living Training.

Cox, C. (1993). Families and the frail elderly. In C. Cox, The frail elderly: problems, needs and community responses (pp. 103-123). Westport, CN: Auburn House.

DeFriese, G.H., & Woomert, A. (1992). Informal and formal health care systems serving older persons. In M.G. Ory, R.P. Abeles, & P.D. Lipman (Eds.), Aging, health, and behavior (pp. 57-82). Newbury Park: Sage Publications.

Dempsey, N.P., & Pruchno, R.A. (1993). The family's role in the nursing home: Predictors of technical and non-technical assistance. Journal of Gerontological Social Work, 21(1/2), 127-145.

Dobbs, A.R., & Rule, B.G. (1992). Behaviour and use of space by residents of special care and integrated nursing home units. In G. Gutman (Ed.), Shelter & care of persons with dementia (pp. 115-132). Vancouver, BC: Gerontology Research Centre: Simon Fraser University.

Duncan, M.T., & Morgan, D.L. (1994). Sharing the caring: Family caregiver's views of their relationships with nursing home staff. The Gerontologist, 34(2), 235-244.

Edelman, P., & Hughes, S. (1990). The impact of community care on provision of informal care to homebound elderly persons. Journal of Gerontology, 45(2), S74-S84.

Fast, J., Keating, N., & Eales, J. (1997). Collecting time use data on infrequent activities: The example of informal caregiving. Paper presented at the annual meeting of the International Association of Time Use Researchers, Austria.

Folkemer, D., Jensen, A., Lipson, L., Stauffer, M., & Fox-Grage, W. (1996). Adult foster care for the elderly: A review of state regulatory and funding strategies (Vol.I). Washington, DC: American Association of Retired Persons.

Foster, P. (1991). Residential care of frail elderly: A positive re-assessment. Social Policy & Administration, 25(2), 108-120.

Garant, L., & Bolduc, M. (1990). Family caregiving: Myths and realities. Quebec, PQ: Ministry of Health and Social Services.

George, L.K. (1984). The burden of caring. Duke University Center Reports on Advances in Research, 8(2), 1-6.

Hall, E. (1980). Acting one's age: New rules for old. Psychology Today, 13, 66-80.

Hooyman, N.R., & Gonyea, J. (1995). Feminist perspectives on family care. Policies for gender justice. Thousand Oaks, CA: Sage Publications.

Horowitz, A. (1985). Family caregiving to the frail elderly. In C. Eisdorfer, M.P. Lawton, & G.L. Maddox (Eds.), Annual Review of Gerontology & Geriatrics: Volume 5 (pp. 194-246). New York: Springer.

Juster, F.T., & Stafford, F.P. (1991). The allocation of time: Empirical findings, behavioral models and problems of measurement. Journal of Economic Literature, 29, 471-522.

Kane, R., Illston, L.H., Kane R., & Nyman, J. (1990). Meshing services with housing: Lessons from adult foster care and assisted living in Oregon. University of Minnesota Long-Term Care DECISIONS Resource Centre.

Kane, R.A., & Kane, R.L. (1987). Long-term care: Principles, programs and policies. NY: Springer Publishing Company.

Kane, R.A., & Wilson, K.B. (1993). Assisted living in the United States: A new paradigm for residential care for frail older persons. Washington, DC: American Association of Retired Persons.

Kaplan, W. (1995). Assisted living in the mid-Atlantic states. Spectrum, (January/February), 29-32.

Keating, N., Fast, J., Connidis, I., Penning, M., & Keefe, J. (1997). Bridging policy and research in eldercare. Canadian Journal on Aging, Canadian Public Policy Supplement, 22-41.

Keating, N., Fast, J., Oakes, L., & Harlton, S. (1996) Defining eldercare: Components and perspectives. Unpublished manuscript.

Keefe, J., & Fancey, P. (1996). Family involvement in long term care. Halifax, NS: Mount Saint Vincent University, Nova Scotia Centre on Aging.

Ladd, R.C., & Hannum, C. (1992). Oregon's adult foster care program: A model for community-based long-term care for elderly and disabled. Community Alternatives, 4(2), 171-184.

Laitinen, P. (1992). Participation of informal caregivers in the hospital care of elderly patients and their evaluations of the care given: Pilot study in three different hospitals. Journal of Advanced Nursing, 17(10), 1233-1237.

Linsk, N.L., Pflaum, R., & Ortigara-Vicik, A. (1988). Families, Alzheimer's disease, and nursing homes. Journal of Applied Gerontology, 7(3), 331-349.

Litwin, H., & Auslander, G. (1990). Evaluating informal support. Evaluation Review, 14(1), 42-56.

Montgomery, J. (1982). The economics of supportive services for families with disabled and aging members. Family Relations, 31, 19-27.

Montgomery, R.J.V. (1982). Impact of institutional care policies on family integration. The Gerontologist, 22(1), 54-58.

Mor, V., Sherwood, S., & Gutkin, C. (1986). A national study of residential care for the aged. The Gerontological Society of America, 26(4), 405-417.

National Advisory Council on Aging (1992). Quality of life in long-term care institutions: A concerted approach. Ottawa, ON: Minister of Supply and Services.

National Advisory Council on Aging (1990). The NACA position on informal caregiving: Support and enhancement. Ottawa, ON: Minister of Supply and Services Canada.

Paille, B. (1994). Estimating the volume of unpaid activities in Canada, 1992: An evaluation of data from the General Social Survey. (Working paper #10) Ottawa, ON: Statistics Canada.

Regnier, V. (1991). Assisted living: An evolving industry. Reprinted article from Seniors Housing News, spring.

Regnier, V. (1996). Assisted living housing for the elderly and frail. Outline from telemedicine Canada conference, University of South California, School of Architecture.

Robinson, J.P. (1985). The validity and reliability of diaries versus alternative time use measures. In F.T. Juster and F.P. Stafford (Eds.), Time, goods, and well-being (pp. 33-62). Michigan: Survey research center, Institute for Social Research, University of Michigan.

Sand, B.J., Yeaworth, R.C., & McCabe, B.W. (1992). Alzheimer's disease. Special care units in long-term care facilities. Journal of Gerontological Nursing, 18(3), 28-34.

Schwartz, A.N., & Vogel, M.E. (1990). Nursing home staff and residents' families role expectations. The Gerontologist, 30(1), 49-53.

Schwenk, F.N. (1993). Long term care trends. Family Economics Review, 6(4), 9-18.

Shanas, E. (1960). Family responsibility and the health of older people. Journal of Gerontology, 15(4), 408-411.

Shanas, E. (1979). Social myth as hypothesis: The case of the family relations of old people. The Gerontologist, 19(1), 3-9.

Shanas, E. (1979). The family as a social support system in old age. The Gerontologist, 19, 169-174.

Sharp, T. (1990). Relatives' involvement in caring for the elderly mentally ill following long-term hospitalization. Journal of Advanced Nursing, 15(1), 67-73.

Sherman, S., & Newman, E. (1988). Foster families for adults: A community alternatives in long-term care. New York: Columbia University Press.

Shuttlesworth, G.E., Rubin, A., & Duffy, M. (1982). Families versus institutions: Incongruent role expectations in the nursing home. The Gerontologist, 22(2), 200-208.

Silverstone, B.M. (1978). The family is here to stay. Journal of Nursing Administration, 8(5), 47-51.

Smith, K.F., & Bengston, V.L. (1979). Positive consequences of institutionalization: Solidarity between elderly parents and their middle-aged children. The Gerontologist, 19(5), 438-447.

Soldo, B. (1984). Supply of informal care services: Variations and effects on service utilization patterns. In W. Scalon (Ed.), Project to analyze existing long-term care data. Volume III (pp. 56-97). Washington, DC: The Urban Institute.

South, N. (1997). Evaluating programs of innovative continuing care. Program descriptions. Edmonton, AB: Unpublished manuscript.

Spark, G.M., & Brody, E.M. (1970). The aged are family members. Family Process, 9, 195-210.

Stevens, G.L., Walsh, R.A., & Baldwin, B.A. (1993). Family caregivers of institutionalized and noninstitutionalized elderly individuals. Nursing Clinics of North America, 28(2), 349-362.

Stone, R., Cafferata, G.L., & Sangl, J. (1987). Caregivers of the frail elderly: A national profile. The Gerontologist, 27(5), 616-626.

Tennstedt, S.L., Crawford, S.L., & McKinlay, J.B. (1993). Is family care on the decline? A longitudinal investigation of the substitution of formal long-term care services for informal care. The Milbank Quarterly, 71(4), 601-624.

Tennstedt, S.L., & McKinlay, J.B. (1989). Informal care for frail older persons. In M.G., Ory, & K., Bond, (Eds.), Aging and health care: Social science and policy perspectives (pp. 145-166). London: Routledge.

Tennstedt, S.L., McKinlay, J.B., & Sullivan, L.M. (1989). Informal care for frail elders: The role of secondary caregivers. The Gerontologist, 29(5), 677-683.

Tobin, S.S. (1995). Fostering family involvement in institutional care. In G.C., Smith, S.S., Tobin, E.A., Robertson-Tchabo, & P.W. Power (Eds.), Strengthening aging families: Diversity in practice and policy (pp. 25-44). Thousand Oaks, CA: Sage Publications.

Townsend, P. (1965). The effects of family structure on the likelihood of admission to an institution in old age: The application of a general theory. In E. Shanas & G. Strieb (Eds.), Social structure and the family: Generational relations (pp. 163-187). Englewood Cliffs, NJ: Prentice-Hall.

Treas, J. (1977). Family support systems for the aged: Some social and demographic considerations. The Gerontologist, 17(6), 486-491.

Walker, A. (1991). The relationship between the family and the state in the care of older people. Canadian Journal on Aging, 10(2), 94-112.

Walker, A.J., Pratt, C.C., & Eddy, L. (1995). Informal caregiving to aging family members. Family Relations, 44,(Oct.), 402-411.

York, J.L., & Calsyn, R.J. (1977). Family involvement in nursing homes. The Gerontologist, 17(6), 500-505.

Zarit, S.H., & Whitlatch, C.J. (1992). Institutional placement: Phases of the transition. The Gerontologist, 32(5), 665-672.

APPENDICES

Appendix A

Aggregate Task Categories and Activities Included Within each Category

Aggregate Task Category	Caregiving Activity
Shopping	• Buying special equipment • Buying medical supplies • Buying other things
Skilled Care	• Helped manage physical health • Helped ensure behavior was safe/appropriate • Helped deal with pain • Watched for reactions to medications
Housework	• Prepare food • Cleaned room • Cleaned common areas • Did laundry • Took care of clothes
Care Management	• Made appointments/arranged services • Kept an eye on things • Spoke up for the resident
Financial Management	• Helped with financial affairs
Personal Care	• Helped get ready for the day • Helped get ready for bed • Helped shower/have a bath • Did hair • Did nails • Helped go to bathroom • Assisted with mealtime • Helped with eating • Helped with medications
Transportation	• Went to appointments/ran errands • Drove resident places
Enhancing Well Being	• Participated in leisure activities • Helped with spiritual/cultural practices • Helped keep in touch with friends/family • Were “there” for the resident • Helped with remembering

Appendix B

Service Event Definitions

1. **Helping her/him get ready for the day** - includes activities that are often part of a "morning routine". Getting ready for the day may begin with greeting the resident or waking the resident from his/her night sleep, and may include activities such as: helping the resident brush his/her teeth or putting in dentures, mouth care, assisting or supervising the resident with washing up, shaving, putting on make-up, picking out an outfit, checking the condition of the garments, dressing, and/or whatever else the resident thinks is necessary to make him/herself "presentable" (i.e., applying hand cream, putting on jewelry or fragrances/aftershave, cleaning glasses, adjusting hearing aids). This service event ends with the resident being fully dressed.
   [*Toileting and giving of medications are NOT included in this service event.*]

2. **Helping her/him get ready for bed** - refers to activities that are often part of an evening routine to prepare for sleep. Getting ready for bed may start with arranging a bedtime with the resident, and may include: escorting, accompanying or assisting the resident with getting to his/her bedroom (walking or wheelchair); helping or supervising the resident change from day clothes to night clothes; aiding or monitoring the resident with removing dentures, glasses, or hearing aids; helping or supervising resident with brushing teeth and other mouth care; assisting or overseeing the resident washing up, shaving, applying cream to face and hands, and/or whatever else the resident thinks is necessary to get ready for bed (i.e., combing hair, setting out clothes for the next day). Other kinds of activities include: pulling down bed covers, setting up water glass, setting out urine bottle, turning off lights, pulling down blinds, opening/closing windows. This service event ends with assisting the resident into bed and any kind of "tucking in rituals"(i.e., prayers, hug and kiss).
   [*Toileting and giving of medications are NOT included in this service event.*]

3. **Helping her/him go to the bathroom** - refers to activities that are typically associated with using the toilet. Toileting may begin with checking with the resident regarding their need to use the toilet and may include assisting or supervising the resident with: getting to the bathroom (walking or wheelchair), removing clothes, transferring on/off the toilet, peri-care, changing incontinence pads, redressing and personal hygiene. The service event ends when the resident leaves the bathroom.

4. **Helping her/him with medications** - refers to activities that are involved in making sure that a resident receives and takes their medicine (prescribed or non-prescribed). Activities associated with giving medication may include: reminding the resident to take their medication, preparing dosettes or medicine trays; checking resident records to ensure the right medicine is given in the right dosage, to the right person, in the right dose and route, at the right time; recording in the resident's medication chart, getting the medication from medical room/cabinet/fridge, preparing the medicine, taking the medication to the resident, assisting or monitoring the resident with taking the medication, and cleaning up/putting away things needed for giving medications.

5. **Helping her/him shower or have a bath** - refers to activities that are part of getting a resident ready for a shower/bath, having a shower/bath, and cleaning or tidying the bath area. Showering/bathing may begin with arranging with the resident the day or time of the shower/bath. Other activities that may be part of showering/bathing include making the bathroom ready; getting supplies ready for the bath; locating the resident and escorting/accompanying the resident to the bathing area (walking or wheelchair); assisting or supervising the resident with: getting into the bath, the washing of his/her body, getting out of the tub, drying off and getting dressed. Also include applying body cream or powder. Showering/bathing ends when the resident is dressed and leaves the bathroom area (walking or wheelchair), and the bathing area is tidied (supplies returned, laundry removed, equipment put away).

6. **Doing her/his hair**- refers to periodic hair care that is often done at a beauty parlor. Activities involved in the resident's "getting his/her hair done" may include: washing, rinsing, setting, drying, perming, coloring and cutting the resident's hair. Activities included in getting hair done may include locating and informing the resident of appointment time; and portering the resident to and from the hairdresser (on-site).
[*This DOES NOT include routine brushing of the resident's hair.*]

7. **Doing her/his nails** - refers to both routine hand, foot and nail care, as well as some extra services for the resident. Routine hand, foot and nail activities may involve: clipping or filing of nails, pushing back cuticles, applying bunion or corn bandages, and/or applying hand or foot cream. Extra services may include activities that are typically associated with manicures and/or pedicures: trimming cuticles, smoothing calluses, buffing, polishing and/or painting finger and toe nails.
[*This DOES NOT include medical treatment for foot conditions.*]

8. **<u>Helping her/him with preparing food</u>** - refers to activities that may be involved in getting meals and snacks ready and keeping clean areas associated with food preparation and eating. Encouraging and supervising resident participation in any or all of the following activities are also included. Food preparation may begin with planning meals or snacks, and could include preparing beverages, snacks, and meals; and setting tables. [*DOES NOT include assisting the resident with eating.*]

9. **<u>Helping her/him with eating</u>** - refers to special activities that are required to help the resident with the eating of their food. Activities involved in assisting a resident with eating difficulties may include: cutting up the resident's food, providing puree food, feeding the resident, cueing the resident for special swallowing techniques, and directing resident to eat.

10. **<u>Assisting her/him with mealtime</u>** - refers to activities that are performed to help the resident with his/her meals. Assisting the resident with mealtime may begin by informing the resident that the meal is ready, and may also include activities where direct or stand-by assistance is provided to the resident with getting the resident to and from the table; offering and assisting the resident with a napkin or "bib", offering the resident a choice of food and beverages, dishing up food on the resident's plate; and serving the food and beverages to the table. Assisting the resident with mealtime ends with clearing the dishes from the table.

11. **<u>Driving her/him places</u>** - refers to providing transportation to a resident from point A to point B. This is the type of activity that could be hired out to a company such as DATS. Driving a resident to a specific place may begin with providing assistance to the resident with getting into the vehicle and includes driving the resident to and from a given destination (time in transit). This service event ends with the arrival of the resident to their destination and may include providing assistance to the resident with getting out of vehicle. [*Time spent with the resident once the resident has arrived at his/her destination is NOT INCLUDED in this service event. DO NOT include the transportation time that is spent performing other service events such as, shopping for the resident, doing the resident's banking, going to the dry cleaners, or the transportation time spent if the purpose of driving the resident is for leisure (i.e., "going out for a drive").*]

12. **<u>Going with her/him to appointments; running errands with her/him</u>** - refers to accompanying a resident to an "in-house" or "off-site" activity. For off-site

events, accompanying the resident begins **after** the resident has exited the transportation vehicle. The purpose of accompanying a resident is to provide supervision or physical assistance to the resident. Accompanying the resident may begin with assisting the resident to get ready for going out, and include other activities such as, escorting the resident to and from their appointment or planned event (walking or wheelchair), staying with the resident before, during and after the planned event. This service event may end with the return of the resident to their lodgings or room. Examples of accompanying the resident include: going with a resident to appointments, waiting for a resident while they are receiving services (i.e., eye examination or hair care), running errands with a resident (i.e., going to the bank or store with the resident).

13. **Making appointments and arranging for services for her/him** - refers to those activities that are needed to make assistance, products, or resources available and accessible to a resident. Typically the activities involved require information gathering, matching a resident's needs to available resources, and making appropriate arrangements. Gathering information may include: inquiring in-person about available services; making telephone calls, writing letters, sending faxes or e-mails requesting information, and/or picking up information packages (brochures, newsletters). Matching resident's needs with available resources may include reading information packages, visiting program sites or interviewing potential service providers. Making appropriate arrangements may include: arranging for transportation (DATS, handy bus, family members); informing pastoral care staff of a resident's need; making appointments for the resident with professionals (i.e., doctors, dentists, podiatrists, speech therapists, occupational therapists, social workers, lawyers, ministers, rabbis, pastoral care counselors); arranging appointments for hair and nail care; making arrangements for a care companion to accompany resident on outings (i.e., church services, family functions, leisure activities); arrange for others to provide spiritual/cultural or leisure activities for the resident.

14. **Acquiring medical supplies** - refers to activities that are involved in making medical supplies available. Activities to acquire medical supplies may include: shopping and purchasing prescribed drugs/medication and supplies for ongoing health needs (i.e., incontinence supplies, bowel and bladder management supplies, wound management, infection control, batteries for hearing aids, etc.); transportation time; in-house ordering of medical supplies for a specific resident; updating inventory to make

sure that there are adequate supplies on hand per resident; and/or recording use of medical supplies for the purposes of billing individual resident.

15. **Getting her/him special equipment** - refers to activities that are involved to make equipment available. Activities to make equipment available may include transportation time involved in shopping and purchasing or renting of prescribed or non-prescribed mobility aids (e.g. wheelchairs, walkers, canes), adaptive devices (i.e., utensils, shoe inserts, special telephone, communication aids), commodes, grab bars, or lifts; checking the condition of equipment; arranging for equipment repairs; ordering new equipment; and billing appropriate persons.

16. **Shopping for other things for her/him** - refers to activities that are necessary in obtaining products. Shopping for goods may begin with making a list of the goods needed and may include travel to and from the store; shopping around and purchasing the requested or required items. This event ends with delivering the "goods" to the resident. Items that are considered "goods" include: non-prescribed medications, toiletries, groceries, clothing, leisure items, etc. [*Shopping for goods DOES NOT include shopping for medical supplies such as incontinence pads, hearing aid batteries, wheelchairs, or prescribed medications.]*

17. **Cleaning her/his room** - refers to activities generally considered to be light housecleaning. Housekeeping may include making the resident's bed, vacuuming the resident's room, washing the floors in the resident's personal living area, dusting the resident's furniture, getting rid of odors in the resident's room, and/or defrosting the fridge in the resident's personal living space (Assisted Living). Time spent in performing housekeeping tasks apply only to the time spent in maintaining the resident's space and belongings. [*This service event DOES NOT include the time spent housekeeping areas that are common to other residents or household members. Laundering of the resident's clothes and linens are NOT included.*]

18. **Cleaning common areas** - Cleanup may begin with the completion of the meal or snack, and includes loading and unloading the dishwasher, washing pots and pans, wiping tables and chairs, changing tablecloths, washing kitchen counters, sweeping/mopping the floors in the eating and kitchen areas, and ends with dishes being put away.

19. **Taking care of her/his clothes** - Care of personal wardrobe may also include labeling clothes with the resident's identification, taking inventory of the resident's clothes, mending resident's clothing, and taking to and picking up resident's clothes from the dry cleaners.

20. **Doing her/his laundry** - refers to those activities that are typically associated with keeping resident's clothing clean, in good repair and organized. The care of personal wardrobe includes gathering dirty laundry, hand and machine washing, drying, sorting, folding, ironing, and putting away the resident's clothes and linens.

21. **Helping her/him with financial affairs** - refers to activities that are involved in attending to the resident's finances and personal business. Commerce and correspondence activities may include assisting with or doing the resident's banking; paying the resident's bills; getting money out of the resident's bank account and giving it to the resident; helping the resident write out cheques; providing assistance to the resident with financial matters such as budgeting; keeping proper files; writing letters about financial matters; preparing income tax returns; estate planning and wills; Transportation time needed to carry out banking and payment of bills services ARE included. [*This service event DOES NOT include giving the resident money from your own resources.*]

22. **"Keeping an eye on things"** - refers to watching and "checking up" on the resident to make sure that the resident's needs are recognized and met. "Keeping an eye on" a resident may include: checking up on the resident (physical, mental, and emotional states); assisting or monitoring the safety of the resident and the security of his/her belongings; and checking into resident's complaints or grievances.

23. **"Speaking up for" her/him** - refers to those activities that are undertaken to support or defend the rights and preferences of the resident. "Speaking up for" a resident may include: informing other staff, family members, and residents of a resident's preferences; correcting other staff, family and residents when a resident's choice are not respected; protecting the resident's rights to privacy; safeguarding equal treatment of all residents; reporting concerns to appropriate authorities.

24. **Providing emotional support** - refers to activities that are designed and delivered with the specific intent of respecting and meeting the emotional needs and preferences

of individual residents. Emotional support may include those occasions when the primary activity provided to the resident is listening to the resident; providing chances for the resident to air grievances; validating the resident's feelings; talking with the resident about the resident's family (e.g., asking questions about photos or visits); giving reassurance or encouragement; offering to give, or upon the request of the resident, providing a back rub or massage for non-therapeutic purposes; and/or offering appropriate physical touch (i.e., hugs) with the intent of giving comfort to the resident. Providing emotional support may also include: confirming with a resident his/her expressed wishes; talking with a resident regarding his/her preferences; encouraging the family and friends of the resident to visit; and discussing concerns or issues with a resident's family and friends. [*This DOES NOT include formal counseling.*]

25. **Helping her/him connect with others** - reading letters to the resident; writing letters for the resident; and providing help to the resident in making telephone calls (looking up numbers, dialing, answering the phone).

26. **Participate with her/him in leisure activities** - refers to activities that create opportunities for the resident to choose to take part in individual or group leisure events or outings. Activities involved in supporting leisure participation include: organizing activities for residents; informing residents, family members and staff members of leisure events; inviting residents, family members and staff members to participate in planned leisure activities; encouraging and motivating the resident to make decisions regarding leisure participation; assisting, supervising, or participating with a resident in a recreational event or outing, hobby or interest (i.e., cooking, listening to music, singing), going for a drive, staying with the resident during social events (i.e., family gatherings, leisure activities) or religious/cultural events (i.e., church service). [*This DOES NOT include off-site transportation.*]

27. **Helping with her/his spiritual/cultural practices** - refers to activities that enhance, promote or preserve the cultural/religious/ethnic customs practiced by the resident. Activities that support spiritual/cultural practices may include: organizing celebrations for special religious/cultural days; providing ethnic foods selected by the resident; nightly prayers; and making available hymns or spiritual music of the resident's preference.

28. **Help manage her/his physical health** - refers to the assessment, treatment, and management of blood sugar, blood pressure, heart rate, pulse, respiration, temperature, weight, circulation, and/or skin condition. Assessing a resident's health status may include: checking for pressure sores; weighing and recording of the resident's body weight; checking the resident's hands and feet for indications of circulation problems; taking and recording the resident's pulse; monitoring of the resident's blood sugar. Treating and managing of the resident's physical health may involve: reviewing the resident's chart, following up doctor's standing orders; notifying the doctor when necessary; seeking a second opinion from the resident's family members, other staff, supervisor, visiting nurse, resident or family doctor or other health professionals about concerns of the resident's physical health.

29. **Helping to ensure her/his behavior is appropriate and safe** - refers to the assessment, treatment, and management of a resident's behavior. Managing behavior activities may include (altering the resident's sleep patterns?); redirecting them; intervening between different residents; cueing the resident; smoking, use of a stove.

30. **Helping her/him deal with pain** - Treatments for managing pain may include: supervising prescribed exercise routines, applying hot/cold packs, assisting with passive manipulation, and giving a body massage. [*This service event DOES NOT include giving medication or monitoring the effectiveness of medication.*]

31. **Watching for her/his reaction to medications** - refers to observing for and recording of indicators of medication interactions and/or toxicity. Activities involved with monitoring effectiveness and tolerance of medications may include: reading resident records to become familiar with medication changes; reviewing resident's medication schedule; documenting medication changes; consulting with the resident's family members, other staff members, supervisor, pharmacist, doctor, or registered nurse about medication concerns.

32. **Helping her/him with remembering** - refers to activities designed to assist the resident with making choices, remembering, and being oriented to their reality. Activities that facilitate cognitive ability may include: preparing memory aids, providing environmental cueing and redirection. Specific activities to facilitate cognitive ability may include: using calendars and notes to remind the resident of things to do, upcoming activities and important dates; encouraging or assisting the resident to use a

diary or daily log to record activities, visitors, appointments, weather conditions, or important events for the purposes of client's recall; providing current newspapers and magazines to keep the resident updated and oriented to world events; helping the resident recall and talk about past events; providing verbal indicators of the day, time, month; calling the resident by name; giving verbal directions to the resident.

Appendix C

Stylized Interview Script with Family Members

General Information

Name of Respondent _______________ Code: ______ Phone #__________
Name of Resident _______________ Code: ______ Interviewer ________
Relationship of resident to callee: _______________ Code: ______

Name of resident's program: MPN WH CC FH

Record of call

Date	Start Time	Stop Time	Comments

Introduction

Hello, may I speak with *(name of respondent)*? *(Proceed with designated person).* I'm *(interviewer's name)* from the EPICC project at the University of Alberta.

If we have consent:

You may recall reading about our project at *(name of facility or caregiver's home)* where your *(state relationship to resident)* is living. We are evaluating new ways in which long term care services are provided to seniors. You signed a consent form indicating that you are willing to participate in our study. I would like to talk with you about the ways in which you may help your *(state relationship to resident)* since she/e has been living at *(name of facility or caregiver's home).*

If network call:

I got your name from *(person X) who indicated that you were involved in helping* (indicate name of the resident). We are evaluating new ways in which long term care services are provided to seniors. I would like to talk with you about the ways in which you help your *(state relationship to resident)* since she/he has been living at *(name of facility or caregiver's home).*

Ethics Clause

All information collected in this interview will be kept strictly confidential. Your participation is voluntary but essential if we want to talk about the assistance that families provide to residents of these new long-term care programs. This interview is expected to take about 15-20 minutes, depending on the amount of information you provide. Is this a good time to talk?

Yes___[proceed]
No___[schedule a more convenient time] Specify date_________ Time______

Length of Stay Screen:

Has your *(specify relationship of resident to respondent)* lived at *(name facility or caregiver's home)* for longer than one month?

Yes - (If more than one month) I will read a list of activities that family members may do to help an elderly relative. No one does all of these things. You may have done none of these or many of these for your relative. Please answer as accurately as you can. [Go to Assistance Screen]

No - (If less than one month) We are interested in things you do for your relative after she/he has been there longer than one month. Can we call you back in one month's time?

Yes___[Schedule a more convenient time] Date__________ Time ______
No___[Discontinue Interview]

Don't Know - [Go to Assistance Screen]

Assistance Screen

In the last month have you done any of the following for your *(specify relationship of resident to respondent)*?

<u>Shopping</u> Yes No	Helping your *[specify relationship]* with shopping, such as acquiring special equipment, medical supplies or other things she/he may need? [If yes go to shopping section at end of assistance screen].
<u>Transportation</u> Yes No	Transporting your *[specify relationship]* by driving her/him places, going with her/him to appointments or running errands with her/him? [If yes go to Transportation section at end of assistance screen].
<u>Housework</u> Yes No	Helping your *[specify relationship]* with housework such as preparing food, cleaning her/his room, doing her/his laundry or taking care of her/his clothes? [If yes, go to Housework section at end of assistance screen].
<u>Personal Care</u> Yes No	Helping your *[specify relationship]* with personal care activities such as getting her/him ready of the day or for bed, showering or bathing, doing her/his hair or nails, taking medications, going to the bathroom or assisting with mealtime? [If yes, go to Personal Care section at the end of the assistance screen].
<u>Care Management</u> Yes No	Managing her/his care by making appointments, keeping an eye on things, or speaking up for her/him? [If yes, go to Care Management at end of assistance screen].
<u>Financial Mgt</u> Yes No	Helping your *[specify relationship]* to manage her/his financial affairs? [If yes, go to Financial Management at end of assistance screen].
<u>Enhancing WB</u> Yes No	Enhancing your *[specify relationship]* 's well-being by just being there, talking and listening, helping her/him keep in touch with family or friends, participating in leisure activities, taking her/him to church or other special places, or helping her/him with remembering? [If yes, go to Enhancing Well-Being section at end of assistance screen].
<u>Skilled Care</u> Yes No	Providing skilled care such as managing her/his physical health, ensuring her/his behavior is safe and appropriate, helping her/him deal with pain, or watching her/him for reactions to medications? [If yes, go to Skilled Care section at end of assistance screen].

[Go to each section in which the respondent answered Yes]

SHOPPING

1. Got her/him special equipment

In the last month, have you...? Yes_____ No______	DEFINITION: refers to activities that are involved to make equipment available. These activities may include transportation time involved in shopping and purchasing or renting prescribed or non-prescribed mobility aids (wheelchair, walker, can), adaptive devices (utensils, shoe inserts, communication aids), commodes, grab bars, or lifts; checking condition of equipment; arranging for equipment repairs; ordering new equipment, and billing appropriate persons.	**During the last month, how many times did you provide these services?** ___times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

2. Acquired medical supplies

In the last month, have you...? Yes_____ No______	DEFINITION: refers to activities that are involved in making medical supplies available. Activities may include: shopping and purchasing prescribed drugs or medications, and supplies for ongoing health needs (incontinence supplies, bowel and bladder management supplies, wound management, infection control, batteries); transportation time; in-house ordering of medical supplies for a specific resident; updating inventory to make sure that there are adequate supplies on hand per resident; and/or recording use of medical supplies for the purposes of billing individual resident.	**During the last month, how many times did you provide these services?** ___times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

3. Shopping for other things

In the last month, have you...? Yes_____ No______	DEFINITION: refers to activities that are necessary in obtaining products. Shopping for goods may begin with making a list of the goods needed and may include travel to and from the store; shopping around and purchasing the requested or needed items. This event ends with delivering the goods to the resident. Items that are considered goods include: non-prescribed medications, toiletries, groceries, clothing, leisure items, etc. [shopping does not include shopping for medical supplies or special equipment].	**During the last month, how many times did you provide these services?** ___times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

TRANSPORTATION

4. Went with her/him to appointments/ran errands with her/him

In the last month, have you...? Yes_____ No______	DEFINITION: refers to accompanying a resident to an "in-house" or off-site activity. For off-site events, accompanying the resident begins after the resident has exited the transportation vehicle. The purpose of accompanying a resident is to provide supervision or physical assistance to the resident. Accompanying the resident may begin with assisting the resident to get ready for going out, and include other activities such as escorting the resident to and from their appointment or planned event, staying with the resident before, during and after the planned event. This service event may end with the return of the resident to their lodgings or room. Examples include going with the resident to appointments, waiting for the resident while they are receiving services, running errands with the resident. Does not include time spend driving or transporting the client.	**During the last month, how many times did you provide these services?** ___times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

5. Drove her/him places

In the last month, have you...? Yes_____ No______	DEFINITION: refers to providing transportation to a resident from point A to point B. Driving the resident to a specific place may begin with providing assistance with getting into the vehicle and includes driving the resident to and from a given destination and may include providing assistance to the resident with getting out of the vehicle. [Time spent with the resident once arrived at destination is not included in this service event. If the purpose of driving the resident is for leisure, include time spent under participating in leisure activities. Do not include transportation time spent performing other services such as shopping for/with the resident, doing the resident's banking, etc.]	**During the last month, how many times did you provide these services?** ___times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

HOUSEWORK

6. Prepare food

In the last month, have you...? Yes_____ No______	DEFINITION: refers to activities that may be involved in getting meals and snacks ready and keeping clean areas associated with food preparation and eating. Encouraging and supervising resident participation in any or all of the following activities are also included. Food preparation may begin with planning meals or snacks, and could include preparing beverages, snacks, and meals; and setting tables. [Does not include assisting the resident with eating].	**During the last month, how many times did you provide these services?** ___times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

7. Cleaned her/his room

In the last month, have you...? Yes_____ No______	DEFINITION: refers to activities generally considered to be light house cleaning. Housekeeping may include making the resident's bed, vacuuming the resident's room, washing the floors in the resident's personal living area, dusting the resident's furniture, getting rid of odors in the resident's room, and/or defrosting the fridge in the resident's personal living space. Time spent performing housekeeping tasks apply only to time spent in maintaining the resident's space and belongings. [This service does not include the time spent housekeeping areas that are common to other residents or household members. Laundering of clothes and linens are not included.]	**During the last month, how many times did you provide these services?** ___times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

8. Cleaned common areas

In the last month, have you...? Yes_____ No______	DEFINITION: refers to cleaning any areas of the residence that are used by everyone. Kitchen cleanup may begin with the completion of the meal or snack, and includes loading and unloading the dishwasher, washing pots and pans, wiping tables and chairs, changing table cloths, washing kitchen counters, sweeping/mopping the floors in the eating and kitchen area, and ends with dishes being put away.	**During the last month, how many times did you provide these services?** ___times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

9. Did her/his laundry

In the last month, have you...? Yes_____ No______	DEFINITION: refers to those activities that are typically associated with keeping resident's clothing clean, in good repair and organized. The care of personal wardrobe includes gathering dirty laundry, hand and machine washing, drying, sorting, folding, ironing, and putting away the resident's clothing and linens.	**During the last month, how many times did you provide these services?** ___times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

10. Took care of her/his clothes (excludes shopping)

In the last month, have you...? Yes_____ No______	DEFINITION: refers to labeling clothes with the resident's identification, taking inventory of the resident's clothes, mending resident's clothing, taking to and picking up resident's clothes from the dry cleaners, and changing wardrobe as the season changes.	**During the last month, how many times did you provide these services?** ___times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

DIRECT PERSONAL CARE SERVICES

11. Helped her/him get ready for the day

In the last month, have you...? Yes_____ No______	DEFINITION: includes activities that are often part of a morning routine. Getting ready for the day may begin with greeting the resident or waking the resident from his/her night sleep, and may include activities such as: helping the resident with washing up, shaving, putting on make-up, picking out an outfit, checking the condition of the garments, dressing, and/or whatever else the resident thinks is necessary to make him/her feel presentable. This service event ends with the resident being fully dressed . [Toileting and giving of medications are not included in this service event.]	**During the last month, how many times did you provide these services?** ___times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

12. Helped her/him get ready for bed

In the last month, have you...? Yes_____ No______	DEFINITION: refers to activities that are often part of an evening routine to prepare for sleep. Getting ready for bed may start with arranging a bed time with the resident, and may include escorting, accompanying or assisting the resident with getting to his/her room; helping or supervising the resident change from day clothes to night clothes; aiding the resident with removing dentures, glasses, or hearing aids; helping or supervising resident shaving, applying cream to face and hands, and/or whatever else the resident thinks is necessary to get ready for bed. Other kinds of activities include: pulling down bed covers, setting up water glass, setting out urine bottle, turning off lights, pulling down blinds, opening/closing windows. This service event ends with assisting the resident into bed and any kind of "touching in" rituals. [Toileting and giving medications are not included in this service event.]	**During the last month, how many times did you provide these services?** ___times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

13. Helped her/him shower or have a bath

In the last month, have you...? Yes_____ No______	DEFINITION: refers to activities that are part of getting the resident ready for a shower/bath, having a shower/bath, and leaning or tidying the bath area. Showering/bathing may begin with arranging with the resident the day or time of the shower/bath. Other activities that may be part of showering/bathing include making the bathroom ready; getting supplies ready for the bath; locating the resident and escorting/accompanying the resident to the bathing area; assisting or supervising the resident with: getting into the bath, the washing of his/her body, getting out of the tub, drying off and getting dressed. Also include applying body cream or powder. Showering/bathing ends when the resident is dressed and leaves the bathroom area, and the bathing area has been tidied.	**During the last month, how many times did you provide these services?** ___times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

14. Did her/his hair

In the last month, have you...? Yes_____ No______	DEFINITION: refers to periodic hair care that is often done at a beauty parlor. Activities include: washing, rinsing, setting, drying, perming, coloring, and cutting the resident's hair. Activities included in getting the hair done may include locating and informing the resident of appointment time; and taking the resident to and from the hairdresser (on-site). [This does not include routine brushing of the resident's hair.]	**During the last month, how many times did you provide these services?** ___times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

15. Did her/his nails

In the last month, have you...? Yes_____ No______	DEFINITION: refers to both routine hand, foot and nail care, as well as some extra services for the resident. Routine hand, foot and nail activities may involve: clipping or filing of nails, pushing back cuticles, applying bunion or corn bandages, and/or applying hand and foot cream. Extra services may include activities that are typically associated with manicures and/or pedicures: trimming cuticles, smoothing calluses, buffing, polishing, and/or painting finger and toe nails. [This does not include medical treatment for foot conditions.]	**During the last month, how many times did you provide these services?** ___times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

16. Helped her/him go to the bathroom

In the last month, have you...? Yes_____ No______	DEFINITION: refers to activities that are typically associated with using the toilet. Toileting may begin with checking with the resident regarding their need to use the toilet and may include assisting or supervising the resident with: getting to the bathroom, removing clothing, transferring on/off toilet, peri-care, changing incontinence pads, redressing and personal hygiene. The service event ends when the resident leaves the bathroom.	**During the last month, how many times did you provide these services?** ___times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

17. Assisting with mealtime

In the last month, have you...? Yes_____ No______	DEFINITION: refers to activities that are performed to help the resident with his/her meals. Assisting the resident with mealtime may begin by informing the resident that the meal is ready, and may also include activities where direct or stand-by assistance is provided to the resident with getting the resident to and from the table; offering and assisting the resident with a napkin or bib, offering the resident a choice of food or beverages, dishing up food on the resident's plate; and serving the food and beverages to the table. Assisting the resident with mealtime ends with clearing the dishes from the table. [This service event does not include helping the resident eat.]	**During the last month, how many times did you provide these services?** ___times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

19. Helping her/him with medications

In the last month, have you...? Yes_____ No______	DEFINITION: refers to activities that are involved in making sure that a resident receives and takes their medicine. Activities associated with giving medication may include: reminding the resident to take their medication, preparing dosettes or medicine trays; checking resident records to ensure the right medicine is given in the right dosage, to the right person, in the right dose and routine, at the right time; recording in the resident's medication chart, getting the medication from medical room/cabinet/fridge, preparing the medication, taking the medication to the resident, assisting or monitoring the resident with taking medication, and cleaning up/putting away things needed for giving medications.	**During the last month, how many times did you provide these services?** ___times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

CARE MANAGEMENT

20. Make appointments and arrange services for her/him

In the last month, have you...? Yes_____ No______	DEFINITION: refers to those activities that are needed to make assistance, products, or resources available and accessible to a resident. Typically the activities involved require information gathering, matching a resident's needs to available resources, and making appropriate arrangements. Gathering information may include: inquiring in-person about available services; making telephone calls, writing letters, sending faxes or e-mails requesting information, and/or picking up information packages. Matching resident's needs with available resources may include reading information packages, visiting program sites or interviewing potential service providers. Making appropriate arrangements may include: arranging for transportation, informing pastoral care staff of a resident's need; making appointments for the resident with professionals; arranging appointments for hair and nail care; making arrangements for a care companion to accompany resident outings; arrange for others to provide spiritual/cultural or leisure activities for the resident.	**During the last month, how many times did you provide these services?** ___times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

21. Kept an eye on things

In the last month, have you...? Yes_____ No______	DEFINITION: refers to watching and checking up on the resident to make sure that the resident's needs are recognized and met. Keeping an eye on the resident may include: checking up on the resident; assisting or monitoring the safety of the resident and the security of his/her belongings; and checking into resident's complaints or grievances.	**During the last month, how many times did you provide these services?** ___times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

22. Spoke up for her/him

In the last month, have you...? Yes_____ No______	DEFINITION: refers to those activities that are undertaken to support or defend the rights and preferences of the resident. Speaking up for a resident may include: informing other staff, family members, and residents of the resident's preferences; correcting other staff, family, and residents when a resident's choice are not respected; protecting the resident's'	**During the last month, how many times did you provide these services?** ___times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

FINANCIAL MANAGEMENT

23. Helped her/him with financial affairs

In the last month, have you...? Yes_____ No______	DEFINITION: refers to activities that are involved in attending to the resident's finances, insurance and personal business. Commerce and correspondence activities may include assisting with or doing the resident's banking; paying the resident's bills; getting money out of the resident's bank account and giving it to the resident; helping the resident write out cheques; providing assistance to the resident with financial matters such as budgeting; keeping proper files; writing letters about financial matters; preparing income tax returns; estate planning and wills; Transportation time needed to carry out banking and payment of bills services ARE included. [*This service event DOES NOT include giving the resident money from your own resources.*]	**During the last month, how many times did you provide these services?** ___times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

ENHANCING WELL-BEING

24. Participated with her/him in leisure activities

In the last month, have you...? Yes_____ No______	DEFINITION: refers to activities that create opportunities for the resident to choose to take part in individual or group leisure events or outings. Activities involved in supporting leisure participation include: organizing activities for residents; informing residents, family members and staff members of leisure events; inviting residents, family members and staff members to participate in planned leisure activities; encouraging and motivating the resident to make decisions regarding leisure participation; assisting, supervising, or participating with a resident in a recreational event or outing, hobby or interest (i.e., cooking, listening to music, singing), going for a drive, staying with the resident during social events (i.e., family gatherings, leisure activities) or religious/cultural events (i.e., church service). [*This DOES NOT include off-site transportation.*]	**During the last month, how many times did you provide these services?** ___times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

25. Helped with her/his spiritual/cultural practices

In the last month, have you...? Yes_____ No______	DEFINITION: refers to activities that enhance, promote or preserve the cultural/religious/ethnic customs practiced by the resident. Activities that support spiritual/cultural practices may include: organizing celebrations for special religious/cultural days; providing ethnic foods selected by the resident; nightly prayers; and making available hymns or spiritual music of the resident's preference.	**During the last month, how many times did you provide these services?** ___times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

26. Helped her/him keep in touch with family or friends

In the last month, have you...? Yes_____ No______	DEFINITION: refers to reading letters to the resident; writing letters for the resident; and providing help to the resident in making telephone calls (looking up numbers, dialing, answering the phone).	**During the last month, how many times did you provide these services?** ___times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

27. Were just there for her/him (e.g. talked with and listened to, visited)

In the last month, have you...? Yes_____ No______	DEFINITION: refers to activities that are designed and delivered with the specific intent of respecting and meeting the emotional needs and preferences of individual residents. Emotional support may include those occasions when the primary activity provided to the resident is listening to the resident; providing chances for the resident to air grievances; validating the resident's feelings; talking with the resident about the resident's family (e.g., asking questions about photos or visits); giving reassurance or encouragement; offering to give, or upon the request of the resident, providing a back rub or massage for non-therapeutic purposes; and/or offering appropriate physical touch (i.e., hugs) with the intent of giving comfort to the resident. Providing emotional support may also include: confirming with a resident his/her expressed wishes; talking with a resident regarding his/her preferences; encouraging the family and friends of the resident to visit; and discussing concerns or issues with a resident's family and friends. [*This DOES NOT include formal counseling.*]	**During the last month, how many times did you provide these services?** ___times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

28. Helped her/him with remembering

In the last month, have you...? Yes_____ No______	DEFINITION: refers to activities designed to assist the resident with making choices, remembering, and being oriented to their reality. Activities that facilitate cognitive ability may include: preparing memory aids, providing environmental cueing and redirection. Specific activities to facilitate cognitive ability may include: using calendars and notes to remind the resident of things to do, upcoming activities and important dates; encouraging or assisting the resident to use a diary or daily log to record activities, visitors, appointments, weather conditions, or important events for the purposes of client's recall; providing current newspapers and magazines to keep the resident updated and oriented to world events; helping the resident recall and talk about past events; providing verbal indicators of the day, time, month; calling the resident by name; giving verbal directions to the resident.	**During the last month, how many times did you provide these services?** ___times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

SKILLED CARE

29. Helped manage her/his physical health

In the last month, have you...? Yes_____ No______	DEFINITION: refers to the assessment, treatment, and management of blood sugar, blood pressure, heart rate, pulse, respiration, temperature, weight, circulation, and/or skin condition. Assessing a resident's health status may include: checking for pressure sores; weighing and recording of the resident's body weight; checking the resident's hands and feet for indications of circulation problems; taking and recording the resident's pulse; monitoring of the resident's blood sugar. Treating and managing of the resident's physical health may involve: reviewing the resident's chart, following up doctor's standing orders; notifying the doctor when necessary; seeking a second opinion from the resident's family members, other staff, supervisor, visiting nurse, resident or family doctor or other health professionals about concerns of the resident's physical health.	**During the last month, how many times did you provide these services?** ____times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

30. Helped to ensure her/his behavior is appropriate and safe

In the last month, have you...? Yes_____ No______	DEFINITION: refers to the assessment, treatment, and management of a resident's behavior. Managing behavior activities may include (altering the resident's sleep patterns?); intervening between different residents; watching resident's smoking, or use of a stove, and . redirecting or cueing her/him (e.g., (1)"You just finished smoking a cigarette. You can have another one before lunch. Would you like some coffee or a snack instead?", (2) at mealtime, "We're having soup today. I see you are using a fork. A spoon may work better. Try this.")	**During the last month, how many times did you provide these services?** ____times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

31. Helped her/him deal with pain

In the last month, have you...? Yes_____ No______	DEFINITION: refers to treatments for managing pain including: supervising exercise routines, applying hot/cold packs, assisting with passive manipulation, and giving a body massage. [*This service event DOES NOT include giving medication or monitoring the effectiveness of medication.*]	**During the last month, how many times did you provide these services?** ___times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

32. Watched for her/his reaction to medications

In the last month, have you...? Yes_____ No______	DEFINITION: refers to observing for and recording of indicators of medication interactions and/or toxicity. Activities involved with monitoring effectiveness and tolerance of medications may include: reading resident records to become familiar with medication changes; reviewing resident's medication schedule; documenting medication changes; consulting with the resident's family members, other staff members, supervisor, pharmacist, doctor, or registered nurse about medication concerns.	**During the last month, how many times did you provide these services?** ___times/mo.	**On average, how much time did you spend on each occasion?** ___minutes

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[Ask the following questions of all respondents.]

33. Is there anything else that you do for your *[specify relationship to resident]* that I haven't asked you about? [For each task provided, obtain information on frequency or occurrences and time.]
______Yes [If yes, please specify.]
______No

34. Do you do any of these activities for other residents at *[name of facility or caregiver's home.]*? [Obtain list of activities only.]
______Yes [If yes, please specify.]
______No

35. Has the time that you have spent helping your *[specify relationship to resident]* had an impact on your personal or family life?
______Yes [If yes, please specify.]
______No

Out-of-Pocket Expenses

36. In the last month, have you had any expenses related to caring for your relative?
______Yes [If yes, please specify.]
______No

In which of the following areas have you incurred expenses?

No	Yes	-Medications
No	Yes	-Transportation such as taxi, bus, DATs or gas for a car
No	Yes	-Special equipment such as cane, walker, wheel chair, lift
No	Yes	-Health supplies such as incontinence supplies or bowel and bladder management supplies
No	Yes	-Goods such as toiletries, clothing, cigarettes or other leisure items
No	Yes	-Groceries
No	Yes	-Long distance telephone calls
No	Yes	-Purchase of services not provided by the program such as companion, homemaker, home care or nursing care services

Demographics

We would like to get some information about you that may help us better understand those family members who help.

37. How long does it take for you to get to your *[specify relationship to resident]*'s place? (Time in hours)

38. Do you have a driver's license?
Yes__________
No__________

39. Do you work outside the home?

Retired
Not Employed
Employed part-time
Employed full-time

40. What is your marital status?

Married/Common-law
Single
Widow/Widower
Divorced/Separated

41. Do you have any children living with you ? (number and age of children in the home)

Yes	Years	Years	Years
No	Years	Years	Years

42. How would you rate your current health?

Excellent
Good
Fair
Poor

43. What is your current age?

Network Questions

Is there anybody else in the family who is doing these things for your *[specify relationship to resident]*?	Will you pass us along? -Yes [Please ask name] -No	[If yes, please ask what his/her telephone number is.]

We have finished the first section of the interview. We have talked about the ways in which you help your *[state relationship to resident]*. Now, I would like to ask you some questions about who you believe should be responsible for helping your *[state relationship to resident]*? These question will take about 10 minutes to answer. Do you have time now?

Yes_________[proceed with Beliefs about responsibility questionnaire]
No__________[schedule a more convenient time] specify date________
specify time________

We have finished the interview. Thank you very much for you time and participation in the project. If you have any questions in the future please call us at 492-2865.

[complete Record of Call on front page at the end of the interview]

Appendix D

Information Sheet

Introduction Of EPICC To Potential Family Member Participants & Informal Caregivers/Volunteers

What's the project?

EPICC stands for Evaluating Programs of Innovative Continuing Care. It is a three year collaborative research project funded by Health Canada to evaluate and describe three innovative approaches to providing residential continuing care. The programs we are evaluating are *(name of dementia care facility), (name of assisted living facility), (names of the adult family living programs).* The research project is based at the University of Alberta and involves partnerships with Alberta Health and participating program sites.

We needed a way to describe and evaluate these innovative programs in such a way that the differences among the programs were considered. To do this we selected five research themes. I'd like to give you a brief overview of each research theme.

The first theme is autonomy and choice. The new vision of continuing care emphasizes the importance of individuality and choices in designing services that support the independence and quality of life of clients. We are interested in talking with clients, family members and staff about their lived experiences in these new programs.

The second theme is consumer satisfaction. In the new vision clients are considered to be consumers of services. We are interested in asking clients and family members how satisfied are they with the services they receive and the setting in which the services are provided. A questionnaire is currently being developed that will measure the level of satisfaction across a number of areas, including the physical and emotional needs of clients, the physical setting, support provided, and links with services in the community.

The third theme is care and service delivery. Emerging policies talk about caring partnerships in which clients, family members and paid service providers work together to provide services to clients. We are interested in describing these partnerships in two ways. The first way is to describe the distribution of services in terms of people's use of time providing services to a given client. We want to answer the question, "Who is doing what for whom." The second way is to find out what people believe in terms of who should do what for whom. Who should have responsibility for the provision of particular services and how should people share the responsibilities of caring for frail seniors?

The fourth theme is cost. Because of cutbacks in health care, programs are being designed to be more cost-effective. How can we provide the same services for less money? We are looking at costs in two ways. The first way is to examine public program costs. How much per day per client does it cost the system? The second way is to look at the total cost of providing care based on replacement costs. In this way, the time spent by informal caregivers such as family members, friends, neighbors and volunteers providing services to frail seniors are given an economic value. By doing this the notion that community care is cheaper may be challenged.

The last theme is process of implementation. In this theme were are looking at documenting the implementation of an innovative program such as *(dementia care facility).* How did it go from an idea, through the planning stages to a fully operational program? What were the challenges along the way in implementing such a program? By tracking the implementation process we can pass important information on to other organizations who may wish to start a similar program.

What would we like from family members:

- descriptive information about yourself
- your involvement in caring for your relative, including the time you spend, and your out-of-pocket expenses
  - ⇒ This will be done in a telephone interview scheduled at your convenience.
- your beliefs about who should be providing what kind of assistance and how much
  - ⇒ This will be done through a questionnaire about how much responsibility each partner (resident, family member and staff member) should assume for a given task. This question is repeated across a number of different elder care tasks such as bathing, hair care, monitoring and emotional support.
- your participation in a discussion group regarding care options that were considered prior to placement, choices and decisions you have made about your relative's care, and your involvement in that care
  - ⇒ These discussion groups will have 8-10 people so we may have more than one depending on interest.
- your overall satisfaction with the care your relative has received
  - ⇒ This will be done through a questionnaire which will be given or mailed to you in 1997/98 fiscal year. The questionnaire is currently being developed and may be complete by next spring.
- your family tree
  - ⇒ This will be done during the interviews with residents. Depending on the cognitive abilities of residents, family members may be asked to provide this information. Information is needed on relatives in 3 generations, as well as the involvement of any relatives in providing care. This may be done in a telephone interview.
- your consent for your relative (resident) to be interviewed
  - ⇒ These interviews will take place at *(dementia care facility)* and will be short conversations and questionnaires about living there and the resident's feelings about the program and services provided.

Timelines

We will be collecting most of the information between now and the end of March 1997. A final report will be written and submitted with recommendations to Health Canada in March of 1998. We hope that you will agree to be involved in this important project. If you are interested in participating please sign a consent form before you leave and write your name, address and telephone number on the form. Once the consents are obtained from family members a research associate from EPICC will begin to interview residents. We will be calling family members and volunteers directly to arrange convenient times to interview you and to set up focus groups. If you have any questions or concerns at any time please call the EPICC Project office at 492-2865. All information will be kept confidential. Your anonymity will be protected.

Appendix E

Evaluating Programs of Continuing Care (EPICC) Project
Consent form for family members

Researchers:
Norah Keating, Department of Human Ecology, University of Alberta, 492-4191
Corinne Schalm, Assurance Branch, Alberta Health, 427-7128
Janet Ross Kerr, Faculty of Nursing, University of Alberta, 492-6253
Donna Lynn Smith, Faculty of Nursing, University of Alberta, 492-9544
Sharon Warren, Faculty of Rehab Medicine, University of Alberta, 492-7856
Leslie Gardner, Continuing Care Outcome Measures Project Manager, 427-7128

Title of the Research Project:
EPICC (Evaluating Programs of Innovative Continuing Care)

Description of the Project:
I understand that the purpose of the EPICC project is to evaluate three new ways of providing long term care for seniors living in Alberta. The three ways are: adult family living (also called family care homes and companion care), assisted living and Alberta's first Alzheimer care facility. Some comparisons will be made with traditional long term care facilities. The EPICC project will be completed in phases over the next two years. Based on the findings, suggestions will be made to the government which may affect future policy decisions in the area of long-term care for seniors. The results of these suggestions have potential to benefit individuals who will need long-term care in the future.

Terms and Conditions:
I understand that several times during the next two years I will be asked to answer different sets of questions, either in the form of a questionnaire or in an interview. Each occasion will take an hour or less of my time. Care will be taken wherever possible so that I will not be inconvenienced or become over-tired by the number of questions asked. I understand that for the purpose of this research project, information is needed about:

- myself
- my relative's family tree (i.e., the resident's family)
- my level of involvement in the long term care program that my relative is in
- my feelings about the program and services that are provided to my relative, and
- my feelings about who should provide services

I understand that the researchers would like to tape record the interviews and transcribe them afterwards, but I am free to refuse permission for this procedure.

I understand that my dignity and identity will be protected. All the information will be kept strictly confidential. No one but the interviewer will know my name or the names of other family members. My name and the names of other family members will be replaced with a code number. My name and the names of other family members will not be used in any report or talk about the project.

I understand that participation in this research project is voluntary and I am free to withdraw at any time from this project without risk to myself or to the care my relative receives. If any questions are asked that I do not wish to answer, I am free to not answer them. If I withdraw from the study, I can ask that the information I have already provided not be used in the study.

I understand that there should be no harm to my taking part in this project. I am free to ask questions at any time, during interviews and questionnaires, or in the future. I can call the EPICC Project Manager, Jacquie Eales, at 492-2865 or any of the researchers listed above if I have any questions or concerns.

If the information obtained in this research study is used for another purpose, permission will first be obtained from an ethics committee.

I understand and agree to the conditions outlined above. I agree to participate in this research project.

____________________ Signature of Participant	____________________ Signature of EPICC researcher
____________________ Printed name of Participant	____________________ Printed name of EPICC researcher
____________________ Date	____________________ Date

____

____
Address

____________________ Phone (Day)	____________________ Phone (Evening)

Appendix F

Evaluating Programs of Continuing Care (EPICC) Project

Consent form for family members of clients in dementia care

Researchers:
Norah Keating, Department of Human Ecology, University of Alberta, 492-4191
Corinne Schalm, Assurance Branch, Alberta Health, 427-7128
Janet Ross Kerr, Faculty of Nursing, University of Alberta, 492-6253
Donna Lynn Smith, Faculty of Nursing, University of Alberta, 492-9544
Sharon Warren, Faculty of Rehab Medicine, University of Alberta, 492-7856
Leslie Gardner, Continuing Care Outcome Measures Project Manager, 427-7128

Title of the Research Project:
EPICC (Evaluating Programs of Innovative Continuing Care)

Description of the Project:
I understand that the purpose of the EPICC project is to evaluate three new ways of providing long term care for seniors living in Alberta. The three ways are: adult family living (also called family care homes and companion care), assisted living and Alzheimer care. Some comparisons will be made with traditional long term care facilities. The EPICC project will be completed in phases over the next two years. Based on the findings, suggestions will be made to the government which may affect future policy decisions in the area of long-term care for seniors. The results of these suggestions have potential to benefit individuals who will need long-term care in the future.

Terms and Conditions:
I understand that several times during the next two years I will be asked to answer different sets of questions, either in the form of a questionnaire or in an interview. Each occasion will take an hour or less of my time. Care will be taken wherever possible so that I will not be inconvenienced or become over-tired by the number of questions asked. I understand that for the purpose of this research project, information is needed about:

- myself
- my relative's family tree (i.e., the resident's family)
- my level of involvement in the long term care program that my relative is in
- my feelings about the program and services that are provided to my relative, and
- my feelings about who should provide services

I understand that information is also needed about my relative who resides at *[Dementia care facility]*. An interviewer will spend some time engaging in short conversations with my relative. I understand that for the purpose of this research project, information is needed about my relative's feelings about the program and services provided, and feelings about the appearance and ambiance of *[Dementia care facility]*. The interviewer will also make observations of the daily life of residents in *[Dementia care facility]*. Care will be taken so that my relative will not be inconvenienced or become over-tired by the questions asked.

Wherever possible, information on my relative will be obtained from other sources to avoid duplicate questions. I give permission to the researchers to use information the Capital Care Group has on my relative's abilities and needs obtained from concurrent research projects at *[Dementia care facility]*.. I give permission to the researchers to use information Alberta Health has on my relative's use of health care services such as physician and hospital visits.

I understand that the researchers would like to tape record the interviews and transcribe them afterwards, but I am free to refuse permission for this procedure.

I understand that my dignity and identity will be protected, as well as the dignity and identity of my relative. All the information will be kept strictly confidential. No one but the interviewer will know my name, my relative's name, or the names of other family members. My name, my relative's name, and the names of other family members will be replaced with a code number. My name, my relative's name, and the names of other family members will not be used in any report or talk about the project.

I understand that participation in this research project is voluntary and I am free to withdraw at any time from this project without risk to myself or to the care my relative receives. If any questions are asked that I do not wish to answer, I am free to not answer them. If I withdraw from the study, I can ask that the information I have already provided not be used in the study.

I understand that there should be no harm to taking part in this project. I am free to ask questions at any time, during interviews and questionnaires, or in the future. I can call the EPICC Project Manager, Jacquie Eales, at 492-2865 or any of the researchers listed above if I have any questions or concerns.

If the information obtained in this research study is used for another purpose, permission will first be obtained from an ethics committee.

I understand and agree to the conditions outlined above. I agree to participate in this research project. I agree to allow my relative who resides at *[Dementia care facility]* to participate in this research project.

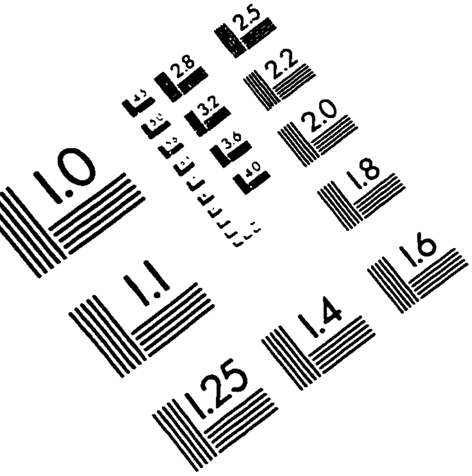
______________________________ Signature of Participant	______________________________ Signature of EPICC researcher
______________________________ Printed name of Participant	______________________________ Date

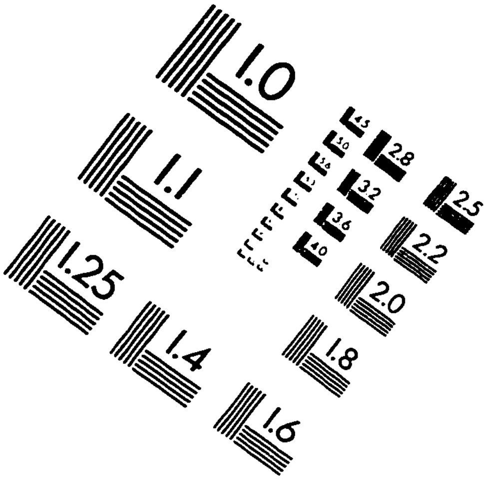
____

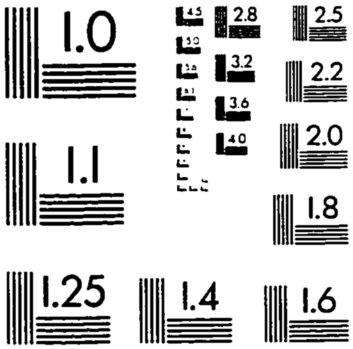
Mailing Address

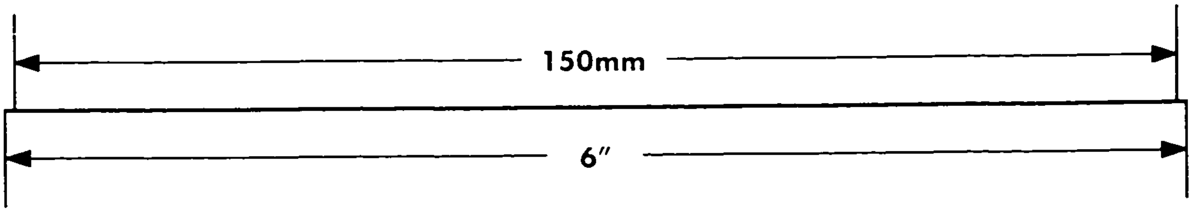
______________________________ Phone (Day)	______________________________ Phone (Evening)

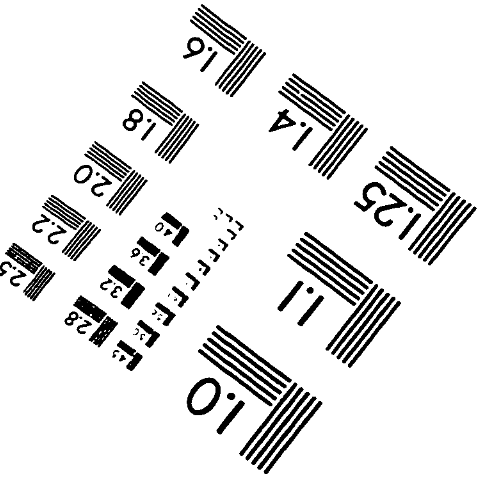
IMAGE EVALUATION TEST TARGET (QA-3)











APPLIED IMAGE, Inc
1653 East Main Street
Rochester, NY 14609 USA
Phone: 716/482-0300
Fax: 716/288-5989