

**Family Involvement in Long-Term Settings:  
Family Perspectives of Opportunity and Importance of Involvement**

by

**Ruth Salome Ali**

A Thesis submitted to the Faculty of Graduate Studies of  
The University of Manitoba  
in partial fulfilment of the requirements of the degree of

**Master of Nursing**

Faculty of Nursing  
University of Manitoba  
Winnipeg, Manitoba, Canada

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**Abstract**

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**Family Involvement in Long-Term Care Settings: Family Perspectives of Opportunity and Importance of Involvement**

While research has debunked the myth that older adults in long-term care facilities have been abandoned by their families, little is known about the involvement of family members in the care of their relative after institutionalization. Family involvement includes visiting, socio-economic care, advocacy and provision of personal care but involvement is dependent on the facility's commitment to family involvement and providing care opportunities that are important to families. A descriptive, exploratory and cross-sectional design using a convenience sample of 12 spouses whose husbands were residents of Deer Lodge Centre, Winnipeg, Manitoba, was conducted. Data collection was carried out with audio-taped interviews using specific items (including a recently developed, F-Involve and F-Important scale by Reid, Gish and Chappell, 2007, to measure family involvement) and open-ended questions to obtain spouses' perspectives of the opportunity and importance of their involvement in the care and quality of life of their relative. Julia Twigg's (1989) model of carers which defines family involvement in relation to family members as resources, co-workers or co-clients, was the conceptual framework used for this study. Findings suggest family members' commitment to remain involved in the care of their relative after institutionalization and the need for ongoing research to provide empirical evidence for family involvement on the quality of life of residents in long-term care settings.

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Dedicated to my mother, Iris Medora Campbell,

Our goal for LTC: was for you 'to live until you....die'...d

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## Chapter One: Introduction

While research has debunked the myth that older adults in long-term care facilities have been abandoned by their families (Gaugler, 2005; Gaugler, Zarit & Pearlin, 2003; Janzen, 2001; Peak & Sinclair, 2002), less is known about the involvement of family members in the care of their relative once this placement has occurred. There is even a greater lack of knowledge regarding the effect of family involvement on the quality of life of their relative in care (Gaugler, 2005). This research aimed to address these gaps in our knowledge of family involvement in long-term care settings. Chapter one has six sections and begins with the statement of the problem, followed by operational definitions and central concepts. Section three provides the goal and objectives. Section four, assumptions, highlights the background and thinking of the researcher. Section five presents the significance on the research. The final section is a summary of the chapter.

### Statement of the Problem:

Family involvement in the care of a relative who is a resident in a long-term care setting varies according to the characteristics of the family, the relative/resident and the facility itself (Dewar, Tocher & Watson, 2003). The facility's mission, goals and policies may encourage family members to be active participants in care or alternatively, to take a more passive role (Janzen, 2001). The physical environment of the facility as it reflects the philosophy of care, according to Blaylock & Johnson (2001), encourages family involvement. The facility may provide opportunities for involvement that family members may decide to accept or reject because of the type and extent of involvement

that they deem important in maintaining a relationship with their relative. Family involvement is therefore dependent on the facility's commitment to family involvement (Dewar et al., 2003) and its provision of opportunities, specifically opportunities for care that are important to family members (Janzen, 2001; Blaylock & Johnson, 2001). Engaging with others in a care partnership is a challenging endeavour and is often seen differently by staff and family members (Chapman, Keating & Eales, 2003).

Currently, a clear understanding of family perspectives on the importance of and opportunity for involvement in care of a relative who resides in long-term care is lacking (Davies & Nolan, 2004; Gaugler, 2005). Twigg's (1989) model of carers suggests that agencies and facilities tend to define family involvement in relation to family members as resources, co-workers or co-clients (Twigg, 1989; Nolan, Davies & Grant, 2001). Using this model and a recently developed tool (Reid, Chappell & Gish, 2007) to measure family involvement, this research explores and examines family perspectives of importance of and opportunities for involvement in the care of a relative who is a resident in a long-term care setting. This research also examines the role of involvement that family members may assume, such as co-worker, co-client or resource, in the care of their relatives, and the relationship between family involvement and resident quality of life.

Family members may take an advocacy role on behalf of their older relatives to enhance the quality of care (Dewar et al., 2003; Nolan et al., 2001) and indirectly quality of life (Kane, 2003). Quality of life is considered a multidimensional construct (Brod, Stewart, Sands & Walton, 1999; Nolan et al., 2001), that is, "ultimately a subjective and individual experience" (Nolan et al., 2001, p16) hence, it is the individual who can best describe what quality of life means to him or her (Kane, 2003). With the understanding

that good quality of life can be achieved even when health problems have lead to placement in a long-term care setting (Kane, 2003), it is critical that “comprehensive and regular assessments of needs in collaboration with the older person and their family” (Nolan et al., 2001, p.98) are carried out.

This research aimed to learn more about family members’ perspectives of their involvement in the care in long-term care settings and how this involvement affected the quality of life of their relatives. Specifically, this research focused on wives and their involvement in the care of their husbands who were residents in a long-term care setting, and how this might affect their husbands’ quality of life. To the researcher’s knowledge, the use of Twigg’s (1989) model of carers as resource person, co-worker and co-client with a sample of caregiver wives in a long-term care setting is novel. No other studies using Twigg’s model in the context of a long-term care setting had been found.

### Operational Definitions and Central Concepts

The following definitions clarify key words and concepts as used in this research.

**Family:** or primary family member refers to the family member/relative who is considered or remains the most involved in the life of the resident after institutionalization (Gaugler, 2004).

**Involvement:** relates to participation/carrying out of activities such as “visiting, socio-economic care, advocacy and the provision of personal care” (Gaugler, 2005, 2006), which includes grooming, hair combing and assisting with feeding.

**Quality of Life:** “sense of wellbeing, meaning and value” (Sarvimaki & Stenbock-Hult, 2000), personhood and the ability to carry out activities of daily living and instrumental activities of daily living.

Co-worker: partnership in the care activities of residents (adapted from Twigg, 1989).

Co-client: family member who is in need of a referral of care assistance or has received such care assistance from staff or facility, to improve that family member's health and wellbeing (adapted from Twigg, 1989).

Resource person: family member who supplies personal, historical/past or needed information about resident/relative to staff or advocates, to enhance the care of the resident (adapted from Twigg, 1989).

Partnership: sharing in activities with mutual understanding and respect and working together for a common goal.

#### Goal and Objectives:

The overall goal of this research was to learn more about family involvement in the care of a relative who was a resident in a long-term care facility and consequently to share this knowledge with families and with staff in long-term care facilities. This research highlighted the role of wives in the care of their husbands in a long-term care setting in Winnipeg, Manitoba.

The specific objectives of this research were:

- 1) To explore wives' perspectives of their involvement in care of their husbands residing in long-term care in relation to the roles of resource person, co-worker or co-client;
- 2) To explore wives' perspectives on the importance of their involvement in care of their husbands residing in long-term care;

- 3) To explore wives' perspectives on opportunities for their involvement in care of their husbands residing in long-term care; and
- 4) To explore wives' perspectives of their involvement in care of their husbands, and how this involvement relates to their husbands' quality of life

### Assumptions

The researcher believes that health care providers need the support, resources and assistance of families to effectively care for older adults in a health care system that is dynamic and challenged by physical and financial demands. Families are faced with major decisions regarding placement of and ongoing involvement with their ageing relatives and effective collaboration between families and health care providers will produce the best outcome care.

The researcher is a nurse and for 15 years has worked with older adults and families in several capacities, including as a Registered Nurse, Staff Development Coordinator, Clinical/Educational Facilitator and Director of Care in long-term care settings in Manitoba and Alberta. Working with families has been an especially rewarding part of the researcher's practice as a nurse and her perspective is that families are partners for best outcome care of the older adults. Furthermore, the researcher does not support the notion, sometimes expressed in long-term care settings that families are demanding and disruptive to care. This notion serves to create barriers that prevent collaborative practice through family involvement. On the contrary, whatever the challenges posed by family involvement, it is unproductive to view families in a negative manner.

The researcher's mother was a resident in a long-term care setting before she passed away. Her mother's experiences and journey through the system served to focus the researcher's passion to improve the qualities of long-term care settings for the benefit of residents and their families. Residents do not come to long-term care settings to die they 'come to live until they die'. The researcher's passion and professional commitment to collaborative practice through family involvement brought her to design a research project that would increase understanding of family involvement through the perspectives of family members, in this case, wife caregivers.

#### Significance of this Research

Nursing, as a discipline, strives to take a holistic perspective of client care that includes family members. This research aimed to learn more about family involvement in the care of a relative who had been placed in a long-term care setting from the families' perspective. More so, the utilization of Twigg's (1989) model of carers (resource person, co-worker and co-client) in this research is a new way to view the roles of family caregivers in long-term care settings. In addition, a relatively new scale to measure family involvement was used to quantitatively measure family involvement. Findings from this research could potentially assist health care providers in long-term care settings to better understand how families perceive the importance of and opportunity for involvement in the care of a relative. Hence, the knowledge gained from this research is aimed at providing a better understanding of family involvement and using a theoretical perspective framework not previously used in the context of long-term care settings.

### Summary

This chapter provided a statement of the problem in relation to the importance of and opportunity for family involvement in long-term care and how it might affect the quality of life of the residents. Operational definitions and the goal and objectives have been outlined. A declaration of the researcher's background, experience and perspective was contained under "assumptions". The fifth section of the chapter provided information on the significance of this research. Chapter two will provide a summary and analysis of existing knowledge through a literature review that encompasses content on: Twigg's (1989) model of carers, personal care homes in Manitoba, family involvement in long-term care settings and quality of life in long-term care settings.

## Chapter 2: Literature Review

This research examined family involvement in long-term care settings in relation to: their perspective on their involvement following Twigg's (1989) model of carers; on importance of and opportunities for their involvement; and on how their involvement related to their relative's quality of life. Chapter two consists of five sections. The first section describes Twigg's (1989) model of carers, highlighting the three roles of family involvement: resource person, co-worker and co-client. The second section provides a context for this research by providing information on personal care homes in Manitoba. The third section presents a review of current knowledge on family involvement in long-term care settings. The fourth section provides a review of current knowledge on long-term care residents' quality of life and family involvement. The fifth and final section provides a summary of the chapter.

### Twigg's (1989) Model of Carers:

Julia Twigg's (1989) model of carers suggests that health care facilities or agencies tend to be the ones that determine family involvement in the care of relative. Julia Twigg, a British gerontologist conducted most of her health organizational research in social care agencies based in the community and she labeled the three types of family involvement as resource person, co-worker and co-client. It should be noted that British terminology of carers is synonymous with the North American terminology for caregivers. Thus, this research makes reference to Twigg's (1989) model of carers and also refers to the wives as caregivers to their husbands. Family caregivers as "resource persons" are family members who are already in place, providing care and subsequently,

formal health care workers become involved to augment or change this care, as needed. Caregivers as “co-workers” are allocated a co-operative and enabling role by health care workers. Caregivers as “co-clients” are seen by health care workers as needing support and health care services and programs on their own.

In Twigg’s (1989) model, caregivers as “resource persons” and “co-workers” acknowledge a “care-providing” role for families, suggesting a partnership with staff for the benefit of the resident; whereas caregivers as “co-clients” suggests that family caregivers are recipients of care similar but not identical to the resident. The idea of caregivers as resource persons has less meaning when transferred to a long-term care setting than it does in the community where formal health care augments, complements or at times, replaces the current care being provided by family members. In contrast, in long-term care facilities, the major source of care is provided by formal caregivers. This reflects the care needs of residents who are most often physically and cognitively frail. Long-term care residents usually require more technical and personal care compared with older adults residing in assisted living in the community (Port et al., 2005).

Family involvement as “co-workers” refers to allocating to families a co-operative and enabling role, and this part of the model is relevant in long-term care settings. For example, family members might provide direct personal care such as washing their relative’s hair or providing foot-care as the facility’s policies dictate, or they might support direct care by formal caregivers by providing information on their relative’s preferences and habits to enable formal caregivers to provide respectful and resident-centred care. Certainly, it is not uncommon as part of the admission (to a long-term care setting) process to ask the new resident about preferences and habits. In the absence of

the new resident's ability to articulate these things, a family member will likely be asked to speak for them and educate formal caregivers about preferences and habits.

Family members become "co-clients" when formal caregivers begin to assess their needs and proceed to provide interventions such as education, counseling or direct service provision. Twigg (1989) notes that a family member's status as a client is "never a fully equal one and [family] carers remain at best secondary clients rather than fully co-clients" (p. 60). Twigg (1989) also notes that the role of co-client is more likely to be given to spousal caregivers rather than younger family caregivers such as adult children or grandchildren. The vulnerability of spousal caregivers who are older and have age-related health problems is thus, acknowledged and prioritized.

#### Personal Care Homes in Manitoba

"Nursing home" is a commonly used term related to residential care facilities primarily for older adults who require personal care support (such as bathing, feeding, toileting, walking, grooming and dressing) or minor medical support (such as oxygen use or dressing changes). In Manitoba, the term, nursing homes is not used. Instead, these residential care facilities are called personal care homes. Personal care homes offer long-term supervision and assistance with activities of daily living and basic nursing care under the supervision of a registered nurse and usually with a medical component to their care (Manitoba Health Services Commission, 1990). Residents in personal care homes are primarily older adults with disabilities or chronic diseases who are unable to receive safe care in their own homes (Doupe et al., 2006; Best in Care, 2007). Personal care homes are licensed to practice by the Government of Manitoba Personal Care Home Program as delegated by the Minister of Health (Best in Care, 2007).

The health care system in Manitoba is divided into eleven regional health authorities and each one is responsible for the delivery of health services for citizens in their given region. The regional health authorities are responsible for ensuring that personal care homes operate within the parameters of government standards in providing a safe and pleasant environment for residents (News Release, Manitoba, 2007). This research was conducted in the Winnipeg Regional Health Authority and the admission process to personal care home placement is through the Long Term Access Centre (Best in Care, 2007). Older adults are admitted to personal care homes through a process coordinated by community-based home care case coordinators in collaboration with a multidisciplinary team including physicians, nurses and social workers. The final decision for admission is dependent on this assessment process. It aims to identify the best facility to meet the resident's care needs (Doupe et. al., 2006) "based on factors such as the amount of assistance needed to complete activities of daily living, the degree of behavioural challenges exhibited by the individual, sources of informal support, and personal safety" (p.11).

At the time of the research, there were 39 personal care homes in the Winnipeg Regional Health Authority. Most were "stand-alone" facilities. However, this research was conducted in Deer Lodge Centre, a 431 bed long-term care and rehabilitation facility that provides a variety of in-patient, out-patient and outreach programs to the community. Among the in-patient services are personal care and chronic care units that provide residential care for older adults with long-term health concerns. The chronic care units (130 beds) provide care to individuals who require professional and/or medical intervention. The personal care home units (235 beds) are for individuals who require some degree of long-term care in a twenty-four hour supervised setting.

Personal care homes in Manitoba are either proprietary (for profit, 19 in total) or non-proprietary (not-for-profit, 103 in total) and all “proprietary PCHs in Manitoba are free-standing facilities; non-proprietary PCHs are either free-standing or juxtaposed to another healthcare facility” (Doupe et al., 2006 p. 8) for a combined total of 122 PCHs. The cost of residency in personal care homes is based on the individual’s net income and/or the earnings of a spouse (Doupe et al., 2006). Residents’ rooms can be private or shared with another resident and less often with more than one other resident. The type of room is not related to the cost of residency.

#### Family Involvement in Long-Term Care Settings

Family support and caring that was evident before the placement of a relative in long-term care will likely be sustained after placement, although changes occur in the type or extent of support and care (Buckwalter, Maas & Reid, 1997; Gaugler, Anderson, Zarit & Pearlin, 2004a). Abandonment (LaBrake, 1996) or the “dumping” of older family members flies in the face of research that has demonstrated the continuing involvement of families who visit weekly or several times a week (Gaugler, 2005). The work of Joseph Gaugler and his colleagues on family involvement is noteworthy. Their research indicates that caregivers whose husbands or wives suffer from dementia, maintain involvement in their spouse’s care after placement and in fact, tend to increase the frequency of their visits over time (Gaugler et al., 2003).

Family involvement in long-term settings is defined as a multidimensional construct (Gaugler, 2005), incorporating various activities carried out by family members in the care of their institutionalized relatives, including “visiting, socio-emotional care, advocacy and the provision of personal care” (p. 105) or hands-on care, financial

monitoring, care planning, decision-making, facilitating family events, attending councils, interacting with facility staff and providing connection with the past (Port et al., 2005; Bright, 2006). According to Gaugler et al. (2004a), family involvement includes assistance with activities of daily living: "eating, going to the bathroom, bathing, showering, washing hair, dressing/undressing, brushing hair/teeth, getting in/out of bed and getting around inside the facility" (p.68-69) and assistance with instrumental activities of daily living: "getting around outside grounds, getting going in an activity, taking his/her medication"(p.68-69), preparation of meals, housekeeping, companionship and assisting relatives with transportation and shopping (Bauer & Nay, 2003).

The literature on family involvement in long-term care draws on a few specific areas and this literature review is organized in relation to those areas. There is much written about the transition from community care of a relative by a family caregiver to institutional care and the family caregiver's involvement in that transition and admission process. This is the first section of this literature review. The second section provides the literature on another area of family involvement, that of the separation between the roles and care provided by families in relation to care provided by formal caregivers (nurse, health care aides and other health care workers). This is often dichotomized into "technical" versus "non-technical" care or caregiving role. The third section speaks to personal care home organizational context in relation to family involvement.

#### Transition and admission to long-term care settings: Family involvement

The literature on placement and transition certainly acknowledges the difficult and sometime untenable position of family caregivers whose relatives are relocating to a long-term care setting. This research tends to be short-term duration of usually less than

one year and most research studies do not follow families past the initial transition period into the longer term relationship between families and long-term care settings. Little is known about how families perceive themselves as caregivers or how their role or involvement may change through time (Gladstone, Dupuis & Wexler, 2006). The transition of older adults from living in the community to residing in long-term care settings focuses on relationships established on admission and during the early transition phase (Caron, Griffith & Arcand, 2005).

Family members are not always prepared for the challenges of having a relative in a long-term care setting and they have reported feeling overwhelmed (Davies & Nolan, 2004). However, their involvement provides an “important link with the outside world” (Davies & Nolan, 2004, p.525). The decision to begin the process of placement is often made in light of the older relative’s declining health, cognitive impairment and increasing frailty (Chen, Sabir, Zimmerman, Suitor & Pillemer, 2007; Janzen, 2001). The placement experience is reported as stressful by family caregivers, who tend to be women, either daughters or wives (Bauer & Nay, 2003). Placement of a family member requires a shift and transition in family caregiving roles (Reus, Dupuis & Whitfield, 2005). The decision-making process and actual relocation to a long-term care setting (Buhr, Kuchibhatla & Clipp, 2006; Reus, Dupuis & Whitfield, 2005) are emotionally charged life events for family members and their relatives (Marziali, Shulman, Damianakis, 2006).

Research by Gaugler et al. (2003) supported a shift from “hands-on” care to more preservative care, where family members aim at “ensuring the provision of emotionally and socially enriching care” (p.114) or preserving their relative’s identity and quality of life. Their longitudinal study of 65 caregivers of relatives with dementia who were

admitted to nursing homes suggested intraindividual heterogeneity in visiting patterns during a two year period. Specifically, spouses compared with adult children were more likely to report having increased visits and this may be due to their having fewer ties and obligations outside of their relationship with their husband or wife. An additional factor was the spousal caregivers' perceptions that their role as family caregivers after placement was seen in positive light by family and friends. The researchers suggested that staff members might build on the strengths of family visiting and caregiving to establish appropriate family-staff partnerships that promote optimal resident quality of life and social well-being.

According to La Brake (1996), family members keep their relative connected to the past, present and future and they "...prevent care from becoming wearisome and perfunctory" (p.1x). Phinney's (2006) research identified that residents with dementia are able to "stay involved in everyday life" (p.85) because of dedicated and committed family members who encourage their relatives to participate in activities, often attending with their relatives. Her study of eight families revealed three strategies used by family members to support their relatives' engagement in activity: reducing demands place on their relatives; guiding their relatives in activities; and accompanying their relatives as they engaged in everyday activities. Family members were determined to prevent their relatives from literally disappearing or 'go into hiding' because of dementia (Phinney, 2006).

According to Gladstone et al. (2006), family members search for ways of maintaining consistency in their role especially in the first year after placement. In earlier study, Gladstone et al. (2006) had examined the development of relationships between family members and staff working in long-term care facilities. Working from interviews

with 17 registered nurses, findings suggested that several factors influenced the development of family-staff relationships including family recognition of staff efforts and open communication. When family members question the standard of care given to their relative, they will increase their frequency of visiting, to become more visible and to monitor their relatives' care (Logue, 2003). Family members face other challenges in maintaining consistency in their involvement including: other demands that vie for their time; transportation difficulties; psychological barriers; associated guilt around the placement process; their relative's impaired cognition or inability to communicate effectively with them; and problems with their relative adapting to the new long-term care setting environment (Gladstone et al., 2006; LaBrake, 1996).

Personal care home managers and staff are familiar with the process that newly admitted residents and their families experience and the literature speaks to the difficulties experienced by families and the role and responsibility of staff to respond and more so, to be proactive. Davies and Nolan (2004) interviewed 48 relatives whose family member had recently been placed in a nursing home in order to explore the process of transition from their perspective. The families' experiences were understood in terms of five continua reflecting the extent to which families felt they were: operating under pressure (or not); working together with staff (or not); being supported by staff (or not); being informed by staff (or not); and in control of events (or not). Findings suggested that nurses, social workers and other health care workers can facilitate a much more positive admission experience to the long term care setting by working in partnership with families (Davies, 2005; Davies & Nolan, 2004).

It is the staff's responsibility to provide complete and relevant information to families including basic information on services and programs (Malench, 2004). Clearly,

the prerogative to invite family members into the new environment of long-term care rests with staff members who should be sensitized to difficulties of the transition process and appreciative of the families' expertise, knowledge and previous caregiving role (Blaylock & Johnson, 2001; Dewar et al., 2003). It is in the best interest of the long-term care setting, families and residents to reduce potential dissatisfaction, anger and helplessness of family members and new residents (Marziali et al., 2006). For caregiving wives, the impact of "no longer living with a life partner" can be substantial (Davies & Nolan, 2004, p.524).

Working effectively with family members necessitates the clarification of their roles and the roles of formal caregivers (Bauer, 2006). Clarifying roles provides a foundation for family involvement and participation in the long-term care setting (Dewar et al., 2003). Guidelines on areas of choice and information on limitations of choice are basic information. For example, in some long-term care settings, the choice of roommates, or where to sit in the dining room are requests that may be difficult to meet given the logistics of communal living. A new resident might prefer a daily bath but this may not be possible given staff human resources and facility equipment (Reus et al., 2005).

Working with families and new residents to deal with transition, loss and adaptation to new surroundings is challenging. Davies (2005) has suggested that family members be involved and empowered as much as possible in decision-making. This can enhance family relationships and improve the transition for the new resident (Davies & Nolan, 2004; Janzen, 2001). Pillemer et al. (2003) designed a program that placed new residents and family members at the centre of care planning with resulting report of reduced conflicts, better interpersonal attitudes and even staff retention. The desired goal

is to promote a resident-family centered environment of trust, ongoing support and integration of skills in the long-term care setting.

#### Technical versus non-technical roles: Family involvement

Lundh, Nolan, Hellstrom and Ericsson (2003) have suggested that a lack of early planning with families and new residents coupled with ambiguity in roles and relationships in the long-term care setting creates a confusing environment for new residents, families and staff. At the core of the ambiguity is an understanding of expectations and roles. Family members may expect to see a continuation of their caregiver role in the long-term care facility, including “hands-on” care, monitoring of formal care and provision of emotional support to their relative.

Ross, Rosenthal and Dawson (1997) studied caregiver wives who reported that the companionship and emotional support that they provided to their husbands were the most important caregiving activities that they performed. Bowers (1988) reported that family members no longer thought about task-based caregiving but instead saw their role as global, as maintaining their relatives’ dignity and identity. The family members in Duncan and Morgan’s (1994) study placed value on their community-based caregiving experiences and wanted to share their insights with staff. For their part, staff members have institutional routines and tasks to complete. Bauer (2006) has suggested that although partnership of family and staff may be the stated mission of the facility, the activities of staff in long-term care settings still focus primarily on providing personal care with families’ needs becoming secondary to getting the work done

In fact, research suggests that family members are inclined to give up some of the more demanding personal care tasks (for example, toileting and transferring) while

remaining socially involved with their relative (Gaugler, 2005). Family members become more involved in supervision and decision-making tasks rather than in providing “hands-on” care (Janzen, 2001). Some family members develop their roles as advocates and emotional supporters of their relatives and do not see themselves as caregivers, per se, (Gladstone et al., 2006). They choose to reduce stressful, "emotionally and physically draining tasks" to increase the time given to visiting and socializing as family members to their relative (Gaugler et al., 2004a, p. 12).

In the division of labour that occurs, staff may expect that “hands-on” care falls within their domain while family members believe that certain tasks are still their responsibility even after placement (Gaugler, 2005; Hertzberg, Ekman & Axelsson, 2003). Family involvement in a variety of tasks may become more acceptable when there are staff shortages and more “hands” are needed. Staff member may embrace family members as partners during selective times, for example, in times of staff shortage and inadequate staffing (Boise & White, 2004) or when the relative is exhibiting challenging or difficult behavior. There is often a division of technical versus non-technical roles. Technical roles such as medication administration are provided by formal caregivers while non-technical roles like hair brushing are performed by family caregivers. However, some family members maintain their commitment as caregivers throughout their relative’s admission to a long-term care setting by being involved in both technical and non-technical care roles (Gaugler et al., 2004). Such care roles include assisting with personal care activities of daily living (for example, feeding and grooming), instrumental activities of daily living (such as recreational activities) while preserving the self-esteem of their relative (Gaugler et al., 2003). In addition, family members’ level of involvement clearly varies according to their personal health and abilities (Bright, 2006).

Many family members, according to Davies (2005), are willing to continue active involvement in the care of their relative but are not encouraged or educated by staff regarding the expectations of the facilities. Concomitantly, most family members are not sure that they are able to continue caring for their relatives after admission to long-term care settings while others are confident in their years of informal care-giving skills and thereby, oppose staff control or attempts to “take over” (p.669) full care needs of their relatives (Davies, 2005).

The literature suggests that the help of family members is valuable and “arguably indispensable” (Bauer, 2006, p.48) to the wellbeing of relatives (Bauer, 2006; La Brake, 1996). Logue (2003) argued that it would be impossible to meet the physical, emotional and psychosocial needs of the older adult in long-term care settings if it were not for family involvement. Boise & White (2004) suggested that family members provide a link to the community as well as meaning and sense to an alien environment, thereby strengthening the relatives’ emotional wellbeing (Bauer & Nay, 2003).

It seems well accepted that the good quality care is dependent on good staff and family partnership (Blaylock & Johnson, 2001), a situation that often integrates the staff members’ technical expertise with the family’s unique biographical expertise and caregiving insight (Levy Storms & Miller-Martinez, 2005; Bauer & Nay, 2003). A trusting and respectful relationship between staff and family members is likely to decrease placement anxiety (Blaylock & Johnson, 2001) and enhance continued family involvement with “greater likelihood of improved resident outcomes” (Gaugler, Zarit et al., 2003, p.115).

The “unique biographical expertise” of family members is their knowledge of their relative’s history, preferences, habits and values. This is valuable information for

health care providers (Fabiano, 2001). This is particularly important when the relative has cognitive limitations and is unable to articulate their needs, likes and dislikes, personality, history and values” (Boise & White, 2004). Families are best equipped to provide insight, life history and other needed information that can help care providers to understand residents’ needs and behaviours (Boise & White, 2004).

While the literature supports family involvement and positive care outcomes, staff members may feel overwhelmed by family involvement in care. In Bauer’s (2006) study, staff members indicated role ambiguity especially in the growing autonomous care environment where families are “free to contribute to the maintenance of a resident’s” (p.45) overall care needs. Staff members indicated a preference for less family visiting as a way to reduce conflicts and interference and for better control of the care environment. Findings suggested that staff believe that: family members are too involved in the care of their relatives; family members are meddlers and trouble makers who interfere and disrupt care routines; and family members are disrespectful of staff’s ability to competently care for their relatives (Bauer, 2006).

On the other hand, some staff members express concern when family members do not visit or are not sufficiently involved (Jervis, 2006). Ironically, non-involvement of family members lessens conflict, which is a favored working situation to staff members yet is unacceptable to them when they consider the consequential loneliness experienced by the relatives (Jervis, 2006). Some family members are considered best to be avoided (Bauer, 2006) and nurses have reportedly avoided family members viewed as ‘difficult’ (Hertzberg et al., 2003; Dewar et al., 2003). Several sources of contention occur when families are seen as expecting privileged treatment, are unable to recognize staff shortages and heavy workloads, and being “complainers” (Bauer, 2006). A qualitative

study done by Davies & Nolan (2006) examined the perceived roles of family caregivers and staff members indicated although family involvement is not always appreciated by staff, “family members monitor standards of care and provide feedback to staff, e.g. removing dentures at night before bed” (p. 287).

Gaugler’s (2006) study of family involvement in three types of living arrangements (nursing homes, assisted living facilities and family care homes) illustrates the complexity of attempting to study family involvement and improved resident outcomes. Interviews with 79 residents, their families, staff persons and administrators suggested that family involvement may be associated with both positive and negative psychosocial outcomes for residents. Generally speaking, positive outcomes were associated with situations where family members had a recognized place and role in the facility or nursing home. This reinforced the family-staff-resident triad partnership and provided opportunities for family members to provide care, as they deemed appropriate for them, and to become involved in the overall organization of the facility (Gaugler, 2006).

The division of labour between staff members and families that constitutes family in long-term care settings has several facets. Although families and staff members do not divide their interests solely along technical and non-technical lines, it does seem that families appreciate their unique role as historians of their relatives’ care, advocates and sources of emotional and social support, as well as liaisons between the community and the long-term care setting. Family involvement is dependent on many factors, including staff need and responsiveness and their own health and personal wishes to continue some aspects of the caregiver role while relinquishing other aspects to formal caregivers. For their part, staff members seem to recognize the ongoing value of family involvement on a

day-to-day basis but may view family members as much too involved, not involved enough and a source of assistance and disruption.

#### Organizational context: Family involvement

The organizational context of the long-term care setting has a major role in determining the presence and extent of family. Family involvement can be integrated into the long-term care setting's mission and vision statement, through the establishment of family support groups and a resident-family council, and by holding regular meeting with families in relation to their and their relatives' needs. The physical environment can be welcoming or discouraging. Gaugler (2006) suggests that facilities that promote a family-centered environment include 24-hour visiting privileges, private meeting places for residents and families, and the opportunity for family members' participation in organizational policies and care planning.

Blaylock and Johnson's (2001) volume, "Advancing the practice of patient-and family-centered geriatric care" identifies the changes that were achieved at several long-term care settings with the goal of creating environments that foster family involvement and empowering residents and families. Changes were made to create more home-like environments and increased family involvement such as: children's playroom for intergenerational visits; kitchenette/staff work areas that replaced traditional nursing station and automatic lighting in bathrooms that turns on, on someone entering and off when someone leaves which helps residents' independence and activity level. Boise & White (2004) suggested making long-term care settings more comfortable, homelike, welcoming and conducive to family visits.

Logue (2003) suggested that long-term care settings are not “family-centred” and that multiple barriers exist including “resistance to institutional change, family members’ fear and hesitation, institutional rules and protocols, lack of institutional encouragement of family involvement, insufficient programs and activities addressing the social and emotional needs of the family and ineffective communication between the staff and families” (p. 24). Many long-term care settings struggle with barriers that interfere with developing a change in culture that promotes family involvement (Robinson & Roshner, 2006; Bauer, 2006).

One major barrier is that of communication. It has been recommended that long-term care settings creatively encourage open dialogue with family members to establish their preferred level of care or type of involvement they would like (Gladstone et al., 2006; Davis, 2005). Issues relating to poor communication between family members and staff can lead to misunderstanding, conflict, tension, unsuccessful transition (Amin, 2004; Marziali et al., 2006), failed partnership and animosity towards staff (Janzen, 2001). A critical aspect of open communication is keeping family members up-to-date with care concerns, just as if they were a valued partner with the health care team (Janzen, 2001).

Gladstone et al. (2006) indicated that long-term care settings must be more attentive to family members’ expectations by establishing clarity of roles and responsibilities (Bauer & Nay, 2003). Clarity of role is beneficial to staff and family members. Staff empowerment is critical to their empowering family members (Davis, 2005). Effective communication means telling families that they have expertise, too and that their expertise is valuable in the care of their relative (Hertzberg et al., 2003). Additional suggestions are open discussions and ongoing meetings to identify problems,

clarify misunderstandings and prevent negative situations (Levy-Storms & Miller-Martinez, 2005).

Essential to effective communication are initiatives such as workshops or in-service sessions that provide useful communication strategies for staff and family members, specifically equipping staff with conflict resolution skills (Marziali et al., 2006). Staff members have reported a lack of confidence in dealing with conflicts with family members (Marziali et al., 2006). They need education and the tools necessary to successfully interface between the family and the resident in long-term care settings (Amin, 2004). It is not sufficient for personal care homes to indicate in mission statements that family members are valuable; action and support to manifest this mission must be put in place. Direction and supports are needed to equip staff to effectively manage conflict resolution, to understand the changing face of health care and the increasing involvement of families and residents in care.

The emphasis on resident-centred care has increased the profile of family members in long-term care settings. The contribution of family members in the care plans of their relatives could be documented by staff and when this happens, the value of family involvement is validated in a tangible way (Dewar et al., 2003). Formal and not only informal communication is vital for an exchange of ideas related to care planning that best suits and benefits the residents (Boise & White, 2004).

The outstanding message is that families want to be involved and organizational structure and function must change to best accommodate that involvement. Long-term care settings must take an organizational and systematic view of how to best involve families in the working of a fairly complex operation that must take into account resident,

families and staff members' needs and talents. Active encouragement begins at the level of the organization (Reid et al., 2007).

### Quality of Life in Long Term Care Settings

While much has been written on the quality of life in long-term care settings, much less has been written on the impact of family involvement on their relative's quality of life. Generally speaking, there is an increased interest in the positive aspects of aging including concepts associated with quality of life such as successful aging and aging well (Keating, 2005). Quality of life as a concept has at least three critical attributes (Mandzuk & McMillan, 2005). First, individuals make their own appraisal of what constitutes their quality of life. Second, individuals identify quality of life as it pertains to their physical, psychological and social being and furthermore, in the presence of illness (a threat to physical being), there can still be satisfactory quality of life in psychological and social being. For example, a resident with mild cognitive limitations who has physical mobility problems may express a higher quality of life compared with an ambulant resident who has moderate cognitive limitations. Third, objective measures may supplement subjective evaluations of quality of life. And to add one more attribute to Mandzuk and McMillan's (2005) list, in long-term care settings, fourth, family or formal caregiver may act as proxies in evaluating a resident's quality of life.

Related literature on quality of life the context of long-term care settings includes: the definition or conceptualization of quality of life; the organization context of quality of life; residents' perspectives on their quality of life; and family members as proxies in defining and evaluating their relatives' quality of life.

Powell Lawton has been credited for his work on the multi-dimensional quality of life conceptual model (Chaudhury, 2003). According to Lawton, quality of life “is the multi-dimensional evaluation, by both intrapersonal and social-normative criteria, of the person-environment system of an individual in time past, current and anticipated (Lawton, 1991, p. 6). Furthermore, Lawton emphasized the social and environmental aspects of quality of life by saying, “...there has been a strong tendency for positive states to occur in older people who are more engaged with other people, leisure activities, and their environments” (Lawton, 1991, p. 192). Others have built on Lawton’s (1991) work, Nolan et al. (2001) described quality of life as “being, belonging and becoming” where aspects of personal identity, aspirations, purposeful activity, leisure pursuits and personal growth are also emphasized (p.15).

Quality of life in long-term care settings encompasses the resident’s ability to carry out activities of daily living which contributes to overall wellbeing and purpose in life (Jablonski et al., 2005). In relation to the quality of life of frail older adults, Hjaltadottir & Gustafsdottir (2007) have suggested four themes including: having security and feeling safe in one’s body; finding solace and comfort in one’s surroundings; feeling affirmed in one’s identity; and preparing for one’s death. It is important to note that quality of care is not the same things as quality of life although good care certainly can add to quality of life (Guse & Masesar, 1999). Quality of life is an expected outcome of quality care (Murphy, Shea & Cooney, 2006). Kane (2003) has gone so far as to suggest that quality of life in an unconscious older adult might be synonymous to their quality of care.

Given the subjective nature of quality of life, it seems imperative to speak with residents about what good quality life means to them. Kane (2003) suggested that

although residents in long-term care settings experience decrements in their emotional, social or physical health, their fundamental desires and concerns are not different from healthier older adults. Guse and Masesar (1999) investigated factors associated with quality of life from the perspective of 32 long-term care residents. These residents indicated that their quality of life was related to feelings of well-being, interaction with family and friends, living in a positive environment, having services as needed, and being able to help others (Guse & Masesar, 1999). The concept of thriving has been used to express quality of life in relation to the residents being able to participate in meaningful activities, enjoy their relationships with family members, have a bright environment, and live in a private room (Bergland & Kirkevold, 2006).

Eliciting responses about quality of life from residents who have cognitive limitations can be challenging. However, some research has reported that residents with cognitive limitations can provide excellent subjective information concerning their well-being (Brod et al., 1992; Gonzalez-Salvador et al., 2000). Several tools have been developed to specifically address residents who have cognitive limitations (for example, the QUALIDEM, (Ettema, Droes, deLange, Mellenberg & Ribbe, 2007). The development and use of specialized quality of life tools for residents with dementia seems preferable to relying on proxies, such as staff caregivers or family members to speak on residents' behalf (Hoe, Hancock, Livingston & Orrell, 2006; Brod et al., 1999). In studies that have compared residents who have mild to moderate dementia with staff caregivers, quality of life has been consistently rated lower by the caregivers (Logsdon, Gibbons, McCurry & Terry 2002; Mittal et al., 2007). Similarly in studies that have compared residents with dementia with their family caregivers, discrepancies in rating quality of life have been reported (Sands, Ferreira, Stewart, Brod, & Yaffee, 2004).

One of the objectives of this research was to learn more about family involvement in relation to the resident's quality of life from the family perspective. As indicated earlier, Gaugler and colleagues have been leaders in this area. According to Gaugler (2005), research has ignored the complex roles that families play in the care of their institutionalized loved ones. Family involvement achieves two objectives for family members. It provides care and support for the relative and it fulfills family members' personal satisfaction as part of the health care team (Bauer & Nay, 2003; Caron et al., 2005). Gaugler's (2006) research on 'family involvement and resident psychosocial status in long-term care' identified that family involvement in care planning conferences was associated with increased wellbeing for their relatives. Family involvement lead to improvement in residents' quality of life and increased participation in social activities, (Gaugler, Leach & Anderson, 2004b); satisfaction with life other than being cognitively intact, economic status, religious beliefs (Brod et al., 1999) and better mood as equivalent to better quality of life (Hoe et al., 2006).

As indicated in an earlier section, the role of organizational context is vital in whether or not the long-term care setting is open to the expressions of family involvement. Resident-centred care settings like those promoted by William Thomas, the creator of the Eden Alternative, (Thomas, 2004), have family involvement embedded in their missions and vision statements. Lundh et al. (2003) suggested that to sustain the individuality and uniqueness of residents and supporting their quality of life, means blending of knowledge of both family caregivers and professional staff. Suffice to say, the relationship between staff and family members is vital to the delivery of quality care through coordination and collaboration of services (Janzen, 2001). Research has found that positive staff-family interactions leads to quality of care and improved residents'

quality of life (Gaugler & Ewen, 2005) and decreased feelings of depression (Gaugler, Leach & Anderson, 2004). Davies & Nolan (2006) advocate the best means of achieving quality of life for older adults is by maintaining continuity in their lives through the unique involvement of family members.

### Summary

This chapter described Twigg's model of carers (1989), the framework used in this study, which focused on the three roles of family involvement (as resources, co-workers and co-clients) and provided a context for this research by providing information on the personal care homes in Manitoba, Canada. This chapter also provided a review of current knowledge on family involvement in long-term care settings including sections on: transition and admission to long-term care settings; technical versus non-technical roles; and organizational context. This chapter also provided a review on quality of life in long-term care settings with emphasis on the attributes and characteristics of quality of life; residents' and family members' perspectives on quality of life; and the organizational context of quality of life.

The next chapter provides information on the research methods including sections on design, setting, sample and inclusion criteria, procedure for access and ethical approval, and data collection and analysis procedures.

### Chapter 3: Research Methods

This chapter describes the research methods used to achieve the following objectives:

- 1) To explore wives' perspectives of their involvement in care of their husbands residing in long-term care in relation to the roles of resource person, co-worker or co-client;
- 2) To explore wives' perspectives on the importance of their involvement in care of their husbands residing in long-term care;
- 3) To explore wives' perspectives on opportunities for their involvement in care of their husbands residing in long-term care; and
- 4) To explore wives' perspectives of their involvement in care of their husbands, and how this involvement relates to their husbands' quality of life

The first section presents the design and is followed by two sections on a description of the setting, and the sample and inclusion criteria. The fourth section describes the procedure for access and ethical approval. The fifth section describes and discusses measurement and tools. The sixth section presents the research analysis procedure. The final section is a summary of the chapter.

#### Research Design

The design of this research was cross-sectional. It was an exploratory descriptive study because little was known about family involvement in long-term care settings from the perspectives of caregiving wives. Data were collected during two periods in January of 2008 by the researcher. The subjects were twelve wives whose physically and

cognitively frail husbands had resided in Deer Lodge Centre for at least six months. These wives had provided care to their husbands prior to their husbands' placement in Deer Lodge Centre. It was a convenience sample. Both qualitative and quantitative data were collected during face-to-face interviews with the twelve wives. The analysis of data was carried out by the researcher and her advisor.

The overall goal of the research was to learn more about family involvement in long-term care from the perspectives of family caregivers. In her clinical experience, the researcher had identified that wives were more likely than other family caregiver to become closely involved with a relatives' care. So, wives were selected to represent a family perspective of involvement in care in a long-term care setting.

Two other things are important in the research design. First, Twigg's (1989) model of carers seemed appropriate to guide questions posed to wife caregivers about their involvement. Twigg (1989) has suggested that organizations determine family involvement in their relatives' care and allocate families the roles of "resources persons, co-workers and co-clients". Second, a relatively new tool had been established, the "Family Involvement (F-Involve) and Importance of Involvement (F-Important) scale (Reid et al., 2007) that claimed to capture important aspects of family involvement in long-term care setting (see Appendix A).

### Setting

The setting for this research was Deer Lodge Center, a large 431 bed rehabilitation and long-term setting in Winnipeg, Canada. Deer lodge Centre provides a wide variety of inpatient and outpatient services for residents, family members and the community. The permanent resident units are the chronic care units (3 units with 130

beds) and the personal care units (6 units with 235 beds). Deer Lodge Centre has several departments including: respiratory services; social work; spiritual care; foods and nutrition; rehabilitation (communication disorders, physiotherapy, occupational therapy); recreation; pharmacy; diagnostic services; a hearing centre; and day hospital. Within its walls, it houses a dental clinic, a senior centre and a prosthetics company. There is a resident and family council in Deer Lodge Centre and it meets every first Tuesday of the month. According to the Deer Lodge Centre website, the goal of the council is to “help keep patients, residents and families updated on activities of the Centre”.

A rare feature evident at Deer Lodge Centre is that the personal care home units have higher male population compared with females. This is an outcome of the history of Deer Lodge Centre. It was originally designated as a veteran’s hospital (after World War I) and through a few transition phases, Deer Lodge Centre became less exclusive to veterans and more inclusion of the older adult community. However, out of respect for earlier agreements between levels of government during these transitions, a high proportion of personal care beds are held in preference for veterans and military personnel. In fact, two of the six personal care units are designated as “Veteran Units”. For this research on wife caregivers, Deer Lodge Centre seemed ideal in terms of the likelihood of efficiently recruiting several wives who are caregivers to their husbands.

Deer Lodge Center also has a reputation for valuing and participating in research including involvement on site in multi-site national research projects. Deer Lodge Centre also has good academic relationships with the University of Manitoba including the establishment of a Collaborative Research Unit.

### Sample and Inclusion Criteria

Approximately 2/3 of the residents in Deer Lodge Centre are male and this meant that there were likely several wives who would meet the inclusion criteria. A preliminary meeting with nurse managers had also suggested that there would be a number of wife caregivers who might be interested in participating.

The inclusion criteria for family members, was that they were: spousal caregivers (because Twigg, 1989 suggested that the co-client role is more likely with older more vulnerable family carers); female caregivers (because the caregiving roles tend to be gender-based with females providing more “hands-on” care); and visiting their relatives at least once a week. The wife caregivers had to be able to speak English and respond to interview questions. The wives’ husbands had to have been residing in Deer Lodge Centre (personal or chronic care units) for at least six months. This time period would enable a “settling-in” period to occur and the establishment of a formal caregiving plan.

A total of 17 family members who fit the inclusion criteria were identified by nurse managers. The researcher was unable to contact three wives by telephone, and one family member scheduled an appointment for interview that was subsequently canceled by her daughter. Her daughter indicated that participation in the study would not be in the best interest of her mother who “went through a lot this year”. Another family member was recovering from surgery and declined to participate. This left the twelve wives who agreed to participate.

It should be noted that the researcher was not directly involved, initially, in the recruitment process. The researcher resides in another province (Alberta) and so the recruitment was delegated to a research assistant with experience in conducting research on older adults. The researcher and the research assistant consulted and were in regular

contact through telephone and emails during the recruitment process. The research assistant and the researcher scheduled the interviews with the wives at a time that was convenient for the wives and the researcher. The researcher came to Manitoba in order to have face-to-face contact with the wives during interviews, rather than have someone else conduct the interviews. This was the recommendation of the researcher's committee and it benefited the interview process and later data analysis.

#### Procedure for Access and Ethical Approval

Any research conducted by graduate students or faculty members of the University of Manitoba that involves human subjects must be reviewed and approved by a Research Ethics Board prior to the recruitment of subjects for that research. Because this was a nursing research thesis, the application for approval was sent to the Education Nursing Research Ethics Board (ENREB). ENREB operates in accordance with the Tri-Council Policy Statement on Research with Human Subjects at the University of Manitoba. The application for this research with supporting documents included information about the research project: purpose, methodology, research instruments, study subjects, informed consent form, risks and benefits, anonymity, confidentiality and compensation; information sheet for families; 'inclusion' information for nurse managers; and a letter to the Chief Nursing Officer of Deer Lodge Centre, providing information about the research and requesting access to family members.

The ENREB Chair made three noteworthy stipulations before approval was granted. First, there had to be evidence of written permission from the researchers who developed the F-Involve and F-Important tools. Second, because some of the questions might upset or cause sadness for the wives, ENREB asked about resources that might

provide comfort. The researcher responded that in the event that participants become distressed, the interview would be immediately stopped. The researcher would acknowledge the distress and ask the wife if she wished to speak with a social worker or pastoral staff member at Deer Lodge Centre. This concern by ENREB was meaningful in light of the incidences of distress experienced by two wives during the interview process. Both of the interviews were stopped but the wives decided to continue the interviews after a short period of time. Third, ENREB needed clarification to where the raw data would be stored. The researcher responded that the raw would remain with her in a locked desk drawer while copies of raw data would be stored in locked cabinet in the thesis advisor's office. This was deemed necessary as the thesis advisor resided in Manitoba and the researcher lived in Alberta. The advisor and researcher would be working on data analysis individually and collaboratively, hence the need for both to have easy access to the raw data. A copy of the ENREB approval form is attached in Appendix B.

The access approval form for Deer Lodge Centre requires evidence of approval from one of the University of Manitoba Research Ethics Boards. Once the researcher had the ENREB approval form, the access form for Deer Lodge was completed and submitted. The Access Committee at Deer Lodge Centre looks primarily at the potential benefits for residents, patients, families and staff and whether or not the intended subject pool is already being accessed by another researcher. Access approval from Deer Lodge Center came soon after the application was submitted. No questions or stipulations were attached to this approval.

### Measurement and Tools

The face-to-face interviews with family members were conducted in a place mutually agreed upon by the wife caregiver and the researcher. Seven interviews were conducted in a private room in the Collaborative Research Unit at Deer Lodge Centre. One interview was carried out in a staff room on one of the personal care units because the wife wanted to be in close proximity should the staff need her during the time of the interview. Another interview was conducted in the husband's room because the wife wanted to be with her husband. Three interviews were done at the wives' homes.

The interviews were usually 60-90 minutes long with only two interviews exceeding 90 minutes. One of these longer interviews occurred because the wife preferred to expand on answers, stating dislike for any scale items that necessitated two-word responses such as "strongly agree" or "somewhat important". For the other longer interview, the wife caregiver became distressed. As indicated earlier, the interview was stopped and resumed at the wife's request. In fact, there were two wives who became distressed during the interviews. After the interview was stopped, the researcher allowed the women time to become composed and then asked if she could do anything to help or arrange for someone to help. Both of these wives were determined to complete their interviews. One of these wives decided to speak with her family doctor, and expressed her relief in crying which she had not been able to do for more than a year. The wife also voiced her appreciation for the support offered by the researcher. The other wife said that she was experiencing a period of grief, apologized for crying, and assured the researcher that she would be continuing to receive pastoral support from her church organization.

One interview was completed in less than 60 minutes because the wife's only available time for meeting with the researcher was within one hour of her husband's lunch-time, and it was customary for her to feed her husband.

All of the interviews were completed during two periods in the month of January of 2008. The researcher travelled twice from Alberta to Manitoba in order to interview the twelve wife caregivers. In addition to the challenges of travel and scheduling of appointments, tape recorder problems led to the loss of some of the interview data from one wife. This lost information necessitated rescheduling another interview appointment to which the wife graciously agreed.

The complete interview schedule is contained in Appendix C and has sections on: socio-demographics, caregiving and health characteristics of the wives; the Family Involvement (F-Involve) and Importance of Involvement (F-Important) Scale (Reid et al., 2007); closed-ended questions based on Twigg's (1989) model of carers; closed and open-ended questions on the husbands' quality of life; and a series of open-ended questions related to the four objectives.

The following socio-demographic data was collected from family members in order to describe their characteristics as a group: age, family status, ethnic identity, employment status, and religious affiliation (see Appendix C). The wives' caregiving data included: caregiving role prior to their husband's placement, frequency of visits, current caregiving role and a single item on the wives' satisfaction with their husbands'. Some data were also collected on the wives health characteristics (chronic illness, functional ability, single item self-rated health and depression and self-rated quality of life). The socio-demographic, caregiving and health data from the wives was collected in order to provide a profile of the sample.

A relatively new tool to quantitatively measure family involvement was selected for administration during the interview. The Family Involvement (F-Involve) and Importance of Involvement (F-Important) Scale was developed by Reid, Chappell and Gish (2007). There are 20 items based on nine themes from the literature on family involvement:

1. Family members provide information to staff about the life history, coping styles, strengths and weaknesses, and the care needs of residents with dementia;
2. Staff help family members to meaningfully interact with their loved one;
3. Family members are included in decision-making and care activities;
4. Facilities have in place formal and informal support systems in the form of regular meetings and support groups;
5. Educational opportunities for family members are present so that they can learn about how best to communicate with persons with dementia and about how the nature of the disease process progress so that they will be able to make sense of the changes that they observe taking place in their relative;
6. Family members are offered assistance with planning for the future eventualities of death and estate management;
7. Family members are encouraged to participate in the life of the facility (that is, volunteering, social engagements);
8. Family members are oriented to the rules and regulations and how things work in the facility; and
9. Administrators seek out perceptions and opinions about the quality of care provided from family members (Reid et al., 2007, p.93).

The F-Involve and F-Important scale has been tested and it is reported to have “strong evidence of test-retest reliability” (Reid et al., 2007, p.96). Cronbach’s alpha was used to evaluate internal consistency. Factor analysis established construct validity (Reid et al., 2007). The plan for using this tool was to specifically examine any of the items that seem to be rated by the wife caregivers as being a combination of high importance for involvement without opportunity for involvement (“present in the long-term care setting”). Other combinations of high importance and high opportunity or low importance and high opportunity or low importance and low opportunity would not have a major effect on the wives’ caregiving involvement. It is noteworthy that after each item in the F-Involve and F-Important scale, the researcher asked the wives to add comments in relation to importance and opportunity. One small change was made to the F-Involve and F-Important scale, instead of reading “family member” the items were personalized to read “husband”. The F-Involve and F-Important scale was used to address both objectives #2 and #3, to explore the wives’ perspectives on the importance of and opportunities for involvement in care of their husbands residing in a long-term care setting. Box 3.1 holds the source of data that addresses objectives #2 and #3.

Box 3.1 Research Objectives #2 & #3

Research Objectives: #2 & #3	Source of Data
<p><b>Objective #2:</b> To explore family members' perspectives on opportunities for involvement in care of a relative residing in long-term care</p> <p><b>Objective #3:</b> To explore families' perspectives on the importance of their involvement in care of relatives residing in long-term care.</p>	<p>a. The F-INVOLVE and F-IMPORTANT Scales (Appendix 4)</p> <p>b. Open-ended Questions: After each question, the family member was asked "Is there anything more that you would like to say about this?" "Is there anything else that you would like to add?" "Do you have any questions for me?"</p>

In order to address objective #1, to explore wives' perspectives of their involvement in care of their husbands residing in long-term care in relation to the roles of resource person, co-worker and co-client, it was necessary to develop closed-ended and open-ended questions. A tool based on Twigg's (1989) model of carers does not exist. The researcher and her advisor thought it best to continue in the format of the F-Involve and F-Important scale in terms of the closed-ended questions that were developed to address the wives' involvement roles. Fourteen questions were developed by the researcher and reviewed by the advisor for face validity (see Appendix D). These items and their relationship to Twigg's (1989) model were also shared with committee members during the research proposal defense. Each item was to correspond to the roles suggested by Twigg (1989). Items # 2, 6, 7, and 8 were designed as caregiver as "resource person" items. Items #1, 3, 4, 5, 9, 10 and 11 were designed as caregiver as "co-worker" items and items #12, 13 and 14 were designed as caregiver as "co-client" items. After each item, wives were asked to add their comments.

Box 3.2 Research Objective #1

Research Objective 1	Source of Data
<p><b>Objective #1:</b> To explore family members’ perspectives of their involvement in care of a relative residing in long-term care in relation to the roles of resource persons, co-workers or co-clients.</p>	<p>1. Fourteen items developed by the researcher in relation to Twigg’s (1989) model of carers</p>
	<p>2. Open-ended Questions: “Do you feel that the staff at Deer Lodge Centre is concerned about your health and well-being?” “Do you feel that the staff is equally concerned about your health and well-being as they are about your husband’s health and well-being?”</p>

To address objective #3, to explore wives’ expectations of their involvement in care of their husbands, and how this involvement relates to their husbands’ quality of life, closed-ended and open-ended items again had to be developed. The researcher developed four items in the same format as the F-Involve and F-Important scale and asked two open ended questions, “What does quality of life of your husband mean to you?” and “ In general, what would be a good quality of life for your husband?”

Box 3.3 Research Objective #4

Research Objective: #4	Source of Data
<p><b>Objective #4:</b> To explore family members’ perspectives on their involvement in care of their relatives, and how this involvement relates to their relatives’ quality of life.</p>	<p>1. Four quality of life items developed by the researcher using the format of the Family Involvement (F-INVOLVE) and Importance of Family Involvement (F-IMPORTANT) Scales.</p>
	<p>2. Open-ended questions: “What does quality of life of your husband mean to you?” and “In general what would be a good quality of life for your husband in this facility (Deer Lodge Centre)?”</p>

Finally to address the four objectives, a series of open-ended questions were developed that asked wives about: their involvement in care (objectives #3 and 4); their relationships with staff at Deer Lodge Centre (objective #1); and the relationship between the care that they were providing and their husbands' quality of life (objective #4). Each open-ended question could be probed with additional questions as needed.

### Research Analysis Procedure

The audio-taped interviews were transcribed by a transcriptionist with experience working with researchers from the University of Manitoba. Quantitative data were tabulated using SPSS (Statistical Package for the Social Sciences) by the Manitoba Nursing Research Institute, a research unit within the Faculty of Nursing at the University of Manitoba. For this research, univariate (frequencies) analysis was used to present a profile of the wives who participated (socio-demographic, caregiving and health characteristics) and to examine individual items on the F-Involve and F-Important scale (Reid et al., 2007). Qualitative analysis of the open-ended interview questions aimed to identify prevalent themes in the answers to these questions.

For the questions on the F-Involve and F-Important scale (for objectives #2 and 3) and the other closed-ended questions on the tools developed to address objective #1 (wives as resources, co-worker and co-clients) and objective #4 (wives' involvement and husbands' quality of life), the thrust was to identify items of high importance and low opportunity for involvement. In order to facilitate analysis, the researcher and advisor elected to collapse the response categories of "unimportant" and "somewhat important" to "low importance" and "quite important" and "extremely important" to "high importance". Similarly, the categories for "present in the facility" were collapsed from

“strongly agree” and “somewhat agree” to simply “agree” and from “strongly disagree” and “somewhat disagree” to simply “disagree”. By doing this, it was possible to cluster the ratings by wives and more easily identify items of high importance and low opportunity.

The researcher and advisor dealt with each closed-ended item that indicated high importance and low opportunity by checking the transcripts for any additional comments that might shed light on any underlying issues. It was important to try and explain or speculate on any operating factors. This analysis was conducted on all the closed-ended items. Furthermore, there may have been other parts of the interview that were relevant and these relevant other questions and answers were linked to the closed-ended items of high importance and low opportunity, as appropriate.

In terms of the audio-tapes, the researcher first compared the transcripts with audio-taped interviews, a rudimentary type of analysis that is in keeping with Sandelowski's (1995) direction. This proofing process gave the researcher an appreciation of the “interview as a whole” (p.373) and it also revealed the transcriptionist's omission of repetitious statements and places where the transcriptionist had condensed data by paraphrasing the wives' comments. The transcriptionist was redirected to revise all transcriptions to reflect raw data as taped or verbatim transcription (including sighs, laughs and all comments, regardless of any repetitions) to ensure credibility of data. According to Sandelowski (1995), the “selective preservation of elements of the research interview” (p.373) is not appropriate at the early stages of analysis. The revised transcriptions indicated consistency and yielded an increase in the length of interviews from two to four pages in length for each interview.

Line numbered copies of transcriptions were prepared for the researcher and advisor, bearing only participants' research code numbers (e.g. 002, 0017). The researcher and advisor reviewed the transcripts from the audio-taped interviews with wives individually and then together. The fact that the closed-ended and open-ended questions were so closely linked to the objectives facilitated the individual and collective analysis of the data. The formal analysis started with the revised and accepted transcriptions as "the raw data that will be analyzed" (Sandelowski, 1995, p.373) and was done in a systematic and consistent approach. It should be noted that much of the collective analysis of open-ended questions was done through telephone conference meetings between the researcher and her advisor. Although this is certainly less than ideal, it is workable.

Together the researcher and advisor dealt with open-ended questions that related to the study objectives, that is, themes as related to family as resources, co-workers and co-clients; opportunities for involvement; and the importance of involvement. The open ended questions as well as probes (e.g. "Is there anything more that you would like to say about this?") were used to encourage wives to provide full answers and create data that was rich in detail. Overall, they seemed to be more comfortable and more expressive with open-ended questions compared with the closed-ended questions.

To shed more light on how the analyses were conducted, more detail is provided in relation to the analysis of data related to objective #4 and what quality of life meant to the residents through the perspectives of the wives. The two questions asked of wives were, "What does the quality of life of your husband mean to you?" and "In general, what would be a good quality of life for your husband in Deer Lodge Centre?" Initially, the researcher and advisor separately reviewed the transcripts for each of these questions.

The first question seemed to elicit fairly general answers, for example, “everything” and “a whole lot”. However the second question brought out more specific responses. The researcher and advisor decided to combine the responses to both questions into distinct categories. Initially, this was done separately and a total of eight categories emerged including: 1) “broad statement” which included the general answers that were given by wives; 2) “health”; 3) “well-being”; 4) “recreation”; 5) “relationships with others”; 6) “being cared for and receiving good care”; 7) “sociability”; and 8) “functional ability” in carrying out activities of daily living. The researcher and advisor reviewed statements that fell under each of the eight categories. However, with further review and discussion, it seemed that two of the categories actually fit under other categories. “Sociability” or the ability to enjoy the company of and interaction with others in a social setting seemed to overlap with two other categories, that is, “relationships with others” and “recreation” so responses under “sociability” were recategorized under either “relationships with others” or “recreation”. And “functional ability” seemed to be so closely related to how the wives described “health” of their husbands that these two categories were combined into “health and functional ability”. So, eight categories of responses became six categories of responses. The researcher and advisor reread the wives’ responses to all of the quality of life questions and through comparison and discussion were able to place all of the wives’ responses into the final six categories.

To maintain trustworthiness of data and subsequent findings of the inquiry being investigated in this study, Lincoln & Guba’s (1985) work on “credibility”, “dependability”, “confirmability”, and “transferability” was adapted. These four terms are “the naturalist’s equivalents for the conventional terms “internal validity”, “external validity”, “reliability”, and “objectivity” (p.300). Credibility of data was maintained

through member checking where researcher used opportunities during the interviews to intentionally assess what each wife intended to say by: asking for clarification, repeating questions to ensure that participants understood what was asked; and asking the question “Do you have anything else that you would like to add?” Member checking ensures intact constructions and validation of lived experiences as described (Speziale & Carpenter, 2003) by participants.

Dependability was maintained by ensuring a paper trail of raw data, journal entry following each interview and notation on reading transcriptions and reviewing audio-taped recordings. Confirmability, according to Speziale and Carpenter, (2003) and Lincoln and Guba (1985) is another process criterion whereby researchers leave an audit trail that provides a means for others to follow as upheld in this study through condensed notes, theme definitions, categorizing and reflective notes. The concept of saturation of data is also included in this criterion. Lincoln and Guba (1985) argued that confirmability is dependent on the “extent to which the data and interpretations of the study are grounded in events rather than the inquirer’s personal construction” (p.324).

Transferability was achieved in this study by providing the thick description of data in the form of exemplars that stay true to the words spoken by the wives to ensure the possibility of transfer by any potential researcher as upheld in the revision of transcriptions to keep raw data intact. This concept is in-keeping with Lincoln and Guba (1985) who are convinced that it is not the responsibility of the naturalist to “provide an index of transferability; it is his or her responsibility to provide the data base that makes transferability judgments possible” (p.316).

### Summary

This chapter described the cross-sectional design of this research. The research was conducted through interviews with twelve wives whose husbands were living in Deer Lodge Centre, a multi-programmed rehabilitation and long-term care setting. The research was exploratory and descriptive and aimed to elicit the perspectives of wives. The research was reviewed and approved by the Education Nursing Research Ethics Board at the University of Manitoba. It used a novel model of family caregivers as resources persons, co-workers and co-clients in long-term care settings. This model had only been used with social agencies in the community (Twigg, 1989). It also used a relatively new tool, the F-Involve and F-Important scale to measure family involvement in long-term care settings. In addition, other closed-ended and open-ended questions were developed by the researcher and advisor to capture the wives' involvement in their husbands care and the relationship between that involvement and their husbands' quality of life. Data analyses was carried out by the researcher her advisor.

The next chapter presents findings from this research including information on the socio-demographic, caregiving and health characteristic of the wives and findings in relation to the four objectives plus some additional findings.

## Chapter 4: Findings

This chapter presents the findings on family involvement in long-term care settings in six sections. The first section provides a socio-demographic, health and caregiving profile of the twelve wives who participated in this research. The second section relates to research objective #1 and outlines the wives' perspectives on their involvement in the long-term care setting as a resource person, co-worker or co-client, as outlined by Twigg (1989). Emphasis is placed on those items that generated situations of "high" importance and "low" opportunity. The third section relates to research objectives #2 and #3, and provides the wives' perspectives on the importance of and opportunities for involvement in the long-term care setting. Again, emphasis is placed on items from the F-Involve and F-Important Scales (Reid et al, 2007) that generated situations of "high" importance and "low" opportunity. The fourth section addresses research objective #4, and presents the wives' perspectives on how their involvement contributes to the quality of life of their husbands. The fifth section is titled, "additional findings" and presents findings not directly related to the research objectives but of interest to other questions of family involvement in long-term care settings. The final section provides a summary of the chapter.

### Socio-demographic, Health and Caregiving Characteristics of the Wives

The twelve wives were either retired from paid employment or had been housewives, and their ages ranged from 70 to 88 years of age (mean age of 81 years). They all had at least one child (range of one to four children). All of the wives reported that they believed they could call upon their children and other relatives, such as nieces

and nephews for assistance, when needed. Seven wives reported being affiliated to a church group, the most often cited being the United Church.

All of the wives identified themselves as being caregivers to their husbands prior to placement in Deer Lodge Centre. The wives visited often, with six of them indicating that they visited seven or more times during the week. This frequency and consistency of visiting fit well with other studies that report wives visiting several times per week (Gaugler, 2005; La Brake, 1996; Gaugler et al., 2003). The husbands had been residing at Deer Lodge Centre for at least six months to meet the inclusion criteria, and eight of them had lived there for between one to five years, so most of these wives had been visiting for at least one year. Six of the wives usually drove themselves to Deer Lodge Centre and the other six walked or used public transportation (taxi and/or handi-transit) or obtained a ride from family or friends. It took less than one hour for ten of the wives to travel to Deer Lodge Centre, while the other two wives reported that it could take up to two hours and that this situation meant that they visited their husbands less often.

In terms of health characteristics, overall the wives were optimistic but reported several chronic illnesses often associated with aging. When asked the self-rated health item, one wife rated her health as “excellent”, nine wives rated their health as “good” and two wives rated their health as “fair”. None rated their health as “poor”. Nine of the wives reported chronic illness including: arthritis (hip and knee), hypertension, heart problems, eye problems (macular degeneration and glaucoma), asthma, and cancer. Bright (2006) has noted that family members’ level of involvement varies according to their health status and for caregiver wives optimistically present their health status with 75% of them reporting chronic conditions often associated with aging.

When asked the self-rated depression item, "*Do you often feel sad or depressed?*", six of the wives (50%) reported that they often felt sad or depressed. This percentage was much higher than anticipated by the researcher, and when probed for more information, the wives talked about social and family losses and loneliness. Their comments included: having "good day" and "bad day" experiences; feeling frustrated with husband's declining health; feeling sad since a family member had relocated to another province; "deciding where to go or what to do from here"; feeling "sad for what lost in life" and; the loneliness of "not being able to do things together" after several years of marriage. Davies and Nolan (2004) have suggested that the impact of "no longer living with a life partner" can be substantial, creating feelings of despair and loneliness. At the end of the interview, the researcher went back to this question and asked these six wives if they would like to speak with someone about their feelings of depression.

In relation to their caregiving characteristics, all of the twelve wives provided for physical and psychosocial care of their husbands as residents in Deer Lodge Centre. The type and amount of care provided depended on the needs, and the cognitive and functional ability of the husband. For example, one wife reported that the staff members were having difficulty providing the medications that had been prescribed to her husband. Her husband was suffering with dementia and sometimes became confused and agitated when medications were offered. When his wife offered the medications, there was little resistance, and so the staff members came to rely on this wife to assist with medications whenever she was in the facility. In fact, at the wife's request, staff members would phone the wife at home and ask her to come in, if she wanted to help with her husband's medications. This is an example of a "technical care" role that was given by the staff members to the wife because her husband was more receptive to fulfilling this function.

The staff were promoting a dialogue with the wife regarding preferred roles (Gaugler, 2005; Bauer, 2006).

The physical care that wives provided was similar to what a health care aide might provide and could most often be classified as “personal care”. The wives provided the following physical care to their husbands: washing face, hands and body; shaving; cutting hair; trimming nose hairs; applying cream (sometimes brought from home) to dry skin areas; feeding (including bringing food from home); brushing teeth; washing and ironing clothing; cleaning shoes; walking with husband; and checking for bedsores. The wives provided the following psychosocial care for their husbands: bringing in family photographs, and hobby and other activity materials; taking their husbands for walks outside and within the facility; massaging and touching; co-participating in recreational activities; accompanying on events and outside activities; and keeping company during the day. Although most of the wives did not explicitly mention it, they essentially provided comfort and support during their conversations and interactions with their husbands. The extent of family involvement in physical and psychosocial care iterates Gaugler’s (2004, 2005) research and definition of family involvement as multi-dimensional in meaning and reflecting a wide range of activities from grooming to co-participating in recreational events.

A few of the wives mentioned taking their husbands home for special family occasions, such as birthdays and Christmas. One wife creatively brought “home” into the facility by bringing in patio plants and placing them in the dining room for her husband and other residents to enjoy. This wife not only maintained a link with the community for her husband (Davies & Nolan, 2004), she brought his home and community to him. A few wives also referred to themselves as “advocates” for their husbands in relation to the

formal care that was being provided. These twelve wives were clearly very “involved” in their husbands’ care and well-being. Two of the wives stated it in the following way;

“I am here everyday...check him...for bed sores...check his teeth, I am very involved... I am there every night at supper, I feed him his supper”. (0016)

“I do everything for him...I am here all the time...[I phone to see how he is doing]. I do his mouth. I do his face. I do his hands in the evening”. (0017)

These two wives’ global assessment of what they do for their husbands resembles what Gladstone et al. (2006) referred to as caregivers’ taking on an overall purpose, as well as outlining the specific caregiving tasks.

In summary, these wives are older women (mean age of 81 years) who have provided care to their husbands in their homes in the community and have continued to be involved and provide care since their husbands’ placement in Deer Lodge Centre. They tend to visit their husbands often and several of them are there every day, staying most of the day and into the evening. They see themselves as relatively healthy although six of the twelve wives indicated that they often felt sad or depressed. This is noteworthy with respect to their mental health, and although this high percentage (50%) was not anticipated by the researcher, it is perhaps not surprising given the wives’ current situation. They are traveling, often daily, from their homes to provide care to physically and/or cognitively frail husbands for most of the day before returning home again. For most, their lives have changed radically within months to a few years. Their current caregiving to their husbands includes physical and psychosocial care. The physical care component is similar to the personal care provided by health care aides and their psychosocial is likely a continuation of the interactions that they had with their husbands prior to his placement in Deer Lodge Centre.

Research Objective #1: Wives' Perspectives of Involvement as Co-worker, Resource Person and Co-client

Research objective #1 was: "To explore wives' perspectives of their involvement in care of their husbands residing in long-term care in relation to the roles of resources person, co-worker and co-client". The two sources of data were from the tool developed by the researcher, following the format of the "Family Involvement (F-INVOLVE) and Importance of Involvement (F-IMPORTANT) scales (Reid et al., 2007), and the open-ended questions that probed the roles of resource person, co-worker and co-client.

The researcher developed fourteen items, four of which tapped the role of resource person (2, 6, 7 and 8) while seven items tapped the role of co-worker (1, 3, 4, 5, 9, 10 and 11) and three items tapped the role of co-client (12, 13 and 14) (see Appendix D). The development of these items has been described in chapter 3. Three items on the tool developed by the researcher (3, 9 and 14) were rated by the wives as having high importance to them but relatively low opportunity for involvement in the long-term care setting (see Table 4.1). The other items showed tended to show high importance and high opportunity for involvement. A further analysis of these three items where opportunity for involvement was low was possible because after each item, the wives were asked to talk more about their responses.

Table 4.1: Items developed by the researcher related to Twiggs'(1989) model of carers

Items	Present in Facility		Important to Me	
	Disagree	Agree	Low Importance	High importance
1.I feel that my role as a caregiver ended on the admission of my husband to this facility.	0	12	0	12
2. Staff has implemented some of my suggestions when they provide care to my husband.	0	11	0	11
3. Staff has encouraged me to participate in certain 'hands-on' care with my husband e.g. assisting with grooming; hair combing; or as facility's policies dictate.	6	6	2	10
4. Staff has asked me to participate in the group activities that I attend with my husband.	4	8	2	10
5. The facility has an open door policy which helps me to discuss any concerns readily with Administrators or Managers.	1	11	0	12
6. The facility recognizes me as an important resource in the care of my husband	0	12	0	12
7. The staff seeks my advice before certain care decisions	1	10	0	11
8. The staff contacts me to clarify new concerns regarding my husband's care.	1	11	0	12
9. Staff has asked me to evaluate the care that is being provided for my husband	6	6	1	11
10. The staff demonstrates appreciation in the assistance I give in caring for my husband	0	12	2	10
11. The staff expects me to carry out certain care needs (e.g. grooming, combing of hair) for my husband.	1	11	5	7
12. The staff recognizes my inability to cope and has been supportive	2	10	1	11
13. Staff has offered to provide any counseling or teaching that I feel I need.	3	9	1	11
14. The facility has contacted and or referred me to related agencies to assist me in dealing with personal health or other concerns.	8	3	6	5

The frequencies are not always based on n=12 because some of the wives indicated that the questions were not applicable to them.

Item # 3 was intended to tap the role of co-worker and stated: "Staff has encouraged me to participate in certain 'hands-on' care with my husband, e.g., assisting with grooming, hair combing, or as facility policies dictate". The follow-up probed responses indicated that most wives participated in 'hands-on' care but this was not related to being "encouraged" to do so, as indicated by the following responses.

"I don't think they have asked me. I just do it." (001)

"They haven't encouraged me. I just do some of it myself. I put cream on him sometimes and I trim his nose hairs." (009)

"I don't remember them ever [encouraging me]. I do comb his hair if it needs it but they usually have it done. When I go downstairs, if I'm there to push him, and I take him outside to the courtyard." (0013).

It may be that wives are continuing their home community-based care caregiving activities into the long-term care setting, and so none of the staff members has encouraged or discouraged this activity. The literature has suggested that family members try to maintain consistency in their caregiving role after placement of their relatives (Gladstone et al., 2006). Two of the wives indicated that they had some concerns that if they didn't provide this hands-on care, then it might not happen. One mentioned her role as an advocate as ensuring that care was provided.

"At one stage I sort of got the impression that I shouldn't come so much [for visits] and that maybe I should let the staff take over because it was better for my husband to get used to the staff. I have tried to do this to a great extent. Otherwise I would probably be here more often but I feel to a great extent that I want him to participate and cooperate with staff but on the other hand I feel that I still have to advocate to make that happen in many cases." (0015)

"They have not encouraged me to do any hands-on care. After his lunch, I make sure that he brushes his teeth because they are in a sad state but I don't know if the staff looks after that when I am not here." (0010)

Again, it seems likely that these wives are continuing to provide care as they have done when they were living in the community with their husbands. Although, data were not

collected specifically on the husbands' health, it became clear during the interviews that these women had been caring for their husbands for an extended period of time in the community. It also became clear that most of the husbands had some limitations in cognition, either related to stroke, dementia or another chronic neurological disease.

Item # 9 was intended to tap the role of co-worker and was stated: "Staff has asked me to evaluate the care that is being provided for my husband". The probed responses to this item resulted in very few additional comments from the wives.

"I don't remember them ever asking but I know they do care." (0013)

"I had one meeting where they all got together. It was quite a while ago." (0014)

"...they don't ask me because it is routine, the care is routine every morning they wash and everything they do." (0017)

Although the literature does indicate that family members tend to monitor their relative's care and evaluate the care of formal caregivers (Logue, 2003), there are no studies that report that staff asked to have their care evaluated. So, when the wives say they have not been asked to do this, this is likely the case in practice as well as in research.

These two items (#3 and #9) were aimed at the wives' role of co-worker. In the open-ended question section, wives were again asked about their "partnership" with staff at Deer Lodge Centre in providing care to their husbands. In response to the question, "do you feel like a 'partner' in planning care or activities for your husband", most said "yes" and one commented on feeling a part of the "family" at Deer Lodge Centre.

Another one commented that she did not feel like a partner:

"Not really. [I don't feel like a partner] You are sort of told what they are doing...I think they have their program. They do have a group meeting where spouses can go and get together once a month so you can learn what the plans are and what they are going to be doing. The program chairman plan things pretty well, I think. You are free to take your husband out anytime if you are able to." (0015)

Of those wives who indicated that they felt a partnership in planning activities and care, there seemed to be a passive nature on their side of the partnership.

“Usually the girls plan the activities and if they ask me if I want to take part, I do if I possibly can and I guess that’s it.” (0013)

“We did have an initial meeting and every department was there. They asked me a lot of questions and seemed happy that I knew so much about my husband’s medications and all that and they were quit willing to implement the things that we were doing at home with him as much as possible.” (0016).

It should be noted that on admission to Deer Lodge Centre, a social assessment form is completed by the resident and family member, usually with the social worker. The form is designed to capture information on the new resident’s social interests, and preferences for care and recreational activities. This form is updated as time proceeds and interests and preferences change. A year after admission and every year after that, there is a “full review” of the resident’s care and activities. This annual review involves the resident, family and all members of the health care team (physician, nurse, social worker, recreation worker, pastoral care worker, physiotherapist, occupational therapist and others such as speech and language therapist, where appropriate). The second wife (0016) who talked about the ‘initial meeting’ was likely referring to the completion of the social assessment form. Her husband has been admitted to Deer Lodge Centre, less than a year before the interview was conducted.

The third item that was rated as high importance and low opportunity was item #14 and it stated: “The facility has contacted and/or referred me to related agencies to assist me in dealing with personal health or other concerns.” This item was designed to tap the wives’ role as co-clients. The probes that followed this item elicited few responses but the responses seemed to indicate that wives believed that staff would help them, if asked, but that the need was not currently there.

“I haven’t really any need for assistance.” (006)

“I haven’t been asked because I haven’t needed it. It would be extremely important if I needed it.” (009)

“I guess if I needed anything. I would speak to [name of staff member].” (0013)

Later in the interview, wives were asked two follow-up open-ended questions about their health. One question asked if the wives felt that the staff at Deer Lodge Centre were concerned about their health. The other question asked if staff had equal concern for them and their husbands. These questions emphasized the potential “co-client” role of the wives who might be having physical or psychosocial health problems. As co-clients, staff members would be assessing the needs of the wives and discussing interventions with them, as appropriate. Most of the wives responded that staff members at Deer Lodge Centre were concerned about their health, but concern was not equal, with husbands being the focus of more concern. Some wives talked specifically about the concerns expressed by staff related to their health and well-being.

“Yes, they are [concerned about my health]. They ask me how I am and everything. They ask me if I want tea or coffee. They ask if I want anything to eat. They ask about transit [bus service] and make sure that I get down downstairs early enough. They are very helpful.” (005)

“Oh yes, they are [concerned about my health]. They always tell me I should take a weekend off or something. And I’ll say if I do that I’ll be thinking about him the whole time so I might as well just stay here.” (006)

From the wives’ responses, it does seem that staff members demonstrate concern but the examples provided by the two wives (005 and 006) seem to be general concern rather than health-focused concern. It appears that the wives’ status as clients is as Twigg (1989) has suggested, not a full and equal one and “carers remain at best secondary clients rather than fully co-clients” (p. 60). Some wives indicated that they did not share

their health and well-being concerns with the staff members. The wives' primary concern was their husbands' health and well-being.

"... I don't know, they are always concerned anyway but it would only be natural for them to be more concerned about my husband because they see him every day and they work with him. They just see me when I am there and I wouldn't be telling them very much about my problems generally speaking, Why should they worry about me?" (0013)

"I have no idea how they [the staff] feel about my well-being because they don't know how I feel. So, how could they possibly have concerns about my well-being." (009)

It was noteworthy that two of the wives demonstrated a caring attitude toward others and indicated that they had concerns for the health of others, including staff members and other (older) visitors.

"Well, they [the staff] don't like to see any of us [family visitors] getting older and more tired. They can tell we are getting tired and we can tell when they are, too." (0012)

"I don't know how they [the staff] would show it [concern] myself, because I am well...Maybe if I was like some people - I see them here almost ill themselves and they are elderly and they are looking after a person. I take care of myself as well as I can and I feel it is important that I keep healthy so that I am there for him." (0015)

These two wives had been caregivers for their husbands at Deer Lodge Centre for between two to four years and likely had an opportunity to get to know staff and other visitors.

While the focus of analysis was on the items that tapped high importance and low opportunity, the findings also indicated several areas of high importance and high opportunity and these likely reflect a positive involvement experience for these wives. Nine of the fourteen items indicated high importance and high opportunity. Three of the nine items that were designed to tap wives as co-workers, including item #1 ("I feel that my role as a caregiver ended on the the admission of my husband to the facility"), item

#5 (“The facility has an open door policy which helps me to discuss any concerns readily with administrators or managers”) and item #10 (“The staff demonstrates appreciation in the assistance I give in caring for my husband”) and these items were consistently indicative of high importance and high opportunity. These results indicated that wives felt their caregiver role did not end when their husbands became residents, that the staff appreciated the wives’ caregiving assistance and that there was an openness among staff including administrators and managers to hear the wives’ concerns.

Four items designed to tap the role of resource person also exhibited a positive relationship between importance and opportunity. These were: item #2 (“Staff have implemented some of my suggestions when they provide care to my husband”); item #6 (The facility recognizes me as an important resource in the care of my husband”); item #7 (“The staff seeks my advice before certain care decisions are made”); and item #8 (The staff contacts me to clarify new concerns regarding my husband’s care”). These items seemed to indicate that wives see themselves as resources for care and that their suggestions and advice for care are sought and acted on.

Two items designed to tap the role of co-client also demonstrated high importance and corresponding high opportunity. These were item #12 (“The staff recognizes my ability to cope and has been supportive”) and item #13 (“Staff have offered to provide any counseling or teaching that I feel I need”). Again, these are positive findings, likely indicating that wives felt that staff recognized their coping abilities and would provide counseling and teaching as needed.

In summary, for objective #1, “to explore wives’ perspectives of their involvement in care of husbands residing in long-term care settings in relation to the roles of resource person, co-worker or co-client”, the findings do not strongly suggest a single

role for wives. This would fit with Twigg's (1989) position that the three roles of family caregivers do not address the full complexity of relationships between formal (facility) and informal (family) caregivers. The findings suggest that wives seek and carry out their roles without encouragement from staff members. The 'hands-on care' provided by wives likely is likely a continuation of the care that wives provided in the community and for some, it is care that might not occur without their involvement. Of further interest is that wives indicated that while it was important that staff ask them to evaluate staff-provided care, the opportunity to do so was not present at Deer Lodge Centre. This tends to suggest that formal and "wife" care occurs in a parallel way. The wives' caregiving occurs without encouragement from staff and staff caregiving occurs without evaluation from wives. In addition, the caregiving partnerships that wives' say they have with staff members might be relatively passive on the part of the wives.

In terms of wives as co-clients, all but one of the wives indicated that staff members do care about them but either the wives have not needed help or have not asked for help. This is intriguing and it is speculative at best, to query how health-trained staff members would not have taken the initiative to ask more directly about the wives' health and open some dialogue on their health needs. It might seem obvious that wives who visit every day for the whole day are at risk of fatigue, anxiety and burnout. Indeed, staff members may have asked more about the wives' health concerns than the wives have indicated. Data were not collected from staff members; data were only collected from the wives. Twigg (1989) has cautioned that regarding family caregivers as co-clients might lead to two undesirable ends. One outcome might be the "imperialistic take-over of what are normal processes of life" and, the other might be "the swamping of the social care system with 'ordinary misery'" (p. 60).

Of note are the positive findings of high importance and high opportunity for nine of the fourteen items that attempted to tap the role of wife caregivers in personal care homes. The wives responses indicated that they felt their role as caregivers continued in the personal care home, was recognized and appreciated by staff members, and that there were ways for the wives to provide suggestions and advice on their husbands' care to staff members. Furthermore, wives indicated that there were available avenues to pursue regarding their concerns and that staff would provide support in counseling and teaching as needed.

#### Research Objectives #2 and #3: Wives' Perspectives on Importance and Opportunity for Involvement

Research objectives #2 and #3 were stated to explore wives' perspectives of importance and opportunities for involvement in care of their husbands residing in long-term care. Although stated separately, these two objectives come together in the "Family Involvement (F-INVOLVE) and Importance of Involvement (F-IMPORTANT) scales (Reid et al., 2007) where the wives responded to twenty statements or items indicating the level of importance and presence (opportunity) in the facility, from their perspective. Eight of the twenty items were rated as having high importance and high opportunity for involvement. But, of the twenty items, five (c, f, h, i and l) showed "high" importance and "low" opportunity for involvement (see Table 4.2). A further analysis of these five items was possible because during the interview after each item, the researcher asked the wives to talk more about their responses.

Table 4.2. F-Involve and F-Important Scales – (Reid, Gish &amp; Chappell, 2007)

Scale Items	Present in Facility		Important to Me	
	Disagree	Agree	Low importance	High Importance
a. Staff has created opportunities for me to meaningfully participate in my <i>husband's</i> day.	1	11	1	11
b. I have been asked about my <i>husband's</i> personal history.	4	8	3	9
c. I have been asked about my <i>husband's</i> preferences and values.	6	6	1	11
d. Staff has helped me to understand how dementia affects my <i>husband</i> .	4	8	1	11
e. I am able to dine with my husband if I want to	0	12	1	11
f. I have been asked to bring in pictures, letter, and other personal items to teach staff about my <i>husband</i> .	9	3	3	9
g. I feel like I am involved in decision-making about my <i>husband's</i> care when he cannot make decisions for himself.	1	11	1	11
h. Staff has taught me how to communicate with my <i>husband</i> as the disease has progressed.	8	4	5	7
i. The facility has a support group.	5	6	1	10
j. I was introduced to the different staff members at the facility when my <i>husband</i> was admitted.	2	10	1	11
k. Staff explained to me the rules and procedures at the facility upon admission.	4	8	1	11
l. Administrators have asked my opinions about the quality of care provided at this facility.	6	6	2	10
m. The facility holds family information meetings.	2	9	2	9
n. I feel like my <i>husband</i> has been well cared for.	0	12	0	12
o. I trust the staff members at this facility.	1	11	0	12
p. I am informed about changes in my <i>husband's</i> care plan.	3	9	0	12
q. Staff has helped me understand the difficult behaviors that my <i>husband</i> sometimes has.	3	8	1	10
r. Staff has helped me to plan for the death of my <i>husband</i> .	3	9	2	10
s. Staff has helped me plan for the handling of my <i>husband's</i> estate upon his death.	8	2	5	5
t. I feel comfortable phoning staff members and talking to them about how my <i>husband</i> is doing.	0	12	0	12

The frequencies are not always based on n=12 because some of the wives indicated that the questions were not applicable to them.

Item #c stated, "I have been asked about my husband's preferences and values".

When asked to speak more about this item, about half of the wives indicated that they had not been asked about their husbands' preferences and values.

"They would ask if he wanted to go to any of the programs but not about his preferences". (003)

"They haven't asked. I think that is very private". (006)

"He has a strong belief in God. He is a strong Christian. We both are". (0013)

In examining the responses from wives who indicated that they had not been asked about their husbands' preferences and values, two things should be noted from the exemplars above. First, two of the wives (006 and 0013) have focused on the "values" part of the question. One wife responded that a person's values (perhaps beliefs) are private and the other wife speaks to her and her husband's religious faith and beliefs. This may be a problem with the phrasing of the item.

Second, as indicated earlier, a social assessment is completed on admission to Deer Lodge Centre and then annual full reviews take place. The husband of the wife (003) who indicated that staff had not asked about his preferences, had been admitted to Deer Lodge Centre about 18 months prior to the interview. She may not have recalled working with the social worker to complete the social assessment form. It is possible to speculate that given the stressful nature of transition and admission of a relative to a long-term care setting (Bauer & Nay, 2003; Marziali et al., 2006), it is reasonable that wives may not recall every aspect of the initial admission process. However, collecting information from wives about husbands' preferences and values is not a static assessment and should be ongoing as care is an ongoing process. The literature indicated that wives are the biographical experts and the ones most competent (other than the husbands

themselves) to provide information to staff members (Fabiano, 2001; Boise & White, 2004).

Item #f stated, "I have been asked to bring in pictures, letters and other personal items to teach staff about my husband". Most wives did not have further comments on this item. A few of the wives indicated that they had brought photographs in and placed them on their husbands' bulletin board in his room but this seemed unrelated to being "asked" to do it or to having these items "teach staff about my husband".

"We have some pictures up there [on the bulletin board] but I found that people were ripping them off so I haven't done too much but we have a book on my husband's life and it is excellent". (0013)

"Well, I've got the board that we have there full of his photos and of mine, my whole family is there, grandchildren and every body is there. They didn't ask but it is there". (0017)

Of the nine wives who disagreed that the opportunity was present in Deer Lodge Centre to bring in pictures, letters and personal items to teach staff about their husbands, two indicated that they did not recall or were not asked to do it.

"I don't remember being asked [to bring in personal things]". (005)

"They have not asked me to bring in things to show them". (0010)

It is not clear from this item or earlier items where wives indicated not being asked or not being encouraged, whether or not recall of events was a factor. However, the aim of this research was to gather information from the wives' perspective and from their perspective, wives are saying that they have not been asked or encouraged in activities that depict involvement in care and involvement in the long-term care setting with staff. This may be related to organizational context and a lack of clarity in communicating the value of family involvement. Hertzberg et al. (2003) have suggested that effective

communication means telling families that they are experts and that their expertise is valuable in the care of their relatives.

Item #h stated, "Staff have taught me how to communicate with my husband as the disease has progressed". Several of the wives indicated that communication with their husbands was difficult and sometimes not possible. This was because of neurological damage to areas of the brain related to speech or to memory functions. Sometimes, communication was of a more physical nature with husbands' confusion and frustration becoming manifest in agitation and even aggression toward wives.

"The only thing they say is if he is acting up in the morning just to walk away. I don't know just how to answer that." (002)

"They have not discussed it so far. Again, I don't know if I want to know. It's like being the ostrich right now. Thinking about what's down the road. I find it very difficult to cope with that." (0010)

"I have managed myself. Just talk to him and explain things to him, sometimes he does understand and sometimes he doesn't. It just depends on the day." (0017)

The husband of the wife (0010) who indicated that the staff had not taught her communication strategies had been residing at Deer Lodge Centre for about six months. Her comment about "being an ostrich" [with its head in the sand] speaks to the anxiety that this wife is likely feeling and it may be connected with the stressful and overwhelming feeling associated with her husband's transition to a long-term care setting (Davies & Nolan, 2004). The comments from the other two wives (002 and 0017) seemed to suggest that a formal approach to teaching or counseling wives on how to communicate with husbands who have lost or are losing the ability to communicate was lacking.

Item #i stated, "The facility has a support group" and the responses from wives to this item were mixed. On one hand, some wives indicated knowledge of facility-run

support groups. On the other hand, other wives indicated no knowledge of such support groups. Deer Lodge Centre does have unit-specific support groups and a notice of meetings is often posted on unit bulletin boards.

“I don’t think it has [a support group]. I never heard of a support group there.” (003)

“I have never been asked.... Nobody [here] has ever mentioned to me that there is a support group here as far as I know.” (0016)

“Well, the support group is on Wednesday. Everything comes at once. I don’t know what’s going to be on the agenda this time but I’ll be there.” (0012)

It is the staff’s responsibility to provide information on the available services and programs (Malench, 2004) and while this may be most emphasized during the admission procedure, it must be ongoing as the wives’ role in caregiving is ongoing. It is possible that staff members cease to see the wives as needing this information because their husbands have been residing at Deer Lodge Centre for six months or more.

The final item of high importance and low opportunity was item #1 and it stated, “Administrators have asked my opinions about the quality of care provided at this facility”. The wives seemed unclear about this item, perhaps because they had no contact with an administrator. At Deer Lodge Centre, the wives would have had contact with the unit manager, a nurse who is in charge of the unit. However, it is doubtful that the wives would have had contact with the Director of Nursing unless they initiated this contact or if the administrator came to the support group or to the resident and family and council meetings.

“I don’t think it would change anything even if I were asked. I don’t know what I am seeing. In this facility, people are saying, ‘well there is no sense’, for instance going to a family resident council meeting....out of this whole facility you might get 4 or 6 people there because people say it doesn’t do any good anyways”(002)

“We have had meetings so I guess it is the same thing”. (005)

This item on “administrators” is similar to an item asked under objective #1 and relating to caregiver roles (Twigg, 1989), “Staff has asked me to evaluate the care that is being provided for my husband”. For both of these items, wives indicated that it was important to them that staff ask them to evaluate care, and that administrators ask their opinions on the quality of care, but the opportunity to do at Deer Lodge Centre was not present.

One open-ended question asked, “In general to you think that Deer Lodge Centre is committed to having families become involved in the care of their relative? Have they invited you to become involved? More involved?” The wives’ responses seem to focus on “social” involvement in the facility rather than involvement in their husband’s care. A few wives spoke about participating in the Christmas bake sale and about joining their husbands in recreation activities including going on trips outside of Deer Lodge Centre, to theatres and parks. Phinney’s (2006) study found that family involvement often has a social involvement aspect, as family members encouraged their relatives to participate in recreational activities, usually by accompanying them in those activities. Two wives spoke about their purposeful involvement in staff and family group functions.

“I don’t know what it is like on other wards.... [We have this group of caregivers and we have a meeting once a month]. We have a bazaar in the Spring. We have each other’s phone numbers...in June, we have a luncheon and in December we have a luncheon. We met down on the second floor.... There is a recreation worker, the spiritual care worker, the physician, we have physiotherapist, occupational therapist, dietician. I think people who don’t go are foolish because we get to know all the staff this way...and I think it is important to know [the staff] and I think it is important for the staff to get to know us. Then they know when we phone whether she is just a worry-wart or maybe there is something to look into”. (0012)

“Yes, on the other floor they had a family support group and every month they would give us information and new developments and bring in speakers. They always let me know what is going on and then I go. One of the aides said that when I make my husband happy it makes it easier for him to do his job”. (009)

It should be noted that because Deer Lodge Centre is a large long-term care facility that include residential care (chronic care and personal care home units), compared to other personal care homes in Winnipeg, it has more resources for recreations and external events. A smaller personal care home in Winnipeg might have a part-time recreation therapist and an on-call physiotherapist; Deer Lodge Centre has both a recreation department and a physiotherapy department.

As indicated earlier, there were eight of the twenty items that indicated high importance and high opportunity, a positive involvement situation for wives. Six of the items dealt directly with the wives' involvement and two related more to staff competency and trustworthiness. The six items were: item #a ("Staff have created opportunities for me to meaningfully participate in my husband's care"); item #e (I am able to dine with my husband if I want to"); item #g ("I feel like I am involved in decision-making about my husband's care when he cannot make decisions for himself"); item #j ("I was introduced to the different staff members at the facility when my husband was admitted"); item #p ("I am informed about changes in my husband's care plan); and item #t ("I feel comfortable phoning staff members and talking to them about how my husband is doing"). These items seem to demonstrate a positive involvement for wives that includes being involved in care, decision-making and everyday activities as well as knowing and feeling comfortable with staff members. The two items related to wives' positive perspectives on staff competency and trustworthiness were: item #n ("I feel that my husband has been well cared for") and item #o ("I trust the staff members at this facility").

In summary, research objectives #2 and #3 were stated to explore wives' perspectives of importance and opportunities for involvement in care of their husbands

residing in a long-term care setting. Using the F-Involve and F-Important Scale developed by Reid et al. (2007), several areas of involvement were tapped with five items indicating high importance and low opportunity. Three of these items were phrased to read either, "I have been asked..." or "Administrators have asked me..." For these items, most of the wives seemed to be saying, "I haven't been asked". And as mentioned earlier, while this could be a function of poor recall, it is still the wives' perspective that they have not been asked. In response to being asked to bring pictures, letters, and other personal items to teach staff about my husband, some wives indicated that they had done this but none related it to teaching staff about their husbands.

For the item on the facility having a support groups, the wives' responses were mixed. Again, with some saying that they had not heard about support group meetings and others indicating their attendance and interest in these meetings. The fifth and final high importance and low opportunity item related to staff teaching wives how to communicate with their husbands as the (neurological) disease has progressed. This item was not relevant to all of the wives but seven of them indicated that it was important. Overall, the wives' responses seem to suggest that a formal approach to teaching or counseling them on how to communicate with husbands who have lost or are losing the ability to communicate had not occurred.

Given some of the responses to the F-Involve and F-Important items, it might follow that when asked if Deer Lodge Centre was committed to involving families in the care of their relatives, the responses would be somewhat negative. However, most of the wives responded "yes" to the open-ended question and went on to describe not only their involvement in their husbands' care but also their social involvement with their husbands in Deer Lodge Centre's programs and events. Had their husbands been placed in a

smaller personal care home, there may have been less opportunity for this social involvement.

It may be the F-Involve and F-Important scale items tap fairly passive functions of family involvement such as “being asked” rather than “I asked about”. For example, the wives indicate that they felt involved but their involvement was about their independently bringing in the photographs, not being asked by staff to bring them in.

Finally, it should be noted that eight of the twenty scale items indicated high importance and high opportunity. This speaks well generally of the wives’ perceived involvement at Deer Lodge Centre. These responses suggested that wives trust in staff members and feel that their husbands are well-cared for. In addition, the wives’ responses also suggested that wives felt involved in care and decision-making, and were comfortable knowing and speaking with staff members.

#### Research Objectives #4: Wives’ Perspectives on their Involvement in the Care and their Husbands’ Quality of Life

Research objective #4 was stated, “To explore wives’ perspectives on their involvement in care of their relative, and how this involvement relates to their husbands’ quality of life”. The wives were first asked to express their meaning of quality of life for their husbands. Then, four items developed by the researcher to address this objective, were administered. The format of the items followed the format of the “Family Involvement (F-Involve) and Importance of Involvement (F-Important) scales (Reid et al., 2007). Probing questions were asked after each item to clarify the response and allow an opportunity for greater expression. Finally, two open-ended questions, with several probes, were asked after the four items were completed.

In response to the question, “What does the quality of life of your husband mean to you?” there was variation in the context in which wives thought about their husbands’ quality of life. Some of the wives focused on previous times and events with their husbands, while more often, they focused on current activities including their husbands’ participation in recreation and in activities of daily living, such as self-feeding. This variation was not unexpected given the individualistic and multidimensional aspects of the concept of quality of life. Together, the researcher and her advisor coded the responses of the wives and finally, six major themes emerged and are presented in Box 4.1.

These themes are not surprising and fit well with the literature on the multi-dimensional nature of quality of life. Certainly, aspects of health, well-being, and relationships with others are common themes among the general population. For residents in long-term care settings, health and functional ability, including the ability to carry out activities of daily living, contributes to overall well-being and purpose in life (Jablonski et al., 2005; Guse & Masesar, 1999). Lawton (1991) emphasized the link between quality of life and being engaged with others and with the environment. Similarly, Nolan et al. (2001) and Bergland and Kirkevold (2006) stressed quality of life in relation to purposeful and meaningful activity, relationships with family member and leisure pursuits.

Because the husbands are residents in a long-term care facility, the themes of “recreation” and “being cared for and receiving good care” are also expected themes. Again, Lawton (1991) and Nolan et al. (2001) linked quality of life to engagement and leisure activities. In relation to care and receiving good care, the literature suggests that quality of care is not the same as quality of life, but that quality of care contributes to

quality of life in long-term care settings (Guse & Masesar, 1999; Murphy et al., 2006). Hjaltadottir & Gystafsdottir's (2007) themes of having security and feeling safe in one's body and finding solace and comfort in one's surrounding is also relevant here.

Box 4.1 Themes: Wives' responses to their husbands' quality of life

Themes	Exemplars
1.health and functional ability	"It [quality of life] means the whole world to me. He has always been the strong one in our life and now it's me that has to be. I would like to see him a lot better healthwise, that's for sure. It breaks my heart that he can't walk". (005)
2.wellbeing	"It is very important. He needs to still have dignity and quality of life no matter what condition he is in". (0016)
3.recreation	"It means for him to be comfortable and to be able to enjoy things he has always done and be able to participate to the best of his ability." (0015)
4. relationship with others	"I like to see him relaxed and not upset. I like to see him enjoying the things that we like. We like listening to music together and when we go to the different events, I like to see him enjoying that."(009)
5. being cared for/ receiving good care	"That he is well-looked after and not in pain. That he can enjoy visits from me and [other family members]. A nurturing and caring staff". (0010)
6. broad statement	"[The] best for him". (002) "It [quality of husband's life] means everything to me". (0013)

Missing from the wives' expression of what their husband's quality of life means to them, are expressions of personal identity and growth, aspirations and goals. It may be that because most of the husbands suffer from losses in cognition and communication because of neurological damage that the wives did not think of these other aspects of quality of life. As indicated earlier, discrepancies exist between what residents and their

family caregivers report in relation to quality of life (Sands et al., 2004). Data were not collected from residents to compare their meanings of quality of life.

In terms of the four closed-ended items developed by the researcher, the findings are displayed on Table 4.3 and indicate “high importance” and “high opportunity” for the first three items. The wives were almost unanimous in saying that it was important that their husbands respond positively to their care; that this involvement contribute to husbands’ quality of life; and that quality of life was a factor in placing their husbands in Deer Lodge Centre. Furthermore, all but one of the wives responded that there were opportunities for this involvement in Deer Lodge Centre.

For item #4, while the wives all agreed that it was important for the facility to conduct annual surveys that include quality of life concerns, there was some variation related to whether or not this occurred at Deer Lodge Centre. Four wives indicated that they did not know if surveys were conducted. Seven indicated that they had not participated or been asked to participate in this kind of survey. In fact, Deer Lodge Centre does conduct annual satisfaction surveys with family member but it is with a random sample of family members so it is possible that these seven (or more) wives were not selected to participate.

Table 4.3 Items developed by the researcher related to involvement and quality of life

Items	Present in Facility		Important to Me	
	Disagree	Agree	UI	EI
a. My husband responds positively when I assist in his care	0	12	0	12
b. Involvement in my husband's care contributes to his quality of life.	0	12	1	11
c. The importance of my husband's quality of life is one of the major reasons for placing him in this facility	1	11	0	12
d. The facility conducts annual surveys that include quality of life concerns.	7	1	4	8

All wives indicated that their providing care to their husbands added to his quality of life.

Two open-ended questions elicited more comments from the wives regarding their involvement in care and their husbands' quality of life:

1. Describe your husband's response when you provide care for him?
2. Do you believe that the quality of life of your husband is a major focus at Deer Lodge Centre?

In relation to question #1 and husbands' responses to their wives' care, the wives' shared some of their happier moments.

"I know when I get off the elevator, sometimes he is sitting there in the wheelchair and when I get off the elevator, he says, 'Oh, what a lovely surprise.'" (006)

"He used to tell me that he was so proud of me and that I was beautiful and 'you always dress so nice' and now he will say, 'Oh, I am so glad you came'. He seems to feel now that he is taking up a lot of my life and he is so sorry. I try to assure him that if I didn't have him to take up my life, I wouldn't have any life". (0012)

In providing care to their husbands, the wives described their husbands as being in a good state of mind, receptive to care and appreciative of the care being provided.

"He just shuts his eyes and relaxes [when I provide care]. He likes it when I put cream on his head and stroke his head". (009)

“He is in the best state of mind. He is always appreciative. He is easy to do things for because he appreciates things. He always looks to me for certain things....I speak to him in a loving way”. (0013)

Gaugler (2005) and Logue (2003) have both emphasized findings where family involvement demonstrates the means of promoting physical and psychosocial well-being for residents. Kane (2003) has suggested that more research is needed on the importance of interpersonal relationships and interactions between residents and family caregivers.

It is not always easy for the wives to be caregivers. Sometimes caregiving means arguments and conflict. One wife described providing care for her husband, a man who no longer always recognized that it was his wife providing care.

“Sometimes, when I discover that he has left his hip savers off and I say to him that he has got to wear this [hip saver undergarment], he is a little uptight that I am... I guess you would say telling him off and I guess I would do the same thing, but I am doing it for his own good... but whether he realizes that or not is hard to say”. (0010)

“Now there doesn't seem to be much response [from him]. I think he considers me just another caregiver [since he had his stroke]. But like I say, he'll cry now – whether that's a sign of anything?” (0015)

In relation to question #2 and their husbands' quality of life as a major focus at Deer Lodge Centre, almost all of the wives responded “yes” and then proceeded to describe how that focus was made manifest in their husbands' care.

“Yes. They do everything to make him happy and comfortable and be involved in everything that goes on here. I always feel that this is one big family that a person participates in if one wants to”. (006)

“Yes...The way they treat him in a loving and kind way...They encourage him to play the piano. They encourage him to walk... They encourage him to eat and if they see that he likes something, they will try to get an extra one for him. Just things like that”. (0013)

It is interesting to note that as well as emphasizing loving care, encouragement and comforting that staff members contribute to their husbands' quality of life, some wives also made special mention of recreation activities and recreation therapists. The

stimulation of recreation programming, entertainment and special activities was presented as contributing to their husbands' quality of life. And in an earlier section, the wives similarly identified their participation in recreation and "outings" as their (social) involvement at Deer Lodge Centre.

"Yes. You have to give credit to the recreation girls because they try to stimulate them [residents] in many ways. We went to [a plant nursery] and we go on different trips. I can go with him because I am free to do and I can push his wheelchair. There is a lot of music. I think they realize how important that is. They have concerts downstairs. Four nights a week and they have bingo and travel logs". (009)

"Yes... The fact that they have recreation programs. He likes to bowl. When you make him go, he seems to enjoy it... There is a lot of entertainment that they have here that when they get him to go I am sure he enjoys it".(0010)

It may be that the literature on family involvement has neglected to fully explore the relationship between family involvement, recreation and quality of life for both residents and family caregivers. Recreation and the co-participating in events and outings may be a sustaining feature for family involvement with their relatives in long-term care settings.

In summary, research objective #4 was stated to explore wives' perspectives of their involvement in their husbands' care, and how this involvement relates to their husbands' quality of life. The twelve wives were asked about what the quality of life of their husbands meant to them. Their responses can be categorized into six themes: health and functional ability; well-being; recreation; relationship with others; being cared for and receiving good care; and global expressions of quality of life. The themes are not surprising in relation to the literature on quality of life. However, missing from the wives' expressions are themes of having personal identity and growth, aspirations and goals. This may be related to their perceptions of their husbands' cognitive and communication limitations. The wives were unanimous in stating that their husbands responded positively to their care, and that their involvement in their husbands' care contributed to

the husbands' quality of life. There was some variation in the importance of an annual survey by Deer Lodge Centre and their opportunity to participate in this survey. The important part is that most wives felt it was important to have the survey and again most wives felt that they had not had an opportunity to participate.

Finally, the two open-ended questions on the husbands' response to wives' caregiving and whether or not quality of life is a major focus at Deer Lodge Centre, add to our understanding of family involvement and quality of life. Wives' reported receiving loving and appreciative comments from their husbands. However, caregiving could also be difficult and stressful for wives. When asked about Deer Lodge Centre and the focus on quality of life for residents, almost all of the wives indicated "yes". Specifically, wives spoke about staff who provided care and comfort to their husbands. Of note, some also praised the recreation activities and staff. This is of interest in relation to wives' earlier identification of their "social" involvement at Deer Lodge Centre. Recreation activities, events and outings seem to be a large part of the wives' involvement at Deer Lodge Centre as well as related to their husbands' quality of life.

### Additional Findings

The interviews with the wives consistently addressed the four research objectives but during the interviews, the wives made comments that were within the context of family involvement but did not directly relate to their involvement with their husbands' care. When these comments are individualistic and provide no apparent pattern across interviews, the comments stand alone. However, when such comments are repeatedly heard, then this is no longer idiosyncratic and in fact, such comments warrant attention whether or not they are directly related to the wives' involvement with their husbands'

care. There were three such areas that are included here as “additional findings”, sometimes called “unexpected” or “serendipitous” findings. The three areas are: concerns about staff, including shortages and rotations; concerns about other residents; and concern about their own deaths and subsequent care of their husbands.

Following from what was said in relation to Deer Lodge Centre staff members focusing on husbands’ quality of life (objective #4), one wife said:

“You know certainly they [Deer Lodge Centre staff] are doing their utmost to make him comfortable and to keep him comfortable and when he has problems, certainly they are looking after that. I don’t know how much more they can do in quality of life personally through visitation unless they were more people who had the time, maybe apart from the actual staff who don’t have the time to spend with him.” (0016)

Other wives also commented on their not being enough staff, including physiotherapists, health care aides and others.

“I mean the bathing situation...is atrocious but there is not the time. They just don’t have the staff to bathe people [residents] any more often than that [once a week].” (002)

“I feel there should have been a therapist come and walk him...Had there been a therapist come every day and walk him once a day event down the hall from one end to the other...[The therapist] said they didn’t have other people [available volunteers or staff] so...once a week was just not enough and gradually the walking absolutely deteriorated and he[my husband] couldn’t walk at all.” (003)

“If it is a bad day and there are a lot of things not done then I want to know if they are short staffed and that’s why. Or if it is the same staff who have been dealing with him for many months, then I will say something to the nurse [manager].” (0015)

Concerns about staff not only related to staff shortages, the wives also expressed concerns about staff rotations within the unit and also situations where staff might be called to another unit to relieve a shortage there.

“My only complaint would be staffing. I know that they have to do it the way they do but quite often there is staff here who don’t know the residents. Sometimes the nurse doesn’t know who is who and who gets what medication. It doesn’t happen very often but it would be nice if there was more stability in the staff. Some are excellent and others are, I’m sure they trying but it is hard when they don’t know the residents and they have to be switched around from ward to ward. It is tough on them, too.” (0014)

“I think the whole thing really is when there is so many people [staff] involved in the care that there is no one person that is always on top of his [husband’s] case in a sense....somebody is on duty for three days to date but then you might not see them for a week because they’ll go then to the other unit.” (0015)

The wives placed value in getting to know staff members on their husbands’ units.

One mentioned the importance of getting to know the names of staff members and another commented on her particular problem with reading staff members’ name tags.

“[It is important] I think just relating with the staff and getting to know their names.” (009)

“The only thing I wish is that the staff could display their name tags more clearly and they are not large and I can’t read them without my glasses.” (0013)

Wives expressed their perspectives on staff shortages and rotations, and they also had concerns about other residents. One wife’s comment puts both of these concerns together.

“...the little man across the hall and [he] doesn’t have anybody. He will constantly call out ‘is there anybody out there?’ and I’ll go in and say ‘what would you like?’ and [he says] I’d like to go to sleep’ and I’ll say ‘Well, you go to sleep, you are already in bed’. Poor little soul but you know it just seems like there is nobody to attend to him because they hear it all time and so I guess they feel that they can’t be in that room all the time but I strongly and I have said this at resident and family council meetings so often ‘there is not enough staff. I am referring not to nurses but to health care aides, definitely not enough staff.’” (002)

So, the second area of additional findings is related to wives’ concerns about other residents and their care in the absence of family members. Given the amount of time that some of the wives spend at Deer Lodge Centre, it seems likely that they will begin to

notice or get to know other residents. Some will reach out and help other residents as they are helping their own husbands.

“I know one day the duty manager said to me because I helped someone with eating that I was told not to do that. [She said], ‘Would you like to have some training and volunteer some time to help with meals?’ Well, I don’t really have time to do that but it was just this person needed some help so I helped them.” (002)

“One of my biggest beefs...you could feed your own [husband] but you couldn’t feed anyone else [residents who were waiting to be fed]. Because that’s taking a job away and the union...I get very upset when I think about it. I used to feed people [other residents]. To heck with it. Nobody knew. The girls [health care aides] didn’t complain about it because you were helping them.” (0016)

“I wish there were more families involved. I wish there were more visits. The residents here who do have families and don’t see their families very often are very depressed. It is very, very sad.” (006)

The third and final area of additional findings relates to the wives’ concerns that they might precede their husbands in death. This is likely something that the wives have thought about and some expressed their fears about “if I go before him” to the researcher.

“Oh, he is a very, very, very dependent on me. I shudder to think if anything were to happen to me before him. That is a big concern.” (002)

“I take care of myself as well as I can and I feel it is important that I keep healthy so that I am there for him.” (0015)

To summarize, these additional findings have a context within the topic of family involvement in long-term care settings but they are not directly related to the four objectives. Because these three areas of concern were voiced by more than a few wives, it is important that the concerns be recorded as potential future areas of research or practice. The three areas were: concerns about staff, including shortages and rotations; concerns about other residents; and concern about their own deaths and subsequent care of their husbands.

## Summary

The overall goal of this research was to learn more about family involvement in the care of a relative who is a resident in a long-term care setting. Twelve wives whose husbands were residents in Deer Lodge Centre agree to participate. These are older women (mean age of 81) who have been caregivers for physically and cognitively frail husbands in the community prior to their husbands' placement in Deer Lodge Centre. They visit frequently and are optimistic about their health but half of them report often feeling sad or depressed. They are continuing their involvement by providing personal and psychosocial care to their husbands including keeping him company and joining him in recreation activities and outings.

Objective #1 explored the wives' perspectives of their involvement in their husbands' care in relation to the roles of resource person, co-worker and co-client. The findings suggested that staff and wives provide care in a parallel way. Wives' caregiving occurs without encouragement from staff and staff caregiving occurs without evaluation from the wives. Wives indicate that they have a partnership with staff but it may be a relatively passive partnership. In relation to a role as co-clients, wives indicated that staff members do care about them but that they neither need nor ask for help from staff members. This is interesting in view of the amount of time most of these wives spend at Deer Lodge Centre, and their reporting of often feeling sad or depressed. Although staff members do not have this research finding, they should be wondering about risk of fatigue, anxiety and burnout among the wives. Perhaps, the role of co-worker or partner is the sole role assigned to these family caregivers.

Objectives #2 and #3 were stated to explore wives' perspectives of importance and opportunities for involvement in the care of their husbands. A relatively new tool to

measure family involvement was used: the F-Involve and F-Important Scale (Reid et al., 2007). Finding indicated that the wives' involvement was determined mostly by their own initiative. For example, one scale item was phrased to read, "I have been asked to bring in pictures, letters and other personal items to teach staff about my husband". Most of the wives responded by saying, "I haven't been asked..." but I do this anyway. Wives were not uniformly involved in support groups and some reported not hearing or being informed about these groups. Most of the wives responded "yes" to the open-ended question on Deer Lodge's commitment to involving families in the care of their relatives. Most of the wives also proceeded to describe not their involvement in their husbands' care but their social involvement with their husbands in Deer Lodge Centre's programs and events.

Objective #4 was stated to explore wives' perspectives of their involvement in care of the husbands, and how this involvement relates to their husbands' quality of life. The wives indicted six areas of quality of life for their husbands: health and functional ability; well-being; recreation; relationship with others; being cared for and receiving good care; and global expressions of quality of life. Missing from the wives' expressions are themes of having personal identity and growth, aspirations and goals. This may be related to their perceptions of their husbands' cognitive and communication limitations. The wives strongly indicated that their husbands responded positively to their care, and that their involvement in their husbands' care contributed to the husbands' quality of life. While they reported receiving loving and appreciative comments from their husbands, they also acknowledged that caregiving could also be difficult and stressful. The wives spoke most positively about quality of life at Deer Lodge Centre. Specifically, wives spoke about staff who and provide comfort and care, and recreation activities. This is of

interest in relation to wives' earlier identification of their "social" involvement at Deer Lodge Centre. Recreation activities, events and outings seem to be a large part of the wives' involvement at Deer Lodge Centre as well as related to their husbands' quality of life.

Finally, there were three topics of "additional" findings and these findings were not directly related to the four objectives. However, when wives repeatedly made similar comments, these comments were deemed worthy of consideration. The three topics were: concerns about staff, including shortages and rotations; concerns about other residents; and concern about their own deaths and subsequent care of their husbands.

Overall, this research on family involvement has added to our knowledge base and it is because twelve wives agreed to share their perspectives on involvement in their husbands' care and life at Deer Lodge Centre. They demonstrated much devotion to their husbands and one wife expressed her feelings this way:

"You get up every day and you deal with what happens that day and maybe because we (wife and husband] are the kind of people we are, that's why we are still together 54 years later, after 35 years of [husband's]disease. You just never think of walking away, never." (0016)

The idea of never walking away certainly speaks to wives' devotion and to the continuation of marriage, family life and involvement in caregiving once their husbands have been placed in a long-term care setting.

## Chapter 5: Discussion and Recommendations

This research aimed to explore family involvement in the care of a relative through the perspectives of wives who provided care to their physically and cognitively frail husbands who were residing in Deer Lodge Centre. Specifically, the research examined wives' perspective on the importance of and opportunity for involvement in the care of their husbands, and furthermore the research examined wives' perspectives of the relationship between their involvement and their husbands' quality of life. A model (Twigg, 1989) that depicted the role of family caregivers in relation to formal caregivers was used to explore family involvement in relation to staff members' involvement. A recently established tool, the F-Involve and F-Important scale (Reid et al., 2007), was used to quantitatively measure family involvement. Otherwise, closed-ended and open-ended questions that focused on the four objectives were used in the face-to-face interviews with the twelve caregiving wives. This chapter provides a discussion of the findings, followed by a section on implications of the research. The third section outlines the limitations of the research while a fourth section presents some future research directions. The final section is a summary of this chapter.

### Discussion of the Findings

The objectives of this research were:

- 1) To explore wives' perspectives of their involvement in care of their husbands residing in long-term care in relation to the roles of resource person, co-worker or co-client;

- 2) To explore wives' perspectives on the importance of their involvement in care of their husbands residing in long-term care;
- 3) To explore wives' perspectives on opportunities for their involvement in care of their husbands residing in long-term care; and
- 4) To explore wives' perspectives of their involvement in care of their husbands, and how this involvement relates to their husbands' quality of life.

Stated as such, these objectives suggest a dyadic relationship between the caregiving wives and the husbands who are residents in a long-term care setting. However, the findings suggest that while this dyadic relationship occurs, more accurately it occurs in a larger context that sometimes does and sometimes does not affect the interaction in the dyadic relationship. Family involvement occurs at two levels, one level is with their relatives and the other level is with staff, other residents and other families, and both levels of involvement occur within the organizational context of the long-term care setting. The findings from this research have informed and highlighted two areas: 1) wives' involvement with their husbands, and 2) wives' involvement with others in Deer Lodge Centre.

First, to consider the level of wives' involvement with their husbands, it is clear that the wives, even wives who have been visiting their husbands for five years, maintain a caregiving role. The care that they provide is likely a continuation of care provided in the community and it consists of personal care and psychosocial care, from feeding their husbands, to cleaning their shoes to co-participating in recreation activities. These wives are very involved, visit frequently and for extended parts of the day and have a presence in the long-term care setting. They are also advocates for the care that their husbands' receive from staff members.

Findings indicate that wives initiate their caregiving and generally speaking, are not asked to do things by staff members. Similarly, staff members carry out their care without asking wives to evaluate or assess this formal care and so, it may be described as a parallel caregiving relationship between the wives and staff members. Wives rated eight of the twenty items from the F-Involve and F-Important scale (Reid, et al. 2007) as high importance and high opportunity, a positive finding, and only a five items were reported as having high importance and low opportunity for involvement. If the tool is capturing aspects of involvement that are relevant for these wives, then the findings speak well for the long-term care setting. It should be noted that three of the items are phrased around the wives being asked to do things, to which the wives responded that they have not been asked but they do these things anyway.

The open-ended question that asked, "In general, do you think that Deer Lodge Centre is committed to having families become involved in the care of their relative?" garnered agreement from the wives. But, their examples of evidence of this commitment had no connection with "involved in the care of their relative". The examples stressed the wives' social involvement in fund-raising, luncheons and recreation activities and were unrelated to their husbands' care except in terms of their co-participating in recreation and outings with their husband. It is not clear whether or not Deer Lodge Centre is committed to having families involved in their relatives' care from the data that were collected in this research. It does seem that wives equate their involvement with certain activities, especially recreation activities which were mentioned again by wives in relation to their husbands' quality of life. Recreation activities likely contribute to the wives' feelings of involvement as well as to their husbands' quality of life. The idea that

recreation programs might be sustaining or enhancing family involvement in long-term care settings is worthy of further consideration.

Another aspect of the dyadic relationship of the wife caregivers and their husbands was the wives' expression of what constituted a good quality of life for their husbands. Although, the wives did mention health, well-being, recreation, relationships with others, and receiving good care, missing, were expressions of personal identity and growth, aspirations and goals. In their involvement with their husband's care and their relationship with him as a person, there may be a kind of disheartenment that sees none of the higher levels of well-being and purposeful future. This is likely related to the cognitive limitations that the husbands were experiencing as the result of chronic neurological diseases. But, even in the face of this there was great devotion shown and expressed as the wives were not "walking away" from marriage, family and involvement with their husbands. In fact, some wives were concerned that they might precede their husbands in death and they expressed fears concerning what might happen to their husbands once they were gone.

The second level of wives' involvement was with others in Deer Lodge Centre, primarily with staff members but also with other residents and perhaps with other family members. While the wives indicated that they were partners with staff in providing care to their husbands, that partnership seemed rather passive on the part of the wives. Their examples of partnership were instances of the staff asking them to take part in an activity or provide information. Wives in the role of co-client did not exist for this group of family caregivers and yet, it does seem that these wives are a high risk group for fatigue, depression and burnout. The wives demonstrated a caring attitude toward staff and other

family visitors, something that has not appeared in the research literature on family involvement.

Wives also showed concern for staff members in relation to issues of being short-staffed and having to rotate from unit to unit and this is also something that has not been widely reported in the research on family involvement. This concern was focused on the heavy workload with resulting lack of time to spend with residents, overall. It is important to note that this concern was phrased in terms of residents, generally, for example, not having enough staff on hand to bathe residents more than once a week. But part of this concern might be related to their husbands' care, for example, for one wife, the lack of physiotherapy meant her husband lost the ability to walk. Staff rotations meant that staff members did not become familiar with the residents' needs and no one "was on top" of the care, according to the wives. They indicated that they wanted to get to know the staff members and be able to know their names.

Wives were also involved with care for residents other than their husbands. This was sometimes related to staff shortage or staff not having the time to spend with residents. So, these wives fed other residents and came to them when they called out. Wives expressed distress and sadness for residents who did not have family caregivers like them to provide care and support. This aspect of providing care, to and caring about other residents also has not been widely reported in the literature.

The organizational context is a factor at both levels of involvement, in the wives' involvement with their husbands' care and with their involvement with staff and others in Deer Lodge Centre. Questions were directed toward the organization context in relation to Deer Lodge Centre's commitment to family involvement in care and to quality of life. Both questions were answered positively but the answers were not informative. Perhaps

other questions that focused more directly on “involvement in care” would have been more productive or maybe the wives see their involvement in their husbands’ care as dyadic and personal, whereas involvement in Deer Lodge Centre is about how the long-term care setting involves them (the wives) as individuals. The wives’ involvement is absolutely and primarily with their husbands but they are also involved with staff, residents, and others. Metaphorically speaking, this two level involvement makes them less “visitors” and more “citizens” of Deer Lodge Centre.

#### Implications of this Research to Personal Care Homes

The mission and vision of most long-term care settings indicates the importance of families. If long-term care settings wish to involve family caregivers in the care of their relatives and in other activities, the findings from this research point to several initiatives. First of all, on admission when the social worker completes the social assessment form for the new resident, there could be a second “social and caregiving assessment” form for the family caregiver that acknowledges family caregiving role and asks specifically what caregiving role they would like to continue in the long-term care setting. This would involve asking about tasks that the family caregiver would like to relinquish and tasks that they would like to retain. Twigg’s (1989) model of carers might be used as a guideline for this sheet so that the role of co-client is not lost, particularly for older caregivers who may have their own health problems and risks.

Second, given that half of the wives indicated that they often felt sad or depressed, staff members in long-term care must be proactive in asking about family caregivers’ health and well-being and not simply suggest that they visit less often. Deer Lodge Centre may be the family caregiver’s new or second “home”, and their frequency and

length of visiting may not be an issue for them. Third, the wives' satisfaction and interest in recreation activities as examples of their involvement is evidence of the importance of continuing to involve family caregivers in activities that they might have participated in with their relative prior to placement.

Fourth, if the annual survey of quality assurance is not reaching 80 or 90% of families, maybe an alternative strategy could be used, for example, self-administered questionnaires. This would signal that family involvement in evaluation is an important consideration. Fifth, new staff orientation and staff development sessions might include information on family involvement in general and on using Twigg's (1989) model of carers specifically to roles and involvement of family members in long-term care settings.

### Limitations

There are several limitations that must be acknowledged. First and foremost is the limitation of a convenience sample of wives who self-selected themselves into this research project. It would have been useful to know more about their reasons for participating. A question asking about reason for participation could have been asked but was not asked. The inclusion criterion was broad in terms of how long the husband was a resident at Deer Lodge Centre. Given that much of what we know about family involvement is from studies that looked at the transition to long-term care settings, admission and the first year of residence, it might have been useful to have narrowed the criterion to include husbands who had resided in long-term care settings for a longer period of time such as two to three years. As it was, with this sample, husbands had been living in Deer Lodge Centre for a range of six months to more than five years. Although,

it provided a variety of experience, this range may have been too broad to see patterns of early to relatively later involvement.

A second limitation is that data were not collected at an organizational level. This data would have been informative in relation to policies, procedures or strategies that were in place to encourage or discourage family involvement. Data were not collected from staff and some of the F-Involve and F-Important scale (Reid et al., 2007) suggest that staff members have not spoken to family caregivers about caregiving related topics, for example, about the relative's preferences and values. For that item, wives indicated that it was important to have been asked but that they had not been asked. It might have been useful to follow-up with staff members on this and ask about how they learn about residents' preferences and values.

A third limitation is the use of the F-Involve and F-Important scale. Although this relatively new tool has performed well in other studies, there was an item that caused some confusion. The item indicated above that asked about the relative's preferences and values was misunderstood by a few of the wives who interpreted "values" as beliefs and felt that either this information was private or they responded by declaring their religious background. The F-Involve and F-Important scale (Reid et al., 2007) also might not fully explore family involvement in the sense that some of the items are passive, that is, "being asked" to do things rather than having a more active dynamic for family caregivers who, at least in this research, do things without being asked. That being said, the tool assisted quite well in identifying things that were of high importance but presented low opportunity for family involvement in the long-term care settings.

### Future Research

This research was focused on wives who were caregivers to their physically and cognitively frail husbands in long-term care settings. The researcher identified this group as an appropriate one to study. The researcher's clinical experience with older adults lead her to believe that wife caregivers should be studied separately as a group because they are visible as a group of caregivers who spend extensive time in the long-term care setting with their husbands. However, this research might be conducted with other caregivers such as filial caregivers, either sons or daughters. A comparison of involvement of wives and daughters might further our knowledge of family caregiving. It seems likely that daughters would be involved in the level of care to their parent but have much less involvement with others such as staff and other residents.

A second area of future research that comes from the findings is related to family involvement in relation to their involvement with staff, residents and others in the long-term care setting. Wives indicated concern about staff workload and rotation and how it affected the staff themselves and the care of other residents. This concern was not just about their husbands' care, it was a broader concern for staff and residents. These findings are not widely reported in the literature and this area could be for further study. In terms of the wives' involvement with other residents, research might focus on asking family caregivers what they do for other residents. This would be a new area of research. Another area for further study might be family caregivers' involvement with other family caregivers in long-term care settings. This is another area of family involvement where little is known.

A third avenue of future research is tool development. Certainly, the F-Involve and F-Important scale (Reid et al., 2007) was useful in identifying things of high

importance but low opportunity for family involvement in long-term care settings. However, a tool that focuses on the “active” and “continuing role of families at both levels of involvement, that is, the level of family involvement with their relatives’ care and the level of family involvement with staff, residents and others in the long term care setting would be beneficial. The tool could be developed from Twigg’s (1989) model of carers to include items related to the family caregiver as resource person, co-worker and co-client but also expand to included aspects of involvement with staff, residents and others

### Summary

This chapter provided a discussion of the findings and speculated in relation to implications to long-term care settings, limitations and suggestions for future research. The findings and analysis indicate two levels of the wives’ involvement in long-term care setting. This research focused on the level of wives’ involvement with their husbands’ care but the findings also include what the wives had to say about the second level of involvement which includes involvement with staff, other residents and others in Deer Lodge Centre. The implications of this research for long-term care setting focused on: ways to involve families that are embedded in procedure (“social and caregiving assessment sheet); identifying family caregivers’ health problems and risk; recognizing the role of recreation activities in family involvement; and ensuring opportunities for families to participate in evaluations Three limitations were identified: self-selection of a small convenience sample; lack of data collection on the organizational context; and some of the strengths and limitations of the F-Involve and F-Important scale (Reid et al., 2007). Future research included: expanding the sample to include filial caregivers such as

daughters, focusing on the involvement of family caregivers with staff, residents and other family caregivers; and tool development to capture more fully the levels of family involvement in long-term care settings.

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**APPENDIX A: F-Involve F-Important Scale (Reid, Gish & Chappell, 2007)**

Family Involvement (F-INVOLVE) and Importance of Family Involvement (F-IMPORTANT) Scale Items

The following statements refer to the different ways that staff members and facility management at long-term care facilities can include family in the care of persons with dementia.

Directions: Read each statement and think about the extent to which it is present in the facility that your family member lives in. Place your responses to these statements in column A on the *left* hand side by using the scale provided. Then consider how important each of these ways of including you in the care of your family member is to you regardless of whether or not the facility provides it. Place your responses to these statements in column B on the *right* hand side by using the scale provided.

**Table 2: Family Involvement (F – INVOLVE) and Importance of Family Involvement (F – IMPORTANT) Scale Items**

<b>Present in Facility</b>		<b>Important to Me</b>
<b>SCALE</b> 1. Strongly Disagree 2. Somewhat Disagree 3. Somewhat Agree 4. Strongly Agree		<b>SCALE</b> 1. Unimportant 2. Somewhat Important 3. Quite Important 4. Extremely Important
a. _____	Staff has created opportunities for me to meaningfully participate in my family member's day.	_____
b. _____	I have been asked about my family member's personal history.	_____
c. _____	I have been asked about my family member's preferences and values.	_____
d. _____	Staff has helped me to understand how dementia affects my family member.	_____
e. _____	I am able to dine with me family member if I want to.	_____
f. _____	I have been asked to bring in pictures, letters, and other personal items to teach staff about my family member.	_____
g. _____	I feel like I am involved in decision-making about my family member's care when he or she cannot make decisions for themselves.	_____

Present in Facility		Important to Me
SCALE 1. Strongly Disagree 2. Somewhat Disagree 3. Somewhat Agree 4. Strongly Agree		SCALE 1. Unimportant 2. Somewhat Important 3. Quite Important 4. Extremely Important
h. _____	Staff has taught me how to communicate with my family member as the disease has progressed.	_____
i. _____	The facility has a support group.	_____
j. _____	I was introduced to the different staff members at the facility when my family member was admitted.	_____
k. _____	Staff explained to me the rules and procedures at the facility upon admission.	_____
l. _____	Administrators have asked my opinions about the quality of care provided at this facility.	_____
m. _____	The facility holds family information meetings.	_____
n. _____	I feel like my family member has been well cared for.	_____
o. _____	I trust the staff members at this facility.	_____
p. _____	I am informed about changes in my family member's care plan.	_____
q. _____	Staff has helped me understand the difficult behaviors that my family member sometimes has.	_____
r. _____	Staff has helped me to plan for the death of my family member.	_____
s. _____	Staff has helped me plan for the handling of my family member's estate upon his or her death.	_____
t. _____	I feel comfortable phoning staff members and talking to them about how my family member is doing.	_____

Taken from: Reid, R. C., Chappell, N.L. & Gish, J.A. (2007). Measuring family perceived involvement in individualized long-term care. *Dementia, Research and Practice*.

Appendix B: Approval Certificate



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**APPROVAL CERTIFICATE**

21 September 2007

**TO: Ruth All** (Advisor L. Guse)  
Principal Investigator

**FROM: Stan Straw, Chair**  
Education/Nursing Research Ethics Board (ENREB)

**Re: Protocol #E2007:068**  
**"Family Involvement in Long Term Care Settings: Perspectives of Opportunity and Importance of Involvement"**

Please be advised that your above-referenced protocol has received human ethics approval by the Education/Nursing Research Ethics Board, which is organized and operates according to the Tri-Council Policy Statement. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

<b>Please note:</b>
<b>- if you have funds pending human ethics approval, the auditor requires that you submit a copy of this Approval Certificate to Kathryn Bartmanovich, Research Grants &amp; Contract Services (fax 261-0325), including the Sponsor name, before your account can be opened.</b>
<b>- if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.</b>

**The Research Ethics Board requests a final report for your study (available at: [http://umanitoba.ca/research/ors/ethics/ors\\_ethics\\_human\\_REBforms\\_guidelines.html](http://umanitoba.ca/research/ors/ethics/ors_ethics_human_REBforms_guidelines.html)) in order to be in compliance with Tri-Council Guidelines.**

## Appendix C: Interview Schedule

**Family Demographic and Health Characteristic Sheet**

Research Code #: \_\_\_\_\_ Date of Birth: \_\_\_\_\_

**Support Related Questions**

1. Do you have children? Yes  No
2. If yes, do they reside in Winnipeg? Yes  No
3. Can you readily call on your children for assistance? Yes  No
4. If no, are there other persons that you may contact for assistance? Yes  No
5. Are you a member of any ethnic or church group? Yes  No
6. If yes, what is the name of the group? \_\_\_\_\_
7. Are you presently employed? Yes  No
8. If yes, what is your area of work? \_\_\_\_\_
9. How many hours do you work weekly? \_\_\_\_\_

**Accessibility Related Questions**

10. How often do you visit your husband?  
2-3 times weekly  4-6 times weekly  7 or more times weekly
11. Do you drive? Yes  No
12. If no, what is your method of transportation? \_\_\_\_\_
13. How long does it take you to get to Deer Lodge Health Centre  
Less than 1hr  1-2 hrs  2-3 hrs  3 hrs or more
14. Do you have any problems or concerns getting to DLC?  
Yes  No

15. If yes, tell me a little more about those problems or concerns : \_\_\_\_\_

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16. Would you visit more often if you did not have those problems or concerns?

Yes  No

17. If no, why? \_\_\_\_\_

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18. How long has your husband been a resident in DLC?

6 months or more  1 yr  1 - 2yrs.  3 - 4yrs.

4 -5yrs.  5 - 8yrs.  8 -10yrs.  10 yrs or more

**Personal Wellbeing Related Questions**

19. Do you have any chronic illnesses? Yes  No

20. Additional comments (Optional):

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21. How would you rate your health? Excellent  Good  Fair  Poor

22. Additional comments (Optional): \_\_\_\_\_

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23. Do you often feel sad or depressed? Yes  No

24. Additional comments (Optional): \_\_\_\_\_

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**APPENDIX D: Additional Items Related to Opportunities for Involvement**

Table 1: Family Involvement (F-INVOLVE) and Importance of Family Involvement (F-IMPORTANT) Scale Items Incorporating the Concepts of Twigg’s “Model of Carers” Developed by Researcher

<b>ADDITIONAL STATEMENTS: Incorporating Concepts of Twigg’s “Model of Carers”</b>		
<b>Present in Facility</b>		<b>Important to Me</b>
<b>SCALE</b> 1. Strongly Disagree 2. Somewhat Disagree 3. Somewhat Agree 4. Strongly Agree		<b>SCALE</b> 1. Unimportant 2. Somewhat Important 3. Quite Important 4. Extremely Important
1. _____	I feel that my role as a caregiver ended on the admission of my husband to this facility. <b>Cw</b>	_____
2. _____	Staff has implemented some of my suggestions when they provide care to my husband. <b>rs</b>	_____
3. _____	Staff has encouraged me to participate in certain 'hands-on' care with my husband e.g. assisting with grooming; hair combing; or as facility's policies dictate. <b>cw</b>	_____
4. _____	Staff has asked me to participate in the group activities that I attend with my husband. <b>Cw</b>	_____
5. _____	The facility has an open door policy which helps me to discuss any concerns readily with Administrators or Managers. <b>Cw</b>	_____
6. _____	The facility recognizes me as an important resource in the care of my husband <b>Rs</b>	_____
7. _____	The staff seeks my advice before certain care decisions <b>Rs</b>	_____
8. _____	The staff contacts me to clarify new concerns regarding my husband's care. <b>rs</b>	_____
9. _____	Staff has asked me to evaluate the care that is being provided for my husband <b>Cw</b>	_____
10. _____	The staff demonstrates appreciation in the assistance I give in caring for my husband <b>Cw</b>	_____
11. _____	The staff expects me to carry out certain care needs (e.g. grooming, combing of hair) for my husband. <b>Cw</b>	_____

Present in Facility		Important to Me
SCALE		SCALE
1. Strongly Disagree 2. Somewhat Disagree 3. Somewhat Agree 4. Strongly Agree		1. Unimportant 2. Somewhat Important 3. Quite Important 4. Extremely Important
12. _____	The staff recognizes my inability to cope and has been supportive <b>Cc</b>	_____
13. _____	Staff has offered to provide any counseling or teaching that I feel I need. <b>Cc</b>	_____
14. _____	The facility has contacted and or referred me to related agencies to assist me in dealing with personal health or other concerns. <b>Cc</b>	_____

**Open Ended Questions**

Families often experience a change in role once their relatives move to a long term care facility like Deer Lodge Centre. I will be asking you some questions about your involvement in the care of your husband. To begin with, I will ask some general questions about your relationship with the facility and then I will ask some more specific questions.

**Objective 1:** To explore wives' perspectives of their involvement in care of their husbands residing in long-term care in relation to the roles of resource persons, co-workers or co-clients.

1. In general, how would you describe your involvement at Deer Lodge Centre, that is, how are you involved in the care of your husband?
2. Do you feel like a "partner" in planning care or activities for your husband?

If yes, probe: How has this partnership happened? What kinds of things have helped this partnership to happen? Can you give me some examples of this partnership?

If no, probe: Why do you think that this partnership has not happened? What are some of the things that have prevented a partnership? Can you give some examples when partnership did not occur?

3. Do you feel that the staff at Deer Lodge Centre is concerned about your health and well-being? Do you feel that the staff is equally concerned about your health and well-being as they are about your husband's health and well-being?

If no, probe: Would you like the staff to show more concern about your health and well-being? Would you like the staff to do something to improve your health and well-being?

If yes, probe: How does the staff show concern about your health and well-being? What are some of the things that the staff does for you? Describe how those things fit with your husband's care or your role in providing care for your husband?

4. In general, do you think that Deer Lodge Centre is committed to having families become involved in the care of their relatives? Have they invited you to become involved? More involved?

**Objective #2:** To explore wives' perspectives on opportunities for involvement in care of their husbands residing in long-term care and **Objective 3:** To explore wives' perspectives on the importance of their involvement in care of their husbands residing in long-term care.)

The F-INVOLVE and F-IMPORTANT Scales (Appendix 4) will be administered and then the following additional questions will be asked. After each question, the family member will be asked "Is there anything more that you would like to say about this?" so that family members can go beyond the questions of opportunity and importance of involvement to provide more detail. This process will provide richer more in-depth data.

Thank-you for answering all of my questions. Is there anything else that you would like to add? Do you have any questions for me?

**Objective #4:** To explore wives' perspectives on their involvement in care of their husbands and how this involvement relates to their husbands' quality of life.

Items related to opportunities for involvement and quality of life

<b>QUALITY OF LIFE</b>		
<b>What does the 'quality of life' of your husband means to you?</b>		
<hr/> <hr/> <hr/> <hr/> <hr/>		
<b>Based on your understanding of QOL, indicate your response to the following statements.</b>		
Present in Facility <b>SCALE</b>		Important to Me <b>SCALE</b>
1. Strongly Disagree 2. Somewhat Disagree 3. Somewhat Agree 4. Strongly Agree		1. Unimportant 2. Somewhat Important 3. Quite Important 4. Extremely Important
1. _____	My husband responds positively when I assist in his care	_____
2. _____	Involvement in my husband's care contributes to his quality of life.	_____
3. _____	The importance of my husband's quality of life is one of the major reasons for placing him in this facility	_____
4. _____	The facility conducts annual surveys that include quality of life concerns.	_____

### Open Ended Questions

1. In general what would be a good quality of life for your husband in this facility (that is, Deer Lodge Centre)?

2. Describe your husband's response when you provide certain care for him. Do you believe he is more relaxed, pleasant, easier to direct or easier to carry out care when you are involved in his care?

If yes, probe: What are some of the approaches that you use in caring for your husband?

Do you believe that these care approaches help to improve your husband's quality of life?

If no, probe: Is there any assistance that the facility staff could offer you personally to help in your involvement in your husband's care?

3. Do you believe that the quality of life of your husband is a major focus at Deer Lodge Centre?

If yes, probe: What are some of the things that are done at this facility that encourage quality of life outcomes for your husband?

If no, probe: Why do you think that the quality of life of your husband is not a major focus? What are some of the things that the facility could do or implement to improve in this area?