

All my mother wants is family:  
Family members of parents with cognitive impairments share  
their experiences with caregiving and community supports

by

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## ABSTRACT

The purpose of the study was to explore the experience of caregiving and the use of community supports from the perspectives of adult children providing care to their cognitively impaired elderly parents. Designed as an exploratory qualitative study within a framework of feminist postmodernism, the research process utilized a semi-structured interview format to capture the stories of caregivers' experiences. An advertisement as well as a purposeful criterion sampling method, applying a snowball approach, was used to recruit nine caregivers. Data collection occurred through individual and small family group interviews, and a subsequent focus group session. Thematic analysis of the data revealed that, despite caregiver burden and objective need for formal services, families underutilize services available to them due to the values and attitudes of the caregivers and care-recipients. Although service characteristics are important determinants of service use, other important factors which influenced formal service utilization are gender, availability of informal supports, family relationships, and perceptions of responsibility and of the services itself. Family caregivers want information and formal supports that are appropriate, adequate, and flexible so that when the caregiving context changes, they have knowledge of and access to options. They also want to be seen as partners in the process and to be valued for their contribution as caregivers. Formal service providers may be able to use these results in helping families improve their access to resources, designing programs that better serve their needs, and incorporating the family as a valuable supplemental resource when formal care becomes necessary for care recipients.

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## Chapter 1

### INTRODUCTION

#### **Background to the Problem**

Caregiving to elders has become an important theme in public policy debate of countries like Canada as we enter the new millennium (Harlton & Keating, 1998). With a greater percentage of the population living longer and developing chronic impairments or disabilities associated with advanced aging, more and more families are being confronted with the possibility of caring for frail elderly relatives (Hooyman & Gonyea, 1995), many of whom may suffer from some form of cognitive impairment. Concurrently, health care reforms and economic constraints have resulted in a shift from institutional to community-based care (Health Canada, 2001). In the community, most of the care is provided not by professionals but by relatives and predominately by female members (Aronson, 1986).

This topic of community care of chronically ill older people has both professional and personal relevance for me. My experiences in both these aspects of my life were the impetus for this study. My experience as a social worker in an acute care setting has exposed me to the complexities of the caregiving experience, and the impact of caregiving on one's well-being. My experience has shown me that families flounder, at least initially, as they juggle competing demands and make decisions about the care of their elderly family members.

Furthermore, many frail elderly lose their independence prematurely due to problems in their relationships with those in their informal support system. Sometimes this is due to family caregivers not being able to manage the caregiving demands. Often it is the result of the family not knowing how to access services to assist them to continue with their efforts. At other times it is due to attitudes of either the caregiver or the care recipient about accepting or accessing outside supports. Whatever the reason, the consequence is often a period of hospitalization while

families regroup and make alternative arrangements. As a hospital social worker, I believe it is important to try to understand the caregivers' experience, and their perspectives of support services available to them.

The scarcity of resources to assist caregivers also affects the work I do with families. While family and community care is the preferred model of eldercare, families have few affordable options available to them outside of the publicly funded model which controls what, how, and to whom services are provided. I was curious to know how caregivers experienced the options currently available to them. I had a hunch that there may be other influencing factors that may be more important to caregivers than the characteristics of the service delivery options themselves.

This topic was also relevant to my personal experience with friends who have struggled to juggle their caregiving demands with their employment and family commitments. Recently I had dinner with a friend and the main topic of our discussion that evening focused on the challenges that she and her sister had faced in their efforts to access formal supports that would allow them to continue caring for their mother in the community. Another friend shared with me, over the bulk carrot bin at the grocery store, her own difficulties with her mother who was refusing assistance with her bathing from a homemaker. These and other similar experiences reinforced to me the complex nature of caregiving to a frail elderly parent.

### **Problem Statement**

A number of converging social, political and demographic trends have resulted in an increasing number of adult children becoming caregivers to community-dwelling frail elderly parents. A significant number of the frail elderly are cognitively impaired, requiring considerable supervision and increasing help with daily activities. This caregiving is often provided at substantial financial, emotional, psychological, and social costs to the caregiver

(Gottlieb, 1998). Patterns of service have shown that as the needs of an elderly parent increase, some families supplement their caregiving efforts by accessing support from both informal and formal supports within the community (Noelker & Bass, 1994). However, despite the strain and burden that caregivers experience, they underutilize community services available to them (Pedler & Biegel, 1999). This poorly understood phenomenon invites an exploration of the context within which caregiving occurs.

I have specifically focused on adult children providing informal care to frail elderly parents to better understand the specific needs of this group of caregivers. In the absence of spousal caregivers, adult children - predominately women - are expected to provide the majority of informal care to the frail, elderly parents. This is in addition to balancing work and other family responsibilities. By listening to what these caregivers have to say about their experiences, I am hoping to gain a sense of what it is like to access assistance from both informal and formal community supports. In order to develop responsible and responsive home care policy we must seek to understand the interaction of caregivers with the community care system. Although it is recognized that families play a significant role in maintaining the elderly in the community, little is known about the process of becoming a caregiver.

This enquiry, which is intended to illuminate the essential qualities of caregiving, will contribute to the knowledge about ways in which social work and the formal system of care can be helpful to the elderly and their families. Furthermore, it will add to the body of knowledge available for educating caregivers about the experience of being a caregiver. In addition, a process whereby caregivers discover commonalities in their day-to-day struggles can be validating and empowering and may increase the caregiver's capacity to problem-solve and seek social support. On a more personal level, it may help me in my work when answering the questions of other caregivers approaching similar circumstances.

Social workers aid caregivers through the caregiving process by assisting them in finding the supports and information needed to mediate the stress of caregiving. However, the particular region where the study took place does not extensively employ social workers as case managers in the community, neither in long-term care nor mental health. Yet, social work's holistic approach renders social workers ideally suited to geriatric case management in community settings. Social workers need advanced knowledge in this special field of clinical practice to educate families, each other, and students coming into the field. Furthermore, knowledge in the field of family caregiving is needed to develop informed policies, programs and services.

Therefore, using an exploratory qualitative approach, which is informed by postmodern feminism, this study will focus on the experience of caregiving families faced with the challenge of caring for a cognitively impaired parent. Specifically, the study will focus on the experience of becoming a caregiver and providing care to a parent with confusion, and the process of seeking help from formal and informal supports in the community.

### **Definition of Terms**

*Caregiver:* one who provides direct care and attends to the needs of a disabled or dependent adult with memory impairments (Merriam Webster, 1997).

*Cognitive-Impairment:* used interchangeably in this report with dementia.

*Dementia:* "a clinical syndrome of signs and symptoms associated with the impairment of the higher central nervous system affecting at least three of five cognitive domains: (1) memory, (2) language, (3) visuospatial skills, (4) complex cognition, and (5) emotion and personality" (Fitzgerald, 2000, p. 41). Essentially, dementia is used to describe an acquired (possibly through a stroke) or progressive loss of intellectual functioning, which limits one's ability to take care of him/herself. Alzheimer's is the most prevalent cause of dementia,

accounting for 60-75% of cognition problems in the elderly (Fitzgerald, 2000). This is why Alzheimer's disease and dementia are terms that are often used synonymously in the literature.

*Long-term care:* a broad range of services that are designed to provide help with activities needed by chronically disabled individuals for a long period of time (Stone, 2000). Typically, these are low-tech services provided to help individuals compensate for and to some extent rehabilitate the loss of physical and mental functioning. These services include assistance with basic activities of daily living (ADLs); as such, they provide help with bathing, eating, dressing, and other personal care. Long term-care may also provide assistance with instrumental tasks of daily living (IADL's), which may include help with shopping, money management, and medication supervision. Long-term care services are provided both in residential settings and in community settings. In British Columbia, home care services are provided through the Continuing Care Branch of the Ministry of Health.

*Family caregiving:* the provision of unpaid care to dependent family members. Typically the family caregiver who provides the most assistance is called the primary caregiver (Fitzgerald, 2000; Stone, 2000).

*Informal care:* care provided by unpaid "informal caregivers". Informal caregivers - predominately family members - constitute the major long-term care provider (Stone, 2000).

*Formal care:* care provided by community social service agencies, many of whom are paid to provide a service. For the purposes of this study, the term formal care will be used to define a set of services used by caregivers to support them in caring for their cognitively-impaired parent. These services include: respite in the form of an adult day program and or a short-term stay in a long term care facility; residential care (in an intermediate or extended care facility); education, training, and support through various support groups, such as the Alzheimer's Society; case management services, including assessment and support through

Continuing Care or Geriatric Outreach Programs; homemakers, either private or provided publicly through the community long-term system; provision of transportation and meals; and, services provided by physicians, community physiotherapists, and occupational therapists.

### **Organization of Thesis Content**

This thesis is comprised of five main chapters. The following chapter reviews theories and literature relevant to caregiving to the elderly and service utilization. Chapter 3 describes the research design and practical methodological issues. Chapter 4 presents the findings generated from the data. The findings are discussed in detail in Chapter 5, along with implications and recommendations for policy and practice with caregivers to the elderly.

## **Chapter Two**

### **REVIEW OF THEORETICAL AND RESEARCH LITERATURE**

#### **Introduction**

In this chapter a review of the literature is presented in two major sections. The first section specifically focuses on theoretical frameworks that may be useful in the study of caregiving. Two social theories, systems-ecological and socialist feminist, are discussed with respect to their relevance to caregiving and community care policies for the elderly. In addition, a summary of selected theories of service utilization is presented. Next, attitude theory is discussed as it relates to decisions caregivers make about service use. The final section is a review of the pertinent literature on aging, caregiving, and community policy to support eldercare.

#### **Theoretical Framework**

##### **Systems-Ecological Perspective to Eldercare**

A systems-ecological theoretical approach is a useful tool for understanding the experiences of caregivers with the service delivery system because it takes a person-in-environment perspective. This particular perspective is useful when attempting to understand the experience of caring for someone impacted by disease and disability (Rutchick, 1990). It helps service providers "avoid linear, deterministic cause-effect explanations of behavior or social phenomena" (Payne, 1997, p. 154). This is especially important in our health care settings where services to the frail elderly and their families have traditionally reflected a medical model with doctors acting as gatekeepers to services. Instead, the systems-ecological perspective focuses on the interaction and adaptation of the individual with the environment (Payne, 1997). Problems may develop in this interaction from time to time - the result of life transitions, environmental needs, and poor communication and relationships (Coxe, 1992). My friend's

exasperating experience accessing formal supports to assist her with the caregiving of her mother justified the use of this theoretical perspective for my study.

A systems-ecological approach to life transitions helps to explain the effect that declines in adult functioning have on family members. Understanding how individual family members previously adapted to the stress of various life transitions can help to predict how an individual will cope with the demands of caregiving. When exploring the adequacy and appropriateness of formal services to assist caregivers of family members with dementia, it is important to understand what aspects of caregiving might interfere with the caregiver's own social, physical and development needs and how formal supports can mitigate the burden for caregivers. This perspective considers the cognition and capacity of the family system to adapt to the changes in a family member with dementia (Greene & Blundo, 1999) and work towards interventions that enhance the caregiver's capacity to adapt and cope.

This framework will be useful to me when I explore other environmental factors of the client system that impact the caregiving experience and work towards finding a better fit between the needs and environmental capacities (Germain & Gitterman, 1980). It helps to explain the complex and diverse environmental pressures – such as unemployment, employment demands, social class, access to community services, and unresponsive organizations – that make caregiving problematic. Furthermore, it is flexible enough to allow me to work with caregivers towards models of service that are more integrated with community life.

Moreover, a systems-ecological perspective provides a framework for understanding relationships between the individual, the family, and society. Recognizing the significance of family involvement, it guides me to seek information about how the family operates in context with larger systems and other institutions across the life cycle. The perspective will be useful in exploring structures within families, rules for behavior, assigned roles, power structures, and

communication patterns (Greene & Blundo, 1999) and designing more humane and responsive formal care interventions that support caregivers in this role. This approach is grounded in the belief that competency in caregiving is best achieved when the intervention addresses the whole ecological unit rather than only the individual (Coxe, 1992); thus the emphasis is removed from individual change.

However, while systems-ecological theory is a useful tool for my work with individuals, families, and communities, its exclusive use poses a dilemma to my research problem. While it attempts to improve interactions of the individual with the environment so that individuals and families can remain as independent and autonomous as possible, in doing so it may avoid necessary conflict or preserve systems that should be changed (Payne, 1997) and may, therefore, limit my analysis of problematic social structures. Baines (in Ristock, 1993) argues that the caregiving systems and organizational structures, of which the frail adult, the caregiver, the professionals and the volunteer helpers are a part, have hierarchical divisions that reflect differences in power, esteem and autonomy. While these differences may influence the outcome of the intervention, they are not recognized as significant or particularly relevant. A systems-ecological perspective alone may not allow me to see that the inequitable allocation of caring responsibilities within both families and the formal system may be a result of values and beliefs that have been socially constructed over time. Yet societal ideals about women as carers result from processes that are interacting, reinforcing and persuasive (Hooyman & Gonyea, 1995).

While a systems-ecological approach guides social workers to include as many critical variables and systems as possible in their assessment and to consider the interrelatedness of all systems, this emphasis does not help social workers examine the possibility of some factors and some systems being more important than others (Payne, 1997). Using this perspective, we are left to grapple with deciding whose interests, demands, or needs take priority. My analysis of

caregiving has highlighted the notion that caregiving impacts members of our society in different ways. While health services are officially gender neutral, women have been impacted by changes to formal community health services more than men (Neysmith, 1993). These inequities emphasize the need for a theoretical perspective that will help me to understand oppression and the sociopolitical aspects of caring that present challenges for some caregivers. Therefore, in searching for a perspective that works towards gender justice and a redistribution of power, I have also used a feminist lens to complement a systems-ecological analysis of this problem.

### **Feminist Perspective to Eldercare**

A feminist approach brings with it inclusiveness, and a focus on power, oppression and the social construction of gender roles, equality, and diversity. This perspective is not only concerned with women's issues; rather, it is concerned with eliminating oppression and concerns shared by men and women (Hooyman & Gonyea, 1995).

Hooyman and Gonyea (1995) argue that feminist theories start from the assumption that the prevailing standpoint of social reality has been shaped by sexist values and a male perspective known as androcentricity. As such, the experiences of white middle class males become the norm and the diverse experiences of women and those of color are located on the periphery. Feminists, therefore, argue for deconstructive strategy, which attempts to question the "objective" or value-free knowledge and "universals" that have largely been based on the white male experience (p. 16). Deconstruction strives for explanations of the social world that are nonuniversalistic, explicit about values, and open to the complexity and diversity of experiences based on gender, sexual orientation, race, class, and culture. As such, it is not concerned only with women's issues; rather it strives, through personal and social change, to eliminate oppression in any form.

Within feminist theory, however, there is a range of political orientations. The orientation most suited to this study on caregiving is a socialist feminist approach. Browne (1998) contends that a socialist feminist approach builds on the ideas of Marxism to provide a more inclusive approach to diversity and an understanding of the intersection of multiple oppressions. It recognizes the power derived from patriarchy. Social feminists may differ slightly from Marxist theorists in that they see patriarchy as more rooted in economics than psychology and domination. Thus, they believe that social relations between men and women have a material base, which is hierarchal in nature, allowing for the solidarity of men and the domination of women. According to social feminists, this dominance ensures that the labor force is organized in a way that women's work is less valued. This perspective guides me to be critical of the inequities in community home care policies and programs that may extend the domination of women's lives in the private sphere (Baines, Evans, & Neysmith, 1991). Socialist feminism guides me to work towards strategies that will effect wide-scale social changes in the way society defines, distributes and rewards caring work (Pohl & Boyd, 1993).

The analysis of caregiving using both a systems-ecological and a socialist feminist perspective provides a useful tool for understanding the complexity of caregiving to those with dementia and for designing support services to address caregivers' needs. Both theories are described by Payne (1997) as being expository rather than explanatory; that is, they do not prescribe a course of action but allow the client to be self-determining in choosing home care supports that address their most problematic concerns.

However, while I believe a feminist perspective complements the systems-ecological perspective to provide a comprehensive social welfare perspective for understanding and intervening with the frail elderly and their caregivers, I believe that the sole use of a feminist perspective has limitations. While a feminist perspective allows me to understand oppression

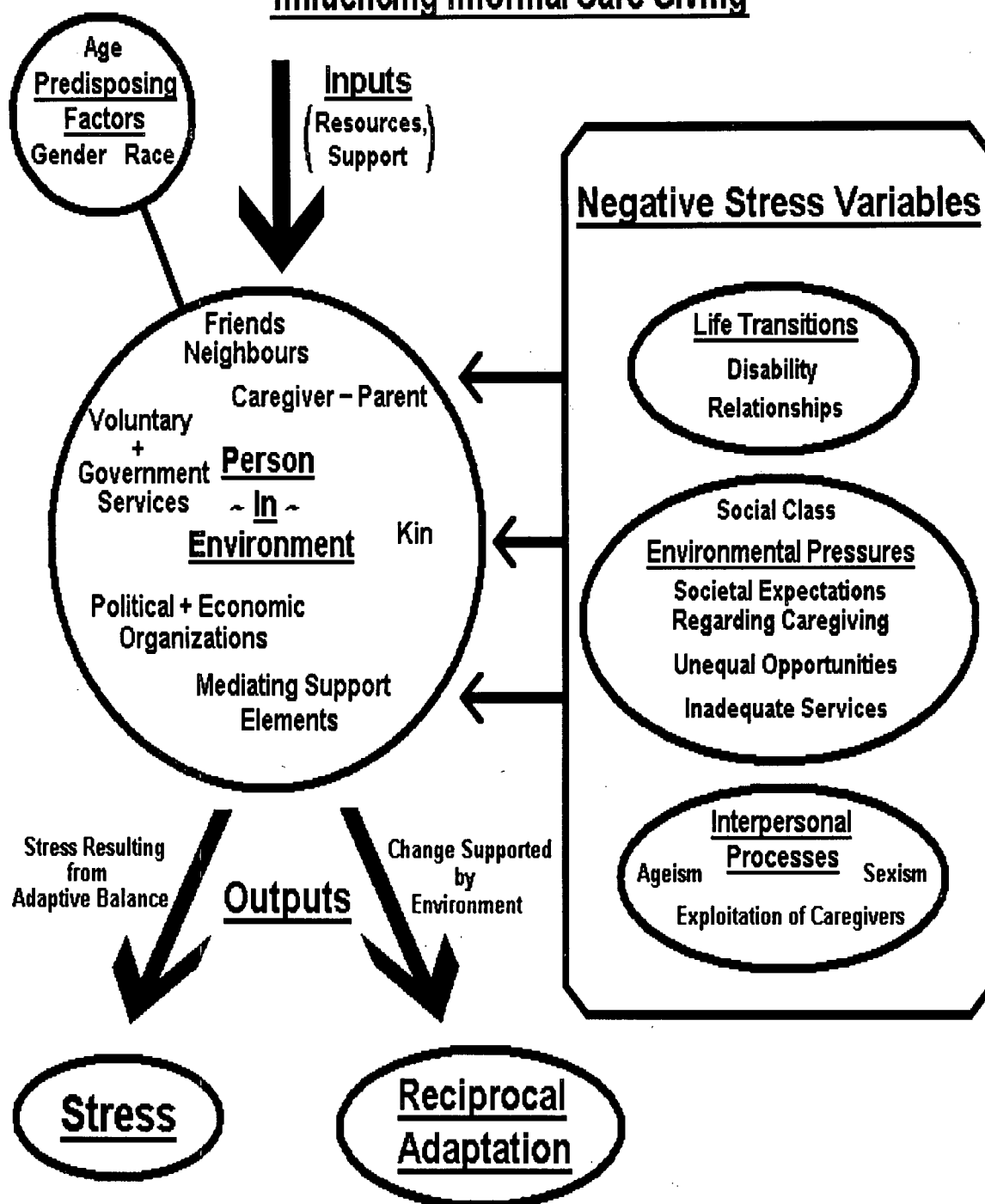
and its effects on women, its deterministic orientation to social control does not provide a framework for explaining the diversity in the experience of caregiving (Baines & Evans, 1992). It fails to consider how class, race, and ethnicity intersect with patriarchy to influence the caregiving experience (Abramovitz in Baines, Evans, & Neysmith, 1991).

Collins (in Nelson-Gardell, 1995) argues that there are many similarities to these perspectives in that both view the individual and their situation as connected to and inseparable from their context. The ecological perspective emphasizes the person in the context of the environment, while the feminist perspective views the personal as political.

Figure 1 provides a diagram proposing a model of caregiving, using a combined feminist and systems-ecological perspective. This model envisions the caregiver and the care recipient in the center of a circle that contains different kinds of support, such as kin, friends, and informal and formal support. This model shows that people are in a constant process of interchange and adaptation with their environment. Stress resulting from variables such as life transition (disability), environmental pressures (values regarding the aged and women), and interpersonal processes (poor communication styles and the exploitation of women) can upset the adaptive balance unless there is a supply of appropriate inputs (resources such as social support).

Figure 1

# Integrated Model of Factors Influencing Informal Care Giving



### **Theories about Service Utilization**

The utilization of community services is influenced by many factors. The Anderson medical use model, which was designed to predict physician utilization (Andersen & Newman, 1973), has been used extensively to explain service utilization by the elderly (Levesque, 2000; O'Conner, 1995). This model proposes that the use of services is determined by three categories of factors: predisposing factors (age, gender); enabling factors which facilitate or impede use and, finally; need factors (health problems) (Levesque, 2000). More recently, Bass and Noelker (1987) expanded on Anderson's & Newman's (1973) conceptual model to include caregiver characteristics in the predisposing and enabling factors. Furthermore, they divided the need factors to include both the caregiver's needs and those of the care-recipient. This theory provides a framework for understanding formal service utilization and caregivers' experiences with the services.

Denton (1997) describes several theories that have been proposed to explain the link between informal and formal care:

- The substitution model of care suggests that there is a commensurate and parallel decrease in informal care as formal services are provided.
- A compensatory model of social support suggests that patterns of assistance involve a hierarchical process determined by individual's preferences. According to this model, most elderly prefer to receive assistance from a spouse, a child, or neighbors and friends in the absence of family. In this model, formal care would only be utilized when the preferred informal source is not available.
- A third model which has been proposed to explain service use is a supplementary model of care, which suggests that formal care is supplementary to the care provided by

informal helpers, particularly when the resources of the informal network no longer meet the needs of the older person.

- A fourth model of service use suggests that formal care has compensatory and supplementary functions. According to this model, formal care is accessed only when health deteriorates to the point that the informal care system is no longer able to provide the assistance required.
- A fifth model proposed by researchers in the field of gerontology is the task specificity model. This model proposes that informal and formal service providers are best able to provide assistance with the tasks that match their structure.

Research conducted on these various models suggests that there are recognized limits to the amount of care that families are willing and able to provide and, for most families, there comes a point at which families are willing to call in the formal care system (Chappell & Blandford, 1991). A review of these models was necessary to understand the theories that have been used to understand informal and formal caregiving partnerships and the development of community care policies, programs and services.

### **Attitude Theory and Service Utilization**

Other theories of service utilization look at attitudes as important factors in understanding service use. An attitude can be described as a “belief or opinion that has an evaluative component – a belief that something is good or bad, likeable or unlikable, moral or immoral, attractive or repulsive” (Gray, 1994, p. 514). Gray contends that attitudes arise from one’s experience in the social environment and serve a guiding function for the individual’s behavior in that environment. When attitudes in relation to service use are examined, one can follow the example set by Pedlar and Biegel (1999) and define attitudes as “favorable or unfavorable feelings towards use of community services among family caregivers” (p. 2). Using this

example, service perceptions are defined by how a family perceives the service, i.e. convenient or inconvenient, adequate or inadequate. Attitudes towards services will be examined as part of caregivers' experiences with formal services.

A further theory, which can build on theories of service use and attitude change, is cognitive dissonance theory. This theory proposes that an awareness of contradiction or disharmony among elements of one's mind propels people in the direction of attitude change (Gray, 1994; Weiten, 1995). Through the uncomfortable state that results from dissonance, people are motivated to change their attitudes. Although there are many theories that exist to explain the mechanisms that contribute to attitude formation and change, cognitive dissonance theory allows me to look at how caregivers' attitudes towards services may be changed as a result of positive and negative caregiving experiences.

## **Literature Review**

### **Aging and Demographic Change**

The 1996 Canadian census showed that 12% of Canada's population of 30 million was over the age of 65 (Martin-Matthews, 1999). The percentage of seniors has doubled in the past 50 years, and by 2031, those over 65 will comprise one-quarter of the Canadian population (Gottlieb, 1998). The elderly, those 65 and older, are now the fastest growing population segment in Canada. This trend, which essentially reflects the aging of the baby boomers, is due to declining birth rates as well as increases to life expectancy.

Some authors argue that increased life expectancies will result in an increase in years of disability and dependence (Shah, 1990), while others contend that this is not necessarily so (Manton, Corder & Stallard in Cohen, 1994). Regardless of the argument about increased disability and dependency rates, demographic changes and an emphasis on community care means that there will be greater numbers of older people receiving care in the community.

Currently, 7% of the Canadian elderly population (now almost 3.8 million Canadians) require institutional care and over 10% require some form of home care (Chisholm, 2000). There are 2 million Canadians caring for elderly relatives at home (Chisholm, 2000; Frederick & Fast, 1999). Of the elderly population, a large number experience some form of cognitive impairment, including dementia. Typically, the kind of informal help provided by family members to the elderly to maintain or enhance their independence involves assistance with instrumental activities of daily living (IADL) and activities of daily living (ADL) (Cranswick, 1997; Lechner & Neal, 1999).

Furthermore, it is estimated that 80 to 90% of assistance to the frail elderly is provided by informal caregivers, with the greatest share of this support coming from spouses and adult children, predominately daughters (Denton, 1997). Hooyman (1992) argues that since women comprise more than 80% of family caregivers, the term "family care" is a misnomer for "female care". These figures and a number of studies of family caregiving challenge the misperception that families abandon their elders to institutional care (Brewer, 2001). These figures also highlight the importance of a gender analysis to the study of caregivers and care-recipients with dementia and other cognitive impairments.

### **Overview of Dementia**

Dementia, a clinical syndrome characterized by severe losses of cognitive and emotional abilities, is a condition that primarily affects older people (Monahan, 1993) and is the predominant cause of mental disability. Dementia does not refer to one disease but includes a variety of disorders whose hallmark is progressive mental deterioration, often referred to as "cognitive impairment". Those with cognitive impairments can lose their ability to communicate or perform even simple personal tasks such as dressing or bathing. By far the majority of those

who develop dementia will have Alzheimer's disease, which is progressive and irreversible and becomes increasingly common with aging (Herrman, 1991).

### **Prevalence of Dementia**

The 1991 Canadian Study of Health and Aging (CSHA), found that 8% of Canadians over 64 experience symptoms of dementia - including 2.4% of seniors aged 65-74, 11% of those aged 75-84 and 35% of those over 84 (Canadian Study on Health and Aging Working Group [CSHA], 1994). It is estimated that by 2031, the number of Canadians diagnosed with Alzheimer's disease will triple to 750,000 (Wickens, 2000). Women disproportionately experience dementia; in 1991, 68% of those over 64 with dementia were women (Canadian Study of Health and Aging, 1994). Based on current projections, a female born in the last decade has a one in six chance of developing Alzheimer's disease if she lives to 80, the average life expectancy for women (Women More Affected, 1998).

### **Family Care of the Cognitively-Impaired Elderly**

Typically, the family is called upon very early on in the course of a dementing illness to perform the tasks that the person can no longer manage (McCabe, Sand, Yeaworth, & Nieveen, 1995). In caring for someone with Alzheimer's, families may initially find themselves dealing with the following challenging behaviors: wandering, restlessness, repeated actions, suspicion, inappropriate sexual behavior, and aggression (Alzheimer Society of Canada, 2002).

Wandering often results in the person walking away from home and getting lost. As many people affected by Alzheimer's disease continue to have tremendous endurance and physical strength, they can walk for hours. Restlessness often results in the person pacing for hours. Repeating actions may result in the person repeating requests, words, and actions, over and over again. Suspicious behavior can result in the person believing that someone has stolen something or is attempting to hurt them. Inappropriate sexual behavior may result in the person undressing

and exposing himself or herself, or in making sexual advances towards others. Aggressive behavior typically results in verbal and physical outbursts towards someone in the environment.

In the late stages of Alzheimer's disease, an individual may experience a number of progressive losses (Bonnell, 1996). These typically are the loss of ability to: ambulate independently, engage in meaningful communication, and recognize caregivers. At this point they may even progress to a vegetative state. Due to the unpredictability of the course of the disease causing dementia, caregiving can have a profound and far reaching effect on both caregivers and their families. For example, Alzheimer's disease can last between 2 and 20 years (Ganzer & England, 1994).

Approximately 80% of seniors with dementia are living in communities as opposed to institutions (Clarke & Watson in Bar-David, 1999). In most cases, the critical variable that determines placement vs. community care of the elderly is not the degree of functional impairment, but access to family care (Arendell & Estes in Brewer, 2001). This fact is underscored by statistics which show that 50 percent of the elderly with long term needs who lack family support are living in some kind of nursing home compared to 7 percent of those with family caregivers (Stone, 2000). Thus, while this trend towards community care has many benefits for the elderly, the ultimate result is that much of the responsibility for care falls on family members, mainly women. Although there are many factors that determine which family members will be responsible for the provision of informal care to their frail elderly, a study of professional women engaged in the provision of care management services to homebound elders found that gender role assumptions may be the greatest influencing factor regarding care of elderly parents (Brewer, 2001).

Geographic proximity of the care recipient to the caregiver also affects caregiving arrangements. Where family members at one time may have lived in close proximity, a trend

towards increased geographical mobility has resulted in family members living further apart from one another. Thus, with the exception of parents who co-habit with their children, a distance barrier inevitably must be overcome to provide informal eldercare (Litwak & Kulis in Hallman, 1999). In a study of male & female caregivers, Hallman (1999) found that not only did women demonstrate a greater engagement with caregiving but they also showed a greater commitment to the traveling required to do so if the parent lived apart from the caregiver. Furthermore, the women in this study were more likely than their male counterparts to urge or facilitate residential relocation of their parent as a means of renegotiating eldercare responsibilities. While women tend to be more proactive in manipulating their eldercare time-space context in order to meet other work and family obligations, their greater engagement in eldercare provision comes at a cost to woman. The author suggests that men may find it easier to find a balance between paid work and family responsibilities by “drawing a line in the sand” (p. 401) when it comes to meeting the additional demands of eldercare, including travel, on already limited personal and family time.

Providing care to a dependent family member, especially one with a cognitive-impairment is a challenging activity. Although caregivers of people with mild to moderate dementia expend an average of 3.2 hours of care per day (Health Canada, 1998), 1 in 10 caregivers provide care around the clock (Atchley in Brewer, 2001). Furthermore, the amount of time devoted to caring for someone with dementia differs along gender lines. One study showed that the number of hours per week devoted to care of the elderly is highest among daughters (7 hours) and daughters-in-law (5 hours), followed by sons (4.5 hours), and sons-in-law (3 hours) (Women More Affected, 1998).

Caregiving, in general, can have long-term effects on many aspects of a caregiver's life. Several studies have focused on caregiving outcomes, such as the significant impact that caring

for a family member with dementia has on the physical, social, and psychological wellbeing of the caregiver (Gottlieb, 1998; Low, Payne, & Roderisk, 1999; Monahan & Hooker, 1997).

Research has shown that caring for a partner with a cognitive impairment, such as Alzheimer's disease, results in isolation, which impacts on the help/service-seeking behaviors among caregivers (Tebb & Jivanjee, 2000).

Furthermore, caregiving may have an impact on marriage/relationship issues, especially if one or both spouses may feel neglected or unfairly burdened by the caregiving responsibilities (Ward & Spitze, 1998). Of those Canadians providing care to people with long-term health problems in 1996, 45% reported that caregiving responsibilities impacted negatively on their social activities and 21% reported that their health was adversely affected (Health Canada, 1999). A Health Canada survey clearly demonstrates the association between caregiving demands for someone with dementia and levels of depression; in this survey, the prevalence of depression rises from 16% for caregivers of persons with mild dementia to 40% for caregivers of persons with severe forms of dementia (Northcott & Millikin, 1998).

While it is recognized that there are many individual and situational factors that determine the caregiving experience, studies have shown that disease characteristics of the care recipient can exacerbate the burden of caring for them. Specifically, the stress of caring for someone with Alzheimer's disease, dementia, and Parkinson's disease is typically worse than the stress of caring for someone with other afflictions, such as cancer, and stress levels of the caregiver typically increase with the patient's deterioration (Grunfeld & Glossop, 1997; Hughes, Giobbie-Hurder, Weaver, Kubal & Henderson, 1999).

Some research focuses on self-care strategies that may mitigate the burden of caregiving (Connell & Grant, 1999). Other research has focused on the role that personality and social support plays in the health outcomes of those caring for someone with dementia (Monahan &

Hooker, 1995). However, these studies provide limited understanding of the contextual experience of caring for a parent with a cognitive-impairment, such as dementia. Moreover, few have examined the context and its influence on decisions about caregiving and formal service utilization.

Studies also show that wives and daughters exhibit greater burden than husbands and sons, and younger caregivers, both wives and daughters, exhibit greater burden than older caregivers (Hughes, Giobbie-Hurder, Weaver, Kubal, & Henderson, 1999). Qualitative studies have focused on the experiences of spousal caregivers of people with Alzheimer's disease (O'Conner, 1995; O'Connor, 1999; Perry & O'Connor, 2002). However, there is a need for additional qualitative research to examine the experience of adult children providing care. While it is recognized that community care of the elderly is the mode of care most desired by family members and care-recipients, it is also the mode of care that tends to be disproportionately shouldered by women (Opie, 1992).

### **Impact of Caregiving on Women**

While women have always provided the majority of the caregiving in families, their increased participation in the labor force intersects with the demands of informal care to add considerable strain to their lives. In 1941, only 4.5% of all married women were in the labor force; by 1992, that number had risen to 61.4 percent (Gottlieb, 1998). The burden on women, therefore, is tremendous; not only are they expected to be the primary caregivers for their children and the homemakers in the household, but they are also expected to provide unpaid care to assist relatives to remain independent and at home as long as possible, thereby saving government health care dollars.

It is little wonder, then, that so many women report high levels of conflict between their paid and unpaid work as a result of their caregiving responsibilities. In a 1994 national survey of

Canadian adults, more than 25% of employed women felt that they did not have a good balance between their jobs and their caregiving responsibilities (Angus Reid Group in Gottlieb, 1998). As many as 20% of the women surveyed said that their caregiving responsibilities limited their career advancement opportunities.

Caregiving not only limits one's options for financial security and career opportunities, but it also impacts other aspects of one's work experience. Over half of Canadians caring for someone with a long-term health problem reported problems at work as a result of their caregiving responsibilities (Health Canada, 1999). The tensions of caregiving on top of paid work results in job dissatisfaction, absenteeism, and work interruptions. Another survey found that 9%-28% of caregivers for elderly relatives retired early, quit work, or took an extended leave of absence, in order to fulfill their caregiving responsibilities (Scharlach, Lowe, & Schneider in Gottlieb, 1998).

In addition to the impact that caregiving has on one's education and employment plans, caregivers also forego employer-sponsored benefits and contributories to the Canada Pension Plan, training opportunities, and experience in one's field and promotions (Morris, Robinson & Simpson, 1999). These losses are exacerbated, of course, for women who find themselves divorced or widowed at retirement, especially if they had assumed that their spouse's retirement income would provide adequate financial support.

### **Health Care Reform and Home Care Policy Context**

In British Columbia the formal system of home care is provided under the continuing care arm of the provincial health care system (Northcott & Milliken, 1998). Services provided under the province's continuing care system are separate and distinct from hospital and medical services because they fall under the extended health care services portion of the Canada Health Act (Institute of Health Economics, 2000). These services are not insured under Medicare and

guaranteed standards of portability, accessibility, and universality do not apply. Moreover, user fees can be charged. Programs and services are, therefore, unique to the communities and regions in which they are provided and are generally provided under a system of means testing.

Although the Canadian health care system was originally only concerned with the provision of medical and hospital-based services, it became apparent in the 1970's that dependence on the extended family for social support was no longer a viable policy option (Crichton, Hsu, & Tsang, 1990). Demographic trends increasingly began to influence the availability of informal caregivers. Concurrent with these demographic trends came a heightened awareness of health care expenditures generally, and acute care utilization, specifically (Northcott & Milliken, 1998). These events resulted in the reformation of health care services, placing greater emphasis on community initiatives and means-tested services, such as home care, to enhance the universally insured health services (Northcott & Milliken, 1998). In British Columbia "home care" refers to services provided in the home and community to assist individuals with functional disabilities and their families (Health Canada, 2001). Locally, these services range from home support, such as a few hours of meal preparation and assistance with bathing, to home care nursing and rehabilitation. Eligibility for services is based on provincial long-term care criteria. To date, funding for community services is minimal and is concentrated in larger centers, thereby reducing accessibility for those in rural areas.

### **Service Utilization**

As the burden of providing care to frail elderly persons increases, family caregivers may seek professional assistance from community service providers. Typically, the experience of caring for cognitively impaired elderly members results in a progression from using no formal services to a situation where care is provided entirely by formal service providers (Canadian Study of Health and Aging, 1994). A number of theoretical perspectives on service utilization

exist in the gerontology literature. Selected models were discussed earlier in this chapter.

Certainly, evidence shows that a comprehensive system of formal care services can mitigate the burden for families caring for dependent family members (Coxe, 1992). Formal care services typically include respite, adult day programs, and home health care services. Although the value of formal care services is recognized, recent pressures in health care expenditures across Canada have resulted in reductions to programs that support community care of the elderly (Hollander & Tessaro, 2001). Currently, home care supports are reported to fall critically short of meeting the emotional, physical, financial, and social needs of caregivers, and especially the women who perform a disproportionate share of both the paid and the unpaid caring labor (Morris, Robinson, & Simpson, 1999).

However, even if community support systems across Canada were adequately funded, simply providing services does not guarantee families will use the services available to them (O'Connor, 1995). Despite the stress and strain, research indicates that home care services are underutilized by those with cognitive impairments and the family members who care for them (O'Connor, 1999; O'Connor, 1995; Pedlar & Biegel, 1999; Penning, 1995). Furthermore, some caregivers are so reluctant to use formal supports that, by the time they do seek assistance, their personal resources are taxed beyond the ability of formal services to help (O'Connor, 1999). While it has been suggested that older people may be more receptive to formal care when they perceive themselves to be a burden to their children (Wielink, 1999), it may be that a cognitively-impaired person lacks the ability to rationally analyze their own caregiving situation. Thus, attitudes towards service utilization may be influenced by the nature of the cognitive-impairment itself. Research to date only provides a limited understanding of the complex set of interacting personal and environmental factors that predict or explain the use of formal support services (Wielink, 1999).

Recent research has focused on the experience of living with a memory-impaired spouse and the use of formal support services (O'Connor, 1999). In this research, the author shows that spousal caregivers jeopardize their own health while they attempt to meet their caregiving demands. However, while it is recognized that the provision of formal support services can make a positive contribution to alleviating the burden of caregiving, spousal caregivers have been identified as particularly reluctant to use formal services. While O'Connor's (1995, 1999) studies are helpful in understanding the meanings associated with service use among spousal caregivers, we may be limited in our ability to extrapolate this knowledge to our understanding of the meaning of service use among adult children providing care in an environment complicated by health reform and the competing demands of work and family. Since children provide the majority of informal care to parents in the absence of a spouse, additional research is needed to determine their perceptions of the caregiving experience. Supporting adult children in their caregiving activities is critical to both maintaining the independence of the frail elderly and to maintaining a sustainable community care system.

It is also recognized that adult children must juggle competing interests and commitments, such as work and attention to other family members (Gottlieb, 1998). This reality provides justification for a study which goes beyond simply exploring the instrumental, invisible tasks of caregiving to one which explores the role that relationship, family history, personal character, values and attitudes play in influencing decisions regarding the use of formal services. Research that is focused exclusively on either the chores that caregivers perform or the stresses they experience restricts our understanding of the experience of care and consequently narrows policy concerns (Abel, 1994).

In a study of family members caring for someone with a chronic mental illness, Jeon and Madjar (1998) identified two interrelated existential themes, temporality and relationality, that

described family caregiving. Although this study provides excellent insights and increased understanding of caregiving practices in a family context, the research question itself did not address the caregiver's experiences with the formal support systems. Nevertheless, it provides an excellent methodological framework that will be useful for data collection and analysis.

### **Justification for Study**

Most of the research to date on caregiving to the elderly has been based on quantitative studies of the relationship between caregiving and burden, or particular variables, which lead to greater caregiver vulnerability. Little is known about the experience which leads up to the caregiver's decision to access formal supports. This gap in knowledge is a justification for a study, which explores the contextual factors which influence the caregiver's decision to access formal supports to modify the nature of their involvement in caregiving.

Other literature has highlighted demographic trends and health care reforms that have influenced the restructuring of the health care system, relegating greater caregiving responsibility onto families. This literature has failed to provide the depth and detail of the actual experience of caregiving. Furthermore, despite debate at the regional and provincial level about the feasibility of expansion to home care services, there is little scholarly publication about caregivers' experiences with British Columbia's home care practice. This situation highlights the need for research that explores the experience of caregiving to the frail elderly in order to understand the impact of community care policies and services on those who provide informal care. Caregivers are rarely consulted for their perspectives of community care policies and programs, yet there is growing recognition that any future assessing and planning of community care should take their perspectives into consideration (Geron, 1998).

Gwyther (in Opie, 1992) has suggested that formal support services are not beneficial to caregivers unless they meet the following standards: high quality, flexible, appropriate,

convenient, available, family-centered and accessible. Presently, there is a lack of qualitative research from a feminist perspective on caregiver's evaluations of their contact with a range of service personnel within the public community health care system.

### **Research Question**

The primary purpose of this qualitative study was to develop a better understanding of the experience of caregiving and the use of community supports from the perspectives of adult children caring for their frail, elderly, cognitively impaired parents in the community. The main question that guided the research was:

***What are the caregiving experiences, including the use of community supports, of adult children who care for a parent with a cognitive impairment?***

## **Chapter Three**

### **METHODOLOGY**

#### **Qualitative Research**

This study employed a qualitative research design to explore the experiences of family caregivers. Qualitative research is consistent with the main purpose of this research in that it is exploratory and descriptive and intended to furnish a deeper understanding of the lived experiences of persons who share time, space and culture (Frankel & Devers, 2000).

The design of this qualitative study was drawn from the theoretical perspectives of feminism and postmodern feminism. These perspectives were selected as the most effective means by which to achieve the aim of the study. The following section will discuss how these particular theoretical perspectives informed the research process.

#### **Feminist Research**

Many feminist social scientists argue that the positivistic approach to research "reflects the creation of male-stream thought, inasmuch as women have been excluded from the creation of those activities purported to generate knowledge" (Bungay & Keddy, 1996, p. 2). In an attempt to discover an approach that would best explore the social and political forces that shape the experiences of women, a feminist methodology has emerged. Ultimately, the goal of feminist research is to improve the lives of women, and other oppressed groups, by developing knowledge that can contribute to the elimination of oppression (Neysmith, 1995). This approach, which directs us to look at "the political significance of the personal experience" (Bungay & Keddy, 1996, p. 2), is well suited to my research question which attempts to understand the influence of formal community policies and services on the experiences of family caregivers.

There are several general principles that guide feminist research. Feminist research should be for women, not on women (Wuest, 1995). According to Opie (1992), when we focus only on women carers, we essentially reinforce their visibility in the role and reinforce the very structure feminist research seeks to critique. Instead, the assumed transparency of male caregivers requires scrutiny. This perspective influenced my decision to explore the experiences of both genders caring for adult parents, rather than focus specifically on adult daughters.

Furthermore, the information should be useful to the participants (Wuest, 1995) and should provide women with the information they need (and want) to change oppressive and exploitative conditions in their lives (Bungay & Keddy, 1996; Wuest, 1995). My hope was that by participating in this study, participants would become more aware of the social and political impact of community care policies on their lives. The interview framework was designed to identify gaps in service or barriers to accessing existing services. Through participation, caregivers may actually have enhanced their knowledge of existing services.

In a similar vein, feminist research aims to transform knowledge rather than to simply accommodate women (Neysmith, 1995). The purpose of this research was to incorporate knowledge about the complexities of caregiving to the frail elderly into improved models of service delivery. Currently, community care policies are designed on the assumption that in the absence of spouses, adult children are willing and available to provide the majority of the care needs to frail elderly. Furthermore, it was my perception that there was an underlying assumption in community care policy that caregivers would know what services are available and how to access them. This research aimed to transform prevailing knowledge of what adequate, appropriate, accessible, and acceptable service entailed.

Feminist research methods concern themselves with the notion of reflexivity (Bungay & Keddy, 1996; Wuest, 1995). A reflexive process allows for the recognition of the researcher's

influence in the process (Maxwell, 1996; Neysmith, 1995) and a critical reflection on the progress, the analysis, and the intellectual traditions of the study (Wuest, 1995). This principle recognizes that controlling researcher bias is an illusion; instead, the researcher is seen as an active presence that will ultimately affect the process and construction of findings. This principle required that I acknowledge in detail the purpose of the research, the assumptions underlying it, my experience in the area, and my biases. Following this guiding principle, I had a responsibility to create an atmosphere that was interactive, non-hierarchical and allowed for the mutual participation of myself as the researcher and the participants (Bungay & Keddy, 1996).

Another principle that guided the research was that individual experience must be placed within a social context (Neysmith, 1995). This principle was used to formulate the interview questions to ensure that the data collected would be useful in understanding the social location of caregivers. Furthermore, this principle recognizes that the social location of individuals influences the language, concepts, and comparison points available to them to describe their experience. For example, although women are experts on their experience, their way of knowing has largely been ignored in favor of male-dominated discourses (Bungay & Keddy, 1996). Thus, feminist research guided me to collect data that illuminates the oppressive nature of social structures and ideologies and validates women's experience.

### **Postmodern Feminism**

In addition to a socialist feminist perspective, which has been outlined in the conceptual framework in Chapter 2, postmodern feminism was used to assist me in designing the study and in the analysis of the data. Postmodern feminism concerns itself with assumptions that argue for one single truth (Wuest, 1995). As such, postmodernism questions and analyzes accepted constructions of basic concepts of power, knowledge, truth, and gender, and recognizes that experiences vary according to many characteristics, such as race, location, gender, and class

(Wuest, 1995). The contextual nature of a qualitative study from a postmodern feminist perspective, allowed me to recognize that the experience of caregiving is embedded in particular relationships, and social and political circumstances (Opie, 1992). Where the caregivers are situated within this context influences how they understand their freedom to make meaningful choices to assist them in caring for their frail, elderly parents. Furthermore, a postmodern perspective to research, which argues against single truths (Wuest, 1995), helped me to recognize and make explicit the limitations to my own and any other research, and acknowledge that the research would only capture partial realities or understandings (Cheek, 2000).

In summary, the theoretical foundation of the qualitative study was largely guided by Neysmith's (1995) description of feminist research and Wuest's (1995) description of postmodern feminism.

### **Sampling**

Two sampling methods were used to select participants for the study. A notice (Appendix III) was posted at the office of the Alzheimer's Society and at seniors' centers and care homes. This method resulted in a poor response as no caregivers came forward offering to participate. The second method used to select participants was a purposeful sampling technique, applying a snowball approach. Using this method, caregivers who fulfilled the criteria were located through the researcher's personal contacts by the distribution of a recruitment letter inviting caregiver participation (Appendix IV). Through a snowball process, these participants assisted in finding others who also fit the criteria. Purposeful sampling is valuable in qualitative research because it allows the researcher to use her own judgment in selecting a sample that will yield considerable data (Grinnell, 1997) and ensure information richness (Wackerbath, 1999). Therefore, although the caregivers chosen would not necessarily be representative of all caregivers, their perspective may provide insight into the needs of family caregivers and barriers

or gaps in community supports. As such, the non-randomized sample is not considered biased; rather, it is considered to be inclusive of experts experiencing the phenomenon being studied (O'Donnell, 2000).

Once caregivers identified themselves as interested in participating in the study, they were contacted by telephone. At that time, the purpose of the study and the methods that would be used to collect the data were discussed and a date, time and location for an interview was agreed upon.

The participants were selected from adult children, 19 years of age or older, providing informal caregiving to parents 65 or older, with cognitive-impairments. Delimiting the sample to caregivers of a "parent 65 or older" was done to ensure that issues concerning the elderly and, specifically, their caregivers were illuminated in the process. For the purposes of this study, "caregiving" meant providing some assistance with personal care (eg. bathing), instrumental activities (such as shopping or cleaning), or supervision (such as caring for someone with a cognitive-impairment). A criterion for participation was that the caregiver had, at some time, accessed or had some contact with some aspect of the formal community support system within the region to assist with caregiving. Caregivers known to me through my work as a clinical social worker at the local hospital were excluded.

This sampling method resulted in nine participants; three of these were from the same family. Seven of the nine participants were willing to become part of a focus group. The sample included seven females and two males, caring for a total of seven elderly women. All caregiving dyads and groups were middle class. Two of these were from rural centers. Three families were European immigrants.

I acknowledge that my social characteristics may have ultimately limited my ability to access a more diverse sample. Although I had additional calls from friends and acquaintances

offering to participate or provide me with names of potential participants, I was selective as to who was interviewed as I felt that data collected from white, middle class caregivers resulted in near data saturation with a sample size of nine.

### **Data Collection**

This study employed qualitative, feminist methods to data collection. Prior to beginning the interview I explained to the participants the purpose of the research and acknowledged my biases with respect to community supports for caregivers. As I had no personal experience caring for someone with dementia, my beliefs around caregiving had largely been influenced by my work as a hospital social worker. My experience there had left me feeling that community supports were paternalistic and inadequate.

Data was collected using a variety of methods. First of all, an in-depth semi-structured face-to-face interview was held with six participants. The same format was also used for a small family group interview. Semi-structured interviewing has become "the principal means by which feminist researchers have sought to achieve the active involvement of their respondents in the construction of data about their lives" (Bologh in Reinharz, 1992, p. 18). Unlike survey research, interview research typically includes opportunities for the participant to clarify and discuss concepts and themes.

An interview guide (Appendix V) containing seven open-ended questions was designed to elicit caregivers' experiences with caregiving and their attitudes about the utilization of formal care services. The interview questions were broad in nature and were intended to serve as a starting-point to more in-depth discussion of the caregiver's situation. Probing questions were used to encourage elaboration when more information or clarity was required. This process recognizes the emergent nature of qualitative research; such that, as the researcher becomes more familiar with the context at hand, questions emerge and change radically (Gillham, 2000, p.17).

The interviews were audio taped and later fully transcribed. The transcriptions were then returned to each participant to allow them to have control over what was used for research purposes. The participants were asked to review the transcript and provide clarification or feedback on points raised in the taped interview. Two participants provided feedback on their transcript in a second interview. Notes were taken of these feedback sessions.

Each initial interview lasted between 45 and 120 minutes. Of the six individual interviews, three were held in the caregivers' home, two were held in my home, and one was held in my office at the hospital. Three additional caregivers, from one caregiving group, requested a group interview in their home - a symbol of how they had cared and made decisions together. After the individual and group interviews were completed, and participants had reviewed their transcripts and provided feedback, a focus group was held as another means of data collection. Seven of the nine interviewees served as focus group participants.

#### **Rationale for use of a focus group**

A focus group approach to data collection is essentially a group interview that allows members to interact with others (Granito Jr., 2001). The participants' interactions and responses to a discussion topic in the focus group becomes the data source. The group dynamics enhance individual participation, thus enriching the data regarding perceptions and opinions (Carey, 1994). This method, which allows "participants to react, agree or disagree, build on and provide further insight into the comments made by other participants" (Granito Jr., 2001, p. 67) is congruent with feminist methods which emphasize "personal empowerment through consciousness raising" (Fonow & Cook, 1991 in Wuest, 1995).

In accordance with feminist research, a focus group was chosen as an appropriate method of data collection as a means to strengthen the findings. The purpose of the focus group was to present the themes that had emerged from the individual and group interviews and to allow

caregivers to express further their thoughts and perceptions about caregiving and the use of formal supports. Participation in a focus group interview can be empowering for individuals by contributing to their knowledge and skills. It may also help to normalize the experience of caregiving (Montell, 1999). In addition, through a process of questioning and explaining, focus groups can provide useful insight into complex issues involving many levels of feelings and experiences (Carey, 1994), including attitudes towards treatment options (Calderon, Baker & Wolf, 2000). As the goal of this study was to examine the experience of caregiving, including attitudes about formal service provision, this method of interviewing a group of individuals who share a common experience was justified.

Feminist researchers also consider the interviewee to be the “expert” on the topic or phenomenon studied. Focus groups give the “experts” an opportunity to interact and test their interpretations of events and processes with others (Montell, 1999). It thus made sense to interview caregivers in a group setting. As caregiving can be a very isolated and private activity, caregivers may find little acknowledgement for the knowledge, skills, and strengths they bring to the role. A focus group allows caregivers the opportunity to validate their experience. By sharing their personal experiences with others, knowledge is gained, competencies are enhanced, and oppressive conditions may be addressed in the process. Furthermore, complementing the individual interviews with a focus group allowed participants of culturally diverse backgrounds to share their different values and opinions about caregiving. Montell (1999) suggests that a feminist researcher would attempt to “bring together participants who are as diverse as possible in terms of categories relevant to the topic of the study” (p. 59).

### **The focus group process**

The focus group was conducted after the individual and group interviews were completed and transcripts had been returned to participants for feedback. Seven caregivers agreed to

participate in the focus group. The focus group took place in a quiet section of a local restaurant. Limitations for safeguarding and assuring privacy were acknowledged and accepted. As with the individual interviews, the entire discussion was audiotaped with the permission of the participants. The audiotape was subsequently transcribed verbatim.

Ground rules concerning the process were agreed upon amongst participants prior to the focus group discussion. The listing of categories and themes that had developed from the data obtained through the individual and group interviews was provided to each focus group participant upon arrival. The list of categories and themes acted as a springboard to further discussion of the experience of caregiving. As few of the participants were known to each other, this served as a useful way to break the ice and introduce concepts that had emerged from the data. Several participants commented that they could see themselves in every category and theme. Providing a summary of my preliminary analysis did not appear to deter participants from making additional comments that either contradicted or confirmed the themes and categories initially established.

Recognizing that focus groups promote a "multiplicity of voices speaking from a variety of subject positions" (Montell, 1999, p. 51), I was conscious of my role in anticipating their various needs and reflecting on how each participant would benefit from the process. I explained to the group at the beginning that I was interested in hearing as full a range of experiences and opinions as possible, and participants were encouraged to question, respond or disagree with each other. As the process went on, most participants became more comfortable testing their interpretation of events and challenging the comments of others. There were some topics, however, that were more sensitive than others to discuss. When the group was focused on these topics, I attempted to validate each caregiver's position on the topic and ask for further explanation on views so that the source of disagreement could be better understood or eliminated

altogether. Using this method, the group did not resolve all issues of disagreement, but came to some consensus on the topic. As Montell asserts, focus groups provide valuable insight into the social nature of knowledge and the extent to which participants share understandings within a culture. Although the individual experience is valued in focus group discussion, the primary goal is to generate a group point of view. With this in mind, I attempted to promote as much interaction between participants rather than between each focus group participant and myself.

### **Ethical Considerations**

The research project and its proposed methodology, interview questions and consent forms were approved by the University of British Columbia Behavioral Research Ethics Board (Appendix I). According to the expectations of the Ethics Board, certain safeguards were employed to protect the rights of the participants interviewed. First of all, potential participants were informed about the voluntary nature of their participation and the estimated time commitment. The interviews and focus group were scheduled at a time and place convenient to the participants. The research objectives and methods were described verbally and in writing so that they were clearly understood by each participant. Written consent (Appendix II) was obtained from each participant prior to collection of data. Since informed consent is a "static, past tense concept" (Munhall in Carlisle, 2000, p. 2), process consent was also used to renegotiate consent as the interview progressed. This practice recognizes that consent is an ongoing process (Munhall in Carlisle, 2000; Morse, 1998) and that the participant is free to withdraw from the interview at any time without recrimination. Participants were also asked for their permission to audiotape the interviews. Those caregivers who agreed to participate in the focus group interviews agreed to participate knowing that safeguards to protect their confidentiality and anonymity were limited. Caregivers participated knowing they could leave the focus group session if they wished.

To ensure the confidentiality of the information obtained, I personally transcribed the audiotapes. The transcripts and audiotapes were kept in a locked cabinet and computer files were password protected. The data will be retained in its original form for at least five years beyond the completion of the thesis. At that time, audiotapes will be erased, transcripts of the interviews will be shredded, and computer disks will be erased. Participants were notified that my faculty advisor and the principal investigator associated with the project would have access to the data. However, Morse (1998) argues that assurances that data obtained from the research interview will not be divulged is a problem in qualitative research because the transcribed interviews are typically retained in entirety except for the removal of names. Thus, participants were informed that segments of the interview text might be published as exemplars in the final document.

Confidentiality of the participant was further assured through the use of code numbers on transcribed documents and by using pseudonyms in published reports. However, I am aware that this may not be enough to protect the participant's anonymity. Morse (1998) argues that participants may be recognized by a number of identifiers, and when these identifiers are linked in paragraphs or presented as a description, the risk increases that the identity of the participant will be revealed. Furthermore, a researcher threatens the anonymity of the participant when all but the participants' name is disclosed and a pseudonym is consistently linked with all of the quoted material pertaining to that participant's interview throughout the document. To overcome these challenges, I have attempted to limit the number of times quotations are attributed to particular participants.

### **Data Analysis**

Ensuring rigor in qualitative research requires careful documentation of the conceptual development of the project (Morse, 1994) and evidence of adequacy of data collection. To

ensure that interested parties could reconstruct the process, an audit trail was maintained which documented my decisions, choices and insights. Field notes, interview transcriptions, data reduction and analysis products, visual products, diagrams, and reflective notes were kept in marked folders.

Adequacy of data collection can partly be measured by time allocated to analysis and amount of data collected. Approximately twelve hours of audio-taped interviews were collected during the seven interviews and one focus group. The researcher transcribed these tapes verbatim. Although transcribing the interviews verbatim was a time-consuming process, it allowed me to become more familiar with the data. Approximately sixty hours were required to transcribe interviews, summarize field notes and typed interviews, and categorize data.

The primary methods used to analyze the data were a categorizing strategy called thematic analysis (Cresswell, 1998; Kvale, 1996; Luborsky, 1994) and a feminist postmodern approach to text analysis (Kvale, 1996). Using these methods, I acknowledged that the interview statements were influenced by the interpersonal context, in which I was an active participant informing the dialogue that produced the texts to be interpreted. In the interview, participants were first of all encouraged to simply describe their experience, without interpretation. Next, participants were encouraged to interpret and find meaning in what they experienced and did as caregivers. Then I condensed and interpreted what the caregiver had described and reported this to the caregiver. This dialogue allowed for early feedback from the participant as to the meaning of the experience.

The next step used to analyze the data was a general review of data collected (field notes and interview transcriptions). In this stage the transcriptions of the interviews were read several times to gain a sense of the overall data and to obtain a full description of the experience of

caregivers and what the experience meant to those who lived it. In this stage, I made notes in the margins of the transcripts.

The second step used in the data analysis was a method to reduce the data. First of all, I summarized field notes and documented reflections. In this stage, I engaged in a critical reflection on the contents of the description. Individual narratives of family caring were then formulated for later comparison and more detailed analysis. Once familiar with the data, selective reading was undertaken, and significant statements, directly related to the phenomenon of family caregiving, were identified and highlighted. These were read and reread to formulate conceptual meanings and explore essential qualities of described experiences. Whole texts were compared with whole texts, as well as parts with wholes, allowing similarities, dissimilarities and relationships within the narratives to be explored. Through a process of continually shifting and comparing the data, writing and rewriting, interrelated themes and sub-themes were identified. The themes were presented to focus group participants for feedback.

As I moved along in my analysis, I used a hermeneutic approach to critically reading the texts so that attention was called to larger social, political, and economic issues (Kvale, 1996). In this stage I looked for elements that were not necessarily visible but could be uncovered in the description; for example, questioning power dynamics and social patterns not explicitly stated but implied. Although my analysis was influenced by a postmodern feminist framework, which provided not only conceptual and analytical direction but also methodological direction, I attempted to look for alternative explanations in the data that may have limited my ability to fully understand the phenomenon. This included an intense period of self-reflection to determine the impact of my cultural values, age, sex, socioeconomic status and other personal attributes on my analysis.

Essentially, data analysis involved an inductive process whereby themes and categories were established. The key feature in this method of analysis is that the coding is “grounded in the data” (Maxwell, 1996, p. 79) and that important contextual data remains linked to the code. Subsequent to this, the qualitative analysis involved a deductive process whereby themes generated in the inductive analysis were tested by examining deviate cases or data that did not fit the categories developed. Furthermore, the themes were compared to existing literature on caregiving, resulting in the generation of theoretical propositions.

The coding and categorizing of the focus group data and the individual and group interviews was similar. However, the focus group data was further aided by Henderson’s (1995) approach to analyzing focus group data. This approach focuses on: tone of discussion; points made by “thought leaders”; dissenting statements; freewheeling discussions; and participants’ reactions (p. 467). As the focus group followed the individual and family interview, the data was analyzed separately, with both sets of data eventually integrated together. For the most part, the focus group confirmed the thematic categories and the conceptual meanings and relationships that had emerged from individual and group interviews. However, in some instances, the focus group provided clarification and more detail on issues, which resulted in additional sub-themes and some regrouping of the data.

A feminist postmodern perspective to data analysis also guided me to consider the data as text, “cultural reproductions open to multiple readings and interpretations” (Opie, 1992). This perspective was helpful in allowing me to recognize that qualitative research is an art that does depend on reliable outcomes (Sandelowski, 1993). Indeed, no two researchers will produce the same result as they both come to their research with different sets of perspectives & philosophies. A postmodern feminist perspective recognizes that the analysis is not intended to be a final interpretation; rather, the interpretation “is endorsed by the participants, confirmed by

readers, and cognitively satisfies the researcher” (Reinharz in Bungay & Keddy, 1996, p. 447).

The most important goal of the research is to keep the dialogue going.

### **Validity**

Establishing rigor is an important issue in qualitative research design. Lather (in Webb, 1993) argues that feminist and post-modern approaches to research focus on rigor as well as relevance. Rather than focusing on validity, feminist researchers concern themselves with the degree to which the research is worthwhile and adequate (Webb, 1993). Worthwhileness concerns itself with the degree to which the emancipatory goal of the research is achieved. Adequacy is evaluated using the following criteria: 1) the participants’ voices are heard in the research reports; 2) the role of the researcher and that of the participants is theorized; and 3) the analysis must reveal the social relations in the lives of those studied.

Clearly, feedback from participants suggests that the process was empowering and relevant. Caregivers were pleased at the opportunity to both tell their stories and reflect upon them. These stories are included in the Findings section of this report. Along with these stories I have attempted to provide a structural analysis of social relations that impacted the caregivers’ experiences.

One caregiver commented that the interview had provided her with a process and an opportunity to explore the context and the meaning of her caregiving experience, including her relationship with her mother: “having the interview opened my eyes to a lot of things in my mother’s and my relationship”. The interview had given her an opportunity to reflect on this and resolve some of the guilt that she had about what she could no longer do for her mother. Other caregivers indicated that they intended to provide their children with a copy of their transcript in the hopes that reading it would give them a better understanding of the dynamics and complexity of their parents’ caregiving relationship with their grandmothers. Other

participants were appreciative of the opportunity to gain knowledge that may help them to interact more effectively with formal community supports. Others expressed their appreciation of being included in the focus group process as it had given them the opportunity to talk and share with others in a way that allowed them to deal more effectively with a challenging situation. More importantly perhaps, these discussions helped them link what they previously perceived to be a personal issue with larger structural issues. Furthermore, the research raises important issues that could potentially contribute to improvements in current practice and the existing literature on caregiving. These will be discussed later in this section.

Adequacy of research and establishing rigor also involves addressing the issue of reflexivity (Webb, 1993), which refers to my ability to consider how my values, characteristics and motivations affected the theoretical framework, literature review, design, data collection, sampling, and interpretation. References have been made throughout the Methodology section to ways in which the data was described, interpreted, and used for theory proposition to ensure rigor.

Credibility of feminist research is determined “by assessing whether participants’ experiences have been faithfully represented” (Webb, 1993, p. 421). To ensure that the caregivers’ experiences were adequately reflected in the report, I have indicated areas where consensus and divergence occurred. Negative cases and alternative explanations are discussed in the findings to give strength and credibility to the themes. Furthermore, to seek validation of the conceptual meanings developed and to ensure that the voices of the participants had been captured adequately, a second interview was offered to each participant to review the transcribed interviews and the significant themes that had emerged. Only two caregivers chose to participate in a second interview. The repeat interview, known as member checking (Cresswell, 1998), invited the caregiver to participate in the interpretation of the data. This step had the added

potential benefit to the caregiver of reducing oppression through the fostering of critical reflection and growth (Wuest, 1995).

Participant validation was sought again during the focus group discussion. The seven caregivers who agreed to become focus group participants were asked to review a summary of themes and subthemes that had emerged from the interviews. While the respondents were initially satisfied that the thematic analysis captured their experience, the focus group discussion which followed the review of the study findings resulted in participants requesting the addition of several sub-themes, which were later merged into a more general sub-theme.

Although member checking is a method proposed for establishing the credibility of the findings and ensuring that participants have access to interpretations made from the experiences, this method may also serve to undermine the trustworthiness of the project (Sandelowski, 1993). It is possible that the process of member checking may fail to acknowledge that the members and researchers are stakeholders in the research process, each concerned with staking claims or being a good person or subject. One participant confided in me several days after the focus group that she felt her attitudes towards facility placement of her mother were contrary to those of the other focus group participants. Her inclination to be a "good person", however, curtailed her ability to speak against other attitudes being expressed. Sandelowski (1993) suggests that "members are sometimes more interested in concrete descriptions of their own experiences than in abstract syntheses that incorporate them with other members' experiences" (p. 5).

Another problem with member checking occurred as a result of returning the transcripts to the participants. One participant was disappointed with the disjointed nature of her transcript and felt she had somehow failed the interview. That experience taught me to return the transcripts along with an explanation of the characteristics of verbatim transcription.

In addition to member checking, triangulation, which is the process of collecting additional sources of data to examine discrepant findings, was used to increase the study's credibility. Other sources of data used for this study were notes that I had collected from interviews with other caregivers and from observations of family caregiving in my work setting and in social settings with friends caring for their elderly parents.

Another method that was used to increase the credibility of the study, and to guard against researcher bias, was the peer review method described by Cresswell (1998). Since the beginning of my graduate program, I regularly met with a group of classmates to share resources and provide feedback to each other on projects and research ideas. Throughout the project I continued to use these classmates as peer supports and as external checks of the research process by requesting their critical review of the study's methods, meanings, and interpretations. Once the conceptual categories and themes had been developed, they were discussed with a few of my colleagues, some of whom had significant experience working with families of the cognitively-impaired. Furthermore, my research committee was invaluable in presenting questions that helped me to address issues that threatened the credibility of the research.

## Chapter 4

### FINDINGS

In this chapter, the study findings are organized into two main sections. The first section introduces the participants and provides a contextual landscape to these caregivers' experiences. The second section presents the findings of the interview analysis according to the five themes identified by the caregivers as the most pertinent. Included in this section I have provided my own interpretation of the meaning of these experiences. This discussion will be expanded upon in Chapter 5.

#### **The Participants**

Seven of the nine caregivers referred to the study were drawn from an urban center, while the remaining two lived in a rural area of a health region located in the interior of British Columbia, Canada. During the timeframe of this study, this health region was in the process of restructuring and making significant changes in both acute and community care policy.

Nine caregivers expressed an interest in participating in the research project and seven of these agreed to also be part of a focus group. All nine participants (i.e. 7 women and 2 men) were caring for their mothers or mothers-in-law. Three of them were from the same family. Of the caregivers, two were actively caring for their mothers at home, three were continuing to care for their mothers who were recently institutionalized, and one was caring for a parent in the community in a care-sharing arrangement with two brothers in distant communities. A group of three family caregivers had cared for their mother at home until she died two weeks before the interview. Although six of the caregivers had children of their own, the children were either living elsewhere with another parent or were grown-up and independent. Thus, none of the caregivers interviewed were managing a double dependency of parent and children. Seven of them lived in urban areas and two in rural areas. Participants' ages ranged from 45 to 60. Care

recipients' ages ranged from 71 to 90. Five of the care recipients had an Alzheimer's dementia and two had suffered strokes resulting in cognitive impairments. Caregivers came from a similar socioeconomic grouping.

The following table highlights some characteristics of the caregivers:

<b>Table 1. Characteristics of the Sample of Caregivers<sup>1</sup> and Care Recipients</b>			
Caregiver age group		Recipient age group	
<45 years old	0	65-75	1
45-59 years old	7	76-85	4
60+ years old	2	86+ years old	2
Caregiver gender		Relationship of recipient to caregiver	
Male	2	Son	2
Female	7	Daughter	5
		Daughter-in-law	2
Race/ethnicity of caregiving dyad		Recipient's relationship to caregiver <sup>2</sup>	
White	7	Mother	6
Others	0	Mother-in-law	2
Length of caregiving		Cognitive-impairment of care-recipient related to diagnosis of:	
1 year or less	0	Alzheimer's disease	5
2-5 years	3	Stroke	2
6-10 years	2		
>10 years	2		

<sup>1</sup> Three of the caregivers in the study were from one caregiving family. Therefore, although there are nine caregivers, there are only 7 care-recipients.

<sup>2</sup> One care recipient had both a mother and a mother-in-law status.

### **Profiles of the Participants**

In this section, I provide a brief profile of each participant. They are described in the order in which the interviews took place. Some of the details pertaining to the participants have been deliberately changed to protect their anonymity.

## SAM

Sam is a 49-year old married caregiver who lives in a rural area. He is a professional who is very involved in community affairs. He is one of four sons from a European immigrant family. Despite the fact that Sam and his brothers live far apart (the brothers live in the US Southwest), they have worked together for the past five years to provide alternating levels of care for their 80-year old mother with Alzheimer's disease.

When the mother began to experience confusion related to Alzheimer's, Sam and his brothers rallied together to find the most suitable arrangement for caring for her. Initially this arrangement involved the expansion of the informal network in their mother's neighborhood so that neighbors and other community members, who had been alerted about her confusion, could provide a watchful function for the family. Eventually, however, the confusion impacted her physical and mental functioning to the extent that she needed to be hospitalized for stabilization. After some time in hospital, her condition improved and she eventually returned to the community where Sam's family have made various informal arrangements to care for her. This care initially involved moving their mother from brother to brother as appropriate, depending on the extent of conflicting demands that each experienced. The confusion that she experienced from frequent moves was difficult to manage, however, and this arrangement eventually became too difficult for Sam and his brothers. The solution to this dilemma was to move their mother to California into a supported living arrangement in an apartment adapted to the special needs of someone with confusion. The setting provided plenty of supervision and access to her oldest son. Meanwhile, Sam's mother is waitlisted for an intermediate care facility in this region. To ensure that his mother maintains her British Columbia residency requirements, as outlined in the province's criteria for long term care, Sam's keeps in regular contact with case managers with

the long term care system in this region and he arranges for his mother to return to Canada every few months for visits with her regular doctor.

Sam's ability to access formal supports to assist with caregiving was hampered by his mother's attitudes towards formal care. Her experience in a European country that had seen tremendous oppression under foreign domination resulted in a fear and mistrust of so called "help" from others in the form of formal supports. Recognizing their mother's attitudes towards community services, Sam and his brothers accommodated the caregiving demands as best as they could.

My interview with Sam took place in his home. The interview was one-hour in length. It was obvious throughout the interview that Sam was very proud of his family's unique efforts to care for their mother. He wanted me to understand the cultural values and the salient events that have influenced this family's use of formal supports. By giving me examples of his mother's challenging behaviors, Sam was able to show me the role that humor plays in coping and living with a family member with a cognitive impairment.

#### BETH

Beth is a 46-year old caregiver who lives in an urban center. She is married and has three children who are now married with one child each. She is on long-term disability due to a chronic health condition. In addition, she performs bookkeeping and other administrative functions for her spouse's business.

Beth's 71-year old mother has had Alzheimer's disease for approximately ten years. Beth and her family initially noticed peculiarities in their mother's behavior, but their father had trivialized these. After Beth's father passed away in 1993 and she became the primary caregiver for her widowed mother, Beth began her search for answers to explain her mother's increased anxiety and confused behavior. Initially the behavior was attributed to depression due to the

loss of her spouse. Eventually, a change of doctors and a visit to the UBC Alzheimer's Clinic resulted in a probable diagnosis of Alzheimer's disease. Beth's mother continued to live independently in her home for several years after being diagnosed with Alzheimer's. As her confusion increased, homemaker services and a live-in worker provided support and helped to maintain her independence. Beth and her sister, who also lives in the same city, provided the majority of their mother's care until she finally entered an intermediate care facility one year ago. Beth remains very involved with her mother's care and acknowledges changes in her role now that her mother is in a care facility. My 45-minute interview with Beth was the shortest of all interviews conducted.

#### KATHLEEN

Kathleen is a 55-year old, full-time professional, married caregiver who lives in an urban area. She has five children, four grandchildren, and two siblings who live in other urban centers in the province. She has been the primary caregiver for her 83-year old widowed mother for approximately 8 years. After their father's death in 1993, family members began to notice that their mother was becoming more dependent and confused. The confusion was attributed to vascular dementia resulting from a series of small strokes.

Kathleen's mother was also a professional and had always been a very independent, mild-mannered person who was held in high esteem in her community. People in the community frequently went to her for advice, counseling, and other assistance. However, when she had to rely on others for assistance, it was a difficult adjustment for her to make. She was critical of Kathleen for exposing her deficiencies. She became obstinate and refused to cooperate with the homemakers whom Kathleen hired to relieve the burden. Kathleen persisted, however, and managed to access the supports that were needed to allow her mother to live independently, despite her confusion, in a supported-living seniors complex. Finally, however, Kathleen's

mother was experiencing ambulation problems due to muscle weakness. After a fall, she ended up in the hospital and was eventually transferred into an extended care facility. Kathleen continues to provide care, but it is now less demanding. My interview with Kathleen took place at my home and was approximately one hour in length. Kathleen was very frank in her discussions, both in her accolades and criticisms of community services.

#### BECKY

Becky is a 60-year old married caregiver who lives in an urban area. She has six children, two of these are biological and four are stepchildren, and two grandchildren. She is a professional woman with a great deal of expertise in her field. She felt pressured to retire early from her career when her mother began to have increased problems with confusion. Her 90-year old mother, who has outlived two spouses, has Alzheimer's. Becky has one male sibling living in a distant province. She said that he would like to be more involved in his mother's care, but the distance prohibits greater involvement.

Becky's mother had always been a competent, capable, and generous person who had dedicated her life to helping other people. When she was 75 years old, subtle changes were detected in her behavior, but these changes were not significant enough to warrant any particular change in her housing arrangement. At that time she was living in another urban city about three hours' drive time away from Becky's home. Becky would commute frequently to visit her mother. Eventually, Becky was commuting to spend time with her mother every week. She would stay overnight and return the next day. When Becky's mother was 85, her confusion had increased to the point where neighbors and friends were calling Becky to voice their concerns. Becky finally moved her mother to her own city and found her a very attractive apartment in a supported-living seniors complex. Her mother continued to live independently for five years; however, her wandering behaviors created risks for herself and possibly others. Despite Becky's

efforts to use homemakers, her mother resisted all forms of support, wanting only Becky's assistance. Eventually Becky's mother was put in hospital where she now awaits placement in an intermediate care facility.

My interview with Becky was two hours long. It took place in my office at the hospital. Becky, like other caregivers, initially felt that her story held no significance so she had to be reassured many times that it was very rich in context and worthwhile in so many ways. Becky was very emotional at various times during the interview and stated that the experience of finally bringing her mother into the hospital was emotionally difficult for her as her mother was her best friend. When the interview broached the subject of Becky retiring to care for her mother, she became very tearful, as this was an additional loss that she was grieving.

LIZ

Liz is a 59-year old married caregiver from an urban area. She has two sons and one grandchild who live in other cities. She is a European immigrant. Liz is the primary caregiver to her 83-year old widowed mother who suffers from vascular dementia due to a stroke in 1995. She has one male sibling, but he is of no help to Liz or their mother because he lives in another country, as do the majority of Liz's relatives. Although Liz retrained and re-entered the work force after her children had left home, her time in the workforce was short, as she eventually had to quit her job when the load of caring for mother became too great.

Liz's mother had been a very competent and independent businesswoman prior to her stroke. When she left the hospital after the stroke, she returned to her own home and, with Liz's support, she managed to live independently for two years. However, Liz found that her mother was so dependent on her for everything, from grocery shopping to food preparation, that she became exhausted with this arrangement. Five years ago Liz's mother moved in with Liz and her spouse. Increasingly, Liz finds that she has no time for herself as her mother's needs

demand all of her time. She is afraid to leave her mother alone in case she falls and injures herself. She did so last year and her mother fell and broke her hip. Although Liz had tried to hire homemakers to give her some respite, her mother refused to accept help from anyone other than Liz. Liz described her desperation to find a family care home that would meet her mother's needs, even if only for a month or two, and give her a rest.

My interview with Liz was 50 minutes long and it took place in her home. After the interview I was able to provide Liz with information regarding resources for family care options in the region.

#### LYNN

Lynn is a 55-year old caregiver from a rural area. She has four children aged late 20's to early 30's. One of Lynn's children lives in her area and the other three live elsewhere in the province. Lynn and her spouse, an only child, are the primary caregivers for his widowed 87-year old mother who has Alzheimer's. Lynn is a professional and her spouse is an unemployed laborer. He gave up his job one year ago because his caregiving responsibilities conflicted with his work commitments.

Soon after Lynn's father-in-law passed away in 1998, Lynn and her spouse recognized their mother's confusion. She was no longer able to cook a meal and was getting lost in her seniors-oriented building. Her neighbors became frustrated with her constant pleas for assistance with kitchen gadgets that she could no longer operate. Lynn and her spouse decided to move their mother into their home in the country. While this caregiving arrangement was an enjoyable novelty at first, it soon became a very trying experience for them both. Despite the devotion that they have always felt and shown towards his mother, they were now feeling that she had become "a guest that has overstayed her welcome". Lynn's mother is now waitlisted for facility care. They use adult day care services and respite to give themselves breaks. However, the behavioral

problems and the constant supervision required by their mother have taken a toll on both Lynn and her spouse. As a result, they feel they have “been robbed of the best years of our life”. They feel that they have no one to share the tremendous caregiving load with them. Lynn provides all the personal care and her spouse provides much of the supervision to his mother.

My interview with Lynn was two hours long and it took place in my home.

#### CLAIRE, DAVID AND JAYNE – Members of the Jackson Family

Claire, David and Jayne are three members, aged 46, 45, and 45 respectively, of a European immigrant family. They had been providing care for 5 years to their widowed mother who suffered from Alzheimer’s disease. Claire and David are siblings and Jayne is David’s spouse. Their mother died two weeks before my interview with them. The family also included additional caregivers (i.e. a sibling and spouse) who were not present for the group interview. Strong traditional values about caregiving influenced this family’s decision to care for their mother with very little use of formal care services.

The Jackson family’s caregiving experience began five years ago when their mother began to experience periods of confusion. She got lost in an airport while on holiday. Soon after, she lost the ability to manage her finances and prepare meals. She began to wander at night. Eventually, the Jacksons felt that their mother would be safer if she was living with one of her children. For the next several months, Mrs. Jackson’s three children alternated caregiving for their mother until such time as she could be moved to one of their homes. Finally, she moved in with Claire, her only daughter, where she lived until she passed away at the age of 77.

Claire continued to work as a professional throughout the entire time that her mother lived with her. She did this with the help of her two brothers and their spouses who would either come to Claire’s home to care for their mother or take Mrs. Jackson to their own homes. As Claire worked shift work, she would often go to one of her brother’s homes when she wanted to

be assured an undisturbed sleep. In addition, this family hired a private homemaker to give the family respite from their caregiving responsibilities.

My initial contact with this family occurred almost two months before the actual interview. Due to the failing health and subsequent death of Mrs. Jackson, the interview was postponed until more important matters were dealt with. Finally, I was contacted by a family member who suggested that Claire would be the most suitable person to be interviewed as she had shouldered the greatest portion of the caregiving responsibilities. I arranged for an individual interview with Claire in her home. One hour before the scheduled interview, Claire called me to ask me to meet her at her brother's home. When I arrived there, Claire met me at the door and directed me to a family room where David and Jayne were waiting. The three of them wanted to be interviewed together, just as they had cared for their mother together. They were very proud to tell their story. At times it was very emotional for the three of them, as their loss and the intensity of their experience was very fresh in their minds. The interview was 120 minutes in length. Even as they saw me to the door, the family continued to provide rich narrative about their experience. At one point, at the door, I pulled my tape recorder out of its bag and plugged it into the hall plug so I could capture their final thoughts on tape.

### **Themes and Subthemes Generated from the Data**

Five larger themes and 27 sub-themes, as indicated below, emerged from the caregivers' account of the experience. In vivo labels (words of the participants) have been used to title the themes and the sub-themes. These labels have been deliberately chosen to reflect the perceptions, attitudes, and emotions of caregiving. The results that follow are my own interpretations of the caregivers' experiences. Although there were many similarities in the caregiving experience, there were also differences. While most of the findings include themes and sub-themes common to the majority of experiences, known exceptions are explicitly stated.

Verbatim quotations from the transcripts have been used to illustrate the themes generated from the data analysis, and to make audible the voices that have been substantially absent from caregiver research. When presenting quotes from the interviews, the carers are identified by letters in order to protect their anonymity. Furthermore, demographic facts that might reveal identity have been altered or deleted to ensure the anonymity of the participant.

**Table 2. SUMMARY OF THEMES AND SUBTHEMES DERIVED FROM CODING THE TRANSCRIPT**

**“I have always been a good daughter”: Becoming a caregiver**

- 1) “Mother would say, ‘don’t tell anyone I am having trouble’”: Recognition of the problem
- 2) “I am the only [caregiver] here”: Taking on the role of caregiver
- 3) “Mom would wander at night and it would be very frightening”: Challenging behaviors
- 4) “[Caregiving] was really exhausting”: Emotional and physical demands of caregiving
- 5) “Something had to go”: Conflicting demands of work and family
- 6) “We [took] Mom to church because that was important to her”: Efforts to preserve the parent’s personhood
- 7) “My sister was involved with the health care system so we had a total advantage”: Personal resources that eased the caregiving experience
- 8) “[Having Mother stay with us] is like company that has stayed too long”: Limitations to caregiving

**“All [my mother] wants is family [care]”: Values, beliefs, attitudes and experiences that influence caregivers’ help-seeking behaviors**

- 1) “In her community [Mother] was sort of up on a pedestal...she would never ask for assistance”: Family history
- 2) “[Mother] would say to the home support worker, ‘I want you out of here’”: Resistive behaviors
- 3) “My mother would say, ‘you have to look after me’”: Family expectations about caregiving
- 4) “I wasn’t ready for [my mother to be institutionalized]”: Caregivers’ reluctance to access services
- 5) “The relationship [with my mother] was total control”: Relationship between caregiver and mother
- 6) “There was a lot of joy in looking after [Mother]”: Gifts in the caregiving experience

**“I would not have been able to [care] on my own”: The role of informal support networks**

- 1) “Once we realized [Mother] was wandering, we started taking turns staying with her”: Increased needs and expansion of informal care network
- 2) “It made a difference that [family members] were there to support me”: The buffering role of social support network
- 3) “[Friends] don’t really come to help”: Unresponsive social networks
- 4) “Lots of communication needs to be done”: Communicating needs to others in support networks
- 5) “I had to get to be a person again”: Recognizing the need for increased supports

**“The time had come when we could no longer continue as we were”: Links between perceived responsibility and formal service use**

- 1) “You can’t win either way”: Maintaining a precarious balance between respecting parent’s independence vs. risk to self and others
- 2) “Everybody’s upset...we need some help here”: Re-evaluating responsibility & commitment

**“I just had to move on”: The use and acceptance of formal services**

- 1) “You just move on”: Finding acceptance with new role
- 2) “You don’t know what there is until it is too late”: Confusion & fragmentation in formal care system.
- 3) “[Long term care] don’t phone and say ‘how are things going’”: Lack of recognition for caregivers’ efforts
- 4) “I don’t want to be stuck if this (caregiving arrangement) doesn’t work”: The need for flexible formal support system criteria
- 5) “[Long term care] doesn’t give you what you need”: Adequate and appropriateness of formal support services
- 6) “[Respite] is my life-line”: Community resources perceived to be helpful by caregivers

The qualitative findings are presented below under the headings that are listed in the table above. These headings will serve to guide the reader through the complex experience of caregiving for a parent with a cognitive-impairment.

**“I have always been a good daughter”: Becoming a caregiver**

Becoming a caregiver typically involved a gradual process whereby caregivers stepped in to accommodate for problems identified in their parents’ level of functioning. As the progress of the cognitive impairment tended to be slow and insidious, caregivers adjusted their own lives as the needs of their parent increased over time.

- 1) “Don’t tell anyone I am having trouble”: Recognition of the problem

Every caregiver described his or her own experience of recognizing the subtle differences in their parent’s previous level of functioning. Becky spoke about her mother’s gradual inability to problem-solve at the grocery store and her ineffective handling of food items:

Near the end, she always bought the same thing, like chickens that were cooked, and then in the end, I noticed that she had put the chicken in the cupboard, and ice cream in the cupboard, like she was getting everything confused.

Another caregiver described her mother losing her ability to cook. She would put fruit on a pizza. She could no longer prepare traditional dishes at Christmas time.

Several caregivers described their parents' withdrawal from activities, such as cooking, that they had once done so proficiently. This was as if the parent had some self-awareness that she had lost her ability to perform certain tasks and had found a way to avoid the activities that may emphasize these deficits.

Participants described the feelings of distress their parents experienced when they realized they were experiencing a loss of mastery and control. Kathleen described her mother's plea when she realized she was having problems with confusion: "Don't tell anyone that I am having trouble". Her mother's attitude reflected her own pride and embarrassment that she could no longer manage.

Initially, caregivers respected their parent's wishes to hide the problems they were having with memory and functioning. Eventually, however, families took their mothers to the doctor to have their memories tested. Becky described the challenging experience of taking her mother to the doctor:

She was furious with me because I had told the doctor those things [memory problems]. She was very ashamed, very defensive. She felt she was hiding her disease process and her disability that was developing and she was scared people would find out and oh, she was brutal. She was just furious.

Lynn commented that the embarrassment her mother felt with respect to her memory problems was a "generational thing": "Mom keeps all these secrets, she is too afraid to tell or too proud".

## 2) "I am the only one here": Taking on the Role of Caregiver

The results will show that the decision to care for a parent with a cognitive-impairment is based on many factors. Most of the caregivers found themselves providing care to a parent after the death of the parent's spouse. All of the caregivers were providing care to their widowed mothers. Although all of them were identified as the primary caregiver in their particular caregiving dyad, four were receiving some assistance from siblings with caregiving tasks.

Analysis of narratives of the caregivers showed that gender was a factor that influenced

caregiving arrangements in the majority of the situations. Where families consisted of both male and female siblings, a female was identified as the primary caregiver; in the majority of these families, males were virtually not involved or had adopted a minor role in caregiving. A male caregiver stated that the absence of females in the family had resulted in a caregiving arrangement that was shared amongst him and two male siblings. Liz reflected on her experience with caregiving to her mother and said, "oh, my, it would have been nice to have had a daughter". This caregiver was also looking ahead to the time when she herself may be dependent on others and was questioning the willingness of her two sons to provide her with care. Her comment provides insight into gender expectations that are perpetuated through family generations.

Daughters-in-law were able to set reasonable boundaries around caregiving, but this was not without some guilt that they should be doing more:

My husband is the main caregiver. He is with her all day. I am more just to support him a little bit and take over the personal kinds of things that he is not feeling good about. I am also there to give him some time when we are home so that he can go to his shop and go outside for a while but I am really digging my heels in now. Like tonight I am going to go stay at my sister's. Like I haven't seen her for a while". (Liz)

When Liz's text, particularly her comment "I am really digging in my heels right now" is examined, efforts towards challenging gender role assumptions are revealed. Clearly, changing roles and establishing boundaries is a struggle for Liz. The fact that Liz feels she needs to defend her position, highlights the powerful forces that place caregiving in the hands of women.

Two male caregivers considered the role that their spousal relationships had in influencing their caregiving commitments. Sam said: "I could easily make the adjustment to take her...but it wouldn't be fair to my marital relationship. You know she will just start picking on my wife". Conversely, other caregivers considered their unmarried status at the onset of caregiving as a factor that contributed to their availability to care for their mother: "When we

first started caring, none of us were married and therefore didn't have a family, which would also take up an awful lot of time." (David) Sam and David's narratives highlight the assumptions that are made about men's role in caregiving. Caregiving is not meant to conflict with other priorities, such as marriage or relationships. These male caregivers were able to "draw a line in the sand" as to the extent of their involvement in caregiving.

Caregivers described the relationship that family size and proximity had played in influencing caregiving options within their families. Lynn's spouse was an only child. Furthermore, there were no other relatives, except for the Lynn's children, living in close proximity. Proximity to parent was a critical factor that ultimately determined which family member took responsibility for the majority of care provided to the parent. In all but one of the caregiving situations, the caregiver and care recipient were living in the same town. However, three of the caregivers in the study had previously relocated their mothers to their hometown so as to reduce the travel time required to provide the necessary care and increased monitoring of their mothers' needs.

Five of the caregivers identified themselves as the only child living in the same location as their parent. This geographical isolation from other siblings at the time when their parent required more assistance was difficult for caregivers. Liz's comment, "I am the only one here...it would be nice if I had another sibling, you know that could help", provided insight into the isolation felt by caregivers who have no family supports to access to mitigate the strain of caregiving. Liz's brother, who lived in another country, had undertaken a very passive role in his mother's care. In situations where other siblings also lived in the same city, caregiving typically took on a shared arrangement between siblings; however, female siblings assumed the majority of the care.

Prior relationships within the family and family dynamics also determined who provided

care and how the care was managed within families. Becky commented that her only sibling, a brother, had not had a close relationship with their mother and so the responsibility for caregiving rested on her shoulders: Becky's comments, "I have always been a good daughter", "just did what she told me to do", "our relationship was total control", and "I was very submissive person in our relationship" highlighted the power differences in her relationship with her mother. Becky provided contrasting details of the relationship between her mother and brother: "like my mother has never really been totally happy visiting him because he doesn't do as he is told".

3) "Mom would wander at night and it would be very frightening": Challenging behaviors

While assistance with bathing, shopping, meal preparation, cleaning, and finances are important components of caregiving to the cognitively-impaired elderly, caregivers identified supervision as the most demanding and time-consuming activity performed. The supervision task was largely due to the parent's tendency to wander away from home: "Mom would take off and she is quite a walker...eventually she would get lost, and either the police or the ambulance would be called...it was a huge problem." (Becky) Claire echoed this sentiment about her mother's wandering behavior: "she would wander at night and it would be very frightening." This was more of a problem when the care recipient was experiencing a cognitive impairment related to Alzheimer's. These caregivers talked about their parent's physical strength and endurance, and the impact this had on wandering behaviors. Parents with confusion showed little insight into the problematic aspects of their wandering. Claire, David, and Jayne attributed their ability to sustain the informal caregiving relationship as long as they did to the fact that their mother stopped wandering very early in the course of her Alzheimer's disease.

Other caregivers described the incremental progression of Alzheimer's disease. Upon reflection caregivers could recognize their adjustment to challenging behaviors over a long

period of time:

It really sneaks up on you. When we started looking after Mom she could be left alone within the confines of the house, then all of a sudden you get to the point where it is almost total care and you wonder what happened in-between. It had been so slow and progressive that you really don't notice the increase in care as you go along. (Claire)

Since caregivers made adjustments along the way to adapt to the needs of their mothers over time, their perceptions of their mother's needs were not always the same as outsiders. Thus, caregivers often found themselves justifying their decisions to others.

#### 4) "It was really exhausting": The emotional & physical aspects of caregiving

Although the behaviors that are typical in the early and middle stages of Alzheimer's disease are not typically physically demanding on the caregiver, they are certainly mentally demanding. However, caregivers found that as the cognitive deterioration and the physical frailty of their mother progressed, so did the demands on them as caregivers. Caregivers who cared for their mother in the latter stages of AD experienced not only an emotional burden, but also significant physical demands, due to the activities of lifting and transferring.

Becky described the emotional and physical burden of caregiving for a dependent parent with confusion: "Actually, it was really exhausting... You know I would be called over in the night because Mom had taken off." Of the nine caregivers interviewed, five were dealing with fairly serious health issues of their own that had either developed or become exacerbated during the period of caregiving. Three caregivers had developed cardiovascular disease, one had developed celiac disease and one was having rejection problems as a result of a bone marrow transplant for cancer.

Caregivers described a range of emotions that they experienced throughout the period of adjustment. Loss, and the grief associated with loss, was a significant theme of each caregiver. Caregivers described a long tentative process of coming to terms with the nature of the illness, including changes that had occurred to their relationship with their parent and the inevitable

changes that had also occurred in the caregivers' lives. Due to the protracted nature of the illness, feelings of grief tend to fluctuate as each exacerbation occurs. Family members described a range of feelings associated with their grief.

All caregivers of those with Alzheimer's described the subtleness and insignificance of early behavioral changes so that months and in some cases years went by before caregivers began to look for answers to explain the changes. Often these changes were not as apparent to the family members with the most contact with the person with the cognitive impairment. Beth described how she had questioned her father about her mother's behavior: "I think something is wrong with Mom. She's not keeping things straight. She's confused, she's doing funny things.' Her father's reply was: 'Ah, she's not paying attention.'"

Claire said that her mother had gone on a holiday to visit relatives in another country. Once she arrived the relatives called Claire to report that her mother was very confused. Claire described her response: "Uh, no, you know long trips, a little older, she's a little hard of hearing." Caregivers initially made excuses for their mother's behavior. It was only upon reflection that caregivers could link the unusual behavior with the progressive deterioration of cognitive abilities that is typical to a dementing illness such as Alzheimer's disease.

Other caregivers described how caring for their mother had resulted in other responsibilities being given less priority. Becky provided an account of a typical workday:

And you know, the days that I worked, I took her out at night, so she was always happy, but as soon as she had to go back [to her own apartment], it was terrible for her, and it was terrible for me to have to leave her. Actually it was really exhausting.

Becky described her efforts to drive well out of her way to pick up her mother to take her on work trips with her. Becky's concern about her mother's wandering from the hotel resulted in her eventually taking her mother to work meetings:

It got to the point where I was scared to leave her in the hotel. Because I thought if she got up and got out the door, she'd be finished, she would never find her way back and

then in the end I was taking her to almost every meeting. And then I thought, “this is ridiculous, you can’t do this”.

Thus, Becky recognized that caring for her mother had contributed to tremendous emotional and physical burden. This situation was ultimately resolved once she took early retirement to accommodate her mother’s needs. However, Becky’s decision to retire early resulted in additional losses that she had not expected. Not only did it affect her retirement income, but it also resulted in a loss of identity, purpose, and social connectedness at a time when she was most vulnerable.

Caregivers described the various ways their caregiving responsibilities competed with their relationships with their spouses, children and other family members. Lynn experienced feelings of anger that caregiving had resulted in broken dreams about her plans for herself and her husband in their “50’s”:

Yikes, I have given her three years now, where she has been the center of attention. I am not sure I want to give her the rest of my 50’s because isn’t this when I am supposed to be having some fun. This was supposed to be our time – we had thirty years of raising kids and suddenly had our house to ourselves and then now it isn’t again. We’re back only it is not the same kind of fun as raising a kid. I mean we were tied down with our kids but we had fun with them.

Lynn’s resentment towards her mother-in-law resulted in vacillating feelings of guilt that she was feeling this way about caregiving:

So that is the guilt. I sort of think, “oh, I should be more giving and kind” but I just don’t have any more to give at the end of the day sometimes. It has changed how I feel about her which is really sad because we were so close.

Lynn, whose relationship with her mother-in-law had been wonderful, reflected on the way her feelings towards caring for her mother-in-law had changed: “when she first came, I liked doing things for her...curling her hair, the little extra things that don’t get done”. After a period of intense caregiving, she had nothing but feelings of resentment, anger and guilt towards her mother-in-law.

Fluctuating levels of confusion resulted in caregivers questioning the diagnosis itself:

You constantly deal with the doubt of what you have done. I mean that is the hardest thing. Sometimes you think "I can't believe that she did that", like it was something so normal and you think "is she just pulling my leg here or what is going on". That is the doubting again. (Beth)

This often resulted in caregivers questioning the decisions they had made to access formal care services.

Due to the fact that cognitive changes occurred subtly and typically fluctuated from day to day and week to week, each caregiver described how precarious the supervision task became. The agitation that the confused parent experiences results initially in reluctance on the part of the caregiver to leave the parent alone for any length of time. Lynn and her spouse agonized over leaving their mother at home alone while they went out to a hockey game. Essentially, their own anxiety about how their mother was coping spoiled their evening. When they returned home after the game, their mother's state of anxiety confirmed their belief that she should not be left alone again:

We got there and there she was looking out the window. She had two hats on, her coat on and she said "Ohh...", there was such panic in her voice, "I am so glad you are here. I was so scared". I thought, "it is not worth it". So she was okay, but she was a mess...if the police had come they would have thought, "who is leaving this poor person?"

This strong sense of responsibility makes it difficult for caregivers to know what level of supervision is required or adequate.

Eventually, caregivers respond to the uncertainty and unpredictability of caregiving to a cognitively-impaired parent by accepting that fluctuations in behavior are a normal part of the disease process. Kathleen described her experience this way:

I think when you go in on a daily basis with somebody with Alzheimer's or another dementia, you are going to get different mood swings and different levels of awareness, so I had to really learn this, is that when I went in and my mother was totally confused that I wouldn't dwell on that...

Coping strategies such as these allowed caregivers to be less reactive to periods of confusion.

Rather than focusing on the behavior on that particular day, this caregiver was able to draw from previous experiences and accept that her mother would be fine, in spite of her confusion.

#### 5. "Something had to go": Conflicting demands of work and family

In addition to emotional and physical demands, caregivers cited work and family commitments that competed with their caregiving responsibilities. Of the nine participants, six had employment commitments and two had left the workforce so they could devote more time to the care of their mothers. The spouse of the caregiving daughter-in-law in the study had also left his work to provide more constant care for his mother. He had found that as his mother's agitation increased, he was constantly being interrupted at work:

Every time he would go to work the phone would ring. [His mother] would say, "you've got to come and help me, something's broken". There was always a reason why he had to come and he'd say, "well if I don't go and it is really is [a problem], then.....so I better go". So he became an unreliable worker and you couldn't count on him to get the job finished. He was taking longer to get jobs finished. For the last two years he just said, "I can't work, I just can't work."

Becky's comment provides insight into the potential impact to one's health of caregiving and maintaining paid employment:

Then for my own health...my blood pressure got very high...something had to go because it was way too much between work and my mother. So I decided to quit work, mainly because of my health...I really miss it but I don't regret it.

The demands of caregiving and employment together contributed to health problems that eventually forced her to consider early retirement. Neither Becky nor Liz, who had both left paid employment to care for their mothers, suggested that their only siblings, brothers, should have given up paid work to care for their mother.

Lynn described the impact that caregiving had on her relationship with her husband: "It has definitely affected my husband's and my relationship...there is no time for us to be together...like we have no time together. She is always there." Becky worried that there would

be nothing left of her marriage when her caregiving responsibilities had ended. Both Lynn and Becky were waiting for their parent or parent-in-law to enter a care facility. These stories provide insight into the fear these women harbor as they consider competing demands and the potential negative impact of caregiving on their relationships with their partners.

6. "We took Mom to church because that was important to her": Efforts to preserve the parent's personhood

The majority of the parents (care recipients) could be defined as family matriarchs who took an active role in caregiving decisions concerning them until they could no longer do so. Caregivers searched for ways to preserve their parent's personhood and find a solution to their caregiving situation within their own resources. By owning the problem, they retained control of the care and thereby ensured their mothers' wishes to remain as independent as possible were respected.

Despite dealing with behaviors that may have been perceived by others as embarrassing, caregivers found ways to involve their mothers in the community, and in activities that had been important to their mother prior to their cognitive decline. Claire and her family members continued to dress up their mother and take her to church every Sunday:

We would make efforts to take her to church, because that was important to Mom...she would never go to the grocery store in rollers, she would dress up...so when we took her out she would be dressed up presentably..

They also took her to their favorite restaurant on the weekends. Becky and her spouse continued to take her mother to the junior hockey league games. Both Becky and Claire made no attempts to hide their mothers' confusion and often had to explain to strangers on their outings that their mother was having difficulty with her memory. Thus, despite powerful messages that perpetuate negative attitudes towards the elderly, these caregivers were able to assist their mothers in maintaining their dignity and remaining active members of their community.

7. “My sister was involved with the health care system so we had a total advantage”: Personal resources that eased the caregiving experience

Most caregivers acknowledged the personal resources that had helped them cope with their caregiving responsibilities while providing the majority of the informal care, then later when interacting with the formal care system. These resources included: the ability to access information on the Internet; the ability to access information through personal contacts in the system; the ability to work at a job that allowed them flexibility to take time when necessary; and the ability to spend the time needed for negotiating the system and advocating for their parent's best interests. Kathleen attributed her family's success with caregiving to the fact that her sister was familiar with the long term care system and the assessment process: “My sister was involved with the health care system so we had a total advantage.” These resources helped the caregivers to feel empowered in their role. While it is important for caregivers to recognize the abilities and attributes that have helped them perform their caregiving responsibilities, it is also important to understand the social context of these arrangements. Access to resources such as those described by caregivers is likely class-specific. Certainly, my experience with caregivers outside of this study would indicate that these caregivers had certain privileges that would not be the norm for most caregivers. Few caregivers have the knowledge initially to successfully negotiate the health care system. Furthermore, most do not have access to computer information or a job that has a flexible policy around family care.

8. “[Having her stay with us] is like company that has stayed too long”: Limitations to caregiving

Despite feeling responsible for their mother's safety, most caregivers consciously decided that moving their parents into their home was neither a viable nor an acceptable option. These caregivers recognized the limitations of their caregiving responsibilities and instead modified

and adapted their parent's environment to support their independence. For three caregivers who decided to move their mother into their home to ensure their safety, this option inevitably turned out to be an unreasonable. Lynn described her experience this way:

In the beginning it was fun...in the beginning you feel sorry for her and you want to be the caregiver and you do it because you really want to do it. Now it is like company that has stayed too long...the novelty has worn off.

Liz spoke of the difficulty in moving her mother-in-law into their home to provide her the care she needed. This move resulted in the suppression of her own life goals:

What happens when you take something like this on is that your own life just goes on hold, it is just on hold. You can't make plans, you really can't do anything, it is just...you just get up in the morning and you start, then you go through the day, then you go to bed and get up the next day. You really don't have any kind of a life, you don't.

Liz's comment highlights the tremendous sacrifices she has made to care for her mother. She describes her life as joyless. Although Liz had once been socially active in her community, she described her role change since assuming her mother's care. Liz indicated that she would have an easier time resolving these losses if her mother would only show some appreciation for her efforts: "Another thing you think about is that my mom never says thanks. She never says 'thanks.'"

**"All [my mother] wants is family": Values, beliefs, attitudes and experiences that govern help-seeking behaviors**

1) "In her community [my mother] was sort of up on a pedestal...she would never ask for assistance": The impact of family history

All study participants commented on the role that their family's history had played in influencing their attitudes about accepting formal supports. Sam's family had immigrated from a European country that had experienced extreme political oppression. The mother's experience with the secret police in her country of origin had taught her to be self-sufficient and wary or distrusting of outside supports:

My mother came from a country where one had to be relatively tight lipped for survival...so she was not particularly trusting of any other group or individual...so we [as a family] were somewhat socially isolated...and away from the mainstream more than others. Other citizens who were born here and lived here all their life would probably appreciate better the social safety net that you have as a Canadian.

Other caregivers described the historical position of their family in the community. As Kathleen put it:

In her community she was sort of up on a pedestal. So, therefore, she had to live that way of life...she would find it very comforting that people came to her for advice but she would never ask for assistance.

Thus, this pretense of independence and self-reliance made it difficult for this family to approach others in both the informal and formal systems for assistance.

2) "[My mother would say,] 'I want you out of here'": Resistive behaviors towards unfamiliar caregivers

An enduring theme throughout the interviews was the role that the caregivers' own attitudes and beliefs, or that of their mothers, had in influencing their decision to utilize formal care alternatives: "Mother was totally obstinate, like totally. Like I never knew that Mother could be like this, because the [homemaker] would come by and [my mother] would say 'I want you out of here', like she was very obstinate." (Becky)

Lynn described her spouse's struggle to make decisions about accessing services for his mother. Although he recognized that he needed help caring for his mother, his mother would not have any of it: "even though he knew in his heart it wasn't the right decision, he let her control the show for a while". Becky and Lynn's examples highlight the issue of power and resistance in the caregiving relationship. Where caregivers attempted to augment their efforts with formal supports, their mothers resisted the loss of self-determination. Caregivers explained most of the resistive behaviors as a combination of the dementia and predisposing personality factors that become more pronounced as a result of the dementia.

The caregivers' indicated that their own resistive behaviors were likely due their goal to support their parents' independence as long as possible and to their reluctance to access services when their parents' future needs were so difficult to predict. Beth commented on her decision about accessing services: "You know the part that gets you is that you think, 'what if something happened to Mom and she went fast?' I still think I should be able to look after her, you know". So, while some caregivers were reluctant to use services because of the uncertainty of their future needs, others felt that, although their current caregiving arrangement demanded enormous strength and reserve, it was sustainable at least in the short-term. Claire's mother's condition deteriorated at a very rapid pace; thus, her decision to care was based on the assumption that although the course of her mother's illness was intense, it would likely be short. Thus, contingency plans are considered on an ongoing basis as the state of the care recipient's health fluctuates and deteriorates.

Becky attributed her own resistance to formal service utilization to her own unresolved grief: "I was quite resistant to doing too much, because I think as much as my mother is going through denial through this whole thing, I am too." The fear of living with the guilt resulting from making a decision that was unacceptable to their parent resulted in many caregivers opposing formal support services even when their parent was objectively assessed by long term care case managers as "needing" services. Becky's quote highlights her struggle between respecting her parent's right to self-determination and attending to her own needs as a woman.

3) "[My mother would say,] 'you have to look after me'": Family expectations about caregiving

Caregivers attribute their own attitudes to their values about family obligation and reciprocity. Claire's mother had instilled the expectation for family caregiving: "She kind of drilled into us how important family was, you know, like "you have to look after me, you have to look after me". Not only was the expectation for family care communicated in this family but

caregiving behavior was also role-modeled. This caregiver's mother had cared for her own husband with senile dementia at home until he passed away. Claire's brother David added: "it would only be fair to look after her in the same way...there was an expectation, kind of, within the family that the caring be done by family members then." The caregivers' stories provide insight into the influence of role modeling within families in influencing the behaviors of caregivers. These caregivers essentially developed their knowledge of caregiving through discourse and example.

Another caregiver felt that, although she had a strong sense of commitment to her mother-in-law, she felt unprepared for the role of caregiving, especially for someone with a cognitive impairment: "Our culture did not prepare us for this caregiving role. In other cultures, there is an expectation that families will care for their elders." (Lynn) This caregiver attributed her lack of knowledge about caregiving to her cultural upbringing, which, in comparison to more traditional European cultures, did not place as much value on family care to the elderly.

4) "I wasn't ready for [my mother to be institutionalized]": Caregivers' reluctance to access services.

Despite feeling burdened by their caregiving responsibilities, most caregivers ignored objective appraisals of their parents' need for institutionalization:

[The community care nurse] said, "your mother should never have been discharged, never. She requires 24-hour care, you can't give it and she has to be in the hospital"...I should have left her [in the hospital], that is what I should have done, but I wasn't ready for that. (Becky)

Thus, these caregivers continued to provide care past the point in which formal service could be predicted using rational perspectives. With these caregivers, preferences for family care take precedence over for the objective need for services, at least until such a time as the memory deficits are so severe that recognition of the carer is indistinguishable: "I would be worried to

take her into a long-term care facility until such time as it really doesn't matter because she will create problems, because all she wants is family...her whole situation is family.” (Sam)

These same attitudes contributed to most carers fearing the day they would be forced to consider institutionalization as the only remaining alternative. Beth described the actual experience of finally putting their mother into care: "On the day she was admitted...my heart was in my throat. I thought I was just going to pass out. It was just...it was awful." These emotions are so strong that caregivers for four of the seven care recipients in the study group initially refused to institutionalize their mothers even when a bed became available for them in a long-term care facility. Becky described her experience when informed that her mother had come to the top of the facility wait list: "I just couldn't do it...just couldn't put her in there. They phoned and said 'we have a place for your mom' and I said 'we just can't do it.'" Sam described an anticipatory reaction to having to place the parent: "I think as soon as we put my mother into an institution we would all feel a collective guilt. The guilt is already there just thinking about it."

Caregivers' sense of guilt and their denial of the nature of the dementing process resulted in moments where they questioned their decision to place their mother in a care facility. Becky said that frequent visits to the hospital to see her mother precluded her from recognizing the deterioration in her mother's condition. She began to second-guess her decision to place her mother:

When you are so close to them everyday you miss it. Like my brother comes every six months, and he can't get over how my mother deteriorated. I don't seem to be in touch with that. I am still thinking "well maybe I can bring her home" and then I think "holy doodle, I could never manage" but I am still on that fairytale idea you know."

Kathleen was unique in her description of the process to place her mother. She did not describe an intensely emotional negative experience; instead she described relief that her mother was in a safe environment and that she was finally relieved of caregiving duties. Furthermore,

she experienced no opposition from her mother about the move to extended care. In her case, however, her mother played a more submissive role in the relationship, while Kathleen made decisions on her mother's behalf. Kathleen's mother was unique in that she had had a stroke and although she had significant confusion, she did not have some of the challenging resistive behaviors that other caregivers described.

During the focus group Kathleen challenged the predominant viewpoint of the group participants that facility placement of their parents should be associated with feelings of guilt. Kathleen said, "the public's perception about nursing homes is so wrong", suggesting that caregivers should give themselves permission to make placement decisions when eldercare becomes unmanageable. Kathleen was eager to highlight differences in caregiving arrangements that were sustainable for longer periods than her own. Kathleen later reported to me that she felt her views and her approach to her mother's placement were very different from the others and this made her feel a bit like a "bad daughter" or an outsider when that topic was discussed. This made her uncomfortable because she did not want to be seen as uncaring. The sharing of ideals and values around caregiving, which were incongruent with Kathleen's beliefs and reality, created some dissonance for her. This illuminates the persuasiveness of caring ideals.

#### 4) "Our relationship was total control": Relationship between caregiver and care recipient

The attitudes and beliefs about accessing formal services may be partly influenced by the relationship between the caregiver and the care-recipient. Becky described the power dynamics in her relationship with her mother: "Our relationship was total control. I was a very submissive person in our relationship." Thus, Becky had difficulty making decisions on her mother's behalf. The dynamics of their relationship with the parent took precedence over decisions to access services:

She was very dependent on me and I was on her too...and you have to realize that she is totally resistant to any kind of help. You have to realize that if I wasn't that involved you

could probably just get the resources going and she would have been looked after probably just as well, but then again I would not have had the pleasure of enjoying this time with her and being with her.

5) "There was a lot of joy in looking after her": Gifts in the caregiving experience.

Thus, while caregivers perceived certain elements of their experience as stressful, some were also able to recognize the "gifts" in their experiences caring for their mothers. Claire said: "There were a lot of good moments, you know, like there was a lot of joy in looking after her...there were some horrible times, but you know I wouldn't change it actually." Some caregivers said that the experience had given them the satisfaction of knowing that they had done what their parent wanted. One carer said that caring for her mother had allowed her to spend time with her mother that she would not have had otherwise. Becky acknowledged that caregiving had allowed her to strengthen her relationship with her only sibling:

Another positive is that through this experience I am getting to know my brother. I have gotten to know this wonderful man. He calls me regularly and he is very supportive of me. He would do anything he can to help. And he is so loving to my mother, which I had never seen.

Other participants allowed themselves to see their personal growth as a result of their experience: "we have spent endless hours looking for money, you have no idea. It has really been good for me because I have learned tremendous patience, you know, looking for it." (Lynn)

However, the idea that the experience of caring for a parent with a cognitive impairment could be perceived as a "gift" was a topic that was debated at length during the focus group discussion. Beth could not identify any "gifts" in the experience: "I didn't find anything rewarding in it at all. I just find it total frustration." Instead Beth remained focused on the emotions of anger, pain, sadness, and guilt that she had experienced as a result of her mother's illness and her caregiving experience. Essentially, variations in caregivers' perceptions of their experience seemed to be reflective of where the caregiver was situated in terms of the grieving

process. While some caregivers were still feeling angry that this illness had dramatically changed their life course, others had come to accept the illness and the prognosis.

Although caregivers could reflect on certain caregiving decisions they would change if they had more knowledge and experience, ultimately they did not regret the decisions they made about accessing formal support services. Essentially, the carers emphasized their satisfaction with their efforts to protect their parent's individuality, autonomy, and self-respect for as long as they did.

**“I would not have been able to [care] on my own”: The role of informal support networks**

- 1) “Once we realized [Mother] was wandering, we started taking turns staying with her”:

Increased needs and expansion of informal care network

Caregivers described their early efforts to provide care. In the early stages of the dementing illness, these efforts primarily focused on supervision. In four of the cases, cognitive changes were initially subtle, but then progressed to the point where much more supervision was needed to ensure the parent's safety. Typically, as the demands and emotional stress of caregiving increased, caregivers used creative ways to expand their informal care networks to supplement the care they provided. Beth described the community support she received: “Yes, the community all knew [Mom was having trouble], and they were really good at letting me know if something wasn’t right.” Claire described her family’s efforts to share the task of supervision: “Once we realized [Mother] was wandering, we started taking turns staying with her.”

- 2) “It made a difference that they were there to support me”: The buffering role of social support

The participants typically sought out family members, spouses, siblings, children, neighbors and friends for informal support. One family apportioned responsibility for caring among all three siblings, with the only daughter becoming the primary caregiver. In this family, the support of each other acted as a buffer, which allowed for the sustainability of the arrangement:

I would not have been able to care for my mother on my own. Even if there were three of us...if my brothers hadn't been willing to give me support, it wouldn't have mattered if they had been in the same town. It made a real difference that they were here to support me. (Claire)

Thus, for Claire, effective informal support meant more than simply the presence of additional family members. It meant that alternate family caregivers had demonstrated a commitment to regular participation, and that their involvement was perceived as helpful.

Caregivers attributed their success in sustaining the informal care arrangement to their ability to share caregiving tasks and collaborate with other family members about difficult decisions. David and Jayne described a process by which the majority of decisions regarding care were discussed amongst the siblings. When a rare disagreement about a caregiving decision occurred, the primary caregiver was given a veto. The words that this family used to describe the decision-making process were: "patience with others", "letting the others digest what was going on", "gave him a little time to think about it", "asked for input", and "we would talk about it and agree on something".

Sam stated it was his responsibility to monitor the informal arrangement that he and his brothers had made for their mother. He described how he expected to deal with decisions regarding his mother's care if the current caregiving situation was no longer sustainable: "I mean if it comes to the point where [the arrangement] is not going to be successful anymore, the decision will be mine but it will certainly be done collaboratively".

Informal support networks allowed four of the care recipients to remain living independently in the community. Their caregivers expanded their informal support network to include neighbors and apartment management personnel who assisted these families by being "watch dogs": "I contacted the management...[to let them] know that she was independent, but that she was also having problems so they would call me if there was an issue that had come up." (Sam)

### 3) "They don't really come to help": Unresponsive social networks

While some of the families were successful in expanding their informal network by alerting neighbors or problem solving with other family members, other caregivers expressed their disappointment that friends and neighbors had not come forward to provide assistance or emotional support. Lynn described her mother-in-law as previously very active and well-connected member in her community. Thus, it was shocking to experience so few offers of assistance when her mother-in-law began to experience confusion:

They would stop and say, "how's Betty" but they didn't ever go and say "come on Betty, I'll take you out for coffee" or "let's go shopping" and that was a real eye opener for me.... They all said "just phone if you need help", but unless you do phone they don't really come and help...so you can't leave her and nobody offers to take her.

Lynn had the same experience with the neighbors in her mother-in-law's apartment building; these neighbors gradually declined to be involved fearing that they would somehow be found responsible for any actions of the confused person. Lynn assessed her ability to expand her informal support system this way: "It is your immediate support system that is not always in place let alone what else is out there and it just gets put on whoever takes the responsibility to take care of that person." Thus, while some caregivers were successful at expanding their informal networks, others struggled to find support. These findings illuminate the sense of isolation felt by caregivers when faced with unresponsive informal social supports.

- 4) "Lots of communication needs to be done": Communicating needs to others in support system

Lynn described the difficulty she and her family had experienced when reaching out to ask for the assistance of others. Lynn was sharing the responsibility of caregiving for her mother-in-law with her spouse. Initially, Lynn's husband wanted total control of all the caregiving responsibilities and decisions and refused to seek the help from others, either in the informal or formal system. Gradually, as he became more and more overwhelmed with the burden of these demands, he had greater expectations of his family. However, these expectations were never communicated; instead, Lynn's spouse harbored feelings of resentment that he was not getting the support that he needed. Finally, one night he imploded and disclosed his feelings at a family gathering. Although the feelings and expectations were finally exposed, family members felt hurt by the process. Thus, Lynn felt that, "lots of communication needs to be done" to enlist the assistance of others in the informal support network.

- 5) "I had to get to be a person again": Recognizing the turning point and need for increased supports

The caregivers, who accessed the residential component of the formal care network, described the point at which they conceded they needed the assistance of formal care supports.

Becky's experience was described this way:

I said, "Mom, I can't keep [staying with you] forever". She said, "I thought you were having a good time." She was just beaming. And I realized then that she is not the mother that she was, she is not her at all. She is somebody else. And I realized that in order to survive I had to get to be a person again, so I said "no, I am not having a good time, I have to go home."

For Becky, and others interviewed, formal service use became more acceptable when the dementia had advanced to the point where the care recipient no longer had the ability to discriminate between family and formal care providers.

**“The time had come when we could no longer continue as we were”: Links between perceived responsibility and formal service use**

- 1) “You can’t win either way”: Maintaining a precarious balance between respecting parent’s independence vs. risk to self and others

Despite the significant confusion experienced by care recipients, caregivers did not use formal community supports extensively. Instead, family caregivers respected their mothers' wishes to be independent, even if it meant letting the parent live at risk. However, the caregivers' efforts to support their parent's wish to live at risk were not without criticisms from friends, family, or formal service providers. Becky reported: "My friend was very critical of my decision to let my mother live on her own." This caregiver resolved the dissonance between the pressures resulting from the expectations of others and her own value of maintaining her mother's independence this way:

We have done really well; she was able to be totally independent. You know I think people want to have prevention the ultimate consideration but I had to basically trust myself that she would be okay. And so I think that it was good that we did it but it was hard.

David was able to resolve the issue of safety by acknowledging to himself that caregiving to a cognitively-impaired parent was a tremendously challenging activity that would likely not result in “perfect” outcomes all the time. Essentially he felt that carers should be acknowledged for the difficult caregiving decisions they face, rather than be made to feel guilty for what they did not do:

You want to provide safety, but I mean there are a lot of things you are responsible for. It is hard to judge from the outside, it really is. I mean you just don’t realize what the person [caregiver] is going through. Because the person [providing the care] is always thinking, “well, what happens if they wander off and get hurt and die”, and then you’re wound up with all this guilt, so I mean you can’t win, either way. You really can’t.

Claire described the comments of a co-worker that eventually provided the impetus for making a different decision about her mother’s care:

One of my co-workers said something along the line like “well you have to look after yourself. You will have to put your Mom in a home.” I didn’t say anything at the time but I remember thinking “who do you think you are telling me...you don’t know my mother, you don’t know my family situation.” But something about what she said, although I resented it at the time, got me thinking about it and then I made an effort to phone home care and get her assessed. And you know maybe sooner than I would have even though I resented her telling me this.

Claire wanted to be seen as responsible. When her co-worker questioned Claire’s decisions around caregiving, Claire found herself feeling resentful that someone had judged her without knowing the complexities of her situation. While Claire perceived her co-worker’s comment as critical, it essentially forced her to consider her responsibility for her own self-care and her mother’s safety. This interaction highlights the powerful influence of caring ideals that are communicated back to the caregiver. These external feedbacks, which can be either negative or positive, has the ability to either reward or punish the caregiver for their efforts.

Caregivers described caregiving as a process that resulted in a constant state of watchfulness and monitoring. This enabled them to maintain the precarious balance between respecting their parent’s wish to live independently and to ensure the safety of their confused parent and others who may be harmed as a result of confusion. Becky described an experience this way:

She was [wandering] and she had walked all the way to the bridge, then she fell and a woman nearly hit her in a vehicle. That is when my spouse said to me "look, we have to do something because that woman could have killed your mother so not only is your mother getting killed but that woman's life is ruined". Somehow that really impacted me, you know as much as we tried to keep Mom independent, the time had come when we could no longer continue as we were...so I phoned the nurses and said we have to make other arrangements.

In most cases, when it became evident that the parent's behavior might have a harmful effect on themselves or others, family members intervened to make alternate decisions. While this example highlighted the problems with wandering, Becky also described other safety concerns, such as the time her mother started a fire in her apartment and “smoked the building down”.

Other family members described their process of intervening when it became apparent that their mother could no longer manage their finances.

2) "Everybody's upset. We need some help here": Re-evaluating responsibility and commitment

For most caregivers, balancing responsibility for parental needs with giving attention to other family members was a stressful experience. For two of the participants, issues within the marital relationship acted as a catalyst to the decision to access formal service use. Lynn described the impact that caregiving had on the deterioration of her relationship with her spouse. Lynn's family had initially refused to consider formal supports because of feelings of guilt. Finally after a family crisis, Lynn went to the offices of Continuing Care and said, "I have to talk to somebody. Our marriage is breaking up. Our (mother) is upset. The kids are upset. Everybody's upset. We need some help here."

Becky described her spouse's perspective regarding the caring situation:

[Caring for my mother] was rather hard on my relationship with my [spouse]...[my spouse] has heart problems and he said, "you know, it is quite possible that Mom will outlive me. She has had an active and a good life." [My spouse] said if I wanted to [have Mom live with us], that was fine, but he was not going to [stay home]. He was going to carry on doing things.

Essentially, Becky's spouse had provided a set of expectations about what he would and would not support for both himself and his spouse in the caregiving role. By placing limits on his caregiving activities, he was communicating to her that she was primarily responsible for the management of her mother's care. Becky, who had significant health problems of her own, eventually decided to institutionalize her parent so that more time could be devoted to other family members. However, in institutionalizing her mother, Becky recognized the concomitant change in her role as the primary caregiver and decision-maker:

You do lose control of their care...they put a catheter in and there was absolutely no output. I knew she didn't need it. I said to the nurse, she hasn't been drinking, there is

not going to be output. I talked [to my daughter] about cutting the catheter, taking the sucker out. By the next morning she had pulled it out. I thought “good for her”. And I talked to the doctor about it and of course I think then I realized that we had lost control of her care because I know it wasn’t right for her but it didn’t make such a big difference.

Becky’s narrative, which repeats “loss of control”, shows the difficulty she experienced relinquishing care to hospital staff. She felt responsible for her mother’s care even after her mother was hospitalized, yet had no way of directing it and felt her expertise as a caregiver was not valued or considered.

**“I finally just had to move on”: Use and acceptance of formal services**

1) “You just move on”: Finding acceptance with new role

All caregivers in the study reported that after a period of adjustment, they found a way to accept and adapt to the type of formal services they were receiving, recognizing at some point that they had exhausted alternative options. Becky’s quote, “I finally just had to move on. You just move on. You realize that you can’t change anything...” shows the shift that occurs when caregivers realize that their efforts are no longer sufficient and it is time to relinquish some control over the care of their parent to formal service providers. Although she was initially reluctant to relinquish her control over her mother’s care, eventually she accepted that the care her mother received in the long-term facility was appropriate for her mother’s needs.

Despite the guilt associated with handing over some of the personal care demands to a homemaker or to residential care, caregivers are often relieved once they are no longer responsible for instrumental care. This transition inevitably results in the caregivers reevaluating their role in the caregiving relationship. Kathleen described her experience as follows:

Like I wasn’t a daughter going to just visit when we didn’t have a care worker. Then when we had people come in and I knew she got her four food groups for every meal, she had her pill, she got a bath, I was a daughter again instead of the caregiver and that made a huge difference in our relationship.

Caregivers whose mothers were eventually institutionalized commented on the transition and their successes in finding roles for themselves as caregivers to parents living in a formal long-term care settings. Sam described himself as the “alternate decision maker” and “negotiator with the long-term system”. Beth described her emerging role as an advocate for her mother’s needs. She took it upon herself to search the Internet for better products to deal with incontinence. So, although family caregivers are no longer involved in the personal care tasks of caregiving once their parents are placed in long-term care, they still remain very involved in meeting their parents’ emotional, social, psychological, and financial needs.

However, the transition to the use of formal care services was not without challenges. All caregivers described certain characteristics that they perceived as barriers to service use. An interesting finding was that caregivers were more inclined to speak out about their concerns and criticisms of the formal system in the focus group discussion than in the individual interviews.

## 2) “You don’t know what is there until it is too late”: Confusion and fragmentation in formal care system

All caregivers emphasized that the lack of information in the early stages of their caregiving experience had created a lot of confusion and difficulty for them. Typically, caregivers' first contact with the formal support system was their own general practitioner. While half of the caregivers in the study felt supported and assisted by their general practitioner, the other half described their contact as “frustrating” due to the fact that their concerns were not taken seriously, nor were they given any useful information to handle difficult behaviors.

Most caregivers reported that, at least initially, they had insufficient information to assist them in choosing alternatives. Beth articulated what she needed: “What is needed is a sort of map of the organizations and what exactly their functions are because I never really knew in the beginning whether I was talking to the right person...”. Jackie said: “I think there are a lot of

resources there but you don't know about them until it is too late and then you say 'why isn't someone helping me'". In the focus group discussion, the fragmentation and lack of information of community services again surfaced as an issue of concern common to the majority of the participants. Despite the fact that the majority of the study participants were professionals, some of whom worked in health care themselves, they encountered difficulties either in accessing information about what help was available or in negotiating existing services. This ultimately acted as a barrier that limited their use of formal services.

### 3) "They don't phone and say 'how are things going?'": Lack of recognition for caregivers' efforts

The enduring theme expressed by caregivers was that they wanted to be recognized and appreciated by the health care system for their efforts. Beth said that her decision to eventually relinquish care to formal service providers was influenced by the lack of recognition she was given by community service providers for her efforts: "what is the point? Why put yourself through 12 hours of torture when there is no recognition of the efforts caregivers put in".

Another concern expressed by caregivers was the lack of follow-up by community case managers to ensure that caregivers feel supported or to see how they are managing. Lynn said: "they don't phone and say 'how are things going? Do you need more help?'" This contributed to a sense of isolation and frustration for caregivers.

Other caregivers described their sense of disempowerment when their needs had changed and they had to approach long-term care for increased home support or placement. They felt as though they had to beg to get additional help and that the assessor ignored or discounted their knowledge about their mother's functioning. Kathleen described her experience with the continuing care assessor: "I knew my mother needed help. Then we had her assessed and they

refused her. They more or less insinuated that maybe there was coercion involved.” Beth described a similar experience:

This woman was about an hour late, then she was there for 15 minutes and the report came back that there was no problem, that they didn’t know what we talking about. Of course then you feel really guilty. Like we are thinking what is happening here and it was just an awful feeling. I was furious. So you get someone telling you that you are not doing a good enough job, that you should be able to look after this person.

Instead, caregivers felt that assessors should be more validating of their efforts and sensitive to their limitations as caregivers:

I mean sometimes you almost have to be encouraged [to access help]...although I initially resented [others telling me what I needed], it got me thinking about it and then I made an effort to [make arrangements to access community supports]...and you know maybe sooner than I would have otherwise.” (Claire)

The fluctuating nature of cognitive-impairments often resulted in the elderly parent performing well during assessments by case managers. When the caregivers attempted to provide a more longitudinal picture of the parent’s functioning, they felt their descriptions were perceived as exaggerated. Furthermore, caregivers felt their particular circumstances were not taken into consideration during homecare assessments. This paternalistic approach to assessing caregiving situations left caregivers feeling misunderstood, unsupported, and exploited.

On the same theme, Becky described the challenges she faced when she finally conceded she needed the help of others. Becky described the advice she was given by professionals in the hospital:

You know, the way this is going you are just going to have to just leave your mom because nobody is going to help you”. She said, “you are just going to have to leave her and refuse to look after her because if you don’t nothing will ever change.

Lynn commented that she had been advised by her general practitioner to “just drop (mother) off in Emergency”, in response to her plea for advice about her caregiving situation. She did not perceive that comment to be helpful in the least as she felt it had undermined her family’s efforts to be responsible caregivers. Her experience suggests that a demonstration of uncaring behavior

is a more effective means of being heard in the health care system than efforts towards dialoguing, collaborating, and negotiating.

4) “I don’t want to be stuck if this (caregiving arrangement) doesn’t work”: The need for flexible formal support program criteria

The caregivers expressed their feeling that the long-term care facility placement criteria should be more flexible and accommodating. They want to be assured that if they choose not to put their parent into a facility when their name comes to the top of the waitlist that they have the option of doing so if a crisis arrives: “to be able to place her in care if the situation ever arose would be a good thing to have; otherwise you just feel overwhelmed” (David). The three caregivers who did say “no” when their parent’s name came to the top, said that when they were called and informed of an opening, they felt they were coping fine with their arrangement at that time. Unfortunately, the Jacksons, who had initially refused a bed when first called by long-term care, subsequently encountered a crisis in the caregiving arrangement. When they called long term care to make alternate arrangements, they were shocked and discouraged to find that their mother’s name had gone to the bottom of the waitlist as a consequence of turning the placement down when first called.

Participants described the process of accepting placement as a decision that is reached gradually. Often caregivers will say “no” initially because they still have guilt about the decision or they believe they can still manage. Beth explained the process this way: “We [refused to place Mom when they called the first time] because we thought that this is what we needed to do. The second time [they called] we had hired someone to come and live in my mother’s home.” The latter arrangement broke down very quickly, unfortunately, and Beth had to finally place her mother in a care home because informal care options had been exhausted. However, what Beth and others wanted to say was that families do want to pursue community options before making

decisions about placement, but if these efforts do not work out, they expect the formal support system to respond appropriately: "I guess you have to keep trying until you can't do it anymore...but I don't want to be stuck if this (caregiving arrangement) doesn't work." (Beth)

5) "They don't give you what you need": Adequacy and appropriateness of formal support services

Caregivers expressed their view that the needs of someone with dementia and their caregiver do not always fit within the services provided within the formal system of care. While caregivers perceive their greatest need to be assistance with supervision of the person with Alzheimer's, the community care system's mandate is to provide assistance with personal care tasks such as bathing and feeding. Claire said, "I remember them phoning offering to come and help get Mom ready for bed. Well getting Mom ready for bed isn't a big deal. This is not what I needed so what help was that?" Becky said, "they don't give you what you need, which is to sit and hold their hand." Thus, in many situations, the care provided by homecare is perceived to be inappropriate to serve the needs of families caring for parents with dementia. Sam described the lack of community supports in his rural areas as a system weakness that ultimately influenced his family's decision to move their mother to the United States. There she could be closer to the family member who could best accommodate her needs for supervision within his community. In the meantime, Sam had his mother waitlisted for a facility placement in this region. However, Sam's efforts to find a creative way to accommodate the needs of his mother until such a time as her needs could no longer be accommodated in the community resulted in conflicts with the gatekeepers of the long term care system. Continuing Care officials had insisted that this caregiver's mother return to Canada every few months to be reassessed. This trip, which requires a significant change in the parent's environment, is difficult for someone with Alzheimer's. Although caregivers recognized the difficulty of the gatekeeper's role, they

also expressed their frustration with the inflexibility of long term care program criteria and the lack of recognition for their efforts in keeping their parent in the community.

Jackie also found herself struggling with the Continuing Care policy criteria when her mother-in-law moved into their rural home. She found that if they accessed homemakers to assist with supervision in their region, they would no longer qualify for the adult daycare respite in the urban area; that is, they could not access services from two different areas of the Continuing Care system. The inflexibility of the system to accommodate this family's needs resulted in tremendous additional travel expenses for commuting to the larger urban center where their respite needs could be better met.

Of the five who had accessed homemakers, all reported that they were dissatisfied with some aspect of the practical help and support they received from these formal service providers. Most commented on their lack of control over care once formal services were initiated, the inflexibility of the service itself, or the inadequate training levels and lack of sensitivity to aging issues of the service providers. Beth described her experience with homemakers provided through community care:

We had homemakers but I don't know, there was one or two...they were never the same...like you'd have one person one week then another the next week...it was a certain quality of person...they are very caring people but not very bright. We really hit a bad string...so that was a very unsatisfactory thing...and when you are dealing with people like that all the time you find that some people have no respect for a person's dignity and they would treat her in such a way...bossy and then she would be so mad.

The majority of the participants commented that the endless stream of unfamiliar homemakers made it difficult for their parent to trust the outsider. As a result, their parent was more resistive to that help. Furthermore, the care plan designed by Continuing Care is very much "top-down", with families having little or no control or input into the care provided.

Two families resolved their caregiving dilemma by hiring private homemakers. This option provided the families with more control over the service. It allowed for the homemaker to

become more familiar with the care recipient. This kind of relationship ultimately reduced resistive behaviors and provided more assistance to the caregiver. Furthermore, the consistency and the quality of the service was found to be superior to that of the publicly funded system of homecare. David attributed his family's ability to sustain their caregiving relationship to the fact that they found a respite worker who "really made a difference." My professional experience, however, tells me that private homemakers are an option that few caregivers can afford, despite the subjective benefits and positive outcomes reported by the participants.

6) "[Respite] is my life-line": Community resources perceived to be helpful by caregivers

Respite in both forms - a day program and a short stay unit within an extended care unit - was mentioned as a service that most participants had utilized and had found to be particularly useful as an emotional and physical time-out from caregiving. Lynn described respite as her "life line" as it had allowed her "time to regroup". She felt by that by using respite she did not resent the caregiving as much as she had initially. However, those who used respite found the criteria inflexible. For instance, short stay respite was only available through an advanced booking system, so caregivers had to plan their breaks months in advance. Such advanced pre-booking did not allow for emotional and physical relief when a crisis in the caregiving arrangement occurred. Furthermore, respite was only available to those who were on waitlists for residential placement. In fact, most caregivers had delayed placing their parents' names on waitlists, preferring instead to see the process through as long as feasibly possible. As such, they were ineligible for respite. Despite these confines, those who used respite found it to be a valuable resource.

The use of respite was not without its challenges, however. Lynn recalled that her first short-stay respite experience had fallen short of her expectations. While the respite was an opportunity to give her and her husband a break from the instrumental tasks of caregiving, they

had difficulty adapting their behavior to take full advantage of their unstructured time together without the demands of their mother. Lynn described her experience this way:

I couldn't wait for [respite] and I thought that instantly we'd be back to normal and things would be really happy, we would be doing things together and it would be lots of fun. We sat exhausted for three days...we just sort of sat like zombies on the couch... I found that so curious and interesting that we were looking so forward to it and we ended up almost wasting it anyway.

Essentially, by the time the respite was booked for this couple's mother, both husband and wife caregivers were exhausted and their relationship was feeling the strain of the caregiving demands. These caregivers felt like they had not had a break and felt a little resentful when it was time to resume the caregiving. Thus, Lynn recognized that respite was most beneficial when the time away from caregiving was carefully planned.

The utilization of respite was not without feelings of guilt. Lynn described her mother-in-law's opposition to respite care: "She is really happy when she comes home, but she was quite mad at us when we picked her up. She did not seem to be happy." They were instructed to not come in to visit their mother during the respite care period. Lynn described how upsetting this was to them: "two weeks is too long for us not to go." Although the instruction to withdraw from everyday visits was likely meant to assist caregivers achieve the maximum benefit of the respite, caregivers had difficulty adjusting to their parent's absence and legitimizing their need for a break.

Other caregivers who had used respite care in the form of a day program found that although their mothers were initially not keen to attend, the caregivers persevered, recognizing that the daycare was essential to their own well being. Employed caregivers stated, however, that as the daycare operated only two days a week, it was a limited option for anyone trying to manage both work and caregiving to a confused parent.

Another resource that caregivers found to be helpful was the Alzheimer's Society,

particularly for education and support purposes. Other caregivers, who had not accessed the support of the Alzheimer's Society, felt that their journey would have been easier if they had. Information that caregivers found particularly useful on the Alzheimer's website were typical behavioral problems and lists of resources (books, videos, and booklets) that could be purchased or accessed through libraries.

The Jacksons, who had cared for their mother at home until her death, could identify two resources that would have helped them care for their mother in the latter stages of Alzheimer's disease. Firstly, they felt that a visit by a community physiotherapist would have been helpful to teach family members proper lifting and body mechanics for transferring their mother from bed to chair, bath and car. The second resource that they identified as potentially helpful would have been a book describing end-stage Alzheimer's and the dying process.

Finally, these caregivers were not looking for answers to their caregiving dilemmas exclusively within the public system of formal support; rather, all participants had the financial resources to explore private options when the public system options were deemed inadequate or unacceptable.

## **Chapter Five**

### **DISCUSSION & RECOMMENDATIONS**

This chapter provides a discussion, which summarizes the conclusions drawn from the findings, and compares these to existing literature on caregiving. Implications of the findings for caregiving theory and social work practice are addressed. Recognizing that this study has limitations based on sample size, tentative recommendations are discussed for changes at the micro and macro levels. Finally, limitations of this research and directions for future research are discussed.

This study illuminates many creative and unique caregiving relationships, some of which are maintained across cities while others are maintained across provinces and countries. Gender role assumptions exert the greatest influence on who assumes caregiving responsibilities within families. Where families include both genders, females adopt caregiving as the “natural order”. Where families include only sons, these sons adopt the primary caregiver role, with their spouses taking a secondary role. Often parents move or are moved from other locations to increase geographical proximity and facilitate the caregiving relationship. These responsibilities impact the caregivers’ health, employment commitments, and family relationships.

Furthermore, gender roles influence the emotional experience of caregiving. While daughters-in-laws in the study group were able to set boundaries around caregiving, it was not without guilt for resisting powerful expectations around women’s roles. On the other hand, most male caregivers providing support to either their mothers or to female caregivers, are able to articulate their priorities assertively and draw the line between what they are prepared or not prepared to do to maintain their health and marriage.

The findings suggest that the physical and emotional toll associated with family caregiving is great. Despite the physical, emotional, and psychological demands, caregivers

choose to continue to provide the majority of informal care to their elderly parents even when options for services within the formal system of care are available to them. Although service characteristics are important, decisions to utilize formal care services are greatly influenced by the values and attitudes of the caregiver and recipient. Many frail elderly in this study resisted formal services due to their own preference for family care and their reluctance to admit their dependency. These attitudes are largely the product of society's expectations around family care and larger societal values that view aging and dependency as negative. These attitudes serve to perpetuate the exploitation of caregivers by hiding the care that is provided by families to the frail elderly.

Despite the emotional and physical strain, the majority of the caregivers in this study make their message clear. It is their preference to take care of their elderly parent in the community as long as possible. They view this responsibility as part of a continuum of family caregiving based on values of family obligation, reciprocity, individuality, and respect. Furthermore, power relations within families dictate who will care and how it will be carried out. This finding is similar to those of Piercy and Chapman (2001) who found that caregivers create their caregiving roles from the expectations and role modeling of others. Caregivers describe how family care has been modeled to them in other caregiving relationships within the family. These findings also corroborate the findings of Piercy and Blieszner (1999), who found that decisions regarding formal service use are based on multiple and complex circumstances as well as the beliefs and values of each caregiving family.

Essentially, families want to be seen as responsible. They want to "do the right thing" for their parent and are therefore reluctant to use formal services until they have exhausted services within their informal networks. However, although caregivers value their relationship with their parent, the findings suggest that when caregivers no longer receive acknowledgement or

appreciatory feedback for their contributions from their parent, friends, or service providers, caring loses some of its rewards. This finding concurs with Wuest's (1997) grounded theory of environmental influences of women's caring. Positive external feedback is a necessary condition for continuing to care.

Caring for a parent with confusion involves more than simply providing assistance with daily tasks. The families describe their efforts towards meeting their mothers' needs for personal care, as well as emotional support, safety, autonomy, and socialization. This finding is consistent with Piercy (1998) who showed that the conception of filial responsibility extends beyond the performance of hands-on caregiving tasks; rather, non-instrumental assistance is a critical component of caregiving to a family member.

Furthermore, wandering is one of most challenging behaviors caregivers have to deal with, yet it is virtually unaccounted for in homecare policy. Thus, it is a "hidden" task of caregiving that can be more arduous and tiring than other more measurable tasks, such as bathing and food preparation.

The findings of this study also highlight the role that informal support plays in sustaining the caregiving relationship. Where possible, families attempt to widen their informal caring network to include other family members, friends and neighbors. However, for some caregivers, this strategy has limitations. Friends and neighbors are often reluctant to get involved due to the lack of caring rewards and the possibility that they may be seen as responsible for any negative outcomes related to the person's confusion.

Other families in this study were successful in sustaining the informal caregiving relationship much longer than one would expect given the degree of decline and dependency of their mothers. Sustaining caregiving relationships, however, is contingent on the families' ability to articulate what they need from others within the informal and formal support systems.

Where families have difficulty doing so within their informal support system, conflict inevitably arises, resulting in greater dependency on the formal system of care. This finding is consistent with those of Wuest, Stern, and Irwin Jr. (2001), which highlighted the impact of negative social support for caregivers. These authors found that the presence of both formal and informal support does not necessarily mitigate the burden of caregiving. Rather, the caregiver must perceive the support to be helpful.

Caregivers in the study also encountered difficulties expressing their needs to professionals within the formal system of care. Often their expressed needs were ignored or devalued. This finding is also similar to those of Wuest, Stern, and Irwin Jr's (2001), which found that formal support providers were often unwilling or unable to provide the support requested by the caregiver, particularly if the caregiver is a woman.

Furthermore, caregivers in this study emphasized their lack of knowledge about services available in the formal system of care. As Wuest (1997) argues, "availability of resources depends on the existence of resources, women's knowledge of them and their accessibility" (p. 54). So, although services may be offered in the community to assist caregivers, they are of limited value when caregivers lack knowledge of their existence and do not feel their needs are being understood.

Although the care recipients in this study were objectively assessed as eligible and indeed requiring many services under the long term care system, family members declined services due to their own or their parent's attitudes about accepting outside assistance. Instead these frail elderly people continued to live in the community, where adaptations were made to their environments to accommodate their confusion and functional decline. In at least two of these cases, these adaptations alone may have been responsible for improvements to their parent's functional level. This highlights the importance of augmenting the efforts of families by

providing support and education to assist them in their efforts to find a solution to their particular caregiving dilemma. These findings do not support rationalist theories that suggest that service use can be predicted based on the amount of functional decline alone (Ganzer & England, 1994).

The findings of the study suggest that the process of becoming a caregiver and sustaining the caregiving relationship is not without tremendous emotional strain. Due to numerous losses and the protracted and uncertain course of the illness associated with the cognitive-impairment, family caregivers tend to fluctuate through various stages of grief. The caregivers' descriptions of their feelings correlate with stages of grief outlined by Ponder and Pomeroy (1996), which include feelings of denial, overinvolvement, anger, guilt and finally acceptance. These findings are also similar to Jeon and Madjar's (1998) findings, which found that caregivers to family members with chronic mental illness suffer from ongoing grieving due to the lost possibilities that a mental illness presents for both the ill relative and the caregiver. Despite the stress and emotional burden of caregiving, caregivers also describe benefits, such as personal satisfaction with one's caregiving efforts, associated with the experience.

The findings show that the emotions associated with grief become strong determinants of behaviors concerning accessing formal support. Caregivers in the study initially experienced feelings of denial and guilt. In these stages caregivers are more inclined to maintain attitudes that favor family care and less inclined to seek the assistance of others in their support network. As emotions and experiences with caregiving became more negative, caregivers typically change their behaviors and seek help. However, for at least one of the study's caregivers, the use of formal support services, i.e. residential services, was not associated with negative emotions; rather, it was regarded as a proactive, preventative measure that ensured both the well being of the parent and the caregiver.

For most carers in the study, the use of formal support services reflected a point at which the informal caregiving arrangement was no longer sustainable, for a variety of reasons. Despite their own and their mothers' preferences for family care, contingency plans within the informal support network typically become exhausted. The caregiving arrangement reaches a point of crisis in which care is reluctantly relinquished to professionals, often with resistance from the frail elderly parent. Fine and Jurdek (in Piercy and Biesznier, 1999), labeled this kind of intervention as parentalism, which is the placement of restrictions on individuals who have demonstrated the potential to harm themselves or others, or to contribute to a loss of benefits for themselves, through their behaviors.

Often the decision to utilize formal services is determined when the caregivers recognize that other relationships within the family have suffered as a result of the caregiving demands. Like Piercy (1998), I found that adult children are more likely to utilize formal supports if other relationships within the family have unattended needs.

As discussed, my findings support and further articulate detailed studies of family caregiving reported to date. For the most part, these findings also corroborate my experience working with families in an acute care setting. The caregivers in this study articulated their challenges accessing information about formal care services and their frustration with the service itself. This finding is consistent with the caregivers with whom I am professionally associated. Caregivers, both in and out of the study, find the formal care system fragmented and do not know where to begin to access appropriate services.

In my work, I also find that women are the predominant providers of care and most of these caregivers are balancing work and family commitments. Yet, this study illuminates unique, and perhaps non-traditional, ways in which male caregivers also care for their parents. The active participation of male caregivers in the study is also consistent with my professional

experience. Increasingly, I find myself dealing with adult sons who are the primary caregivers to their frail parent. Although, in comparison to female caregivers, they may not provide the same degree of personal care, they support their frail parent in many other valuable ways.

It is my experience that families find creative ways to manage caregiving within their own resources and are proud of their efforts. Although I had made an assumption that families would be eager to talk about the challenges of caregiving and their use of formal services, these are not the most important issues for families. Instead, caregivers are more interested in sharing the unique ways in which they sustain their caregiving arrangements. Furthermore, caregivers were eager to share information about their relationship with their mother and how this had influenced their attitudes toward accepting services. This is an important discovery for me because it allows me to recognize the importance of relationship continuity, despite cognitive impairments.

Where my findings conflict with my workplace experience is in the area of utilization of private sector resources. The families in this study utilized extensive private residential and homecare options and, therefore, underutilized options available to them from the public sector. The decisions to employ private homemakers were largely based on unsatisfactory experiences with the services provided in the public system. My professional experience differs in that most families do not have the financial means to access options in the private sector.

### **Implications for Caregiving Theory**

The findings of this study suggest that Bass and Noelker's (1987) modified version of the Andersen and Newman (1973) service utilization model is incomplete. It does not make explicit the powerful influences that societal and political factors have on the contextual experience of caregiving, which ultimately impacts service utilization decisions. A more appropriate model would include the values and expectations of our society, influences of relational and attitudinal

factors within the family and the community, the perception of need, the expectation to care, what services are provided and under what conditions. An expanded conceptualization would emphasize the personal/family and sociopolitical factors that influence attitudes about service use. These factors would include values and norms about the elderly, family caregiving and gender roles. Sociopolitical factors also influence social policy and government priorities towards services and programs for the elderly. Furthermore, these sociopolitical factors contribute to caregiver stress (need factors) and influence access, awareness, and experiences with services.

The caregivers in this study had developed attitudes about service use that were based on powerful internalized and externalized values about family responsibility and family caregiving. Furthermore, attitudes about services are partly based the caregiver's experiences with options and services available to them. Services to support family care are the product of government social policy that, in many ways, contributes to the exploitation and impoverishment of women (Morris, Robinson, & Simpson, 1999). Caregivers found that, for the most part, services provided in the community were neither appropriate, adequate, nor convenient. Caregivers want to remain self-reliant and in control over care to their parents; yet, formal services provided through Continuing Care permit only minimal flexibility or family input. It is only when families do not perceive any alternative options to their caregiving situation that they find a way to accept services provided through the publicly funded system.

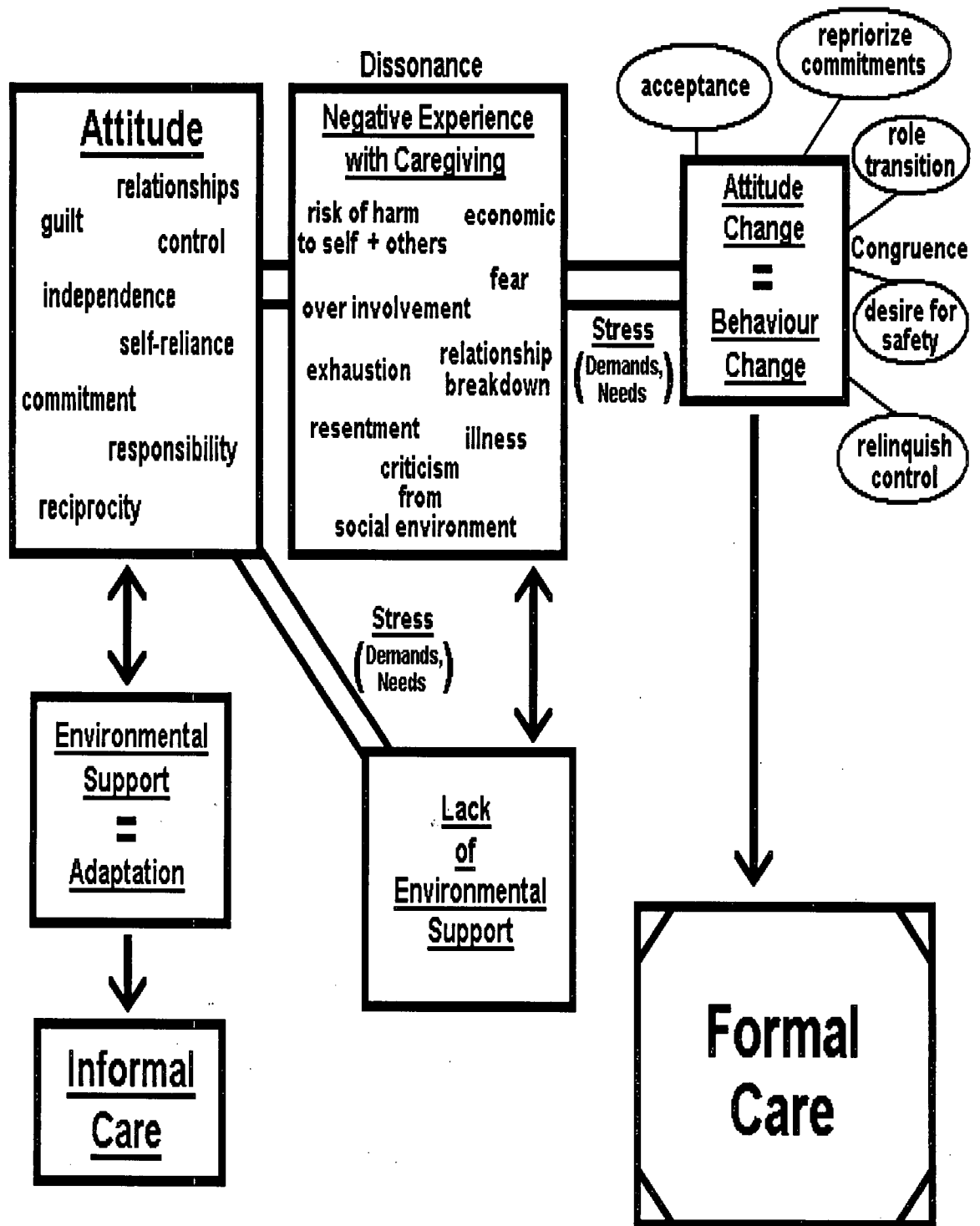
These findings are generally consistent with a systems-ecological perspective, which emphasizes the role of social support in the facilitation of adaptation to environmental pressures. The texts of the caregivers reveal turning points where certain attitudes towards family caregiving and service use change. These are largely based on situations where the stress of caregiving can no longer be accommodated within the informal network.

The flow chart in Figure 2 proposes a process by which families change attitudes towards service utilization. This process uses cognitive dissonance theory and systems theory (explained in Chapter 2) to explain attitude change. Essentially, this conceptualization proposes that attitudes are changed based on negative experiences with caregiving. Where a caregiver embodies attitudes about family care that are based on values of relationship, independence, self-reliance, control, commitment, responsibility and reciprocity, and where there is enough social support to sustain the stress of the caregiving arrangement, informal care options are more likely to be used. In contrast, where a caregiver experiences enough negative experiences with caregiving, including criticism from others in the social environment, risking someone's life due to poor decisions, or contributing to the breakdown of one's relationship, and where there is a lack of environmental support to mitigate the negative experiences, attitudes about caregiving change. The result is greater reliance on, and acceptance of, the services of the formal system. The shift, whereby caregivers conform to external pressures, results in the reduction of cognitive dissonance. This may occur at the expense of one's sense of control over caregiving decisions.

Clearly, while family care was the preferred model of care for the caregivers in this study, few caregivers were actually able to sustain this arrangement over the duration of the caregiving course. The need for approval in the social context outweighs the maintenance of attitudes that produce negative consequences for either the caregiver or the care recipient.

Figure 2

## Attitude Change + Use of Formal Services



This proposed explanation of attitude change is also useful in understanding the consequent behavioral change that occurs when family caregiver's adopt new attitudes about formal services. Essentially, the use of formal supports reflects a transition point where family caregivers relinquish some aspect of control in one area of caregiving. Attitude congruence is achieved by caregivers coming to accept that their ability to provide an increased level of care is limited. At this stage commitments are reprioritized to ensure safety and wellbeing for themselves, their parents and others in their support network. The caregivers in this study found a way to provide assistance even after formal services were present, but in a different way. These findings refute the substitution theory used by health economists that when formal services are provided, there is a parallel and commensurate decline in family involvement in the care. Rather, the findings, which show a strong preference for family care and the use of formal care only when family care is no longer adequate, support the complementary model of care described by Denton (1997) in which formal care has compensatory and supplementary functions.

### **Emerging Implications for Policy and Practice**

This research sought to gather practical knowledge about family caregivers' needs from the perspective of the caregivers themselves. The value of this research lies in the use of the caregiver's voice to develop knowledge and understanding of caregiving to the frail elderly. The findings of this research reveal many important areas that have implications for practice with the elderly and their caregivers. They are presented here as discussion issues rather than formal recommendations. Further enquiry is needed to make formal recommendations in these areas.

- **Recognize caregivers' contributions**

Caregivers must be recognized and acknowledged for the tremendous work they do. Caregivers in this study provided many hours of care to their parents and did not access public resources until they had exhausted their own informal resources. Social workers have a role to play in providing emotional support and assisting these caregivers to deal with difficult decisions in the informal and formal social support networks.

The caregivers in this study want their input into their parent's needs to be heard and validated. More than anyone, caregivers have the experience and expertise to know what works and what doesn't. The formal care system's tendency to medicalize and compartmentalize caregiving tasks into "deserving" and "non-deserving", based on medical necessity, ignores the diversity of caregiving circumstances and caregivers' perceptions of need.

- **Recognize the uniqueness of the caregiving relationship**

Family members in this study accessed formal care reluctantly, due to a variety of complex interrelated factors described earlier in this report. Exploring the caregivers' beliefs and expectations about services will illuminate perceptions about roles and responsibilities. Assessing the uniqueness of each caregiving relationship will allow for the discovery and development of the caregivers' internal and external resources. Carers must be supported in their efforts to sustain caregiving, yet made aware of the formal service options available to them.

- **Recognize caregivers as partners**

The formal care system must recognize family caregivers as partners. The caregivers in this study wanted to remain involved in their parent's care, even after institutionalization. Not only do caregivers hold important contextual information, which is vital to the formulation

of a unique care plan, but also the best care in the community comes from a collaborative effort in which services are provided from a variety of informal and formal providers.

Family caregivers should act as case managers, in a role that directs and controls the care for their parent. This approach requires a shift in assumptions that the trained professional "knows best" to one that respects and accommodates the unique needs of the caregiver and the care recipient (Keating, Fast, Dosman & Eales, 2001). Using this approach, family members should also be consulted for their suggestions on policy development regarding services and supports.

Furthermore, to ensure families, and especially the women that provide the majority of the caregiving to the frail elderly, are not unduly disadvantaged, either financially or socially, by their caregiving responsibilities, changes need to occur at both micro and macro levels of society. At the micro level, community care policies must no longer reflect the assumption that there is a daughter or a wife standing by to assume care. As practitioners, we have a role in constructing caring ideals and creating environments that include men's caring. (Macro level changes will be discussed in Eldercare Workplace Policy.)

- **Improve and facilitate access to formal services**

The findings of this study suggest that decisions to use formal services are emotionally charged. The families in this study did not make these decisions lightly. Therefore, long term care policies, including those around respite, residential placement and homemakers, should recognize that families typically reach a breaking point at which the informal arrangement is no longer sustainable and where families require assistance without delay. In Gottlieb and Johnson's (2000) review of respite programs, they argue that a sense of control is an important variable to consider in mediating the effects of caregiving. They propose that respite programs should acknowledge the tremendous constraints caregivers operate within,

and allow caregivers the latitude and flexibility to withdraw from their duties when they perceive the need to.

Therefore, structural changes are needed in the long-term care system to ensure flexible program criteria and access to quality services when the caregiving context changes. Currently, in British Columbia, the substitution model is the prevalent model of home care; as long as family members are capable of providing care, formal services will not be offered. The results of this study showed that families have a strong sense of commitment and responsibility and want to care until they can no longer do so. Furthermore, contrary to the substitution model of health service, which suggests that informal and formal are essentially in competition, caregivers do not abdicate their responsibility to care when formal services are finally accessed. Access to these services needs to be available not only to the elderly without family care options, but also to those families who have a strong commitment to caring but whose circumstances no longer permit them to do so. Criteria should value the boundaries caregivers must set to attend to other competing, yet important needs.

- **Ensure quality home support services**

Home support services make it possible for the frail elderly to remain independent. Yet, caregivers in this study found that these services are provided in such a way that they are inappropriate or inadequate. First of all, the homemakers, who themselves sit at the bottom of the healthcare hierarchy, are often poorly trained and poorly paid, resulting in a high staff turnover. Secondly, home support services are provided on a rigidly structured basis, which ignores variances in family caregiving arrangements. Furthermore, these services are currently being cut as regional health authorities respond to decreased health care funding. These cuts will make it even more difficult for families to provide care while managing other employment and family commitments. Practitioners must hone their advocacy and

consultation skills in order to work towards a comprehensive homecare system that is appropriate for the families with whom we work.

- **Improve Access to Information**

Families in this study emphasized that the lack of information about dementia care and community supports contributed to their burden. The burden of providing assistance to a confused elderly person, coupled with the perception of “being alone without options”, or feeling ineffective in one’s ability to access appropriate community supports traps caregivers in a downward spiral of stress and frustration. An information package on dementia, coping strategies, support groups, community care contacts, and resources that benefit caregivers should be available at appropriate contact points such as doctors’ offices and hospitals. This would address the concern expressed by caregivers that they did not know what to expect as the dementia progressed or where to go for assistance with their caregiving responsibilities. Community home supports that emphasize education and skills training will allow caregivers to understand the course of cognitive losses and the dynamics of dementia. Not only will this education help caregivers adapt, problem-solve and feel more competent in their role, but it will also enhance their ability to anticipate longer-term caregiving tasks and seek social support. Practitioners working with the elderly and their families have a role in not only assessing the knowledge and skill levels of the caregiver but also in providing the tools to assist caregivers with their role.

- **Education and Training for Health Care Providers**

To ensure that children providing care to frail family members are supported in their efforts, health care providers in the community must become more aware of the impact of caring for someone with Alzheimer’s disease. Currently, there are few social work and nursing programs that have electives in gerontology, yet the majority of our work in health

care is with the elderly and their families. While there are many potential intersection points between the caregiving family and the formal system of support, the primary contact for caregivers was either the hospital or their doctor's office. Thus, members of the health care team are in an ideal position to provide information and assess the caregiver's needs before a crisis occurs. Information packages should be provided in these areas so that families feel validated in their experience and understand the options available to complement their existing supports.

- **Eldercare workplace policy**

Changes are needed at the macro level to accommodate both male and female caregiving. While, caregivers generally perceived their workplaces as supportive and accommodating, two caregivers and one spouse of a caregiver left their full-time work to provide care to their parent. This finding suggests that family care legislation, which recognizes that childcare is not the only issue that women and men face in their working lives and as caregivers, is important for caregivers. Furthermore, pressure should also be placed on workplaces to provide increased flexibility, in the form of flex hours or job sharing, and adult day care so that caregivers can continue to work while assuming care responsibilities. For those who leave paid employment to provide care, retraining or assistance in gaining access to a job would reduce the barriers to returning to work.

### **Limitations of the Study**

This research provides a rich, in-depth analysis of the experiences of nine caregivers. Caregivers in this study were homogeneous in terms of social characteristics in that they were middle class, educated and each one of them had the financial means to access options outside of the formal care system. Although the participants may represent the least oppressed of all caregivers, their experiences provide valuable insight into the challenges and rewards of

caregiving. Data saturation, which occurs when the knowledge gained from the theory “fits all scenarios that may be identified in the larger population” (Morse, 1999, p. 5), was beyond the scope of this particular research. Despite this limitation, this research has generated important questions to be explored in further research.

In addition, the sample included participants from both rural and urban communities, perhaps broadening the scope of the research and limiting the extent to which saturation could be reached. Furthermore, this investigation was limited to caregiving of a parent with a disease causing dementia. In doing so, I may have excluded from consideration those most vulnerable, with their own caregiving and service issues. I realize that these excluded caregivers may include spouses, friends or neighbors, who may be either frail, employed, unemployed, geographically or socially marginalized.

For the caregivers in this study, the degree of cognitive impairment experienced by their parent was central to their decisions about accessing supports. In other contexts, such as in the case of family members caring for a parent with physical limitations, utilization of formal support services is more than likely negotiated with the consent and input of the cognitively-able care recipient. In acknowledging these limitations, I recognize that the purpose of the study was not to capture every permutation of family caregiving or relationships. In addition, I acknowledge that the interview questions may have influenced the solicitation of certain information while neglecting other important elements of the caregiving experience. However, I believe that focusing the interview on specific questions produced more in-depth data and narrowed the scope of the research.

### **Suggestions for Future Research**

This study illuminated unique caregiving arrangements involving sons. With respect to this, further research would be useful in the following areas: 1) an exploration of the male

caregivers' perceptions about appropriate caregiving behavior; and 2) an exploration of the differential treatment of men and women as caregivers by community support systems.

In addition, more research is needed on caregivers' attitudes towards institutionalization of their parents. Although this issue emerged as an important topic of discussion for caregivers, especially during the focus group discussion, it was not addressed in depth. Further research is therefore needed to look at cultural differences in perceptions regarding placement of frail elderly parents in nursing homes.

This study should be replicated using a larger sample of caregivers from diverse backgrounds. To ensure adequate data collection, ethics approval to recruit caregivers obtaining homecare or other services should be obtained. Many caregivers do not have options outside of the formal system and with cuts to these services anticipated in the coming months, further research is needed to explore the implications of these cuts to family caregivers. In particular, many frail elderly are currently being discharged from residential care facilities to accommodate the closure of many facilities in this region. Research with families is therefore warranted to explore the transition of a parent moving back home to family care after a period of institutionalization. Other families impacted by this process are those whose parents were on the long term care "waitlist" and have now found that the list is non-existent. In addition, because perceptions of family caregiving and service use are likely to vary with race and ethnicity, studies similar to this should be replicated among other cultural groups.

### **Dissemination of Findings**

Consistent with feminist research principles, which strive to transform knowledge and eliminate oppressive conditions, the findings of the research will be made available to the lay public as well as the academics and policy makers (Wuest, 1995). A summary of the findings, in a format that is generally written using lay language, will be forwarded to caregiver support

agencies and policy makers in the region. Accompanying this will be an invitation to anyone interested in further detail, to contact me to review the study in its entirety. In addition, UBC Library will have copies of the completed thesis, which may be accessed by library cardholders.

### **Conclusion**

The information produced by this study goes well beyond documenting service needs.

Using qualitative feminist methodology, this study considered the experiences of family members caring for elderly parents with a cognitive impairment. Using interviews and a focus group, caregivers discussed their experience becoming a caregiver and the process of accessing supports to assist with caregiving responsibilities. This approach allowed for the gathering of knowledge and insights contained in the caregivers' stories about their experience. While some information generated in this study can be found in other caregiving literature, this research lends insight into the emotional and gendered experience of caregiving and the physical, social, and cultural environment in which caregivers provide assistance and utilize resources to care for a frail parent. The insights contained in this report will be of considerable value to others involved in caregiving, and to anyone involved in the wellbeing of families providing eldercare.

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**Consent to Participate:**

I understand that my participation in this study is entirely voluntary and that I may refuse to participate or withdraw from the study at any time.

I certify that I have read, understood and received a copy of this consent form and that I consent to participate in this study. I agree that any discussions or interviews in which I participate in connection with this study may be audiotaped and tapes and other identifying data will be disposed of as outlined in the body of the above letter. I have been reassured that every effort will be made to maintain confidentiality and that I will have an opportunity to review the transcript of the interview if I so wish.

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Subject Signature

Date

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Signature of a Witness

Date

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## **APPENDIX V – Sample Interview Questions**

### **Interview Questions**

**Project:**       Caring for a Cognitively-Impaired Parent:  
                      Recognizing the Experience

**Questions:**

1.     Tell me what your experience has been like caring for a family member who has problems with his/her memory.
2.     Describe your experience using formal supports to assist you in your caregiving role. Please comment on the nature of the services you have used, their effectiveness and any barriers you perceive to the use of these and other services in the community.
3.     What were the things that influenced your decision to use or not use services in the community?
4.     How do you perceive your role and the role of formal service providers?
5.     What additional service (or change to an existing service) or information would be useful to family members caring for a confused parent?
6.     If you had to choose the “ideal” service to assist caregivers, what would it look like?
7.     What rewards or benefits have you gained from caregiving?