Partners in Caring: Services Provided By Formal And Informal Caregivers To Seniors In Residential Continuing Care

Norah Keating, Lisa Douziech, Janet Fast, Donna Dosman, Jacquie Eales

With support from:

Research Associates: Annita Damsma, Leanne Leverick, Freda Molenkamp, Teresa O’Riordan, Agnes Pieracci, Linda Plotkins

Program Collaborators: Ellen Ayles, Judy Drebert, Cheryl Knight, Carole Marshall, Nat Mitchell, Susan Rogerson, Dan Wold, Phyllis Hempel, Faith Pilgrim, Barbara Ryan, Colleen Tiedemann

New Horizons Directors: Frank Appleby, Richard Cherry, Wanda Cree, Mary Davis, Fred Engelmann, Mary Engelmann, Neli Jackshaw, Mary Norman, Kenneth Pals, Corinne Schalm

Correspondence to
Dr. Norah Keating
Department of Human Ecology
University of Alberta
Edmonton, AB
Canada
T6G 2E7
phone: 403 492 4191
fax: 403 492 6345
e-mail: norah.keating@ualberta.ca

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This report is dedicated to Mary Davis whose professional life was dedicated to service to Alberta seniors and whose death during this project left us with a profound sense of loss.

This report arises from interdisciplinary research done from 1995 to 1998 in the Evaluating Programs of Innovative Continuing Care (EPICC) project, a research project funded by Seniors Independence Research Program (a division of the National Health Research and Development Program). The research team included Norah Keating, Department of Human Ecology, University of Alberta, as principal investigator; Corinne Schalm, Consultant, Alberta Health, Janet Ross Kerr, Faculty of Nursing, University of Alberta, Donna Lynn Smith, Faculty of Nursing, University of Alberta, Sharon Warren, Faculty of Rehabilitation Medicine, University of Alberta, Leslie Gardner, Alberta Continuing Care Outcomes Project as co-investigators; and Jacquie Eales, project manager.
Abstract

Expectations regarding responsibility for meeting health care needs of frail seniors have been changing toward a philosophy of client centred care provided by partners who have formal and informal relationships to the senior. A tenet of the ‘partnerships’ philosophy is that caring is most responsive to seniors’ needs if seniors remain as much as possible part of the community and retain continuity with informal caregivers, often family members, who know them best. Keeping the family involved serves to maintain family ties and connectedness while family involvement in formal care settings is believed to contribute to better quality care for residents. Within the partnerships paradigm it is assumed that family involvement is an important component of best care to seniors in residential care settings.

The purpose of the service delivery theme of the EPICC project was to describe caregiving partnerships among people who are delivering services to elderly residents living in three types of residential care settings: adult family living, assisted living, and dementia care. Objectives of this theme were to develop research instruments and methods to determine what services are provided by caring partners; to determine how much of a set of services is provided by each of the caring partners; and to determine the attitudes of paid and unpaid partners toward responsibility for delivery of these services.

Research instruments and methods developed to measure how formal and informal sectors collaborate were: a comprehensive operational definition of eldercare that incorporated all tasks done by formal and informal caring partners; time use methods to gather information on the types and amounts of these tasks done by formal and informal caring partners; and a beliefs about caregiving instrument to identify caregivers’ commitment to the partnerships philosophy.

Family members provide approximately 40 hours of the direct services to residents per month. Their main caregiving tasks are enhancing well being and transportation. Staff members spend approximately 100 hours per resident per month in direct service. They spend most time on housework and personal care. Partnerships differ depending upon the model of care. Residents in adult family living received from staff members 152 hours of service per month compared to residents in dementia care (93 hours) and assisted living (45 hours). In comparison, residents in adult family living received 32 hours of service per month, dementia care residents received 34 hours per month, and residents in assisted living 50 hours per month from family members.

Family and staff do not have the same beliefs about partnerships. Family and staff agree that staff should be responsible for skilled care and household work, and family should be responsible for financial management and transportation. They do not agree on responsibility for personal care.

Program and policy recommendations are that:

• family members be given an orientation to the types and amount of service they will be expected to provide and the types and amounts of service that will be provided by paid staff.
• attention be paid to the ability of multiskilled workers to manage the workload, especially in assisted living and adult family living models of care
• attention be paid to the ability of family members to manage the workload. Services they provide amount one full work week (40 hours) per month.
• that families be supported in their primary task of enhancing well being and that efforts be made on the formal care side to provide other care tasks
• that expectations about resident involvement in their own care be explicitly discussed among residents, family members and staff
Chapter 1

Introduction

The provision of health care for the elderly has become a key issue today. Expectations regarding responsibility for meeting health care needs of frail seniors have been changing toward a philosophy of client centered care provided by partners who have formal and informal relationships to the senior (Keating, Fast, Conidis, Penning, & Keefe, 1997). A tenet of the ‘partnerships’ philosophy is that caring is most responsive to seniors’ needs if seniors remain as much as possible part of the community and retain continuity with informal caregivers, often family members, who know them best. Keeping the family involved serves to maintain family ties and connectedness (Schwenk, 1993), while family involvement in formal care settings is believed to contribute to better quality care for residents (Schwartz & Vogel, 1990). Within the partnerships paradigm it is assumed that family involvement is an important component of best care to seniors in residential care settings (Keating et al., 1997).

The renewed emphasis on 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 as a means to reduce health care costs (Chappell, 1993) as well as to maintain responsive care from those who know the client best. Those supporting the partnerships paradigm assume that families have an obligation to be involved, and believe that families should be encouraged to do more (Sharp, 1990).
The aspect of the partnerships discussion that we have addressed in EPICC is how partnerships between paid and unpaid caregivers operate when care is being provided within a residential care setting. The EPICC project is an evaluation of how the new paradigm of partnerships and client-centred care is being applied in three models of continuing care that are new to Alberta.

Partnerships are an explicit element of these programs. Alberta Health has made the following statement regarding fundamental goals of continuing care centres: “All services will be directed toward the goal of providing a safe, compassionate, and caring environment which supports individuals, in partnership with their families” (Alberta Health, 1993, p. 12). The nature of the partnerships and how they might play out in these different settings was not known at the beginning of the EPICC project. In the programs evaluated in EPICC, connections with the community are emphasized and the boundaries around the residential settings are open. By virtue of their staffing patterns, the new models of care may have reduced the distinction between the ‘job descriptions’ of paid and unpaid staff. All three models have changed their staffing patterns so that most employees are hired to undertake a broad range of tasks. EPICC is the first comprehensive assessment of ‘who is doing what for whom’ in these new care settings.

The idea of involvement of informal caregivers in residential settings is not new. For at least 20 years there have been reports of involvement of family members in nursing home settings. Much of this previous work has been focused on admonishments to residential staff to find a place for family members in their institution. Wenger (1997) views this approach as one in which informal caregivers are seen as a resource to be utilized rather than true partners in care. In general, findings from these studies are that informal caregivers were seen to be best at providing general tasks such as emotional support, while paid staff were charged with more technical tasks that
required professional training (Barabash, 1989; Schwartz & Vogel, 1990). There is little in this body of literature to inform us about how groups of caregivers work together, nor about their beliefs about how (or whether) caring responsibilities should be shared.

The 1990s version of partnerships is based on two important policy changes seen in the models of care evaluated in EPICC. The first is that there is a set of family and staff members working together to provide care to a target senior. The second is that employees are hired to perform a broad range of care tasks. Together these two policies result in a new service delivery milieu in which boundaries between tasks done by paid and unpaid caregivers may be less clear, while expectations concerning involvement of informal caregivers are more explicit.

The purpose of the service delivery theme in EPICC was to describe caregiving partnerships among people who are delivering services to elderly residents living in three types of residential care settings: assisted living, adult family living and dementia care. Objectives of this theme were:

- to develop methods to determine what services are provided by caregiving partners
- to determine how much of each of a set of services is provided by caregiving partners
- to determine the attitudes of paid and unpaid partners toward responsibility for delivery of these services.

A related objective which was to determine the economic value of the services provided by paid and unpaid caregivers is reported in the technical report on the costs of caring.
Caregivers and Caregiving: The Context

Who are Formal and Informal Caregivers?

In much of the research literature on eldercare, distinctions between formal and informal caregivers are implied. Informal caregivers are seen to be different than formal caregivers in the nature of the relationship between caregiver and care receiver and in the tasks or services provided.

Cantor (1991) has articulated the structural differences among types of caregivers in her ecological model of the context of eldercare which includes formal and informal caregivers. She describes two components of the informal network: kin, and neighbours and friends. Informal care is based on "normative or voluntary interpersonal association" (Litwin & Auslander, 1990, p. 43). Typical normative associations are kinship relationships; while friendships fall within voluntary interpersonal associations. Within the set of informal caregivers, family members are more obliged to help than neighbours and friends (Jacobson, 1987; Qureshi, 1990) who are most likely to provide assistance in the absence of kin (Baillie, Norbeck, & Barnes, 1988; Wenger, 1997). Informal care is typified by exchanges that are not formalized but are based on people caring about each other and on their natural helping tendencies (Hooyman, 1983; National Advisory Council on Aging (NACA), 1990). In contrast, formal care is based on client-agency relationship and is provided by specially trained persons. The major group of formal caregivers is employees of direct service organizations (Cantor, 1991).

Care has also been defined as informal or formal based on whether tasks are seen as the province of one subsystem or to be performed best by that subsystem (Edelman & Hughes, 1990). The formal care system is believed to be best at providing predictable tasks which can be simplified through a division of labour by profession, or through technological advances (Chappell...
& Blandford, 1991). Therefore, services requiring technical expertise such as nursing care, may be more appropriately provided by trained professionals (Edelman & Hughes, 1990). In contrast, informal caregivers are presumed to be best suited to provide non-technical tasks which do not require specialized training. Informal caregivers are seen as being in the best position to provide tasks such as emotional support because they know most about the wishes and needs of their relative.

In contemporary Canadian models of residential care, the distinctions between formal and informal caregivers may not be as clear as these definitions imply. For example, in two of the EPICC models (assisted living and dementia care), multiskilled workers are hired to provide a broad range of tasks from housekeeping to personal care. The array of tasks is likely to be much broader than that previously expected of formal caregivers who had more focused, discipline-specific job descriptions. In the third EPICC model, adult family living, home operators are paid only to provide room and board for residents. Thus, similar to family members, many of the services they provide may be unpaid services.

What is Eldercare?

In order to explore partnerships in caregiving, it is necessary to understand what is meant by care to seniors. There is no consensus on what is the set of tasks that comprise eldercare (Stone, Cafferata, & Sangl, 1987). This is due in part to the fact that there are separate bodies of information on tasks provided by informal caregivers and tasks provided by formal caregivers, usually to seniors in residential care. Thus it is difficult to determine similarities or differences in tasks done by the two groups since data on tasks provided are not gathered in a comprehensive fashion.
In the following section we review information from both bodies of literature on what are the major categories of caregiving tasks. The purpose of this review is to illustrate the state of our knowledge about the full set of tasks done by informal and formal caregivers. Tasks are reviewed in four general categories: direct service provision, financial assistance, bureaucratic mediation and emotional support.

Direct service provision is the most frequently mentioned component of care. It is conceptualized as the provision of aid or instrumental assistance (Depner & Ingersoll-Dayton, 1988; Parks & Pilisuk, 1991); helping behaviours (Stone, 1991); or the incidence and level of involvement in commonly performed caregiving tasks (Rankin, 1990). Direct service provision is often viewed as the most central component of eldercare (Horowitz, 1985).

One way in which direct service tasks can be organized is by intensity of task. Horowitz (1985) sees three levels of intensity of instrumental assistance. The most intense are personal care tasks; followed by in-home services such as housework and home maintenance. The least intense are shopping and transportation.

Personal care services represent the most intensive and intimate of direct service caregiving and are viewed as the most problematic to caregivers (Rankin, 1990). Personal care tasks listed in the literature on informal care include helping the elderly person bathe, dress, walk around the house, eat, get in and out of bed or chair, groom, take medication, cut toenails, use the toilet (see for example, Brody & Schoonover, 1986; Clifford, 1990; Coward, 1987; Kaden & McDaniel, 1990; Kosberg & Cairl, 1986; Rankin, 1990; Stephens & Cristianson, 1986; Walker, Martin, & Jones, 1992).

Research on tasks performed by formal caregivers also indicates that personal care is the most intensive and probably most time consuming category of tasks which they perform. While
some tasks are similar to those performed by informal caregivers, there is an emphasis on the more technical of these tasks in this literature. An example is a study by Alberta Health (1988) in which personal care tasks were divided into three general areas: personal care, chronic care and therapeutic intervention. Personal care included eating, dressing/grooming, toileting, bathing, ambulating/transferring, and transporting (to another part of the facility or outside the facility). Thomas (1993) found that the majority of time spent by staff members in residential care was in this area. Chronic care included incontinence care, bowel care, catheter care, and turning/positioning. Therapeutic intervention included wound care, rehabilitation therapy and foot care.

The second level of direct services consists of in-home assistance such as meal preparation and household help. These are labour intensive services requiring regular time commitments. Tasks are not universally provided but are still engaged in by the majority of informal caregivers. In-home assistance generally falls into two categories: housework and household maintenance.

Housework includes shopping, running errands for elder, making the bed, doing laundry, meal preparation, cooking, meal clean up including washing dishes, cleaning, washing floors, vacuuming (Cicerelli, 1983; Coward, 1987; Kaden & McDaniel, 1990; Litwin & Auslander, 1990; Stephens & Chrisianson, 1986).

House maintenance includes routine tasks such as washing windows, putting up storm windows, painting, making minor repairs such as replacing worn electrical switches; outdoor yardwork such as gardening, mowing the lawn, shoveling the snow (Clifford, 1990; Coward, 1987; Kaden & McDaniel (1990); Litwin & Auslander, 1990; Rankin, 1990; Stephens & Cristianson, 1986; Walker, Martin, & Jones, 1992). This level of direct services is not always
included as eldercare. Its inclusion or exclusion may be based on whether these tasks are seen as eldercare or as everyday activities that must be done by all adults.

Housekeeping and maintenance tasks are given less prominence in the formal care literature, perhaps because they have not generally been a function of front line caregivers in residential care. Such tasks as ‘facility maintenance’ are sometimes designated as nonresident work (Shore, Lerman, Smith, Iwata, & DeLeon, 1995). However, anecdotal evidence suggests that at least in some jurisdictions, multiskilled workers are expected to do a broad range of tasks including household work.

The least intense level of direct service is assistance with shopping, errands, and transportation. These tasks are often intermittent, but are important in helping seniors remain in the community. For example, the ability to get to needed destinations is seen as an essential component of community living (Keating, 1991). Providing transportation, although less intense and time consuming than personal care and household tasks, is part of most comprehensive lists of informal eldercare (Cicerelli, 1983; Coward, 1987; Rankin, 1990; Stephens & Cristianson, 1986; Walker, Martin, & Jones, 1992). In the formal care literature, assistance with errands and transportation may appear under categories of indirect care (Alberta Health, 1988).

Financial assistance is a second category of informal eldercare tasks. Two types of financial assistance are included. The first includes management of the financial affairs of the elder such as balancing chequebooks or filing income tax (George, 1987). This form of financial assistance may be provided to elders who are unused to doing these tasks for themselves such as those who are recently widowed and whose partners were responsible for financial management; or those who have become unable to manage their finances because of disability or illness.
Direct provision of money such as a monthly stipend; or indirect assistance such as paying for goods such as groceries, or services such as homecare or respite services; is a second type of financial assistance (Rankin, 1990; Soldo & Hill, 1993; Walker, Martin, & Jones, 1992). The National Advisory Council on Aging (NACA) (1990) includes costs of adapting the home and purchasing equipment to meet the care recipient’s special needs. Financial assistance is less often included in eldercare than direct service tasks. Yet researchers have argued that private transfers of resources among relatives constitute a significant component of care (Given, Collins & Given, 1988; Moon, 1983).

Financial assistance is missing from formal care lists. One would not expect such support from employees since the transfer of economic resources between individuals usually occurs among kin.

**Bureaucratic mediation** is a term used in the literature on informal care. It is linkage with the formal service sector and is a third category of caregiving. Because of the increase in number and complexity of eldercare services, there is a new role of mediation between the elder and the service bureaucracy (Lingsom, 1989). Members of the elder’s helping network may increase elders’ access to services directly by applying for services on their behalf, or by improving the link between different services and supplying the bureaucracy with information about elders’ changing needs.

This linkage or bureaucratic mediation is not as intense as personal care since it is not direct service provision. However, the rise in the number and complexity of organizational systems which provide services to seniors means that caregivers may spend substantial amounts of time in tasks such as getting information, completing forms, scheduling appointments, finding out about or
arranging services, calling a physician when the elder is ill; telling the physician about the elder’s needs, or negotiating with agencies to provide, change or increase services (Horowitz, 1985).

Case management is the parallel term used in the formal care literature. Case management involves creating links to community services and advocating on behalf of residents (Kane, Penrod, & Kivnick, 1994; Ruffolo & Nichols, 1994).

Emotional support is a fourth category of caregiving tasks. Emotional support includes maintaining social interaction, cheering up an individual when she is depressed, reassuring and validating attitudes or perceptions (George, 1987). Cantor (1991) places opportunities for socialization, self-affirmation and self-actualization first in her list of important eldercare tasks. Baines, Evans, and Neysmith (1992) believe that emotional support or ‘caring about’ is a valuable but often ignored aspect of care. When emotional support is included in inventories of services, it emerges as the most universal caregiving task, engaged in by almost every caregiver (Horowitz, 1985).

Emotional support has increasingly been a focus of formal care provision. For example, in a recent study of staff expectations of themselves and family members, staff members rated emotional support as a task for which both they and family members were responsible (Schwartz & Vogel, 1990). Residents place high value on concern for the individual in the delivery of services to them (Santo-Novak, 1997).

In an attempt to clarify the boundaries around tasks included in eldercare, Keating, Fast, Oakes, and Harlton (1996) conducted a series of focus groups with people with formal and informal perspectives on care for seniors. These included seniors, family members of seniors, professionals providing services to seniors and policy makers at local, provincial and federal levels. Each group was asked to define what is eldercare. Findings were that there was general
agreement that eldercare is “a comprehensive set of tasks and services that maintain or enhance seniors’ independence” (p. 5). The set of tasks was similar to those found in literature reviewed here. Tasks included: personal care, housework, household maintenance and repair, household adaptations, shopping for goods, transportation, management of financial affairs, and care management. These tasks seem to encompass the set of activities found in individual studies reviewed in this section.

It seems clear from our review of the literature on what is eldercare that there has been little comprehensive assessment of tasks provided by both formal and informal caregivers. The literature has tended to be divided along formal/informal lines, perhaps based on an assumption that there is little caring done at the interface. One of the difficulties with this work is that there are no ready-made operational definitions of care provided by informal and formal partners. Such a definition is essential if we are to understand how a set of people provide services to a target senior. The development of a list of services provided by caring partners was part of the methodological development in the service delivery theme and is described in the methods section of this monograph.
Beliefs about Partnerships in Caring

The idea of formal and informal caregivers working together to provide services to frail seniors is not new. However, as is evident from the previous section of the literature review, much of the literature on tasks provided to seniors has been based on an assumption of separation of the two sectors.

There appear to have been two phases in our understanding of the relationships between these two types of caregivers. The first phase was typified in the caregiving literature by an assumption that formal and informal caregivers do not work together, but that their caring occurs in tandem. The belief was that there are no real caring partnerships, since when formal services are provided, informal caregivers withdraw their services. The second phase is typified by an assumption that caring by formal and informal caregivers is, or should be, complementary and that partnerships are ideal ways to meet the needs of frail seniors.

Substitution versus Complementarity

Substitution. Beginning in the 1960s, research was undertaken to test the assumption that there was relatively little joint provision of care by formal and informal caregivers (Shanas, 1960). During that time there were strongly held beliefs that family members did not live up to their filial obligations. For example, Shanas (1979, p. 3) referred to “the widely held belief in contemporary American society [that] old people are alienated from their children.” Treas (1977, p. 486) reflected on “an oft-voiced sentiment holds that younger people no longer accord the parental generation the respect, love and help which are traditionally its due.” The assumption appeared to be that if formal care was available, informal caregivers would reduce or eliminate their involvement in caregiving and that the placement of elderly in formal care settings
symbolized the failure of families to support elderly kin (Brody & Spark, 1966; Shanas, 1979; Silverstone, 1978). Rather than working with formal care providers, family members were seen as withdrawing from active involvement when their relative was placed in residential care. Formal care then, was a substitute for failed informal care (Brody, 1978; Smith & Bengston, 1979).

Research findings of that era did not support the idea of abandonment (Brody, Poulschock, & Massciocchi, 1978). For example, in a study based on interviews with elderly residents of nursing homes and their most involved family member, Smith and Bengston (1979) concluded that many elderly persons in long-term care are close to and involved with their families. Similarly, York and Calsyn (1977) found that families continued their involvement with relatives in nursing homes through visiting and telephone calls. Overall, this early research provided evidence that families were involved, although there was no documentation of the activities done by families after placement.

**Complementarity.** The 1990s version of the interface between formal and informal caregivers is that the best care emerges from ‘caring partnerships’, a collaborative effort in which services are provided by people with varying informal and formal relationships to a senior (Brody, 1995; Keating et al., 1997).

The current belief is that when elderly individuals are first in need of care, they turn to informal caregivers (Cox, 1993; DeFriese & Woomert, 1992; Garant & Bolduc, 1990; Hooyman & Gonyea, 1995). It has been estimated that nearly three quarters of the non-institutionalized elderly population depend on informal caregivers, not on formal care, for the assistance that they receive (DeFriese & Woomert, 1992; Soldo, 1984). However, as care requirements become heavier, or as families’ resources are diminished because of a long caring career (Gottlieb, 1991), families may utilize formal services to assist them in their caregiving tasks (Kane & Kane, 1987; Logan &
Spitze, 1994). The presence of formal care services does not lead to the replacement of care provided by families (Edelman & Hughes, 1990; Garant & Bolduc, 1990). When substitution occurs it tends to be in circumstances such as the loss or change of the primary caregiver. In these cases, substitution of formal services for informal care was temporary, and ended when a replacement informal caregiver was found (Tennstedt, Crawford, & McKinlay, 1993). These authors argue that in community-based care, formal services complement an already well-established system of informal caregiving.

Within the caring partnerships paradigm, there is the assumption that a caregiving partnership should exist (or continue to exist) between family and formal caregivers when the senior is in residential care, and that increased family involvement needs to be encouraged (Tobin, 1995). There is evidence of the value placed on caring partnerships in federal and regional policy and goal statements. For example, the National Advisory Council on Aging has stated that the success of care to seniors is largely dependent on the interaction and coordination of caregivers (NACA, 1992). Alberta Health has stated that “individuals and families (are) recognized as partners in developing a service plan, and in the planning and evaluation of programs, policies and services” (Alberta Health, 1993, p. 12).

Partnerships are seen as important because the skills that formal and informal caregivers possess are unique and complementary (Walker, Pratt, & Eddy, 1995). The formal care system might include resources such as technical knowledge 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) argue that in a residential care setting, formal care staff and families can provide coordinated care, especially in the area of
‘technical’ tasks, while families would have the main responsibility for performing ‘non-technical’
tasks.

Despite the more positive view of the relationship between formal and informal caregivers,
the complementarity argument has vestiges of the earlier abandonment model. Keating, Fast,
Connidis, Penning, and Keefe (1997, p. 25) have argued that the new complementarity argument
comes from a “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 by informal
caregivers . . .” The authors state that the new paradigm of ‘caring partnerships’ could result in
shifting even more responsibility for meeting seniors’ needs from formal caregiving partners to the
resident and to informal caregiving partners. The question of the relative responsibility by
informal and formal caregivers to carry out caregiving tasks for residents of continuing care has
not been addressed.

Developing Partnerships in Residential Care Settings

It appears that there is general agreement that partnerships can be valuable, although this
agreement is tempered by a view that it can be difficult to develop partnerships. One approach to
addressing this difficulty comes from the small body of literature on caring partnerships which has
prescriptions about the best way to develop and nurture partnerships in residential care settings.
Embedded in this literature is a question concerning whether family members should be presumed
to be caring partners or whether their caregiving role is optional.

Some have argued that families should be able to choose whether they will have a caregiving
role and to what extent they will be involved in task performance (Buckwalter & Hall, 1987;
Laitinen, 1992; Stevens, Walsh, & Baldwin, 1993). These researchers appear to support a two
stage process of developing partnerships. The first stage is an assessment of families’ desire for
active involvement in task performance. The second phase is to build partnerships with those family members who are interested. This is done through making family members aware of the opportunities that exist to take part in care planning, decision making and evaluating care; by clarifying roles and responsibilities for tasks; and by letting family members know about the support available from staff members (Laitinen, 1992; Stevens et al., 1993). Early direction and assistance to families who want to be involved in care is viewed as a way to reinforce family member’s feeling of being valued and welcomed and to increase their satisfaction with the facility (Buckwalter & Hall, 1987; Schwartz & Vogel, 1990).

Others appear to believe that partnerships should be assumed. Thus they make recommendations to encourage family involvement. Recommendations include developing policies to encourage family involvement, disbursement of information on these policies, and increasing communication between staff and families (Sharp, 1990). The National Advisory Council on Aging (1990) states that formal and informal service sectors need to cooperate in an atmosphere of mutual respect and understanding; that formal service providers should work with informal caregivers in planning and providing care services; and that there should be training to prepare and assist formal caregivers in working with informal caregivers. In turn, they also state that information and counseling should be provided to informal caregivers concerning the role and limitations of the formal service sector.

Those who seem to believe strongly in partnerships argue that formal care settings need to decrease the uncertainty experienced by families regarding their role in the facility as a way of encouraging the development of caregiving partnerships (Sharp, 1990). Dempsey and Pruchno (1993) 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.

Within these recommendations, there appears to be clear support for collaborative partnerships between formal and informal caregivers, at least from the perspective of those in the formal sector. Findings from the small body of research on involvement of family members in providing services to their relatives in residential care also point to an interest in partnerships from members of the informal network. However, we know little about the level of commitment of those from formal and informal sectors to the idea of partnerships, nor do we have a clear idea of how caregivers are working together (or not) to provide services to seniors in residential care settings. It is important to know what caregivers are doing and their level of commitment to the idea of partnerships as a basis from which to make recommendations concerning the nature of caregiving partnerships.

**Partners’ Beliefs about Caring Responsibilities**

Although beliefs about importance of caring partnerships seem to be part of the national paradigm, less is known about how the partners themselves view the idea of caring partnerships. Beliefs about partnerships may occur at two levels. The first is whether or not there is commitment in general, to the idea of working together to provide care to a target senior. The second is whether or not there is a shared view of which tasks might best be done by informal and which by formal service providers.
Our review of the literature on family involvement in caregiving suggests that families may feel a strong sense of continued responsibility after placement, and wish to maintain some caregiving function (Foster, 1991; George, 1984; Silverstone, 1978). Providing some help to an institutionalized parent may have positive effects for family caregivers including fulfilling feelings of filial responsibility (Walker, 1991), mitigating the sense of guilt about placement (Brody, Dempsey, & Pruchno, 1990), and showing their relative that they care (NACA, 1992).

A small amount of research on caring partnerships shows that one of the reasons that families are interested in continued involvement is that they were looking for a shared exchange of knowledge about the resident and a shared commitment to the importance of their resident as a person (Duncan & Morgan, 1994). Families looked for staff’s willingness to both recognize the value of their knowledge about the resident and accept their involvement in the caregiving process (Bowers, 1988). Although these studies did not explicitly explore families’ beliefs around partnerships, they do provide evidence of a desire on the part of family members to establish partnerships with formal staff. In turn, staff members have been shown to expect family involvement in care, although they may expect less than families are willing to provide (Schwartz & Vogel, 1990).

Movement of an elder into a formal care setting shifts many of the care demands away from informal caregivers and onto the formal care staff. Given that the responsibility for performing caregiving tasks no longer falls solely on the informal caregiver(s), and that the families may wish to continue involvement, questions arise concerning families beliefs about their caring responsibilities and the nature of their partnerships with formal care staff. Information about beliefs concerning caring partnerships can inform policy about the development of partnerships between family members and formal care providers. Similar questions must be addressed from the
perspective of formal care providers who are being encouraged to develop partnerships with family members.

Partnerships in Action: Beliefs and Behaviors in Residential Care Settings

Research on perceived responsibility for caregiving activities shows a tradition of technical tasks or skilled care tasks (such as providing physical therapy, checking resident’s temperature) being viewed as primarily the responsibility of formal care staff, whereas non-technical tasks (such as emotional and psychological care such as participating in leisure activities, or talking) were seen as the responsibility of family members (Barabash, 1989; Bennett, 1980; Bowers, 1987, 1988; Rubin & Shuttlesworth, 1983; Schwartz & Vogel, 1990; Shuttlesworth, Rubin, & Duffy, 1982; Smith & Bengston, 1979). However, this tradition may be changing. Recent research shows that families are involved in provision of technical and non-technical tasks and expect staff to provide both technically excellent and emotionally involved care (Duncan & Morgan, 1994; Linsk, Pflaum, & Ortigara-Vicik, 1988). Given that partnerships are an explicit part of the philosophy of the models of care evaluated in EPICC, we would expect some sharing of responsibility across technical and non-technical tasks.

Personal care tasks cover a set of activities that require more or less technical skill (from changing catheters to grooming). Although informal caregivers see themselves as responsible for providing personal care tasks (Bowers, 1988), the tasks most often performed do not require high levels of technical skill. They include grooming (Linsk et al., 1988) dressing/undressing, and standing up/getting into bed, using the toilet, eating, drinking, washing, caring for hair, caring for teeth, caring for hands and nails, and caring for skin (Laitinen, 1992). Keefe and Fancey (1996) found that during visits, approximately 21% of families reported giving personal care. These
studies suggest that families believe themselves to be responsible for some personal care activities, and that they actually carry out a variety of tasks in meeting the personal care needs of their elderly family member.

Staff in residential care settings continue to be involved in personal care and believe that they have more responsibility than family members for the provision of personal care (Schwartz & Vogel, 1990). Professional guidelines also delineate responsibilities for personal care (American Nurses Association, 1987; Canadian Gerontological Nursing Association (CGNA), 1996). However, at least one study has shown that staff do relatively less personal care than activities such as cleaning and facility maintenance (Shore et al., 1995).

In residential care settings, a major care management task done by family members is monitoring and evaluating the effectiveness and quality of care (Bowers, 1988; Zarit & Whitlatch, 1992). One of the ways that families monitor staff treatment of residents is to watch how their elderly family members react to different staff members and how staff treat other residents. When monitoring reveals problems families were often proactive in encouraging staff to relate to their elder on a more personal basis. Families reported having responsibility for teaching staff how to deliver high quality care, and helping their elder maintain control over the environment. Family members would give information on preferences, needs and vulnerabilities, as well as show how the resident liked things done (Bowers, 1988). One bureaucratic mediation task assumed by families is selecting a doctor for their relative (Rubin & Shuttlesworth, 1983).

The research evidence on care management suggests that families not only believe themselves to have responsibility in this area of care, but they are actively involved in keeping an eye on and improving the care that their elder received. Monitoring allows families to continually
assess care and identify problem areas. However, we have not established how often families engage in monitoring activities, or how much time they devote to monitoring.

Ensuring high quality care to residents is part of professional standards of practice in Gerontological Nursing (see for example American Nurses Association, 1987; CGNA, 1996). Care management tasks are not always specifically designated but include such things as the evaluation of nursing intervention (CGNA, 1996), recording of resident data, exchange of information and sharing of diagnoses with residents and family members (American Nurses Association, 1987).

Providing emotional support to enhance an elder’s well-being is another area in which families see themselves as having care responsibilities. Families considered themselves responsible for maintaining family connectedness, maintaining the elder’s hope of recovery, and preserving the older relative’s sense of self (Bowers, 1988). Families generally accept greater responsibility for tasks like reminiscing, personalizing a resident’s room, celebrating a birthday, and reading and writing letters (Bowers, 1988). Both staff and family assign to the family primary task responsibility for reading to the resident, and encouraging friends to visit regularly (Rubin & Shuttlesworth, 1983).

Families also enhance well being through interaction with their relative during visits. The most frequent type of interactions in residential care were talking to the relative, holding hands and touching (Keefe & Fancey, 1996; Linsk et al., 1988). Families may also enhance their elder’s well-being by engaging in social events or other leisure activities. Keefe and Fancey (1996) found that about 32% of families went for walks with the elder; 25% went for drives; 15% participated in nursing home activities; and 14% went on outings with their elder. Families were also involved in leisure activities such as playing games, watching television, and reading to the resident (Keefe
Keating, Douziech, Fast, Dosman, Eales. March, 1998

& Fancey, 1996) and helping their relative exercise (Laitinen, 1992). Linsk et al. (1988) also found that families participated in going for walks with their elderly family member. Clearly families perform a variety of leisure and social activities to enhance the well being of their elderly family members.

Research on nurse interaction with elderly residents has shown that “interaction between nurses and elderly patients is limited in duration and linked mainly to the provision of physical care” (Davies, 1992, p. 583). Nurses believe that it is important to get to know residents but they do not consistently foster resident autonomy and self determination. However, compared to untrained staff (nursing auxiliaries), nurses provided somewhat more feedback which provided choices to residents and were somewhat more skilled at noticing verbal cues from residents. Both these activities seem likely to enhance well being (Davies, 1992; Whitler, 1996).

Housework such as food preparation, cleaning, and doing laundry is another area in which families may have perceived responsibilities. One type of housework activity that families reported themselves as having some responsibility for was in the care of the elder’s clothing (Bowers, 1988). Small proportions of families report involvement in tending to clothes and cleaning (Keefe & Fancey, 1996) and in making the bed for their elderly family member (Laitinen, 1992). The research in this area is very limited, although these studies suggest that families perform a limited number of housework tasks and that staff have major responsibility for cleaning and maintaining the residence.

Families are involved in the management of financial and insurance matters for their family member (Keefe & Fancey, 1996; Zarit & Whitlatch, 1992). Both staff and family saw family members as being primarily responsible for financial tasks such as assisting in paying bills (Rubin & Shuttlesworth, 1983). There is little or no information on what financial management entails,
how often families have to attend to financial matters, nor how much time it takes to deal with financial affairs.

Families provide transportation services for their elders living in formal care settings (Keefe & Fancey, 1996). Running errands was a task that both families and staff report as being the responsibility of families (Rubin & Shuttlesworth, 1983).

Although shopping for the elder is an activity that is seen in the community-based literature on eldercare, this activity did not come up in either the perceived responsibility research, or in research examining what family members are doing in formal care settings. Shopping may have not been included in any of the perceived task responsibility lists because in the past, many of the goods needed by residents were provided by the formal care setting. With the focus on increased involvement of family members, such as purchasing items to make their relative’s room more home-like, it was expected that families would report responsibility for some types of shopping activities, and be actively involved in doing this shopping.

As is evident, the research examining actual involvement and perceived task responsibility in formal care settings is sparse and incomplete. Research on perceived task responsibility has given us a glimpse into what areas families feel an obligation to assist. However, our knowledge of responsibilities is fragmented. Similarly, much of the literature on task allocation and responsibilities of formal caregivers comes from the nursing literature, leaving gaps in our understanding of the place of multiskilled workers in these settings.

The current body of literature on what families are actually doing in these setting suggests that they perform a variety of tasks. More work needs to be done to establish a better understanding of all the different types of services families are performing, as well as how often they are performing these tasks. Similar information is needed concerning tasks being provided by
paid staff in the models of care evaluated in EPICC. Information on beliefs about caring partnerships and how those partnerships are being actualized is important background to developing evidence-based policies concerning partnerships in continuing care.

Challenges in Understanding Partnerships

The partnerships philosophy has become part of the national policy paradigm in care for seniors in residential settings. However, as is evident from existing research on caregiving to seniors in residential care, data on service delivery has tended to be segmented into formal and informal sectors. As well, prior research may reflect a philosophy that did not explicitly endorse partnerships. Thus our understanding of how the partnerships philosophy is being implemented is in its’ infancy. As Katz and Gurland (1991, p. 336) have argued, “information about what is done, at what cost, and with what result is in woefully short supply.”

In the remaining chapters of this technical report, we present information on the methodological challenges and substantive findings from our enquiry. We present the development of methods and resulting instruments used to measure partnerships; data on services provided by paid and unpaid people providing services to residents and on their beliefs about caring partners. In the final chapter we discuss policy and practice implications of these findings.
Chapter 2

Methods

In this chapter we describe the research settings and respondents; the development of instruments used to measure time use and beliefs about responsibility of staff and family members; data collection using these methods; and data analysis on time use and beliefs about responsibility.

Research Settings and Respondents

Research Settings

This research on services to residents in innovative models of residential continuing care is part of the EPICC project. EPICC was conducted in five settings representing three models of care. These were Adult Family Living, Assisted Living, and Dementia Care. These models of care are described in the EPICC final report. In this section we describe aspects of these settings that might influence the distribution of services to residents.

Adult family living. The adult family living programs in this study have characteristics that set these programs apart from other models of residential continuing care (Folkemer, Jensen, Lipson, Stauffer, & Fox-Grage, 1996). These include the provision of room and board in a private residence to a small number of residents who live there, by an individual who lives in the home, is unrelated to the residents and receives compensation in exchange for designated services (Ladd & Hannum, 1992; Sherman & Newman, 1988; South, 1997).

Some of the services needed by residents such as services of health professionals are not available on site. Thus we might expect informal or formal caregivers to be involved in bureaucratic mediation and transportation to connect residents with these services. As well,
residents are expected to provide their own linens and may provide furniture and other artifacts for their bedrooms. Thus there may be more shopping for goods on the part of the resident or family members. The home-like atmosphere and small number of residents may foster the provision of emotional support by staff. However, the private nature of these homes may lead to more ‘checking up’ by family members to ensure their relative is well cared for.

Three adult family living programs were involved in EPICC. Two of these programs were in large urban centres and one was in a rural setting. Because of the small numbers of residents in the rural program, we did not collect quantitative data on service delivery. Thus data presented here are from the two urban centres only. These data are combined to protect the privacy of respondents.

**Assisted Living.** One assisted living program was involved in EPICC. This program was in a large urban centre. Assisted living programs share a philosophy of protecting clients’ privacy, dignity, choice, individuality and shared responsibility within a home-like setting (Concepts in Community Living, 1994; Kane, Illston, Kane, & Nyman, 1990; Kane & Wilson, 1993; Kaplan, 1995; Regnier, 1991; Wilson, 1993). The assisted living program in this study was also committed to a philosophy of aging in place, in which the resident remains in the same setting rather than being moved in response to changes over time in functional and cognitive status (South, 1997).

A feature of the assisted living program in this study was a service contract which was an agreement concerning the provision of services to the resident. Residents (or their designates) could undertake some of their own housework such as meal preparation or personal laundry. The service contract might result in higher levels of service provision by family members in these areas as well as in those that support the service contract such as shopping for food. There may be complementarity of involvement with relatively lower amounts of staff time spent in areas such as
housekeeping than in other models of care. The philosophy of aging in place may lead to higher needs for personal care and thus relatively high levels of personal care services by staff members.

**Dementia Care.** Individuals with dementias such as Alzheimer disease have special care needs including the management of behaviour that results from the progressive deterioration of a resident’s mental functioning (Dobbs & Rule, 1992). Residential programs for dementia care are typified by physical settings in which there is an emphasis on a home-like environment with routines and surroundings that are consistent and familiar (Alzheimer’s Association Patient and Family Services; Alzheimer Society of Canada, 1992; Calkins, 1988).

There was one dementia care program in this study which was in a large urban area. The program provides assistance and supervision to residents diagnosed with mid-stage Alzheimer disease. A program goal is to encourage the involvement of family members and to address their health, coping, and educational needs.

Given the cognitive ability of these residents, we might expect family members to be relatively more involved in the financial affairs of their relatives than are family members with residents in other models of care. However, since the program takes primary responsibility for housekeeping, personal care, and skilled care, family involvement might be relatively lower and staff involvement relatively higher in these areas than in other programs.

**Respondents**

Respondents were drawn from two groups: family members of residents, and staff members providing direct services to the residents of each of the models of care. Within each of these groups, respondents were chosen based on the following criteria.
Eligible family members were those family members who had provided at least one service to their relative in the past month. We recognize that there may be other informal caregivers including neighbours, friends, and volunteers. However, collecting data on the services they provided to residents was beyond the scope of this project. Thus in this study, informal caregiver and family caregiver are used interchangeably.

Staff member respondents were those who were employed by the three models of care and who provided direct services to residents. Eligible staff members were those from dementia care and assisted living who provided services on the weekday and weekend day chosen for data collection. All home operators in the two urban adult family living programs were eligible.
Development of Research Instruments

In EPICC we believed that new methodological approaches were necessary to develop an understanding of partnerships. Research on caregiving has been divided into formal and informal sectors, and there were no existing tools to measure how these two sectors collaborate. Methods development was required in three areas:

- The first was the development of a comprehensive operational definition of eldercare that incorporated all tasks that might be done by partners.
- The second was to develop a method to gather information on the types and amounts of these tasks done by each of the caring partners.
- The third was the development of an instrument to identify caregivers’ commitment to the partnerships philosophy by caregivers.

These tools were then used to gather information on the amount of each of these services being provided by all partners to seniors in EPICC models of care and their beliefs about caregiving responsibility of these partners. In the following sections of this chapter we describe the methods development and subsequent data collection.

An Operational Definition of Eldercare

As is clear from the review of literature on what tasks are involved in caregiving, there is no consensus on the set of services provided to frail seniors in residential settings by formal and informal service providers. Thus one challenge in this project was to develop a comprehensive list of services provided by these partners. A related challenge was to describe these services in language meaningful to both formal and informal partners.
A list of caregiving tasks from the perspective of informal service providers was developed from a research project on defining eldercare (Keating, Fast, Oakes, & Harlton, 1996). The list was refined in consultation with our seniors advisory group. Based on their recommendation, we changed the term ‘caregiving’ to ‘services.’ In their view, caregiving denoted dependency. From this point forward, we used the term service event to denote a discrete activity done for or with the resident.

In a parallel activity, a list of service events from the perspective of formal service providers was developed. Items came from the research literature on formal services to frail seniors, a review of service documents from the three new models and from consultation with site representatives and formal service providers.

A goal of this part of the instrument development was to develop a joint list of service events that would cover all services seen as important from both formal and informal perspectives. An initial joint list was developed from all of the sources described above. A work group of site representatives, researchers, and graduate students took the list and developed definitions for each service activity. The seniors advisory group was consulted to help refine and clarify definitions.

The final list of service events comprised a total of 35 events. To reduce repetitiveness of the stylized protocol and to facilitate coding of the recall diaries, these events were organized into eight broad categories. These were: enhancing well being, care management, financial management, transportation, shopping, housework, personal care, skilled care. (See Appendix A for a full list of service events and definitions).

The draft list of service events was tested during the pilot of time-use methods with formal and informal service providers described in the next section.
Time Use Data Collection Instruments

One of the challenges in measuring partnerships in service delivery was to measure time spent in service delivery by formal and informal caregivers. A fundamental difference between these groups of service providers is in the proportion of their time spent in providing services to the resident. While formal service providers spend the majority of their working day or shift in providing direct services, informal caregivers’ service provision is more likely to be episodic.

Existing time use methodologies address data collection requirements for both episodic and intensive time use, although these methods are generally used in separate studies. In this section of the methods, we discuss the decision making and instrument development that lead to the time use data collection used in this study.

Recall methods of collecting time use information were developed to provide a portrait of daily life (Fast, Keating, & Eales, 1997). This method of time use often uses the approach of asking respondents to list all activities in which they were involved over a limited period of time, often a 24 hour day. The major advantage of recall methods over stylized methods (described in the next section) is that recall methods tend to produce more accurate data on the typical day (Juster & Stafford, 1985; Robinson, 1985). A disadvantage is that there may not always be a typical day for the phenomena of interest. For example, weekend days may be quite different than weekdays for people who attend school from Monday to Friday. Sampling several days for each respondent reduces this weakness but increases cost and intrusiveness and requires higher levels of respondent cooperation (Paille, 1994).

Stylized methods of collecting time use information have been developed to capture involvement in activities that occur irregularly over a broad period of time (Paille, 1994). Stylized methods use the approach of asking respondents whether they have engaged in an activity within a
particular time period such as the previous six months. Respondents who say “yes” are asked more detailed questions about numbers of episodes and time spent per episode.

Stylized methods have the advantage of increasing the likelihood of capturing episodic activities (Fast, Keating, & Eales, 1997; Herzog, Kahn, Morgan, Jackson, & Antonucci, 1989; Robinson, 1985). Stylized methods also facilitate reporting of concurrent activities (Fast et al., 1997). The major disadvantage of this method is that accuracy of estimates of time use decrease with the increasing periods of time on which respondents are asked to report (Herzog et al., 1989; Juster & Stafford, 1985; Paillé, 1994).

In this project, formal and informal caregivers had different intensities of caregiving activity. We presumed that informal caregivers would have a range of intensity of involvement in services to their relative but that many of the services they provided would be episodic. While emotional support might happen several times a week, shopping for snacks for their relative might be done weekly, while balancing chequebooks and paying bills might occur monthly. Formal caregivers in assisted living and dementia care had shifts of 4 to 12 hours in which the majority of their activities were direct service to residents. Home operators in adult family living had 24 hour ‘shifts’ since they lived with the residents in their care.

**Development of the recall protocol.** Given the expectation that formal caregivers would spend most of their employment hours providing services to residents, recall methodology was chosen for data collection. There are several protocols that have been used to gather recall data. In the pretest of the protocol, four versions of recall methods were tested. Two versions were recall interviews (during shift and end of shift). During shift recall is a method in which the respondent is interviewed part way through her shift and asked to recall activities from the beginning of the shift. End of shift recall is done over the full shift.
Two versions of the clipboard diary (change in activity and every 15 minute interval) were also pretested. In this method, the staff member carries a clipboard. In the change of activity format, the staff member writes down the first activity with the time the activity commenced. Then the staff member writes down the time that activity ended and the time of the beginning of the next activity. In the 15 minute interval format, the staff member stops every 15 minutes and writes down activities that have occurred in that 15 minute block of time. In all methods, staff members are asked to record primary and secondary activities and the name of the resident receiving the service.

The purpose of the pretest with formal service providers was to determine which recall method was the most accurate but least intrusive. Two staff members at each of the three programs took part in the pretest. Each respondent used each of the four methods for one eight hour shift while being ‘shadowed’ by a trained research associate. The order of methods was randomized to reduce possible effects such as increased skill level after one or two shifts, or fatigue after several shifts of the extra work of doing the recall.

A research associate did on-site ‘shadowing’ of each respondent in all of the four shifts. The purpose of the shadowing was to gain information on accuracy of recall as well as on intrusiveness of the method. The research associate used the clipboard method to record changes in activities as they occurred. Debriefing with staff members included a comparison of staff members and research associates lists of events and a discussion of intrusiveness of each of the methods.

Both clipboard methods were rejected as being too intrusive. Staff members are very busy during their shifts. There are frequent changes in activity especially in dementia care. Finding the time to stop to write was a problem. And writing down activities took as much as 10 minutes in an
hour, changing the rhythm of the day. Finding a way to carry the clipboard was also a problem since many activities required that both hands were free.

The end of shift recall method was chosen over the during shift recall. Respondents found that the during shift recall was intrusive because it often required them to give up much needed breaks for a cup of coffee or some fresh air. The end of shift recall was preferred because staff found it least intrusive, shadowing showed that data were accurate, and data could be collected by telephone similar to the data collection method with informal service providers. (See Appendix B for the recall diary protocol).

**Development of the stylized protocol.** Given the expectation that informal caregivers would provide episodic services to their relatives, the stylized estimate methodology was chosen for data collection. The stylized diary protocol was developed from two sources. The service events list provided the domains of questions about the use of time, while the general wording for the stylized estimates interview protocol was based on the format of the 1996 General Social Survey from Statistics Canada. (See Appendix C for the stylized interview protocol).

The protocol has an ‘assistance screen’ in which informal caregivers are asked whether in the past month they have done any of the eight categories of assistance to their relative. In each category in which respondent has provided assistance, questions are asked to determine whether the respondent has provided a specific service; how many times in the past month the respondent provided that service; and the average duration of that service event.

The period of one month for the time frame for stylized estimates was chosen in discussion with our seniors and program consultants. Our decision was based on the assumption that one month was long enough to capture all but very episodic events such as preparation of income tax returns. To determine how many such events were not captured in the one month time frame, we
added an open ended question which was “Is there anything else that you do for your relative that I haven’t asked you about?” The relatively short time frame was also used to attempt to minimize inaccuracies because of the passage of time. A telephone interview method was used to reduce costs of data collection and to minimize intrusiveness.

Other sections of the stylized interview included demographic information on respondents, network questions and questions concerning out of pocket expenses. Network questions were used to contact other members of respondent’s family who were also providing services to the resident. Out-of-pocket expenses were part of the determination of the cost of services to residents. Results are reported in a separate technical report.

The stylized estimates interview protocol was pilot tested with three respondents who provided care to relatives in a continuing care setting. Respondents were asked to comment on comprehensiveness of the service events, clarity of the definitions, language and terminology, and length of the interview.

The structured interview guide was revised based on feedback from these caregivers and recommendations made by the research associate who conducted the interviews. Based on their feedback and interviewer observations, minor changes were made to the wording and order of items in the protocol. For example, helping resident with remembering was moved from the general category of skilled care to the general category of enhancing well-being. The view was that activities involved in helping someone remember such as looking at photo albums or reminiscing about family events served primarily to help maintain the connection between the respondent and the resident, thus enhancing well-being.

Beliefs about Responsibility for Service Delivery

Keating, Douziech, Fast, Dosman, Eales. March 1998
A small number of researchers have undertaken the development of instruments to measure beliefs about responsibility for service delivery. The general format of these instruments is that staff members and family members are each asked to provide their opinion concerning which of a list of tasks should be the primary responsibility of staff members and which should be the primary responsibility of family members (Rubin & Shuttlesworth, 1983; Shuttlesworth, Rubin, & Duffy, 1982). We used this general format in the development of the beliefs about responsibility instrument with EPICC. However, there were several refinements. First, we used the list of service events as the set of tasks. This provided the opportunity to assess whether family members and staff members were providing the types of services that they thought they should provide. Second, we added the resident as one of the parties who might have responsibility for providing the task. This was an important refinement given the policy underlying the new models that residents should be encouraged to be as independent as possible and that programs should be client-centred. Third, we added a category of volunteers and others to tap other people in the formal and informal sector. Finally, we provided for categories in the instrument in which respondents could indicate if they thought that responsibility for a particular task should be shared.

The first draft of the beliefs instrument was pretested with our site representatives. Based on their feedback, two refinements were made. In that draft respondents were asked to indicate the proportion of the responsibility that they thought should be assigned to each of the caring partners. For example, the respondent might say that for bathing family members had 0%, staff 80% and residents 20% of responsibility. Feedback was that this assignment of percentages was too precise and therefore difficult to do with any sense of accuracy. Thus the protocol was changed so that respondents were asked to check all ‘partners’ who had some responsibility.
The second comment was that the instrument could only be completed with a specific resident in mind. This was not an issue for family members whose relative was the only person in the study for whom they were providing services. However, it was important for staff members. While they might think that Mrs. Jones should have some responsibility for dressing, they might think that Mrs. Smith should not. Thus a decision was made to ask staff members to assess responsibility with a specific resident in mind. (See Appendix D for the beliefs about responsibility protocol).

Screen for Formal and Family Member Caregiver

All staff members identified by program managers as providing direct services to residents were designated as formal service providers. This meant that services such as reception, bookkeeping, and property maintenance were not included. The decision about who were eligible staff members was made based on the service events list so that staff members not providing services on the list were excluded.

A family tree of the resident was used to identify the potential family informal service providers. (See Appendix E for family tree protocol). The family tree was developed in conversation with the resident (where possible) or other family members. Family members included same generation, child generation, and grandchild generation family members. For each family member identified, the resident was asked about this person’s age, relationship to the client, marital status, employment status, and location in which the family member lived. Family members were designated as informal caregivers if they had provided services to the resident in the past month.
Data Collection

Time Use Data Collection

Recall data collection. Recall data were collected for one week day and one weekend day at all sites.

Home operators in adult family living were briefed on the recall protocol and arrangements were made for specific recall days. The interviewer telephoned within 24 hours of the end of the 24 hour recall day. The research associate phoned the home operator who was asked to walk through her/his day and describe what activities were done, when the activity began and ended and, where relevant, which residents were receiving the service. Secondary activities which occurred concurrent with primary activities were also recorded.

At the assisted living program, data were collected on several shifts to comprise one 24 hour weekend day and one 24 hour weekday. At the dementia care program, data were collected on several shifts in each of three wings of the program to comprise one 24 hour weekend day and one 24 hour weekday for each. Staff members at the assisted living and dementia care programs who were working on the target days were asked to do a one-shift recall. In the assisted living and dementia care programs, there were some missing shifts. Data from parallel shifts (same time of day) were duplicated to complete the 24 hour day in each program.

Arrangements were made in advance with staff members so that they would know which shift would be their ‘recall shift’. Data were collected by telephone as soon after the shift as possible. The research associate phoned the staff member who was asked to walk through her/his shift and describe what activities were done, when the activity began and ended and, where relevant, which clients were receiving the service. Secondary activities were also recorded. On average recall data collection took one hour.
Stylized data collection. All family members who agreed to participate in this study were interviewed if they met two criteria. First, their relative must have resided in an innovative care program for at least one month. The purpose of this criterion was to avoid gathering caregiving data during the month the resident arrived at the setting. The assumption was that this might not reflect ongoing interaction with the relative since relatives were often intensely involved in the process of moving in and settling in. If the relative had not lived in the residence for at least one month, the interview was set for a later date. This occurred on only one occasion.

The second criterion was that family members had to have engaged in some type of caregiving activity for their elderly relative within the last month. A set of screening questions was presented that assessed involvement over the last month in different caregiving activities. No one was excluded because of this criterion.

Family members who had provided consent were telephoned and asked to participate in a telephone interview to discuss the caregiving activities they had done for their elderly relative during the past month. Respondents were briefed on the types of questions and the approximate length of the interview. If they were willing to participate, the questionnaire was administered at that time, or a more convenient time was scheduled.

The list of aggregate task categories, along with examples of specific tasks that would be included in these categories, was read to respondents. Respondents were asked if they had engaged in any of the activities within each of the aggregate task categories over the last month. For those aggregate categories that respondents identified as being involved in, respondents were asked whether they had performed specific caregiving activities, how often in the last month they had performed identified tasks, and the average amount of time needed to complete the task on each occasion.
After this section of questions had been completed, respondents were asked if there were any other caregiving activities they provided for their elder that had not been included in the questionnaire. If other activities were identified, respondents were asked information about how often they had performed that task over the last month, and on average how long the task took to complete.

Respondents were also asked whether they did caregiving activities for other residents in the place in which their relative lived and whether caring for their elderly relative had affected their lives.

The next set of questions was focused on out-of-pocket expenses respondents had incurred in caring for their relative over the last month. Finally, demographic information about the respondent was collected.

At the end of the stylized interview, respondents were asked if there were any other family members who were providing any of these services for the same elderly relative. If other family members were identified, respondents were asked to provide names and telephone numbers of these family members so that we could contact them to provide time use information.

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 time estimates. On average, the structured interview took 45 minutes to complete.

Approximately 78% of respondents identified other family members as being involved with their relative. These ‘network calls’ generated a second wave of participants. Family members who had been identified by other respondents as being involved were contacted by telephone. The interviewer explained 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.

Beliefs about responsibility data collection

For family members, the beliefs about responsibility questionnaire was completed immediately following the stylized data collection. This questionnaire took about ten minutes to administer. Each staff member was asked to complete the interview for one to three residents. Each adult family living home operator was asked to complete an instrument for each resident in the home.

Data Analysis

Two sets of analyses were undertaken in order to provide data to address questions about the types and amount of services provided to residents by formal and informal caring partners. These were analysed to determine hours and episodes of services and to determine beliefs about service involvement. In this section of the methods chapter, we describe these analyses.

1. Analyses to determine amount of involvement of informal (family) and formal (staff) partners.

The first set of analyses included episodes and hours per month of services provided to residents for all programs combined and by each of the three models by family and staff. For
reasons of confidentiality and anonymity, data from the two adult family living programs were combined. All analyses were run per resident recipient with the exception of analyses on proportions of family members involved in various service tasks.

1.1 Mean episodes, mean time, services received from family members per resident recipient, all programs.

Episodes are discrete service events. Thus a housework episode is a single event of doing the resident’s laundry. Counts of episodes in task categories and for each individual task in the previous month were done. Time data in hours were gathered on the basis of the previous month. Data for all programs were combined and frequencies were run for episodes and time per month for the 8 task categories and specific tasks.

1.2 Mean episodes, services received from family members per resident recipient, by program.

Frequencies were run for episodes per month for all tasks, the 8 task categories and for specific tasks for the three programs. Anovas and Sheffés were run to determine whether there were significant differences among programs in episodes received per resident.

1.3 Mean time services received from family members per resident recipient by program.

Frequencies were run for time per month for all tasks, the 8 task categories and for specific tasks for the three programs. Anovas and Sheffés were run to determine whether there were significant differences among programs in hours of services received per resident recipient.

1.4 Mean episodes, mean time, services received from staff members per resident recipient, all programs.

Counts of episodes in task categories and for each individual task were developed from time use data on shifts which comprised a 24 hour week day and a 24 hour weekend day. Data were
extrapolated to a 31 day month. Time data in hours were also calculated on the basis of a 31 day month. Data for all programs were combined and frequencies were run for episodes and time per month for the 8 task categories and specific tasks.

1.5 Mean episodes, services received from staff members per resident recipient, by program.

Frequencies were run for episodes per month for all tasks, the 8 task categories and for specific tasks for the three programs.

1.6 Mean time services received from staff members per resident recipient by program.

Frequencies were run for time per month for all tasks, the 8 task categories and for specific tasks for the three programs.

2. Analyses to determine percentage of family members involved in various service tasks.

2.1 Proportion of family members involved by task, all programs, by program.

Number of family members involved in each task category and in each specific task was divided by total number of family caregivers to determine proportions of family members involved in all tasks.

3. Analyses to determine complementary of time spent by family members and staff members.

3.1 Proportion of time spent by family members and staff members on each task category, all programs, by program.

Proportion of total time spent by each of family and staff caregiver groups was calculated for each task category for combined programs, by program.
4. Analyses to determine beliefs of family members and staff members about responsibility for delivery of various services to residents.

4.1 Beliefs about responsibility for delivery of services, family members and staff members, all programs.

Frequencies were run for all programs combined on beliefs of family members and staff members about responsibility by family, resident, staff, volunteers, and others for delivery of service tasks.

4.2 Beliefs about responsibility for delivery of services, family members and staff members, by program.

Frequencies were run by program on beliefs of family members and staff members about responsibility by family, resident, staff, volunteer and others for delivery of service tasks.

5. Analyses to determine beliefs about complementarity of time spent by family members and staff members.

5.1 Beliefs about responsibility for caring partnerships by program, personal care.

Frequencies were run for family members and staff beliefs about responsibility for personal care by the following combinations of caring partners: resident only; staff only; family only; resident and staff; staff and family; resident and family; staff, family and resident; none of the above partners.

5.2 Beliefs about responsibility for caring partnerships by program, enhancing well being.

Frequencies were run for family members and staff beliefs about responsibility for personal care by the following combinations of caring partners: resident only; staff only; family only; resident
and staff; staff and family; resident and family; staff, family and resident; none of the above partners.

Chapter 3

Results

In this chapter, we present results from all analyses and discuss the relevance of the findings. Small sample sizes and uneven cell sizes in data on services received from family members at times result in the underestimation of significant differences. We discuss circumstances in which large differences in frequencies may be seen as meaningful even if analyses show no significant differences. No tests of significance were done on services received from staff members since the unit of analysis is a 24 hour service day. Discussion of findings and their policy and practice implications are presented in the final chapter.

Table 1. Mean Episodes, Mean Time, Services Received From Family Members, Per Resident Recipient, All Programs.

Table 1 shows mean episodes per month and mean amount of time spent per month by family members providing services to their relative. Episodes are incidents of an activity and provide a picture of the rhythm or intensity of caregiving, while time provides a picture of the hours in a month devoted to caregiving. Overall, residents received an average of 52.15 episodes and 38.67 hours of time in services from family members per month.

Episodes data show that task categories of enhancing well being (25.77 episodes per month) and care management (9.22 episodes) have relatively high numbers of episodes compared to other
categories. In comparison, several task categories (housework, shopping, financial management, and skilled care) are done relatively infrequently, about two times per month.

Episodes data also show that while some episodes are concentrated on one specific task within a task category, others are spread relatively evenly over a set of tasks. Thus, for example, the highest numbers of episodes in enhancing well being are in ‘being there’ for their relative, and in care management on ‘keeping an eye on things.’ In contrast, housework, personal care and skilled care episodes are divided more evenly over a number of tasks.

In contrast to episodes, data on time provide information on the hours spent on all episodes in a month. Largest monthly time commitments are in enhancing well being and in transportation. Within these task categories, most time is spent on being there for the relative and participating in leisure activities (within enhancing well being). In transportation categories, time is fairly evenly split between the two tasks. Less than an hour per month was spent on average in personal care and skilled care. Clearly there is no direct correspondence between high numbers of episodes and high amount of time spent on tasks.

The comparison of these two sets of data provides a picture of which activities are done quickly and often and which are done periodically but take more time. For example, personal care activities are done about 4 times per month, but relatively little time is spent on each activity. In contrast, almost one hour is spent each time a family member assists their relative with financial matters. The highest amount of time per episode is in transportation, while the smallest amount is in personal care.

The relationship between number of episodes and amount of time can be explained in part by the nature of the tasks. For example, in relatively large cities with severe climates going with someone to an appointment can be very time consuming. Driving across the cities where these
residents live can take 45 minutes or more. And helping someone navigate slippery streets cannot be done quickly. Time is also spent with the resident waiting for appointments with physicians and other health care providers. Thus transportation tasks require a fairly large amount of time per incident. Clearly, family members are involved in several of these time consuming tasks. In contrast, other tasks such as many in the personal care category are discrete and each episode requires relatively little time. Residents receive few of these small but discrete tasks from relatives.

Table 2. Mean Episodes, Services Received From Family Members, Per Resident Recipient, By Program.

Table 2 shows variation among the models of care in the number of caregiving episodes in task categories and specific tasks. There are no significant differences in total episodes across models of care, nor in any of the task categories. Patterns of episodes show that residents in Adult Family Living receive the same or fewer episodes of service in all categories in comparison to residents in the other programs. Residents in Dementia Care receive fewest episodes of transportation, but most in personal care and enhancing well being. Those in Assisted Living receive more episodes of housework, care management and transportation.

Some of these differences may be accounted for by the terms of the contract with Assisted Living residents who receive a basic service package but can choose to provide some of their own services in areas of housework or to arrange for those services to be provided. Higher numbers of episodes of housework services received suggests that family members are likely providing those services. Similarly, family members do relatively high episodes of care management, especially in keeping an eye on things. This may be a result of the contract in which formal assistance is
provided when needed. Transportation episodes provide an indication of family members’ involvement in connecting the resident to services and to the community in general.

Residents in Dementia Care receive higher episodes of personal care. These may reflect the number of visits family members make to see their relative. Visits may in part be a substitute for activities such as taking the resident for a drive which can be disruptive and upsetting for people with dementia.

Adult Family Living residents may receive relatively fewer episodes of service because they are relatively more independent or because home operators in these family-like setting provide more of the needed services.

Table 3. Mean Time Services Received From Family Members, Per Resident Recipient, By Program.

Table 3 shows the mean number of hours per month of services received by residents from family members in each of the three programs. Residents in Assisted Living received highest hours of service (50.63 per month).

There were differences in hours of services received by task across the programs in housework, financial management and skilled care. Residents of Adult Family Living received significantly more skilled care and financial management than residents in the other programs. Residents in Dementia Care received significantly fewer hours of skilled care than residents in Adult Family Living. (Lack of significant differences in skilled care between Assisted Living and Adult Family Living is an artifact of small cell size in Assisted Living). Residents in Assisted Living received significantly more hours of housework, and significantly fewer hours of financial management than residents in Adult Family Living.
Findings of higher amounts of housework services received by residents in Assisted Living in comparison to the other two programs, provides further evidence that family members are providing unpaid services to relatives who do not contract for the full service package. Clearly these services are personal services to the resident. Family members do not contribute to overall housework in the facility such as cleaning common areas.

Higher amounts of time in transportation and shopping received by residents in Assisted Living, though not significant, may be important indicators of family members assuming responsibility for making certain that their relatives could get to appointments and get out into the community, and had access to equipment and others things which were purchased by family members.

Residents in Adult Family Living received almost no assistance with household tasks. This could be for several reasons: family members’ reluctance to intervene in domestic tasks in someone else’s home; their comfortability with the level of housework provided to their relative; or their assumption that their relative should do some of the housework tasks. Data on beliefs about responsibility for tasks, reported in a later section in this chapter, provide some data on this issue.

Significantly higher amounts of time in financial management in Adult Family Living compared to Assisted Living, probably reflects the special situation of AFL programs. In comparison to other programs, family members may be more likely to be interacting with home operators to check for residents’ needs for money to purchase goods and services. As well, AFL homes do not have an institutional structure to allow for arms length management of residents’ affairs.
Lower amounts of enhancing well being received by residents in Adult Family Living are accounted for in the areas of being there for the relative. It may be that people in Assisted Living have fewer relatives with whom they have close ties. Alternately, since the relative is living with a family, family members may be comfortable with the amount of emotional support their relative receives from the home operator.

Low hours of transportation received by residents in Dementia Care, along with episodes data from Table 1 suggest that residents are taken out of the facility relatively infrequently and for short time periods.

In contrast to low levels of some services, residents in Assisted Living received a large amount of assistance in skilled care (compared to residents in Dementia Care), especially helping to ensure resident’s behaviour was appropriate and safe. This activity may have been done by relatives as a way of monitoring the physical safety of the residence and the ways in which other residents and the home operator were interacting with their relative. Attempting to ensure/foster appropriate behaviour by their relative might also have been a preventive measure to increase the probability that their relative could stay where she was. It may also be an indicator of time spent in discussions with the home operator about the needs of their relative.

Table 4. Mean Episodes, Mean Time, Services Received From Staff Members, Per Resident Recipient, All Programs.

Table 4 shows mean episodes per month and mean amount of time spent per month by staff members per resident. The overall episodes figure of 378.25 episodes received per resident per month provides an indication of the intensity of service provision. Overall, residents receive approximately 12 incidents of service per day.
Four activities were added to the list of services as a result of coding recall diaries on staff services to residents. These were: ‘got resident ready to go out’ (transportation); ‘maintained charts on resident’s status’ and ‘consulted and shared information on residents’ (care management); and ‘did outside work’ (housework).

Highest numbers of episodes are in housework and personal care, while lowest numbers are in shopping, transportation and financial management. Highest numbers of episodes in the housework category are in food preparation and clean up and in cleaning common areas. Highest numbers of episodes in the personal care category are in assisting with mealtime and with medications.

In contrast to episodes data from family members, staff data show that episodes are spread across a broad set of tasks within most task categories. Thus, for example, with the exception of caring for residents’ clothing, there are relatively large numbers of housework activities in food preparation and clean up, cleaning residents room and common areas and in doing residents laundry. Clearly there is a higher intensity of services from staff than from family members.

The overall time of 96.73 hours per month (approximately 3 hours of service per day) provides an indication of amount of service received from staff members. Similar to the number of episodes, staff members spent the most time in housework, with similar amounts of time spent in personal care and enhancing well being. Small amounts of time were spent in skilled care, shopping, financial management and transportation.

These data on episodes and time provide the first look at the set of services received by residents. Data provide a snapshot of the intensity and types of services. Episodes data suggest that while staff must make a lot of changes from one activity to another in high intensity areas such as housework and personal care, some activities such as financial management and transportation are
rarely done. Our later consideration of the complementarity of staff and family inputs will help determine whether residents are receiving all of the services they need.

Time use data show that the biggest time commitment is in housework. This is not surprising given that most people providing direct service to residents are multi skilled workers expected to perform a wide range of tasks. Housework and personal care tasks combined to take up approximately 60% of services provided. A question that arises is what is the impact of this time commitment on staff member’s ability to provide the social model of care which is part of the philosophy of these residential models?

Table 5. Mean Episodes, Services Received From Staff Members, Per Resident Recipient, By Program.

Table 5 shows variation among the models of care in the number of caregiving episodes in task categories and specific tasks. Residents in the Adult Family Living and Dementia Care programs received almost twice the service episodes that are received by residents in the Assisted Living program. Differences in episodes provided by family members are not as striking.

Assisted Living residents received fewer incidents of services than residents in other programs in the areas of housework and in enhancing well being. Within the category of housework, Assisted Living residents received substantially fewer episodes of food preparation and clean up, personal laundry and in cleaning common areas. The first two activities may be accounted for by the service contract, since these are services that residents may have opted not to receive. Episodes received from family members in these areas are high, suggesting that family members are providing some or all of the needed services. Low numbers of episodes of cleaning of common areas may reflect the high staff/resident ratio in Assisted Living compared to other
programs. Relatively low numbers of incidents in enhancing well being are more difficult to interpret. It may be that small numbers of staff preclude time being spent on such activities. Alternately, the high value placed on privacy in this model of care may reduce the amount of contact between staff and residents. Enhancing well being may also be a ‘secondary activity,’ done while performing other tasks such as personal care.

Residents of Adult Family Living received most episodes of housework and transportation. The largest number of housework episodes is in meal preparation and clean up. There are several possible reasons for these high numbers of episodes. First, part of the Adult Family Living contract is to provide meals to residents and most eat all of their meals at home. Second, the large number of incidents per resident is accounted for in part by the fact that there are relatively few residents per operator in each home. Economies that might be taken in preparing meals for 30 are not available to home operators who are preparing meals for 4. Finally, food preparation is done differently at each of the models. In Dementia Care, breakfast is prepared by direct service staff, but other meals are brought in. In Assisted Living, food services are done on site by employees who are not direct service staff members. In Adult Family Living, all meals are prepared and served by home operators. Staff in Adult Family Living also do most outside work. Shoveling walks to that residents can get out accounts for most of these episodes.

Direct service staff in Dementia Care and Assisted Living do not provide transportation for residents. Although transportation is not explicitly part of the set of tasks that are contracted for with home operators in Adult Family Living, clearly many provide these services. The largest number of episodes in transportation is in getting the resident ready to go out, although about one third of transportation episodes are dedicated to taking the resident to appointments, on errands and to other places.
Residents of Dementia Care received the most service episodes of all models of care. This finding corresponds with staff perceptions that their days are very busy and that they are constantly shifting from one activity to another. Relatively high numbers of episodes are received in areas of personal care, care management and enhancing well being. People with cognitive impairment are especially needy of assistance with activities of daily living such as bathing and dressing. These are reflected in relatively high numbers of episodes in these activities. High care management episodes occur primarily at the beginning and end of shifts when staff inform each other about and record daily changes in resident needs and behaviours.

Although residents of Assisted Living received fewest service episodes overall, they received slightly more than those in other programs in skilled care, financial management and shopping. Most episodes within skilled care were in helping residents manage their physical health which includes monitoring residents’ health status and informing staff, family members or health professionals about any concerns. These activities are congruent with the model of assisting residents and families to make decisions concerning the residents’ well being. Episodes in financial management are reflected in the contracting for some services but not others. Shopping done for ‘other things’ is part of assisting residents by shopping for things they need such as personal items and items to decorate their room.

Table 6. Mean Time, Services Received From Staff Members, Per Resident Recipient, By Program.

Table 6 shows the mean number of hours per month of services received by residents from staff members in each of the three programs. As with episodes, there were differences in hours of services received by task category across the programs.
Overall, residents in Adult Family Living received the most hours of service per month (151.93), followed by residents in Dementia Care (93.09) and Assisted Living (45.17). These patterns are different from episodes patterns in which residents in Dementia Care received the most episodes of care, followed by residents in Adult Family Living and Assisted Living.

Residents of Adult Family Living received more hours of service related to enhancing well-being, transportation, housework, and shopping than residents in the other programs. Those in Dementia Care received more hours of care management and personal care than residents in the other programs. Residents in Assisted Living received substantially fewer hours of service in enhancing well-being and housework than did residents in other programs.

Residents in Adult Family Living receive many more hours of service in housework, enhancing well-being, shopping and transportation than residents in other programs. Highest number of housework hours are spent in meal preparation and clean up. Like the episodes data, hours per resident are high because meal preparation is done for a small number of residents. However, the potential for individualized service and catering to personal preferences is also high in this program. Hours spent in providing emotional support and leisure activities (tasks in enhancing well-being) suggest that residents are well served in activities that enhance well-being. Hours spent in shopping and transportation reflect the family-like setting of adult family living homes. Most of the shopping done is for ‘other things’: personal items needed by residents. Home operators are more likely than staff in other programs to go with residents to appointments or on errands or to get residents ready to go with someone else. Transportation is not considered part of the job description of direct service staff at Dementia Care or Assisted Living but is done by home operators. In Assisted Living, residents are likely to get themselves ready to go out and receive transportation from family members. In Dementia Care, residents are less likely to go on outings.
Hours of care management and personal care received from staff by residents in Dementia Care probably reflect both program philosophy and the cognitive status of residents. A large proportion of time spend in care management is in talking to others about the status of the resident. At the beginning and end of their shifts, staff members talk to each other about the resident, ensuring continuity of care. Much of the time spent in personal care is helping residents to do tasks which they can no longer remember how to do: getting ready for the day and for bed, prompting the resident to manage mealtime and helping the resident with medications and with getting to the bathroom.

Correspondence between episodes and time is closest in Assisted Living. Residents in this program received fewest service episodes and well as the least amount of hours of service. In part, the relatively few hours of service may be due to staff/resident ratios which are highest in this program. There are simply more residents to care for, thus each gets less. Whether these hours of service are sufficient depends upon several factors including the ability of residents to do some of their own care and the availability of family members do some household tasks. Findings discussed previously do show that Assisted Living residents receive more assistance with housework from family members than do residents in the other programs. They also receive relatively high amounts of hours of enhancing well being, also from family members. These levels of service from family members may balance the few hours of assistance received from staff members.
Table 7, Proportion Of Family Members Involved By Task, All Programs, By Program.

Table 7 shows that the proportion of family caregivers involved in various service tasks differs considerably. While almost all caregivers are involved in enhancing well being of their relative, about half are involved in transportation, care management, shopping and financial management. Less than 30% do housework, personal care or skilled care for their relative.

These proportions are congruent with the research literature that suggests that family members are involved in non-technical tasks and in tasks that require someone who knows the person well. Enhancing well being is done by virtually all caregivers and may be one of the most important tasks in helping their relative maintain a strong sense of self. The task associated with transportation, care management, shopping and financial management occur primarily outside of the place where the relative lives but serve to bring in goods needed by the resident (shopping) and as a means to connect the resident to needed services (transportation, care management, financial management). Household tasks, personal and skilled care all require being at the residence where the relative lives. Family members seem least likely to assume these tasks as part of their caregiving responsibility when their relative is in a residential care setting.

There are differences in proportions of family members involved in several task categories across programs. Overall, much higher proportions of family members with relatives in Assisted Living are involved than are those with relatives in other programs. Family members with relatives in Assisted Living are significantly more involved in transportation, care management, housework, and personal care than those with relatives in Dementia care; and are significantly more likely to be involved in housework and shopping than those in Adult Family Living. These differences provide a picture of the high proportions of family members from Assisted Living who are involved in task categories. The majority of these family members are involved in seven of
eight task categories. Assisted Living seems to be the model of care that is the most involving of family members across caregiving tasks.

Significantly higher proportions of family members with relatives in Adult Family Living are involved in care management than family members with relatives in Dementia Care. The private nature of Adult Family Living settings may lead family members to be more proactive in speaking up for the resident and keeping an eye on things.

The ‘all programs’ column shows that within most task categories patterns of involvement of family members are uneven. For example, 48% of family members shop for ‘other things’ such as personal items for their relative; while less than 10% shop for special equipment or medical supplies. This may be a result of the way in which individual tasks were grouped in this study. The instrument development phase of this project showed that shopping was a meaningful category to family member respondents. However, family members clearly differentiated between shopping categories that had to do with personal items for their relative and shopping for equipment and medical supplies which they did not do. In some cases, sharing between formal and informal partners is at the specific task level rather than at the aggregate level.

Table 8. Proportion Of Time Spent By Family Members And Staff Members On Each Task Category, All Programs.

Table 8 provides a comparison between the proportion of time spent by family and staff on various service tasks. For family members, enhancing well being is the predominant activity, with transportation second in importance. In contrast, the majority of time spent by staff members is in household tasks. Similar proportions of their time are spent in enhancing well being and personal care.
Clearly family members put most of their energies in areas which require knowing the person and in connecting the person with the community. Emphasis on these tasks points to family members' willingness to put a great deal of time into the social and emotional aspects of their relative’s life. In contrast, staff time is disproportionately allocated to household work. Time spent in household work reflects the staffing models of these programs in which workers are expected to do a broad range of activities. Enhancing well-being still takes up over 20% of their time, suggesting that there is an emphasis on the social and emotional aspects of services to residents.

Data by program show some differences in how family members and staff allocate their time. In general, patterns of family member allocation of time are similar across all models of care. All spend the majority of time in enhancing well-being, although family members with relatives in Dementia Care spend a much higher proportion of their time on enhancing well-being than do those with relatives in the other programs. Transportation is second in time commitment for family members with relatives in Adult Family Living and Assisted Living. All of the remaining activities take up less than 10% of the time of family members.

In general, patterns of staff allocation of time are also similar across models of care. A major difference is in the small proportion of time spent by staff in Assisted Living in enhancing well-being. This may come from the philosophy of Assisted Living in which the philosophy of client-centred service is expressed in placing a high value on privacy and choice. Thus residents might be expected to seek out company of others rather than be seen as those in need of emotional support. Alternately, low ratios of staff to residents may preclude spending a large proportion of time on enhancing well-being.
Table 9. Beliefs About Responsibility For Delivery Of Services, Family Members And Staff Members All Programs.

Table 9 shows results of the beliefs about responsibility questionnaire. In it, family members and staff were asked to give their opinion about who should provide various services to a particular resident: family members, the resident herself, staff, volunteers or others (such as clergy, hairdressers and physicians). Findings are presented by family and staff respondents for all programs.

In general, the majority of family members see themselves as having responsibility for enhancing well being, care management, financial management, transportation, some shopping and some housework. They place primary responsibility for some shopping, most housework, some personal care and skilled care in the hands of staff members. A small majority of family members also expect staff to be involved in some tasks related to enhancing well being. Primary responsibility for some personal care tasks is assigned to residents and to others (for tasks such as doing the resident’s hair and nails). Little responsibility is assigned to volunteers.

Staff members’ patterns of assignment of task responsibility differ somewhat from those of family members. In general most staff members assign themselves responsibility for some tasks in enhancing well being, care management, shopping, housework, personal care and skilled care. They see little responsibility for financial management or transportation for themselves, but assign these responsibilities to family members.

Staff members differ from family members in that they are more likely to assign responsibility for some tasks to residents. The majority of staff members believe that residents should be responsible for all personal care tasks except assisting with medications which they
believe staff members should do. Staff members are also more likely to assign care management and enhancing well being tasks to themselves than family members assign to them.

These patterns suggest that staff members and family members do not have the same vision of responsibility for service provision to residents. Highest levels of agreement are in skilled care and in household work where the vast majority of both groups believe that staff members should be responsible; and in financial management and transportation where the vast majority of both groups believe that family members should be responsible. Disagreement is in personal care which family members see as staff responsibility and staff see as resident responsibility; and in care management where family members and staff members each assign most responsibility to themselves. Variations in these patterns across programs, discussed in the next table, provide some insight into the differences in how staff and family members view their responsibilities.

Table 10. Beliefs About Responsibility For Delivery Of Services, Family Members And Staff Members By Program.

Table 10 shows how beliefs about caregiving responsibility differ somewhat by program. In enhancing well being, family members assign higher responsibility to themselves than staff members across all programs. Staff members also assign higher responsibility to family members than themselves. In Assisted Living staff members assign lower percentage responsibility to themselves than in the other two programs. This belief seems congruent with the Assisted Living philosophy in which value is placed on keeping residents connected with family members.

Across programs, high proportions of family members assign responsibility for care management to themselves. However, staff members in Adult Family Living and Assisted Living assign higher responsibility to themselves than family members assign to them. Staff members in
these programs believe more strongly that they can speak up for residents and keep an eye on them than do family members. This difference may reflect a need by family members to monitor their relatives.

In financial management and in transportation, there is general agreement by family and staff across programs that family members are responsible. The exception is that staff in Adult Family Living are more likely to see themselves almost as responsible as family members. This belief corresponds with their actions. It is staff in this model of care who are most likely to provide transportation services.

Responsibilities for shopping tend to be split by task across all programs for staff and family members. Family members are seen by themselves and staff as being responsible for shopping for ‘other things’ such as personal items. Staff are seen as responsible for other shopping. An exception is in Assisted Living where staff expect family members to have primary responsibility for all shopping. Family members in this model of care do not concur. This difference suggests that in some areas, staff think family members should be responsible for more than family members are willing to assume.

Across programs, housework is seen by family and staff members as a staff responsibility. An exception is care for resident’s clothing which is seen by the majority of family members as their responsibility. This commitment is lowest in Adult Family Living where family members see higher levels of responsibility for staff. There seems to be agreement on this issue from staff.

Personal care is assigned to residents and to staff across programs by family members and staff. While skilled care is seen as a staff responsibility. The exception is in helping manage physical health which is seen by staff in Assisted Living and Dementia Care as a family responsibility.
Staff members in Assisted living and Dementia Care are more likely to assign responsibility for tasks to volunteers than staff members in Adult Family Living. This may be because Adult Family Living programs are in private homes and may be seen by home operators as inappropriate places for volunteers. The majority in Assisted Living and Dementia Care see volunteer responsibility in enhancing well being and in some personal care, skilled care, care management and shopping tasks. There are no tasks in which the majority of Assisted Living staff assign responsibility to volunteers.

Staff in Adult Family Living assign little responsibility to ‘others’ for care tasks. In contrast, approximately half of staff in Dementia Care and Assisted Living assign responsibility for tasks such as shopping for special equipment and medical supplies (shopping), and helping deal with pain (skilled care) to a variety of ‘others.’

It seems that both program and staff versus family perspective are important in the beliefs about caregiving responsibility held by family members and staff members. The private nature of Adult Family Living homes, the service contract in Assisted Living and the staff commitment to the concept of doing a wide range of tasks, each result in slightly different patterns of beliefs about ‘who should do what for whom.’

Table 11. Beliefs About Responsibility For Caring Partnerships, Family Members And Staff Members By Program, Personal Care.

Table 12. Beliefs About Responsibility For Caring Partnerships, Family Members And Staff Members By Program, Enhancing Well Being.

Data in Tables 11 and 12 provide a picture of family member’s and staff members beliefs about shared responsibility for two tasks: personal care, and enhancing well being. The table shows percentages of staff members and family members who assigned responsibility to more than...
one group (e.g. staff plus resident) for each task. These tasks were chosen for illustrative purposes, since we expect that beliefs about partnerships on these tasks might differ.

If seniors have been placed in residential care because they believe that they no longer have the resources to provide personal care and other daily tasks for their relative, we might expect family members to believe that staff are responsible for these tasks. However, because many of these tasks are not technical in nature, we might expect staff to believe that families should do some of these tasks. Residents might be expected to provide these tasks if they have the cognitive ability to do so. And if both family members and staff have internalized the idea that programs are client-centred and social rather than medical in their orientation, we might expect that family and staff place responsibility for enhancing well being with all partners: staff, family and residents. We might also expect some differences by program since residents in Dementia Care might be seen as less responsible for such tasks than residents in other programs.

Results in Table 11 show that few staff members or family members see family members as partners with staff in providing personal care to residents. Small proportions of family members (approximately 15% or less across all tasks) and staff members (approximately 20% or less across all tasks) believe that these two groups have responsibility for personal care.

Similarly, neither staff nor family members see residents and family as the main partners in providing personal care. In fact, the highest proportions of staff in all programs see the main personal care partnership being between themselves and residents. Small proportions of family members (approximately 15% or less across all tasks) and staff members (approximately 17% or less across all tasks) believe that these two groups have responsibility for personal care. Clearly family members are absolved (or excluded) from most personal care responsibilities.
The main partnership seen by both family and staff is between residents and staff. Up to 55% of family members and 74% of staff members believe that these two groups have responsibility for personal care. These beliefs about resident-staff partnerships in personal care differ somewhat by program. In Adult Family Living, most staff members see minimal sharing of responsibility for personal care with the exception of getting ready for the day and bathing in which residents are expected to take part. In contrast, large proportions of staff members in Dementia Care see themselves and residents being jointly responsible for several personal care tasks (getting ready for the day and for bed, assisting with bathing and going to the bathroom). And they believe that staff, families and residents share responsibility for a few tasks (notably doing resident’s hair and nails). Beliefs about staff-resident partnerships among Assisted Living staff fall between those of Adult Family Living and Dementia Care.

These beliefs about responsibility for personal care support the assumption that in general, family members are not expected to have responsibility for personal care. Rather, the emphasis on the staff-resident partnership seems an indication of staff’s belief in a client-centred model of care. The high commitment to this partnership on the part of staff at Dementia Care is especially noteworthy given that residents may have difficulty completing many of these tasks.

In general, most staff believed the relevant partnership in personal care was between staff and residents. In Dementia Care, staff subscribed to this belief most strongly. In comparison, Adult Family Living staff assigned major responsibility for most personal care tasks to the resident, while those in Assisted Living assigned some tasks to residents only and some to residents and staff. In contrast, most family members believed that the major responsibility for personal care lies with staff members. Family members are less likely to assign responsibility to residents only than
do staff. An exception is Dementia Care where higher responsibility for personal care is assigned to residents by family members than staff members.

These findings suggest that there is general agreement that after placement of a senior in residential care, a shift of responsibility for personal care away from family members is appropriate. It is also evident that staff members and family members (to a somewhat lesser extent) believe that some responsibility for personal care lies with the resident. However, neither staff nor family members see the major partnership in personal care being between them. Rather, the partnerships seems to be primarily between staff and residents. This finding also supports the notion of client-centred care being care in which the resident is actively involved. The finding that more family members of Dementia Care think that their resident should have responsibility than do staff members may suggests that family members see their relative as more able to do self care than do staff members.

Findings on enhancing well being from Table 12 show a different pattern. Family members and staff members in all programs assign highest levels of joint responsibility for enhancing well being to family and staff. These patterns are similar across programs, although commitment to this partnership is strongest among staff and family in Dementia Care. Staff members in Adult Family Living and Assisted Living assign lower levels of responsibility to staff-family partnerships than do family members in the same programs.

Partnerships in enhancing well being seem to be part of the beliefs of both family and staff members, suggesting that this task is central to the partnerships philosophy. Unlike personal care, both partners assign responsibility to themselves and to the other for making certain that service are client-centred.

Chapter 4
Discussion

In the first section of this chapter we return to questions raised in the first chapter of this report and discuss how the findings help enhance our understanding of these issues. Three sets of questions are addressed. The first is whether family members are involved in care to relatives in residential care. The second is whether partnerships exist between formal and informal service providers. The third is what is the level of commitment by staff and family members to the idea of partnerships. We augment the discussion in this final section with qualitative data from focus groups with family members and with staff members and interviews with residents.

In the second section of this chapter we discuss policy and program implications of these findings.

Are Family Members Involved in Care to Seniors in Residential Settings?

There is little question that family members of residents in these models of care are involved in providing services to their relatives. Across models of care residents receive almost 40 hours per month of services from family members. This caring input is equivalent to one week of full time work per month. The fact that residents receive an average of 50 episodes of service per month shows that these services are provided frequently. Clearly residents receive care from family members that occurs often and is time consuming.

Care from family members appears to be contingent upon the model of care. For example, those in Assisted Living receive more care from family members than residents in the other two models. There are several ways to interpret this higher level of assistance. One hypothesis is that the substitution model can explain this behaviour. The premise of the substitution model is that if
formal care is provided, family members will withdraw their help. Thus since there is less formal care provided in Assisted Living, family members are obliged to be involved. This hypothesis supports Wenger’s (1997) argument that family members are seen as a resource to be utilized rather than as true partners in care. A second hypothesis is that family members will choose to be involved if they see a real need for their assistance and if their involvement is welcome. From this perspective, the relatively high levels of family involvement is a positive outcome which allows for continuity and connection of families with their relative. Lower levels of assistance received from family members in the other two models of care appear to be due in part to the higher levels of assistance provided by staff members. Services of family members seem to be an important element of the caring environment.

Do Partnerships Exist?

Data from this study provide strong evidence of partnerships in providing care. Family members’ contributions to the total care are substantial. Their 40 hours of service per month amounts to 28.5% of total care received by residents. Staff members provide approximately 100 hours of service per month for a total of 71.5% of total care received per resident. Thus we conclude that staff and family members are partners in care in the sense that each provides substantial portions of the total services received by residents.

There are two other issues concerning partnerships which are pertinent to this evaluation. The first is whether the services provided by staff and family partners are complementary in that partners specialize in tasks for which they are most suited. The second is whether services are complementary in that both partners provide services which are focused on the social model of care which is a basic premise of the models evaluated in this study.
An assumption in the research literature on staff and family caregivers is that each is in the best position to provide different types of care. Staff members are presumed to be best at technical tasks requiring specialized training while family members are seen as best at providing tasks which require knowing about the wishes and needs of their relative.

In some respects this distinction was found among these caregivers. Family members do spend the largest proportion of their time in enhancing well being, in connecting their relative to the community by taking them on outings, and by keeping an eye on things. All of these tasks require knowing the person. In contrast, patterns of staff involvement are less clearly based on a technical set of tasks. Rather than having the focus of their work on technical tasks requiring specialized knowledge, staff in these programs have taken over the day to day activities of caregiving. They spend large proportions of their time in housework and personal care but also spend substantial proportions of time on enhancing well being. These are the very tasks done most by informal caregivers caring for their relatives at home. Thus task complementarity in these models of care is not like those previously described in the research literature. Staff members do the day to day activities that might previously have been done by family members, freeing family members to tasks that require knowing their relative.

Task sharing is also complementary in terms of the pacing of care. Staff do more of the hands-on activities that take short amounts of time. Thus they are ‘on the run’ with frequent shifts from one task to another. The kinds of tasks that they do in housekeeping and personal care require that the caregiver be on location to provide this kind of service. Family members provide services that are done less frequently but take larger amounts of time. The strains in their lives may not be so much in frequent changes in activity but in tensions between eldercare and other demands in their lives such as employment and caring for other family members.
Provision of a safe, compassionate, and caring environment is a goal of the new models of care evaluated in this project. Thus partnerships in service delivery can also be considered in terms of how well the partners are doing in providing services to meet this goal. In terms of the provision of services to enhance well being, partners appear to be doing well. Enhancing well being is the most important task in terms of time spent for family members and second for staff. And personal and skilled care take smaller proportions of staff time (20% and 4%) and little of family time (2% and 2%). If the goal is to keep residents connected to others and to their past life (a family task), to make the residence like home (a staff task) and to reduce the medicalization of residential care (a program philosophy), then partnerships seem to be working well. As seen in the technical report on authenticity of residents in EPICC models, one of the central themes for residents is the maintenance of a sense of self or authenticity. Authenticity is enhanced through the ‘best fit’ between the person and the people providing care (the caring environment). Thus efforts in enhancing well being of residents serve to meet goals of all of the partners: staff, family, residents and program.

**How Do Partnerships Differ Depending Upon the Model of Care?**

Partnerships differ among models of care in terms of amount of services provided and relative proportions of time spent in various services. These differences seem to be most affected by staffing levels and program philosophies.

Adult family living programs are most ‘home like’ in their setting. Home operators have responsibility for a small number of residents, usually one to three. In this program, residents receive the smallest amount of hours of service from family members and the largest amount from staff. It seems that more than in other models of care, staff members in this model substitute for
family members. This may be because residents enter this model of care because they do not have available family members, or because family members are confident that their relatives are ‘at home’ and feel no need to intervene. A concern in this model of care is that of staff burnout.

In Assisted Living, residents receive highest amounts of hours of assistance from family members and lowest amounts from staff members. Low amounts of staff hours fall directly from staffing levels. From 6 am to 11 pm there are two direct service staff members and from 11 pm to 6 am there is one staff member. An RN and Therapy Aide are available for part shifts during the day. There are 30 residents in this model of care. Clearly staff members are more limited in their ability to provide service than in the other models of care. However, the program philosophy is one in which residents choose which services they will receive and often opt to have family members provide services. This results in the high levels of family involvement. A concern with this model of care is whether this level of staff/family involvement is sustainable given the program philosophy of aging in place. As residents become more frail and need more service, it seems likely that both family and staff will be stretched in their abilities to provide increased amounts of care.

In Dementia Care, residents receive hours of service from family and staff that fall between hours provided in Adult Family Living and Assisted Living. In this model of care there are 36 residents living in three wings of the building. In each wing there are approximately two staff members during the day and one evening and nights. Thus staff/resident ratios are also intermediate between the other two programs. In this model of care, family members spend 75% of their time in enhancing well being and have relatively little involvement in other activities. Staff members divide their time almost equally between housework, personal care, and enhancing well being.
Staff provide most episodes of care than in other models. This high-paced caregiving may make staff susceptible to burn out.

**Have Caregivers Accepted the Partnerships Philosophy?**

The partnerships philosophy is one in which staff and family members are expected to work together to provide client-based services to residents. Our findings from questions to staff and family members about their beliefs about caregiving are that staff and family members do not have the same vision of responsibility for service provision to residents.

As discussed in the results chapter, family and staff agree that staff should be responsible for skilled care and household work, and family should be responsible for financial management and transportation. However, in personal care there is no strong support for shared staff-family responsibility from either staff or family. Most staff believed that the relevant partnership in personal care was between staff and residents; while family members believed that the major responsibility for personal care lies with staff members.

There are several possible explanations for differences in perspective. Staff may believe that residents are more able to be partners than family members believe they should be. Alternately, staff may be so pressed for time they need residents to do more. Or family members may think that their relative should receive services because they are paying for those services.

In enhancing well being there is more staff-family view of a partnership. However, staff and family members each assign relatively more responsibility to themselves and less to the partner. While family members appear to feel that enhancing well being is still part of their responsibility, staff members have taken this on as part of the philosophy of client-centred care.
These findings suggest that there are areas of potential disagreement between staff and family members in terms of resident responsibility and in terms of the need for families to be involved in tasks other than enhancing well being.

**What is the Correspondence Between What People Do and What They Think They and Others Should Do?**

The final question we address is whether staff and family members are providing services at the level they think is appropriate. For family members, the vast majority (over 80%) of family members see themselves as having responsibility for enhancing well being, care management, financial management, transportation, and some shopping. Correspondence to proportion of time spend in service delivery is not exact. Time spent caregiving is disproportionately allocated to enhancing well being (60%) and transportation (16%). The rest of the proportions are small (5% or less spent in other task categories-care management, household work, shopping (5%), financial management (4%), personal care and skilled care (2%)). This may mean that family members are not doing as much in care management, financial management or shopping as they think they should do. Alternately, it may mean that these activities can be taken care of adequately in the time allotted.

The vast majority of staff members (over 80%) see themselves as responsible for housework, skilled care and care management. The largest proportion of their time is spent in housework, suggesting that expectations and behaviour in this area of service are congruent. However, skilled care and care management take smaller proportions of time than enhancing well being. It may be that staff spend more time on enhancing well being because they are chosen for
their caring approaches to their work and do these tasks as part of their everyday interaction with residents.

Discrepancies between behaviour and beliefs are illustrated in comments from focus groups with staff members and with family members and from individual interviews with residents. From these qualitative data, there were several areas in which respondents saw discrepancies between beliefs and behaviour of themselves and others:

- staff think that they can’t do all that they are required to do
- staff think families should do more
- staff think that families believe staff should be doing more
- families think their involvement requires sacrifices in other parts of their lives
- families think that staff are asked to do too much
- residents think that both families and staff should do more

Staff members from all models of care shared a belief that they had a tremendous number of duties to perform and could not do the job adequately.

I think this philosophy is great but I think not just myself but we all have so much work that everybody is rushed to the limit.

When we first opened here I used to take a lot of them and go into their room and look at their photo albums and I would spend a half hour with them and they could tell me pictures of who people are but now I can’t do that. That bothers me too because we used to have a lot more time to spend with them and now there is so much more total care in our house. We run constantly with doing things all the time...we’re lifting and transferring and doing all these things that take so much time
that you don’t have the quality time to sit with somebody and look at photos, you know, for half an hour.

Why am I doing this, at a dollar thirty-three per hour and I’m expected to be in the home twenty-four hours a day. You become a prisoner, very soon, pretty soon you get frustrated, you’ll say no, I don’t want to do it.

Staff think that family participation is important but that participation of families often does not meet the expectations of staff. It appeared that because staff had so many responsibilities and tasks to accomplish, having families involved was a necessity.

I was surprised by the lack of participation the family has…it sounded like there was going to be a lot more family participation.

Even just taking out the family member—that’s one of the biggest things that we were talking about. I mean when it comes to personal care, yes, there is staff here for it but we’ve made it clear many, many times that there is not the staff here to take your family member out as regularly as they should be.

Staff also believe that families think staff should do more.

Families think because they pay the amount of money here, they think that we are supposed to be doing one hundred percent.

I find a lot of times the families they are really expecting so much from the staff for the care when they get to this level and the staff are really stressed because they want to be able to, it’s not that they are being neglectful but maybe they have to be in the
dining room serving 30 or 29 residents...But yet the family member is there and wondering why aren’t they feeding, why do I have to wait for this?

Family members found the ongoing caregiving responsibilities were taxing. They talked about how dealing with their relative’s financial affairs had caused a great deal of family tension, how their lives have to be planned around the needs of their relative, how they hesitate to go on a holiday, and how being part of the sandwich generation meant great caregiving demands. Caregivers talked about reduced time to spend with family and friends, and reduced time to spend with spouse. They talked about feeling stressed out and tired but feeling guilty and obligated to care.

One family member talked about how circumstances of the family need to be taken into account when considering how much families should be expected to do.

And it becomes very difficult when you try to group everybody into the same category too. Like we’re a married couple that have two children. There’s going to be some other families where there might be a single mother with children or someone that is trying to cope with a divorce or going through some sort of personal family problem. And to have regulations saying, you know, affecting the care of their father or their mother, um, it’s only going to add to more of a burden on those people. On the other hand, it could be just a single person or son or daughter, a nephew or a niece, or something, who may be able to, you know, go though the checklist because they don’t have any other personal commitment.
A common perception among family members was that the staff were responsible for accomplishing too many tasks in their daily routines.

I feel that this woman is burnt out...and this wouldn’t happen if they would give them more help.

...even if she wasn’t (able to walk on her own) staff wouldn’t have the time to help her, and, ah, you can come in and see, there’ll be two staff members on and they’re cleaning bathrooms, and cleaning the rooms, and then half an hour later they’re handing out pills...the same person or they’re in the kitchen serving the dinner, and I, I just don’t think it’s fair that they should have to cover all those areas.

There was agreement among residents of the different programs that family involvement in their lives is very important. However, for different reasons, those expectations are often unmet.

Well, there’s not that much (contact) anymore....My son and his wife had a little baby at the end of February. And they come in every couple of weeks or so to see me, but that’s it.

They’re not involved as much as I thought they should be.

Similar to family members, residents acknowledged that staff were overburdened. However residents would like to have staff spend more time with them and to provide more services than they are able to do.

I would expect them to do more. Even when you’re sick, you get a Tylenol and then they go. You just sit alone.

That’s why I’m here—for them to look after me—the cooking and cleaning.
These qualitative data point to a caring environment that is stretched in terms of its caregiving resources. Staff and family members believe that they can’t do the tasks that need to be done. Staff resent the lack of family involvement, perhaps because staff are stretched and because they do not see the other demands in the lives of family members. Family members are somewhat more sympathetic to staff workload since they can see all that staff are doing. Residents feel as if there is not enough quality time spent with them by staff or family.

Policy and Program Implications

In conclusion, findings lead us to make several recommendations concerning policies to frame programs of residential care for seniors. These are in three areas: recognizing all of the partners in the caring environment; supporting a client-centred model of care; and adopting methods to assess the caregiving environment in other residential care settings.

Partners in the caring environment. Our premise in this project was that the caring environment has three main players: staff, family members and residents. This premise was borne out with evidence that staff and family members provide large amounts of direct service to residents and that residents are expected to be active players in their own care. Program philosophies in these models of care recognize the importance of these partners.

Given the major involvement of family members in service provision, program policies and practice need to recognize this involvement and the impact of this involvement on family members. This can be done through orientation of family members to the types and amount of service they will be expected to provide and the types and amounts of service that will be provided by paid
staff. This can also be done through orientation of staff members to the interface between the types and amount of service they will provide and those that family members will provide.

Given the broad range of responsibility placed onto staff members who are hired as multi skilled workers, attention must be paid to their ability to manage the workload. Expectations that staff will do a broad range of physical tasks as well as manage social tasks such as enhancing well being may well be unattainable. It is well known that family members provide the best emotional support to their relatives when they are relieved of some of the everyday caregiving requirements such as heavy housekeeping. Yet when these tasks are transferred to staff, no such concessions are made. Higher staff/resident ratios or more workers dedicated to single categories of tasks such as housekeeping would free staff members to do these other important tasks.

The sector of the informal caregiving network that includes volunteers, neighbours, and friends was not represented in this study. Relatively few of these informal caregivers were actively involved in these models of care. We recommend that in residential models of care, the informal caring network be equated with family caregivers.

Home operators in Adult Family Living carry a heavy service load with little family assistance. They are responsible for residents 24 hours a day. Despite access to some respite, our findings suggest that these operators are at high risk of burn out. This model of care is attractive because of its low level of public investment since there are no capital costs. However, it may prove to be expensive if there is a high turnover of operators so that it is difficult to maintain consistent care for residents. Further attention to respite and to payment of home operators is necessary if this model is to be sustainable.

Supporting a client-centred model of care. One of the strongest indicators that services in these models of care are client centred is the amount of time spent in enhancing well being of
residents. This is the primary task of family members. Ideally, expectation of family members to provide other care tasks such as transportation to appointments with health professionals should be kept to a minimum so as not to jeopardize their time and energy for emotional support of their relative. Efforts should be made by programs to provide transportation for such activities. In this study residents often commented that services such as DATS (disabled adults transportation service) were unreliable and relatively inaccessible.

As well, high work loads of staff members in housekeeping may reduce their ability to provide as much social support as they would like and as program requirements mandate. Having some staff members dedicated to housekeeping could free others to focus on social aspects of care.

Families carrying a large caregiving load. Encouraging them to do more is placing undue pressure on them. Program policies that encourage involvement of family members must be worded very carefully so as not to engender guilt among those who are doing their best and who may already be worn down from years of caring at home. We recommend that programs be very specific about areas in which they encourage family involvement and these be primarily in enhancing well being. Assisted Living programs might review with families their ability to take on tasks that residents decide they do not wish to have as part of the service contract.

Adopting methods to assess the caregiving environment. Partnerships in caring are a new way of looking at how services are provided to residents in continuing care. Understanding of partnerships requires new tools to measure the amount of and types of services provided by caring partners. Methods developed in this project can be used to understand the caring environment in other jurisdictions. Use of the comprehensive list of services developed for this project would allow other programs to determine the relative load carried by staff and family members and determine congruence between their philosophy and what is actually happening on the ground.
Combined recall diary and stylized time use methods used in this worked well with staff and family members. However, the diary method requires consent from staff members on all shifts to comprise a 24 hour service day. In small programs in which there may be only one staff member on a shift, the quality of the data are constrained by willingness of staff in particular shifts to take part. We recommend that programs develop agreements with staff members and family members for a yearly audit of services. Such an audit could provide valuable ongoing information to programs to monitor staff and family service loads. They could be especially useful to evaluate changes in work loads in programs which have a philosophy of aging in place.

Results of this theme from the EPICC project provide the first comprehensive view of service partnerships in new models of residential care for seniors. They provide evidence of successes in implementing these models and directions for policy and program change. In general, residents in these programs are receiving high levels of services from caring partners. Partners are feeling stretched by the broad requirements of their work, but are making great effort to provide the social models of care which is the basis for the new models.
References


