Chinese Female Family Caregivers of Persons with Alzheimer’s Disease: Feelings about their Experiences of Providing Care

by

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A thesis submitted in conformity with the requirements for the degree of Master of Science
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University of Toronto

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Abstract

This qualitative study explored Chinese female family caregivers' feelings about providing care for relatives with Alzheimer's disease. Twelve caregivers participated (two wives, eight daughters, and two daughters-in-law); all had emigrated to Toronto from Hong Kong after age 18. Pearl, Mullan, Semple, and Skaff's (1990) conceptual model (adapted) of Alzheimer's caregivers' stress guided the in-depth interviews which were conducted by the researcher in Cantonese. Data analysis was inductive and carried out manually. Responses indicated that all participants had applied to nursing homes but six viewed applications as backup plans only. Participants described caregiving as an obligation determined by their culture. While they appraised the same caregiving demands differently, most reported role conflicts and psychological burden. In general, participants seemed to be coping reasonably well. Responses may have been affected by: acceptance of the role, appreciation for services provided, openness to social support, and residence in an established Chinese community.
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Chapter 1

Introduction

As a result of the aging of the population, the number of persons afflicted by Alzheimer’s disease is expected to increase sharply in the near future. As many of the persons with Alzheimer’s disease remain in their own home in the community (Hall, 1988), there has been a growing concern about the welfare of family caregivers. Despite the extensive volume of literature on caregiving for persons with Alzheimer’s disease, ethnic minorities have been underrepresented in study samples (Aneshensel, Pearlgin, Mullan, Zarit, & Whitlatch, 1995). In fact, no study has been found on the population of Chinese immigrants in Canada with Alzheimer’s disease and their caregivers. The population of Chinese immigrants living in Canada is large and growing rapidly, and they will make up a sizable proportion of the Canadian geriatric population and of the population of persons with Alzheimer’s disease. Thus, knowledge of Chinese caregivers is valuable and warranted, and will contribute to services that better suit their needs.

Background of the problem

In Canada, 8% of people over the age of 65 and 35% of those over the age of 85 are affected by some type of dementia (Canadian Study of Health and Aging Working Group, 1994). Across all age groups, Alzheimer’s disease is the most prevalent type of dementia. For example, it accounts for approximately 60% of all cases in the age range of 65 to 74 years (Canadian Study of Health and Aging Working Group).

Alzheimer’s disease is progressive in nature. Although the onset of disease can occur relatively early in life, it commonly appears in a person’s 60s or 70s (Barlow & Durand, 1995). Common signs and symptoms of Alzheimer’s disease include loss of
memory, inability to learn, language difficulties, poor judgement and reasoning ability, spatial disorientation, and behavioral changes such as sleep disorders, hallucinations, and aggression. As the afflicted person’s personality and character is affected, the disease often leads to confrontation, disputes, and failures (Molloy & Caldwell, 1998). The earliest behavioral change observed in persons with Alzheimer’s disease is often loss of recent memory (Kuhlman, Wilson, Hutchinson, & Wallhagen, 1991).

Most older people with Alzheimer’s disease are being cared for at home (Schulz, Visintainer, & Williamson, 1990) and family caregiving for this population has received a great deal of attention. However, most studies are based on the mainstream population; for example, Kuhlman, Wilson, Hutchinson, and Willhagen (1991) reviewed the literature on Alzheimer’s disease published from 1979 to 1990 and indicated that most of the caregiving studies “have biased toward white, middle-class samples” (p. 334). Yet culture plays an important role as it defines one’s values of elderly people, shapes the meanings of health and death, and influences beliefs in the responsibility of kin to care for their elderly relatives (Lee, Kim, & You, 1997). As Chinese caregivers’ reactions to their caregiver roles may be different from that of the White caregivers (Kuhlman et al.), theories and research findings based on the White population may not be applicable to the Chinese immigrant caregivers.

Little is known about the Chinese immigrant caregivers, yet the population of Chinese immigrants living in Canada is large and rapidly growing. For example, a report released by the Toronto Area Office of the Ministry of Health (1993) has indicated that 3.2% of the general population in Toronto over 65 years of age spoke Chinese at the time of data collection. Furthermore, immigrants from Hong Kong and China accounted for
approximately 28% of the population growth in Ontario from 1991 to 1996 (Statistics Canada, 1997). As the incidence of Alzheimer's disease increases with age (Canadian Study of Health and Aging Working Group, 1994), the number of Chinese immigrants living with Alzheimer's disease is expected to increase sharply. Therefore, their experience needs to be considered within the larger context of research on caregiving for people with Alzheimer's disease.

Caregiving is usually defined as a woman's role and as the traditional responsibilities of a wife or daughter (Zarit, Todd, & Zarit, 1986). For example, Hu, Huang, and Cartwright's (1986) study on the cost of caring for elderly people with senile dementia describes the typical primary caregiver as a woman who provides an average of 6.5 hours of care per day. Chappell (1991) further suggests that for the population of people with Alzheimer's disease, wives and daughters provide the majority of the care. As women are the primary caregivers in the Chinese culture (Fung, 1998), it is crucial to explore the experience and needs of these female caregivers to fully address the issue of caregiving burden in order to prevent negative health outcomes in this population. Therefore, this study explores Chinese female caregivers' feelings about the experience of providing care for their relatives with Alzheimer's disease.

Definitions of terms

For the purpose of this study, terms commonly used in discussion of Alzheimer's disease were defined as follows:

**Persons with Alzheimer's disease**

Persons with dementia of the Alzheimer's Type who experience cognitive impairment "severe enough to cause significant impairment in social or occupational
functioning” such as working, dressing, bathing or other activities of daily living (American Psychiatric Association, 1994, p. 135).

Persons with Alzheimer’s Disease living in the community

Persons with dementia of the Alzheimer’s Type, who may be outpatients but are not patients of formal service providers, and who reside in their own homes or other housing facilities such as seniors’ apartments where formal nursing care is not offered.

Primary Caregivers

Caregivers who are “principally responsible for providing or coordinating the resources required by the persons with dementia” (Brashare & Catanzaro, 1994, p. 438).

As caregiving tasks provided for persons with Alzheimer’s disease living in different settings may vary, the hours of care involved is not specified.

Culture

A system of learned patterns of behavior shared by members of a group and “includes the concept of providing the individual and the group with effective mechanisms for interacting both with others and with the surrounding environment” (Krefting & Krefting, 1991, p. 102).

Caregiver Burden

Caregivers’ subjective perceptions of the negative impacts of the caregiver role related to the stresses and problems experienced (Zarit, Reever, & Bach-Peterson, 1980).

Assumptions

The research design of this study was adopted based on the following assumptions:
1) It was assumed that the Chinese female caregivers themselves could provide the most relevant accounts of their personal caregiving experiences and feelings about providing care for their relatives with Alzheimer’s disease.

2) It was assumed that qualitative methods would allow the researcher to capture the complexity of the caregiving experience and to examine the caregivers’ feelings, values, and beliefs from their perspectives.

3) It was assumed that a small sample size could yield important information to illuminate the research question as each participant has the potential to provide information on the various aspects of the phenomenon.

Significance of the study

Most studies on family caregiving are based on the White, mainstream population and cultural factors are not questioned (Kuhlman et al., 1991). As little is known about caregivers of other cultures, there is a need for research on the minority populations. By exploring the unique experiences and feelings of Chinese female caregivers, this study will contribute to the knowledge on caregiving for persons with Alzheimer’s disease and will begin to fill a gap in the existing literature. While the findings of this study will help to reveal the experiences of Chinese caregivers, they may also be used as a basis for future research on similar or different populations.

This study is also significant on a more practical level for service providers and practitioners. With the knowledge of factors influencing Chinese families’ feelings about providing in-home care for their relatives with Alzheimer’s disease, service providers and individual practitioners may modify or design their services to better meet the Chinese female caregivers’ needs. Such changes may not only alleviate the caregiver burden and
decrease the negative health outcomes for the caregivers, but may also delay institutionalization of the afflicted elderly persons.
Chapter 2

Literature Review

The Chinese culture

In understanding the experience of Chinese female caregivers of persons with Alzheimer’s disease, several components of the Chinese culture require discussion as they not only influence the actions of the caregivers, but also affect their perceptions of their experience. These components include the family as an institution, the responsibilities of the family relationships, and the traditional perceptions of old age.

Family as an institution

In the Chinese culture, the family is the basic social unit and it is the origin from which one’s social ties extend. Converse to the Western culture which values the individual, the Chinese culture emphasizes collectivism with family being the most important unit of social organization. Traditionally, the family’s goals and interests are considered more important than those of the individual family members and they are the basis for one’s judgements and decisions (Elliott, Minno, Lam, & Tu, 1996). As a result, when decisions are made, one should downplay his or her own benefits if they are in conflict with those of the family (Fung, 1998).

Families are organizations with no definite boundaries and they may be expanded and contracted (Hamilton & Zheng, 1992). While one’s communal circle may include both the core and extended families, all members of that circle are expected to help in times of need. Thus, a much larger group than the core family might be involved in the decision-making process (Fung, 1998). The route of expansion to the larger group is patrilineal, meaning only individuals from the father’s side of the family are incorporated.
Married daughters and their husbands (i.e., the sons-in-law) are considered outside of the family (Hamilton & Zheng, 1992).

Despite the flexibility of the size of one's communal circle, there is a typical hierarchical structure of traditionally oriented Chinese families. This hierarchy is based on age and gender and the decision-maker is usually the husband or the oldest male or female in the household (Welty, 1976). Roles in the family are clearly defined, with the father and eldest son being dominant. Authority is passed from the father to the eldest son, and other family members are expected to obey the decision-maker. While the household property and land are divided equally among the sons, females are relegated to a subordinate position (Min, 1995). Yet, women also gain respect as they age. Traditionally, the mothers are the rulers in the home and are responsible for disciplining the females in the household (Welty, 1976).

The importance of the family relationships

The concepts of family relationships in the Chinese culture are largely influenced by the philosophy of Confucianism. The Confucian defined five basic social relationships: ruler and subject, father and son, elder brother and younger brother, husband and wife, and friends (Fung, 1998; Min, 1995; Welty, 1976). Except for the relationship of friends, all the family relationships defined involve superiority and authority of one party over the other. While the superior in the relationship has responsibilities for the inferior, the inferior has to obey and be loyal to the superior (Fung, 1998; Welty, 1976).

Furthermore, Confucianism insists that the names father, son, husband, and wife indicate certain types of conduct. When a son is loving and obedient to the father and the
father is dutifully responsible for the son, the names “father” and “son” have been
fulfilled. If a man does not act like a father, a husband, an elder brother, or a friend, then
he is not really one, because the reality does not conform to the meaning of the terms
(Welty, 1976).

Confucian philosophy emphasizes the fundamental importance of the family.
Traditional cultural and Confucian ethical values specifically mandate that the eldest son
and his wife care for his parents in their old age. When there is no son, or the eldest son
is not able to fulfill this role, elderly parents will still expect one of their other children to
care for them (Elliott et al., 1996). All traditional Chinese families have family rules.
Between husband and wife, there should be mutual respect. For women, there are the
“three followings” and the “four virtues”. According to the three followings, a woman’s
status follows that of her father before marriage, her husband during marriage, and her
son in widowhood. Meanwhile, women have to develop the four virtues of moral virtues,
speech, appearance, and work (Hamilton & Zheng, 1992). Between father and son, there
should be responsibility for the father and obedience for the son. Filial piety consists of
mutual respect for those of equal status and obedience toward one’s elders. Duty,
obligation, importance of the family name, service, and self-sacrifice to the elders are all
elements of filial piety (Min, 1995). These codes are instituted from childhood explicitly
through teaching and implicitly through modeling (Fung, 1998).

In Chinese tradition, children must do everything possible to ensure the comfort
and happiness of the parents. One of the strictest and most important filial obligations is
the support of parents in their old age (Welty, 1976). In fact, when a parent becomes
sick, all the children will, and are expected to, exhaust their resources and do whatever
they can to help the parent (Fung, 1998). The eldest son, in particular, is expected to assume major responsibility and to make decisions if the parent has lost his or her ability to do so (Welty, 1976). To neglect one’s parents is an unthinkable violation of the filial piety principle. The parents’ role and sacrifices in bringing up and nurturing the children are reiterated to the children and the children are expected to provide care for their parents when they are unable to take care of themselves (Fung, 1998).

Belief systems about the causes of misfortune also influence a family’s motivation and endurance in providing care for a family member. Caregivers may fear that failure to care for a family member in need of help will lead to retribution. They may subsequently find themselves bereft of family care in old age (Elliott et al., 1996). In accordance with the maxim “What you do not want done to yourself, do not to others”, Confucius described the right action as “to serve my father as I would require my son to serve me” (Welty, 1976, p. 168).

To understand Chinese caregivers’ views on the caregiver role, Jones (1995) conducted a study on Chinese and Filipino American caregivers. Her participants suggested the importance of respect and honor in the assumption of the caregiver role. They also reported feelings of indebtedness, obligation, responsibility, reciprocity, satisfaction, and paying back. In addition, Mackenzie and Holroyd (1996) conducted a study on caregivers in Hong Kong and reported that caregiving was suggested to be related to love, compassion, duty, and pity.

The traditional perceptions of old age

As a result of the traditional family structure and the importance of family line, power and respect come with age. The aged persons are respected for their knowledge
and for their contribution to the family for a long time. Their wishes are usually respected and accommodated (Fung, 1998). They teach children how to mold themselves according to established cultural patterns, and how to manage social roles embedded in group life. In Chinese thought, every older person possesses the power to teach since “everyone who is older than I must have come across the problems I encounter. Therefore, elders can be my ‘teachers’” (Hamilton & Zheng, 1992, p. 118).

Seniority is an extremely important principle in the Chinese culture and this is reflected in the way people address one another. For example, an elder brother is addressed differently from a younger brother and so is an uncle who is older than one’s father distinguished from one who is younger. Many other societies do not have these distinctions at all (Hamilton & Zheng, 1992). Further, one is taught that when at home, one should be filial, and when out in the world, one should be respectful to elders (Hamilton & Zheng, 1992).

Chinese live in anticipation of old age, for growing old is considered pleasant. Age is respected. It is a time of leisure and of little responsibility. The aged are supported and not requested to support anyone else (Fung, 1998). There are only two periods in the life of a Chinese male when he possesses maximum security and minimal responsibility – infancy and old age. The old age is the better period because one is conscious of the pleasure to be derived from such a tranquil and satisfying period. The women also achieve respect and superiority with increasing age but not to the same extent (Welty, 1976).

In summary, the Chinese culture, which values family as the basic organization, demands individual members of a family to be united and work for the welfare of the
family as a whole. When a family member is sick and needs help, other members are expected to try their best to help. This is especially true for elderly persons as they are revered. However, as a result of individual variations, families' reactions may differ. Also, when families are in a place other than their homeland, their behaviors and values may alter.

**Family Caregiving**

Prior to the exploration of the experiences of Chinese immigrant caregivers, the issue of caregiving for persons with Alzheimer’s disease in general requires examination. Most persons afflicted with Alzheimer’s disease reside at home and are cared for by their families (National Alzheimer’s Association, 1995). Family members go to great lengths to care for their loved ones despite difficulties in various areas. As a result of individual differences and other reasons unrelated to the caregivers themselves, they experience different levels of burden.

*Family caregiving as the dominant care pattern*

While caregiving is known to be a challenge for health professionals, Daniels and Irwin (1989) suggest that most of the caregiving burden falls on family members. As cited by Brody and Spark (1966), “the family has been the safest haven for the aged. Its ties have been the most intimate and long-lasting, and on them the aged have relied for greatest security” (Simmons, 1945, p. 177). In fact, most elderly persons with Alzheimer’s disease reside in the community with 80-90% of their care performed by their adult children and spouses (National Alzheimer’s Association, 1995).
When family caregiving takes place, a member of the immediate family usually assumes the primary caregiver role (Scott, Roberto, & Hutton, 1996). Among the different categories of family caregivers, most are wives or daughters of the person with Alzheimer’s disease (Brody, Johnson, & Fulcomer, 1984; Hasselkus, 1988). Besides the primary caregiver, other family members may also provide support and take on secondary caregiver roles (Semple, 1992).

As families vary in compositions and dynamics, they function differently when faced with problems. According to Cohen and Eisdorfer (1995), there are five general styles: denial, cooperation, alternating leadership, contentiousness, and chaos. For example, while cooperative families communicate well and solve their problems together, chaotic families are disorganized and are engaged in hurting each other (Cohen, Andersen, & Cairl, 1998). As families may or may not work well together, the experiences of the primary caregivers are greatly influenced. Although supportive families may help to lessen the burden of the caregivers, conflicts may arise that add to the stresses of caregiving (Semple, 1992).

Due to the caregiving demands, families pay hidden costs such as reduced productivity, altered family lifestyle, and increased health problems (Cohen et al., 1998). They may also experience more overt physical, psychological, financial, and social problems (Cetinski, 1991). Since maintaining the person with Alzheimer’s disease in the community is preferred by most families (Niederehe & Fruge, 1984), caregivers exhaust their resources and go to great lengths to provide care for their loved ones (Kahan, Kemp, Staples, & Brummel-Smith, 1985).
Family members often find caregiving tasks "energy draining" as they may not have adequate skills in managing the emotional and physical demands required in providing care for their relatives (Harper & Lund, 1990). Research has shown that families may be overburdened as a result of the caregiving demands (Montgomery, Gonyea, & Hooyman, 1985). In fact, Chenoworth and Spencer (1986) reported that 72% of those with Alzheimer's disease in their research sample were institutionalized because their caregivers were being overwhelmed by the constant care required.

Meanwhile, subsystems within families such as parents, spouses, siblings, and children are also affected by the caregiver role (Pruchno, Peters, & Burant, 1995). Creasey and Jarvis (1989) found that grandchildren of persons with Alzheimer's disease had poorer relationships with their grandparents and their fathers if their mothers were the caregivers and were experiencing high levels of burden. Family caregiving is especially difficult since the afflicted person can no longer offer the caregiver the warmth and support associated with the family (Price, 1996).

On the other hand, caregiving may be a satisfying experience for the family as a whole (Beach, 1997). Requiring family members to work together provides opportunities for increasing family cohesiveness, improving relationships, and enhancing personal growth (Gatz, Bengtson, & Blum, 1990). These influences are actually supported by the study conducted by Beach (1997) on the positive impact of family caregiving on adolescent relationships. The participants in the study reported increased sibling activities and improved bonding between the mother caregiver and the adolescent as a result of the caregiving situation.
Primary caregivers may also experience self-gains through caregiving. In Aneshensel et al.'s study (1995), many caregivers reported that caregiving had positive influences on their lives such as self-enrichment and personal growth. In fact, participants were more likely to report positive than negative changes in self-concept as a result of caregiving. Similarly, in their study of caregiver outcomes for people caring for relatives with dementia, enjoyment of caregiving was reported by some participants (Gold, Cohen, Shulman, Zucchero, Andres, & Etezadi, 1995). It was found that caregivers were more likely to report enjoyment if they were experiencing better health and were female.

**Caregiving as a female role**

Caregiving is usually defined as a woman's role and as the traditional responsibilities of a wife or daughter (Zarit, Todd, & Zarit, 1986). In the course of history, caregiving has always been assigned to women (Covan, 1997). They are expected to provide care for either their own parents or their husbands' parents while also being responsible for their own children, their husbands, and in some cultures, their grandchildren, and other daily chores.

This pattern of care is still true in the present time so that when family care is provided, most of the burden is assumed by the female family members (Brody, 1981). According to the National Center for Health Statistics (1987), 75% of the caregivers in the United States are female with an average age of 46. Moen, Robison, and Fields (1994) reported that women are more likely to provide care as they advance in age. As the life span of women is about 7 years longer than that of men (Atchley, 1991), they are more likely to end up being a caregiver.

In the case of caregiving for persons with Alzheimer’s disease, wives and
daughters are reported to have taken most of the burden (Chappell, 1991). In addition to the primary caregivers being female, it was also found that the supportive others of the female caregivers are mostly of the female gender. These others include adult daughters, sisters, and other relatives of the primary caregivers (Penrod, Kane, Kane, & Finch, 1995; Robinson & Austin, 1998).

The perception of caregiving being a female role is supported by the qualitative study conducted by Sterritt and Pokorny (1998) on African-American caregivers of persons with Alzheimer's disease. While all nine participants were female, five of them took on the caregiver role although there were siblings of both genders in the family. Similarly, in their study on the cost of caring for elderly people with senile dementia, Hu, Huang, and Cartwright (1986) described the typical primary caregiver as a woman who provides an average of 6 hours and 28 minutes of care per day. Goodman (1990) further described the participants in her study of Asian American female caregivers of persons with Alzheimer's disease as assuming the defined caregiver role to minimize family conflicts. The participants were responsible for caregiving tasks and arrangements and also for management of affective relationships within the family as well.

While providing care for their aging parents, the daughter caregivers may also be responsible for their own children and paid employment (Moore, 1997). As cited by Beck et al. (1990), the 1988 U.S. House of Representatives report indicated that the average American woman spends 17 years raising children and 18 years caring for aged parents. The National Center for Health Statistics (1987) reported that 31% of female caregivers have children under the age of 12, and 23% of them have children aged 12 to 17.
In addition to their roles as mothers, many caregivers are also paid employees outside of home. Beck et al. (1990) found that more than half of the women who provide care for their elderly relatives also work outside of home. According to Moen et al. (1994), being employed does not reduce the likelihood of women to take on the caregiver role. As the various roles may induce conflicting demands on these caregivers they are, however, more susceptible to additional stress.

**Stresses of caregiving**

Caregiving for persons with Alzheimer’s disease has been confirmed to be burdensome and stressful (Zarit, 1989). According to Pfeiffer (1997), it requires physical strength, emotional stamina, knowledge about the disease, and skills in dealing with someone who is cognitively impaired. In fact, research suggests that caregivers of persons with dementia experience the role differently compared to caregivers of persons with physical impairments. They spend more time providing care for the care-recipients and experience more negative impacts as a result of the caregiver role (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). Thus, family members who have paid employment, household responsibilities, growing children, or other relatives who need care may find it difficult to adapt to the additional role of caregiver to a person with Alzheimer’s disease.

Deimling and Bass (1986) conducted a study of 614 caregivers of cognitively impaired elderly persons. They found that cognitive incapacity had a less important direct effect on caregiving stress than disruptive behavior and impaired social functioning. However, cognitive incapacity had an important indirect effect on caregiver stress through its influence on disruptive behavior and social functioning.

Similarly, Stephens, Kinney, and Ogrocki (1991) conducted a study on caregivers
of persons with dementia and reported that events related to care-recipients’ cognitive impairments were the hassles that occurred most frequently. Also, caregivers reported frequent hassles with the care-recipients’ behaviors such as repetitive questioning as well as with the assistance they provided for the care-recipients in personal care. Stressors as a result of the care-recipients’ problematic behaviors were predictors of caregiver well-being and were most strongly associated with disruptions in caregivers’ interpersonal relations.

In her study of 20 caregivers of persons with Alzheimer's disease, Wilson (1989) reported that family caregivers experienced a wide range of problems including active resistance, agitation, violence, need for constant supervision, depletion of the caregiver’s energy, and family conflicts. She suggested that these problems resulted in prolonged state of fatigue, sense of putting one’s own life in suspension, and physical and emotional exhaustion from continuous care.

Rabins, Mace, and Lucas (1982) interviewed 55 caregivers of persons with dementia and suggested that the frequency of occurrence of problems exhibited by the care-recipients was different from the perceived seriousness of the problems by the caregivers. In fact, the rank order of seriousness of problems was different from the rank order of problems by frequency. For example, physical violence was reported by less than half of the families, yet, it was being rated as very serious when it occurred.

In their study of husband, wife, and daughter caregivers of persons with Alzheimer’s disease, Quayhagen and Quayhagen (1988) found differences between the various categories of caregivers in terms of the stress they reported. Specifically, the wife caregivers were more stressed by the caregivers’ dangerous behavior and
embarrassing acts than were the husband and daughter caregivers. Meanwhile, the
daughter caregivers found their parents’ inability to bath or stay at home alone more
stressful. They also suggested that behavior such as incontinence, repetitive questioning,
and difficulty in money management were stressful for all caregivers in general.

Chu (1991) examined caregiver stress experienced by caregivers for persons with
dementia in Hong Kong and found that family caregivers reported four types: frustrated
social life, caregiver’s emotional response, financial strain, and frustration due to the care
receiver’s impairments. Factors reported as associated with stress were severity and care
demands, social network of family caregivers, and long-standing relationship between
caregiver and recipient. It was concluded that day-care programs should be provided for
elderly persons with dementia to alleviate the family caregivers’ stress.

In Jones’ (1995) study on Chinese and Filipino American caregivers of elderly
parents, several sources of stress were reported. Stress was reported to relate to
caregiving demands and interpersonal relationships such as misunderstandings in
communication and family conflicts regarding care. They also reported stress related to
the culture of the caregivers. For example, conflicts between traditional cultural
expectations and the issue of control such as their parents’ continued authority in their
lives were reported by the caregivers to be stress provoking. Caregivers also reported
stress as a result of the transition of immigration while struggling to cope with the
caregiving demands.

**Caregiver burden**

According to Zarit, Reever and Bach-Peterson (1980), caregiver burden refers to
the caregiver’s perceptions of the negative impact of the caregiver role. As it is the
subjective perceptions of the caregivers related to the problems experienced, it should be separated from other more objective indicators of caregiving effects (Pouloskshock & Deimling, 1984). In the model described and tested by Pouloskshock and Deimling, burden plays a central role between the elderly person’s impairment and the impact that caregiving has on the caregiver’s life. Their results showed that reported burden was linked both to the impairments of the elderly person and to changes in objective conditions within the family.

Morycz (1985) distinguished between stress and strain and maintained that strain or burden had other relevant components beyond objective stress, such as the caregivers’ perceptions of problem severity and the availability of support. It was suggested that there were actual differences between stress and strain and that strain was a critical factor in the caregivers’ desire to institutionalize. Zarit, Todd, and Zarit’s (1986) study also supported the subjective nature of burden. They suggested that although dementing illness brings about changes that cause caregivers to feel burdened and to consider institutionalization, the experience of the degree of burden may be related to many factors, not just severity of symptoms; for example, caregivers felt burdened when the care-recipients manifested deficits in behavior and the caregivers had difficulty tolerating those behaviors.

Meanwhile, caregiver burden and caregiver well-being are suggested to be opposite sides of the same coin as measures of the two concepts appear to tap related contents (George & Gwyther, 1986). In their study of 510 caregivers of persons with Alzheimer’s disease, George and Gwyther found that burden was experienced primarily in the areas of mental health and social participation. Similarly, Reis, Gold, Gauthier,
Andres, and Markiewicz (1994) conducted a study on 157 caregivers of people with Alzheimer’s disease and suggested that caregiver burden and the caregivers’ declining health were strongly related. They reported that caregivers who were able to find some positive aspects in caregiving were less likely to experience burden and poor health. Also, satisfaction with social support and availability of free time reduced burden.

Caregiver burden is suggested to be a predictor for caregivers’ desire to institutionalize the care-recipients (Morycz, 1985; Stukey, Neundorfer, & Smyth, 1996). In Morycz’s study involving both Black and White caregivers, the caregivers’ desire for placement increased when they experienced more strain or burden. The intensity of family strain was best predicted by the availability of social support to the caregivers. Also related to burden was the caregivers’ perceptions of the severity of caregiving problems and the amount of disruptive behavior exhibited by the care-recipients. All caregivers reported similar levels of strain irrespective of their race.

Zarit et al. (1980) examined factors related to the amount of burden experienced by the principal caregivers of persons with dementia. In their quantitative study, 29 White persons with senile dementia and their caregivers were interviewed. The burden reported by caregivers included lack of time for oneself, excessive dependency of patient, and fear of further deterioration. Burden was not related to impairment, but to social support received by the caregivers. Also, they found no differences in caregiver burden between spouse and adult child caregivers.

Several researchers have studied contributing factors to the burden of caregivers (Brashares & Catanzaro, 1994; Chu, 1991; Harper & Lund, 1990; Parks & Pilisuk, 1991).
and indicated that caregiver characteristics, coping, personality, social support, and care receiver's behavior and cognitive impairments are all associated with perceived burden.

Caregiver role fatigue was described as a result of role conflict and role constriction by Goldstein, Regnery, and Wellin (1981). Other factors such as availability of assistance and support and the degree to which caregivers obtain role relief were also suggested to be important determinants of caregiver role fatigue and thus, of a sense of burden. Skaff and Pearlin (1992) further studied the phenomenon of loss of self in caregivers of persons with Alzheimer's disease. They found that loss of self was related to various conditions including those residing in the caregivers' background characteristics and those residing in the caregiving situations. They also suggested that spouses were more likely to experience loss of self than were adult children and that women were more likely to report loss of self than men.

Several researchers have suggested that female caregivers experienced higher subjective burden than their male counterparts (see for example, Reis et al. [1994], Young and Kahana, [1989], and Zarit et al. [1986]). In their study of 176 caregivers of persons with Alzheimer's disease, Parks and Pilisuk (1991) reported that gender made an important contribution to differences in how the caregiver role was experienced. They found that women tended to be more anxious and reported more stress than men. Women with less internal control were found to be more depressed and more anxious. In their study involving 28 caregivers of persons with dementia, Fitting, Rabins, Lucas, and Eastham (1986) found that females were at greater risk of depression than males. Also, younger females felt more lonely than older females and males in all age groups.
Harper and Lund (1990) studied caregiving experience of different categories of caregivers including husbands, wives, and daughters. They found that wives experienced higher levels of burden than husbands did and that higher level of burden was perceived if the caregiver resided with the care receiver. They also reported that different contributing factors were responsible for the subjective burden experienced by the various categories of caregivers. While care-recipients' deficits in orientation and the presence of coresidents in the house led to burden in males, care-recipients' affective symptoms and caregiver life satisfaction were contributors to burden in females. As most of the family caregivers are wives and daughters of the persons with Alzheimer's disease, knowledge of factors contributing to their perceived burden is very important.

Furthermore, wife caregivers of persons with Alzheimer's disease deserve particular attention since they are elderly persons themselves and they may have physical limitations hampering their ability to meet the caregiving demands (Barusch, 1988; Fitting et al., 1986).

Caregiving was suggested to be burdensome by many caregivers. While most of the researchers have focused on the negative aspects of caregiving, less attention has been paid on the positive influences of the role. As positive experiences in caregiving were actually reported by some caregivers, its influence, along with that of others factors such as social support, should be examined.

**Social Support**

Social support has been described as activities involving at least two individuals which is aimed at facilitating the well-being of the recipient of support (Shumaker &
Brownell, 1984). According to Thoits (1982), it is the extent to which one's “basic social needs for affection, esteem or approval, belonging, identity and security are met through interaction with others” (p. 147). Throughout the caregiving literature, social support has been reported to influence the caregiving experience in different ways. As social support and coping may be amenable to intervention, it is a factor for further exploration.

**Conceptualization of social support**

Social support was conceived by Cobb (1976) as information conveying specific messages to individuals which does not include goods and services. The information belongs to three classes: that leading to one’s belief that he or she is being cared for and loved (emotional support), to the belief that one is being esteemed and valued (esteem support), and to the belief that one belongs to a network of communication and mutual obligation. For activities to be considered social support, they must carry at least one of the above classes of information.

Barrera (1986) reviewed the literature on social support and highlighted three major concepts. The first concept is social embeddedness, which refers to the connections that people have to significant others in their social environment. One’s embeddedness is reflected by the presence of ties such as friendship, marital status, and other family relationships and his or her contacts with these individuals. The second concept is perceived social support and it emphasizes one’s “cognitive appraisal of being reliably connected to others” (pp. 416). According to Turner, Frankl, and Levin (1983), this perception refers to both the availability and also adequacy of one’s support. The last concept is enacted support and it refers to the actions which the supporter performs to assist the recipient.
While social support is often described in quantifiable terms such as number of connections and frequency of contacts, Conner, Powers, and Bultena (1979) emphasize the importance of subjective perceptions of social interactions. In their opinion, the quality of one's interactions with significant others is no less important than the quantity of them. Supporting the importance of subjective perceptions of support, Turner, Frankel, and Levin (1983) suggest that social support should be differentiated from social support resources. In their opinion, social support should be viewed as personal experiences of the recipient. They comment that as it is not “a set of quantifiable circumstances or even a set of interactional processes” (p. 74), it cannot be understood in terms of what is available or what the network is capable of providing. Rather, one should focus on the cognitive appraisal of support received.

To conceptualize the notion of social support, Thoits (1982) views support as having two forms. While socioemotional aid refers to affection, sympathy and understanding, instrumental aid includes advice, information, help with family or responsibilities, and financial aid. Together, the support assure the person that he or she is being cared for. She further defines social support system as the subset of people in one's social environment who provide the person with socioemotional aid and/or instrumental aid.

Meanwhile, Fiore, Becker, and Coppel (1983) suggest that social support is a multidimensional phenomenon. In their study on social network interactions, they conceptualized social support as having five components being cognitive guidance, emotional support, socializing, tangible assistance, and self-disclosure. Applicable for each type of support is the dimension of perceived helpfulness of the support. It was
suggested that as one’s perceptions of the various types of support may differ, they affect health to different extents under different circumstances.

According to Gallo (1990), social support may be understood in terms of its quantity and its quality. There are two components in the quantity of support. The first component is one’s social network including its nature, structure, and sources. Also referring to the quantity of support is social integration, meaning the number, density, and range of relationships. On the other hand, in terms of quality, there is social support itself, referring to the functions of the relationships and the kinds of support provided.

Incorporating both the objective and the subjective qualities of social support, Callaghan and Morrissey (1993) suggest that it may be expressed functionally and/or structurally. When it is expressed functionally, the supporter provides the recipient with emotional, tangible, or informational support. When it is expressed structurally, it may be viewed in terms of marital status and frequency of contact. Support may be received from various sources including spouse, colleague, or friend. According to Ruddle and O’Connor (1993), sources of support may be categorized into informal sources such as family, friends, and neighbors and formal sources referring to various services providers. While support may or may not be available, it is the recipient’s perception of its availability that holds its value (Callaghan & Morrissey).

**The effects of social support on caregiver well-being**

Throughout the caregiving literature, social support has been reported to have a positive influence on the caregiving experience. As Haley, Levine, Brown, and Bartolucci (1987) reported in their study with dementia caregivers, higher levels of social network size, activity, and satisfaction with one’s network were related to better caregiver
outcomes such as life satisfaction and health. To understand the role of social support in the caregiving experience, Cohen and Wills (1985) suggested two processes through which social support has a beneficial effect on caregiver well-being.

The first model is the buffering model which proposes that social support is related to well-being only when people are under stress (Cohen & Wills, 1985). While individuals with a strong social support system should be able to cope with major life changes better, those with little or no support may be more vulnerable to life changes (Thoits, 1982). According to this model, social support may influence caregiver well-being by preventing the perception of caregiver stress or by inhibiting or eliminating the stress reaction (Cohen & Wills).

This indirect influence of social support is supported by Avison and McAlpine’s (1989) study on single mothers. They found that perceived social support moderated the effects of stressful life events and chronic financial strain on negative psychological outcomes. In their study of parents of children with autism or Down’s syndrome, Wolf, Noh, Fisman, and Speechley (1989) concluded that social support reduced the fathers’ vulnerability to depression and moderated their parenting stress. Similarly, Dalgard, Bjork, and Tambs (1995) reported a significant two-way interaction between negative life events and social support in their 10-year follow-up of a survey involving 503 individuals. They suggested that good social support reduced the risk of developing depression under exposure to negative life events.

Evidence of the buffering effect of social support was also found in the area of caregiving for persons with dementia. In Zarit, Reever, and Bach-Peterson’s (1980) study on family caregivers, it was found that the experience of social support determined
the caregivers’ ability to cope with stress. The more visits of family members, the less the burden reported by the participants. They further suggested that the caregivers’ experience of interacting with God or a higher power acted as an alternative form of social support, especially when the caregivers became isolated.

Furthermore, Rabins, Fitting, Eastham, and Zabora (1990) examined the adaptation of 32 caregivers of persons with Alzheimer’s disease and 30 caregivers of persons with recurrent metastatic cancer over a two-year period. It was found that the number of contacts had significant influences on the positive outcomes of the caregivers as it explained 30% of the variance in the outcomes.

The alternative model proposed by Cohen and Wills (1985) is the main-effect model which proposes that “social resources have a beneficial effect irrespective of whether persons are under stress” (p. 310). They suggest that as social networks provide persons with regular positive experiences and a sense of predictability and stability, they help one to avoid negative experiences that otherwise would be detrimental to one’s physical or psychological well-being.

This direct effect of social support was found in the study conducted by Cohen, Teresa, and Holmes (1986). In their study involving 133 elderly persons living in an inner-city environment, they reported a direct effect of social networks on psychopathology. Network variables explained 26% and 31% of the variance in psychopathology for the low-stress group and high-stress group respectively.

Spitzer, Bar-Tal, and Golander (1995) examined the effects of social support on adaptation and stress in 77 rheumatoid arthritis patients. They found that social support had a significant impact on stress by moderating one’s sense of control over health. On
the other hand, no interactions were found between support and stress which suggested a buffering effect. Social support was further broken down into its affective and instrumental components and the same results were found.

In addition, Baillie, Norbeck, and Barnes (1988) conducted a study with 87 family caregivers of elderly persons with various impairments. They suggested that social support had main effects on psychological distress and depression in the caregivers. In other words, social support was independently correlated to caregiver depression.

**Social support as a source of stress**

Along with their benefits, human relationships also involve costs such as broken promises, unmet expectations, and network members who are irritating or overinvolved (Simpson, 1972). As social support is a result of one’s interactions with his or her social network, it can be a source of stress although it is often viewed as beneficial to the well-being of the recipients. The notion of social support as a source of stress is particularly pertinent to the caregivers of people with Alzheimer’s disease as they often receive support from various sources (Fiore, Becker, & Coppel, 1983).

Families are often reported to cause conflict and stress among caregivers of persons with Alzheimer’s disease (Chenoweth & Spencer, 1986). Rabins, Mace and Lucas’s (1982) found that family conflict was the problem most frequently reported by the adult-children caregivers after the caregiving strain itself. Caregiving is a situation in which “latent family strains are often activated and conflict may displace prior family harmony” (Semple, 1992, p. 649). Thus, family caregivers may be predisposed to possible negative emotional consequences.
Semple (1992) studied 555 family caregivers of persons with Alzheimer's disease and found that family conflicts of different natures had different influences on the caregivers. Specifically, conflicts involving family members' negative behavior and distance from the care-recipients were more likely to be associated with anger while conflicts related to family members' attitudes and behaviors toward the caregivers were most closely associated with depression. She suggested that as families' negative behavior towards the caregivers may threaten their sense of value and competence as caregivers, conflicts of that nature may result in a negative self-images and feelings of failure.

In addition to the various natures of family conflicts, stresses caused by the different sources of support were also studied. In their study with 95 married daughters caring for parents with dementia, Suitor and Pillemer (1993) examined the support and interpersonal stress in the social networks of the caregivers. It was found that although siblings provided more practical support than friends did, they were also the greatest source of stress. Meanwhile, individuals who had experience caring for a relative were less likely to be a source of stress.

Meanwhile, Pagel, Erdly, and Becker (1987) examined the caregivers' experiences with various sources of support including families, friends, and health professionals. In their study of spouse caregivers of persons with Alzheimer's disease, it was found that while positive aspects of social networks were not significantly related to depression and overall network satisfaction, upsetting networks were predictors of such outcomes. They suggested that upsetting relationships in one's social network may play an important role in the etiology and maintenance of the emotional problems.
Fiore, Becker, and Coppel (1983) have suggested the necessity of assessing the stress caused by one’s social network when examining overall social support. As the social network may act as a source of support and a source of stress concurrently, the sum of the two constitutes the actual perceived adequacy of support. In their study of wife caregivers of persons with Alzheimer’s disease, it was found that while the perceived supportiveness of one’s network did not relate to depression, the extent of upset with one’s social network was the best predictor of depression in the participants. They also highlighted the notion of unmet expectations of support and maintained that such a condition should be considered as stress-provoking. In fact, they found that unmet expectations of support by the network accounted for 37% of the variance of depression in the caregivers.

Similarly, in Harper and Lund’s (1990) study on family caregivers of people with dementia, both the actual and the perceived lack of support were reported by the participants to be stress-provoking. Caregivers residing with the care-recipients often reported burden as a result of lack of support. They also suggested the importance of gender that their female participants reported having 31% more negative contacts than their male participants. Semple (1992) also suggested gender differences with regards to family conflicts in her study of family caregivers of persons with Alzheimer’s disease. She found that women were more likely than men both to experience family conflicts and to experience it with a wider range of family members.

Social support has been reported to have ambiguous effects on the caregiving experience, in general. On the one hand, it may help to lessen the caregivers’ stress and alleviate their burden so that placement of the care-recipients may be delayed. On the
other hand, it may also add to the stress experienced by the caregivers. When the burden is too high, caregivers may seek to yield their roles and institutionalize the care-recipients. As the Chinese culture emphasizes responsibility of family to care for elderly persons, caregiving may be viewed as a family business. As a result, caregivers may not be receptive to outside support. However, as Chinese caregivers’ responses to social support have not been examined sufficiently, their views on and experiences with the notion should be explored.

Coping

Coping has been defined by Lazarus and Folkman (1984) as the cognitive and behavioral efforts made to “manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (p. 141). It includes anything that the person does or thinks, regardless of the outcomes of the process. During a stress encounter, a person continues to appraise and reappraise the environment and his or her relationship with the environment. Coping efforts are then made in response to the stress appraisals. Throughout the stress encounter, appraisal and coping continue to influence each other.

According to Folkman and Lazarus (1991), coping may be emotion-focused or problem-focused. While emotion-focused coping is aimed at regulating emotional distress, problem-focused coping is directed at altering the situation which is causing distress. People rely on both forms of coping to manage the demands of stressful situations. The choice of which form and strategy of coping to use is dependent on the person’s appraisal of the situation. Appraisals of situations are, in turn, dependent on the
characteristics of the person such as beliefs about oneself, recognition of personal resources for coping, and problem-solving skills, and also environmental variables such as nature of the situation and existence of social support resources to facilitate coping.

Emotion-focused coping is likely to be used when an environmental condition has been appraised as unmodifiable (Lazarus & Folkman, 1984). Under such circumstances, the person perceives that nothing can be done to decrease the harm or threat presented in the situation. Emotion-focused coping includes strategies such as distancing, self-controlling, seeking social support, accepting responsibility, escape-avoidance, and positive reappraisal (Lazarus, 1993). When such strategies are engaged, the way in which a situation is interpreted may be changed.

On the other hand, problem-focused coping is likely to be used when the stressful situation is appraised as amenable to change. Similar to problem solving, a person engaging in problem-focused coping defines the problem, generates alternative solutions, weighs the alternatives, chooses among them, and then carries out the action. Problem-focused coping includes the strategies of planful problem-solving and confrontive coping.

Since Lazarus and Folkman's (1984) initial work, many studies have examined the effects of coping strategies on stressful situations. For example, in their study of 141 persons of both genders, coping was found to be associated with changes in all four types of emotions studied: disgust and anger, pleasure and happiness, confidence, and worry and fear (Folkman & Lazarus, 1988). They also suggested age differences in the effects of coping between the two groups of participants. For example, positive reappraisal was associated with decreased disgust and increased pleasure in the younger group, but with increased fear in the older group.
The results of the study conducted by Haley, Levine, Brown, and Bartolucci (1987) also support the effects of coping on stress. In their study with 54 family caregivers of persons with dementia, coping responses accounted for the greatest amount of variance of the participants' self-reported health. Greater utilization of the strategies of logical analysis, information seeking, affective regulation, and problem solving were associated with higher self-reported health.

To examine the influences of personality on coping, Hooker, Frazier, and Monahan (1994) conducted a study with 25 wife and 25 husband caregivers of persons with Alzheimer's disease. It was found that personality factors were related to the use of coping strategies in caregiving situations. Specifically, caregivers who scored high on the Neuroticism scale were more likely to use emotional-focused coping strategies and those who scored high on the Extraversion scale were more likely to cope by seeking social support.

**Institutionalization of the care-recipient**

Due to the progressive nature of the disease, caregivers of persons with Alzheimer's disease must be prepared for personal deterioration and social losses (Colerick & George, 1986). However, when caregiving becomes increasingly demanding and complex, caregivers may decide to yield the role and institutionalize the care-recipients (Lieberman, & Kramer, 1991). As the elderly population continues to grow, the demands for institutional care are expected to increase (Lieberman & Kramer, 1991). As Dellasega (1991) suggest, the majority of persons over the age of 65 will spend some time in an institution before they die. While care-recipients may be institutionalized for
different reasons, placement also carries various meanings for the families and for families within different cultures.

**Predictors of institutionalization**

To better understand the phenomenon of institutionalization, many researchers have focused on finding the predictors of the transition and defining the various factors related to a higher risk of placement. These factors include characteristics related to the caregiving situation, the caregivers, and the care-recipients.

In terms of the caregiving situation, several researchers note that the risk of institutionalization is reduced when the caregiver is a spouse (Colerick & George, 1986; Lieberman & Kramer, 1991; Lund, Pett, & Caserta, 1987). In understanding the influence of the marital relationship on the likelihood of institutionalization, Pruchno, Michaels and Potashnik (1990) conducted a study with spouse caregivers exclusively. They found that fewer positive interactions between the couple were predictive of institutionalization. Also, higher use of services, shorter caregiving duration, and presence of more children were predictors of placement.

Wright (1994) performed a similar study to examine the various aspects of the marital relationship in regard to institutionalization of the afflicted person. He found that positive interactions between spouses, the caregivers' continued commitment to the relationship, and good caregiver health were predictors for continued in-home care. He concluded that nursing home placement was pursued when the relationship was unsatisfactory, commitment was low, and the financial resources for institutional care were available. Zarit, Todd, and Zarit (1986) conducted a study with 64 spouse caregivers and found that the quality of the marital relationship prior to illness was very
important. While caregivers who continued in-home care after two years reported prior high quality of marital relationships, those who institutionalized the care-recipients reported prior low quality of the relationships. Lund, Pett, and Caserta (1987) further maintained that the caregivers' perceived lack of closeness predicted their intent to institutionalize.

In addition to the marital relationship, caregiver arrangements were also reported to be significant predictors of institutionalization. In their study, Lieberman, and Kramer (1991) found that while the risk of placement was lowest when the spouses were the sole caregivers, the highest risk was observed when the primary caregivers were the children, either with or without support from others. Meanwhile, financial and psychological problems were reported more often in families that chose the option of placement.

Caregiver characteristics were suggested by Gilhooly (1986) to be influential in the caregivers' intentions to institutionalize the care-recipients. In his study, 48 caregivers, either living with or not living with the care-recipients, were interviewed. It was found that younger ages of the caregivers, more contacts of the caregivers with friends, dissatisfaction with help from relatives, having another dependent relative, and employment were significantly associated with preference for placement.

The importance of social support to institutionalization was also suggested by Morycz (1985) in his study on caregiver strain. Caregivers were found to have greater desires to institutionalize their relative if they experienced increased caregiver stress. Social support was the most predictive variable in the amount of reported stress. Although social support had little relation to the desire for placement, its contribution to caregiver strain was seen as a precursor for that desire.
Attitudes held by the caregivers were also found to be an important predictor of institutionalization. Deimling and Poulshock (1985) found that caregivers with positive attitudes towards nursing homes were more likely to institutionalize their relatives than caregivers with negative attitudes towards the setting. Attitude towards institutional care was a stronger predictor of actual placement than the subjective burden experienced by the caregivers. Meanwhile, Pruchno, Michaels, and Potashnik (1990) suggested that caregivers who enjoyed their roles were less likely to choose the option of placement.

Besides caregiver characteristics, care-recipient characteristics were studied by many researchers. In their study with 555 caregivers of persons with Alzheimer’s disease, Aneshensel, Pearl, Mullan, Zarit, and Whitlatch (1995) reported that troublesome behavior appeared to increase the risk of institutionalization. As these behaviors may lead to a sense of being captive in the caregiving responsibilities, caregivers were more likely to yield their roles.

Focusing on care-recipient characteristics, Knopmen, Kitto, Deinard, and Heiring (1988) reported that behaviors such as incontinence, impaired communication skills, poor hygiene, and irritability were often the precursors to placement of the persons with Alzheimer’s disease. They also maintained that the disease severity of the afflicted persons at the time of the initial interview was predictive of institutionalization 2 years later. However, the care-recipients’ age and gender and the nature of the relationship between the caregiving dyads were not predictive of placement.

Morycz (1985) examined the relationship between caregiver strain and the desire to institutionalize one’s relative with Alzheimer’s disease and interviewed 80 male and female caregivers with different relationships to the care-recipients. He found that
caregivers had greater desire for placement when the care-recipients were widowed, when there was more physical labor involved, and when the care-recipients lived alone.

Montgomery and Kosloski (1994) conducted a longitudinal analysis to examine the differences in the risks of institutionalization of dependents being cared for by spouses and by adult children. Elderly persons being cared for by their spouses were more likely to be institutionalized if they were female, had better health and fewer difficulties performing personal care, and depended more on the others. On the other hand, those being cared for by their children were more likely to be placed if they had Alzheimer’s disease, required more assistance with household activities of daily living, and had greater difficulty with personal care. For all elderly persons, there were positive relationships between the care-recipients’ age and the likelihood of placement.

**Meanings of Institutionalization**

Family members often perceive institutionalization as the last resort which is pursued only when no other option is seen as available (Johnson, 1990). It is the norm of most societies that care-recipients remain in their own homes for as long as possible. Based on conditions ranging from economic feasibility to well-being of both the caregiver and the care-recipient, the possible duration of in-home care varies for individual families (Edwards, 1994).

Institutionalization may carry various meanings for different families due to the complexity of the phenomenon. According to Townsend (1990), placement of a relative is an ambiguous process. On the one hand, it may be a stressor since it creates new and different types of challenges and does not relieve the caregivers’ responsibilities entirely.
On the other hand, it may be a coping mechanism for the caregivers as it is a solution to the imbalance between the caregiving demands and the caregivers' resources.

Brody and Spark (1966) suggest that the moment in which institutionalization is requested is only part of a continuum of past life experiences. These experiences influence the family relationships and a psychological network is developed. Institutionalization is the way in which the family seeks to regain equilibrium. In other words, the transition may be a positive phenomenon as it is a constructive solution to existing problems.

However, institutionalization may also be a negative phenomenon in that it is "a symptom on which the underlying family difficulties are being projected" (Brody & Spark, 1966 p. 79). Although the crisis which precipitates placement may seem acute, longstanding family problems may surface as the process evolves (Brody & Spark). As Buckwalter and Hall (1987) suggest, placement is most often related to inadequate social or familial supports and resources. However, the care-recipient may misinterpret the decision as unwillingness of family members to fulfill their obligations.

Institutionalization is often viewed as the relocation of the care-recipients to their last homes (Buckwalter & Hall, 1987). The transition implicitly anticipates the ultimate separation by death and family members are often ambivalent about taking this step (Buckwalter & Hall). Irrespective of the underlying reason for the transition, it is a major crisis in many families (Brody & Spark, 1966).

As shown above, there are great variations in families' views on institutionalization. While differences among caregivers of the Western culture exist, differences between these caregivers and caregivers from other cultures may be even
greater. As the Chinese culture emphasizes unity of the family and responsibility of kin to care for elderly persons, Chinese caregivers may perceive the notion of placement as against their traditional values. As a result, they may tolerate great stress to continue in-home care for their relatives. Further, when placement is considered, psychological strain may result as yielding the caregiver role conflicts with deep-rooted cultural values.

**Purpose**

The primary purpose of the study was to explore Chinese female family caregivers’ feelings about their experiences of providing care for their relatives with Alzheimer’s disease. More specifically, the impacts of culture and caregiver stress on the caregivers’ perceptions of providing in-home care for their relatives with Alzheimer’s disease were examined through data gathered. Particular attention was paid to the mediators of social support and coping strategies to explore their modifying effects on the experiences of the caregivers.

**Conceptual framework**

As presented in the preceding section, the constructs of culture, stresses of caregiving, caregiver burden, social support, coping, and the decision-making about institutionalization of the care-recipient are important components in the understanding of the caregiving experience and feelings engendered by it. These constructs are discussed by Pearlin, Mullan, Semple, and Skaff (1990) in their conceptual model of the stress process of caregivers of persons with Alzheimer’s disease. In their framework, the stress process is depicted as made up of four domains: 1) background and context of stress, 2) stressors, 3) mediators such as social support and coping, and 4) outcomes. Within the
component of stressors, they consider primary stressors and secondary stressors. Primary stressors are the problems directly related to the care-recipients such as the care-recipients’ cognitive impairments and behavioral problems and the caregiving demands that result. As primary stressors are likely to be durable and intensify over time, they may produce other stressors, that is, the secondary stressors. These include role strains such as family conflicts, economic problems, and reduced social and recreational life. Another component of secondary stressors is intrapsychic strains, referring to dimensions involving one’s self-concept and psychological state. Intrapsychic strains include loss of self, role captivity, competency, and self gain. The relationships between the different domains of variables are also clearly stated by the authors. While the domains of background and context, stressors, and outcomes have a linear relationship and each domain influences the successive domains, the domain of mediators has influence on the stressors and the outcomes and is influenced by the background and context of stress. For example, social support as a mediator could influence the stressors experienced by the caregivers and the outcomes of caregiving, and will be influenced by the context of caring for someone with Alzheimer’s disease.

The conceptual guide for this study is based on a model modified from the framework put forward by Pearlin et al. (1990). Their model was modified to highlight culture as a background and context variable in the stress process of Chinese female caregivers. The primary stressors were explored to establish the levels of involvement of the caregivers, however, as the caregiving demands for Chinese female caregivers are likely to be similar to those experienced by caregivers of the White population, the individual stressors (i.e., the demands of caring for someone with Alzheimer’s disease)
were not examined to great detail. Instead, more attention was paid to the secondary role strains and intrapsychic strains experienced by the caregivers. The role of social support and coping as mediators of the primary and secondary stressors and of the outcome of continuing in-home care for the persons with Alzheimer's disease was the focus of this study. As culture may affect perceptions of the social support one receives, the relationship between these two domains (i.e., culture and social support) was also explored. Decreased focus was put on the outcomes of caregiving as the goal of the study was to explore the experiences and feelings of Chinese female caregivers of relatives with Alzheimer's disease. Specifically, the area of outcomes was explored only in terms of the caregivers' feelings towards continuing in-home care for their relatives. This variable could also be easily conceptualized as an intrapsychic strain because feelings of ambivalence and conflicts with one's cultural values may be associated with the decision to discontinue in-home care. The schematic representation of the modified model is as follows (see figure I):

Figure I. Conceptual model of Alzheimer's caregivers' stress, as adapted from Pearlin, Mullan, Semple, and Skaff (1990), for Chinese Female Caregivers.
Chapter 3

Method

Research design

Qualitative research emphasizes seeing the world from the point of view of the participant - an emic perspective (Bryman, 1984). The major theoretical principle behind qualitative research is that people’s behaviors are highly complex and dynamic and consist of multiple layers of meaning and perspectives that are strongly influenced by the interaction between the environmental context and the subjective interpretations of the situational actors (Morse & Field, 1995). As little is known about the Chinese immigrant population on their family caregiving experience of their relatives with Alzheimer’s disease, a qualitative approach was employed. Caregiving for persons with Alzheimer’s disease takes place within the social context in which the caregivers interact with their environment, thus, culture is likely to influence their perceptions and experiences of the process. By interviewing the Chinese female caregivers and obtaining their personal accounts of their experiences, the phenomenon was explored from the point of view of the participants. Also, the caregivers’ behavior was understood in the context of their beliefs and values.

Interviews with caregivers of persons still living in the community developed a picture of the context in which caregiving stress was experienced. Also, unanticipated aspects of the caregiving role that caregivers deemed important surfaced throughout the interviews and were incorporated into the analysis. Twelve Chinese female caregivers of persons with Alzheimer’s disease residing in the community were examined to explore the caregivers’ experiences. In particular, information was sought regarding perceptions
of caregiver stress and social support, and perspectives on the notion of institutionalizing their relatives in light of the influence of their cultural background. Compilation of these cases provided the researcher with a rich data source to identify themes common to the given sample. Thus, the twelve Chinese female caregivers could help to shed light on the question of how Chinese female caregivers experience and feel about providing care for their relatives with Alzheimer's disease.

**Eligibility Criteria**

Eligibility criteria for inclusion in the study were: immigrants to Toronto from Hong Kong after the age of 18, Cantonese speaking, female, and related by birth or marriage to a family member diagnosed with Alzheimer's disease. Due to possible variation in cultures, Chinese immigrants from other places of origin were not included in the study.

**Participant Recruitment**

Recruitment of caregivers of persons with Alzheimer's disease was carried out in three ways:

1) Contact was made with staff members at the Yee Hong Centre for Geriatric Care, the Woodgreen Community Centre and Chinese Senior Support Services. They identified the caregivers of people previously diagnosed with Alzheimer's disease and gave them information packages which included the pamphlet, the Information Letter, and the Consent Form. To enhance the likelihood of participation, the researcher attended support groups for Chinese caregivers of persons with Alzheimer’s disease at these facilities and gave brief presentations of the study;

2) Pamphlets were sent to approximately 50 caregivers as part of the mail-out by the
Alzheimer's Society, Toronto Division;

3) Pamphlets about the study were left at nine churches and three community agencies for pick-up by caregivers who were not in contact with formal service providers (see Appendix A for pamphlet).

After pamphlets were left at churches and community agencies, the researcher was contacted by two caregivers who proved ineligible as neither spoke Cantonese. No caregivers contacted the researcher in response to the mail-out by the Alzheimer's Society. This lack of response may have been due to the fact that most of the recipients of the mail-out were professional persons working with people with Alzheimer's disease.

None of the caregivers who attended the caregiver support group at the Chinese Senior Support Services participated in the present study. This situation may have been a result of the small size of the support group at the facility. One participant was recruited from the Woodgreen Community Centre while the remaining 11 were recruited from the Yee Hong Centre for Geriatric Care.

Initial contacts were always made by the caregivers or by the contact persons at the recruiting facilities. Contact persons from the facilities were identified who informed the caregivers about the study and provided them with information packages (see Appendix B for information package). After obtaining the information packages, some caregivers contacted the researcher to discuss the study further. It was stated in the pamphlet and in the information letter that caregivers could contact the researcher if they were interested in participating in the study or getting further information. For the other caregivers who did not want to make the initial contact themselves, they gave permission to the contact persons to release their names and telephone numbers to the researcher.
The researcher then contacted the caregivers.

At the initial contact with the caregivers, the researcher provided detailed explanations of the study and answered their questions. To determine eligibility of the caregivers, they were asked for their age at immigration and their countries of origin. Once eligibility criteria were confirmed, the researcher scheduled individual interviews with the caregivers for times and locations at the caregivers' convenience.

The Participants

Twelve Chinese female caregivers of persons with Alzheimer's disease, previously diagnosed, participated in the study. These caregivers included two wives, eight daughters, and two daughters-in-law of persons with Alzheimer's disease. Among these caregivers, one daughter caregiver and one daughter-in-law caregiver were caring for the same care-recipient. They took turns to care for the care-recipient and were both very involved in care provision. All participants resided within the Toronto area with the exception of one caregiver who lived approximately 60 km from Toronto. Their ages ranged from 30 to 80 years at the time of data collection. They varied in financial status, but none of them seemed to have major financial difficulties. Characteristics of the caregivers are presented in Table 1.
Table 1. Characteristics of the caregivers

<table>
<thead>
<tr>
<th>Case</th>
<th>Relationship to care-recipient</th>
<th>Age</th>
<th>Marital status</th>
<th>Had children under 18</th>
<th>Had paid employment</th>
<th>Years of caregiving</th>
<th>Was the sole caregiver</th>
<th>Lived with the care-recipient</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Wife</td>
<td>75</td>
<td>Married</td>
<td>NO</td>
<td>NO</td>
<td>7</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>3</td>
<td>Wife</td>
<td>80</td>
<td>Married</td>
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<td>NO</td>
<td>5</td>
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<td>YES</td>
</tr>
<tr>
<td>10</td>
<td>Daughter-in-law</td>
<td>42</td>
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<td>YES</td>
<td>NO</td>
<td>1</td>
<td>NO</td>
<td>NO</td>
</tr>
<tr>
<td>4</td>
<td>Daughter</td>
<td>48</td>
<td>Married</td>
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<td>YES</td>
<td>1 ½</td>
<td>NO</td>
<td>NO</td>
</tr>
<tr>
<td>7</td>
<td>Daughter</td>
<td>61</td>
<td>Married</td>
<td>NO</td>
<td>NO</td>
<td>3</td>
<td>NO</td>
<td>NO</td>
</tr>
<tr>
<td>8</td>
<td>Daughter</td>
<td>45</td>
<td>Married</td>
<td>NO</td>
<td>YES</td>
<td>1 ½</td>
<td>NO</td>
<td>NO</td>
</tr>
<tr>
<td>2</td>
<td>Daughter</td>
<td>67</td>
<td>Married</td>
<td>NO</td>
<td>NO</td>
<td>3</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>5</td>
<td>Daughter</td>
<td>66</td>
<td>Divorced</td>
<td>NO</td>
<td>NO</td>
<td>4</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>6</td>
<td>Daughter</td>
<td>50</td>
<td>Married</td>
<td>NO</td>
<td>YES</td>
<td>6</td>
<td>NO</td>
<td>YES</td>
</tr>
<tr>
<td>9</td>
<td>Daughter-in-law</td>
<td>30</td>
<td>Married</td>
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<td>NO</td>
<td>&lt; 1</td>
<td>NO</td>
<td>YES</td>
</tr>
<tr>
<td>11</td>
<td>Daughter</td>
<td>49</td>
<td>Married</td>
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<td>YES</td>
<td>&lt; 1</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>12</td>
<td>Daughter</td>
<td>40</td>
<td>Married</td>
<td>YES</td>
<td>NO</td>
<td>1 ½</td>
<td>NO</td>
<td>NO</td>
</tr>
</tbody>
</table>

Ethical Considerations

Ethics protocol was submitted to the Human Subjects Review Committee at the University of Toronto for review. Approval was given on October 1, 1998 (see Appendix C for Letter of Approval).

Risks and discomforts of the study

The study was designed to be non-threatening to the participants. To minimize inconvenience caused by the interviews, the locations and times of the interviews were of the caregivers' choices. Although a few caregivers responded emotionally due to the sensitive nature of the topic, the risk of discussing with the researcher about their caregiving experiences was low. They were informed that the interviews could be stopped at any time and the interviewer always checked to see if they would like to take a break during the interviews. While no direct intervention or therapy was provided by the interviewer, information regarding various service providers was offered to the subjects.
upon request or if unmet needs became apparent.

**Benefits of the study**

Prior to the interviews, it was explained to the participants that they would receive no direct benefit from participating in this study. However, some appeared to gain self-understanding by discussing their own perspectives and experiences. In fact, ten caregivers expressed appreciation for the opportunities to share their stories. Eight participants further expressed hope that their perspectives could help the others and that they could contribute to an understanding of the experiences of Chinese caregivers.

**Informed Consent**

At the beginning of each interview, the participant was asked to sign a consent form stating the purpose, risks and benefits, and procedures of the study (see Appendix D for consent form). To ensure clear understanding of the study by the participants, the consent form was written in both English and Chinese as five of them spoke and read both languages. Also, verbal explanations of the consent form were given in Cantonese. All participants were notified in advance that the interviews would be tape-recorded and that breaks for resting would be included. Voluntary consent was emphasized and potential participants were not pressurred in any way to give consent. Subjects participating in the study were given copies of the information letter which they could keep (see Appendix E for information letter in English and Appendix F for information letter in Chinese).

**Protection of participants’ rights**

The researcher also discussed with the participants their rights prior to the interviews. Participants were informed that their decision whether or not to participate in
The study would not affect the services they received from the agencies involved and that they could withdraw from the study at any point without fear of any negative consequences. It was also explained to the participants that although their remarks would be presented in the thesis, their identities would be shielded.

Data were collected by the researcher only and information obtained in connection with the study was kept confidential with the exception of discussions with the thesis supervisor, committee members, and independent reviewer. The data were kept in a locked storage and only the researcher had access to these data. Names of the participants were substituted by codes in transcriptions to protect their identities. Thus, the thesis supervisor, committee members, and nurse spot-checker only had access to data for which identities were coded. Taped records of the interviews were destroyed once they were transcribed.

**Data collection method**

Data collection for the present study was accomplished through one semi-structured in-depth interview of each participant. Data collection from the 12 participants occurred over a 6-month period. Interviews were conducted, on average, 2 weeks after the initial contacts. While nine of the interviews were conducted at the participants' homes, two of them took place at the Yee Hong Centre for Geriatric Care, and one of them took place at the participant's office. All interviews were conducted in Cantonese. The interviews took, on average, approximately 1 hour and 30 minutes each with the longest being 4 hours and the shortest being 1 hour.

Throughout the interviews, the model (see Figure I. on p. 4 in thesis) modified from the framework provided by Pearlin, Mullan, Semple, and Skaff (1990) was used as
a conceptual guide for data collection. A list of open-ended questions focusing on the modified model guided the interviews. Participants were asked to reflect on their relationships with the persons with Alzheimer's disease, to discuss the stressors they experience, the social support they receive, and their ideas about their relatives moving into institutions. The interviewer determined the exact wording and order of the questions as the interview progressed. As the aim of open-ended questions is to elicit subjective, idiosyncratic responses, the interviewer was prepared for highly variable answers and adjusted follow-up questions accordingly (see Appendix G for initial guideline questions and subsequent changes to them).

In order to explore the extent to which the caregivers had considered institutionalizing their relatives with Alzheimer's disease, a scale developed for the present study was also administered. The scale contains a series of actions reflecting an increase in intention to institutionalize one's relative with Alzheimer's disease. The interviewer asked the caregivers the questions and then located the caregivers on the scale according to the questions answered in the affirmative (see Appendix H for scale). Following the "yes" or "no" responses, the interviewer probed for more details.

Data analysis

Data analysis was inductive in nature and conducted simultaneously with data collection. Since formulation of ideas or themes may alter the intended course of data collection, there was no definite moment when data collection stopped and data analysis began (Huberman & Miles, 1994).

Data were collected from the interviews on audiotapes and then transcribed. To minimize the discrepancies in meaning due to language differences, transcription of
interviews was carried out in Chinese. As no computerized program for qualitative analysis is available in Chinese, data analysis of the present study was manual. The sequence of analytic procedures for qualitative research described by Miles and Huberman (1994) was adopted as a guide.

The first step was the assignment of codes to the transcription to reduce the unit size of the data and to describe the data (Miles & Huberman, 1994). Initial coding of data was conducted in Chinese. As the initial codes were based on the wordings in the passages, it was important to assign codes that captured the meanings accurately. Thus, rather than translating the Chinese codes into English codes, data were reread and coded again in English so that meanings of the passages were not lost through the process of translation. This approach allowed the researcher to capture the perspectives of the caregivers to the fullest extent without limiting the process of review by others. As this process was carried out in both languages, a spot-check was conducted by a third person (a bilingual health professional) to ensure the accuracy of the codes. Special attention was paid to the agreement between the Chinese codes and the English codes (see Appendix I for letter of approval). The Chinese codes were later used to make interpretations about the data and to guide any subsequent interviews.

In order to categorize the data units, the interviewer went over every coded passage and grouped the ones with similar content together (Lincoln & Guba, 1985). Rules were devised to describe each category and to guide inclusion of future data (Huberman & Miles, 1994). Similar to the stage of coding, this procedure was conducted in both Chinese and English. After categorization based on the Chinese codes was accomplished and rules in Chinese were devised, categories were reviewed and rules
were devised in English. The English and Chinese rules were compared and adjustments of the rules were made for differences between them. As rules in both languages should be consistent if they were accurate, this method allowed the researcher to double-check the accuracy of them. Then, all categories were examined for possible interrelationships; for example, to determine if certain categories were subsumable under others. By examining the category system as a whole, missing or incomplete categories were identified and further explored, as recommended by Morse and Field (1994), through questions in succeeding interviews. In this way, emerging topics or topics that were not adequately covered could be explored further in subsequent interviews. As the interviewer did not conduct second interviews with earlier participants, their direct answers to the new questions were not obtained. However, their perspectives on the emerging topics were evident in their responses, although in a more implicit manner.

The next stage was thematic analysis and was focused on cross-case thematic analysis. Common themes were identified from all data collected from caregivers. Unlike the previous stages in which the Chinese and the English versions of the analysis were performed independently, the procedure of thematic analysis was based on the Chinese version of the analysis and then translated into English. As this stage of analysis was based on the overall categories but not on the individual responses, meanings of the passages would not be lost through the translation of themes. This analysis provided a more global picture of the caregiver experiences and the factors influencing the Chinese female caregivers’ intention about institutionalizing their relatives with Alzheimer’s disease.

Although the process of data analysis has been presented as separate steps, this
distinction is an artificial one. In qualitative research, a succession of “question-and-answer cycles” (Huberman & Miles, 1994, p. 431) is employed. Specifically, a set of data was examined, more data were gathered from additional participants, and the new data were incorporated into the original data set and further affected the data to be collected in the future.

Evaluation of qualitative research

According to Marshall (1990), there are no “rules” which can be conveniently applied to the evaluation of qualitative research. To serve as a guide, Yonge and Stewin (1988) suggested that four criteria should be considered. These include confirmability, auditability, credibility, and fittingness. Confirmability is achieved when the conclusions of a study are based on the participants’ responses and objective evidence rather than on the researcher’s biases (Guba & Lincoln, 1981). According to Yonge and Stewin, the participants and others should feel that the findings are meaningful to their lived experiences. Also, the researcher should be explicit about personal biases and assumptions (Miles & Huberman, 1994). In this study, data analysis was inductive in nature, themes were drawn from the experiences and remarks of the participants who were free to elaborate and provide wide-ranging information in a comfortable and non-threatening environment. To minimize subjective interpretations of the data by the researcher, specific changes in the interview questions and the researcher’s reactions during the interviews were recorded and taken into account. The researcher’s own values and assumptions were also examined and considered during data analysis. The researcher’s reactions to interviews were documented (Appendix J).

The second criteria suggested by Yonge and Stewin (1988) is auditability. It
refers to the ability of another researcher to follow the rationale and methods used by the original researcher. According to Miles and Huberman (1994), this criterion refers to the reliability of the study. To ensure auditability, the researcher should document the entire research process. Also, coding checks should be conducted to ensure the consistency of code assignment. In this study, all research procedures were recorded. For example, the researcher kept fieldnotes of the individual interviews and recorded changes made to the interview questions. To ensure the researcher’s stability, the level of formality during the interviews, the researcher’s tone of voice, and the wording of individual questions were kept consistent across interviews. Although the guideline questions for the interviews were modified as data collection progressed, the method of data collection remained the same. Also, the areas covered were consistent throughout the process. Code assignment was conducted in both Chinese and English and a spot-check was performed to ensure the accuracy of the translation. A nurse fluent in both written English and Chinese conducted the spot-check and agreement proved to be high. Specifically, ten sets of codes were checked and all were approved. Suggestions were made to three sets of codes and two of these required only rearrangements of words. For the last set of codes, the new code, “father fails to deal with emergency” was suggested to replace the assigned code of “father cannot respond to emergency”.

When evaluating the criteria of credibility, one should focus on the accuracy of the findings. The findings should present a portrait of the situation under investigation (Miles & Huberman, 1994). According to Warner (1991), this also includes the idea of “natural” validity. In other words, the setting or situation being studied should not be modified or influenced by the presence of the researcher. During the stage of data
analysis, the researcher often referred back to the caregivers' background and context to note if their responses were consistent with their caregiving situations. In cases where there was inconsistency, it was noted. The researcher then looked for possible explanations for such responses and compared the inconsistent responses with the caregivers' answers in general and reported that information. By allowing flexibility in the guideline questions, the researcher was able to explore the participants' perspectives to a fuller extent and get a portrait of their caregiving experiences. As data were collected through individual interviews at locations of the participants' choices with confidentiality emphasized, participants were able to express their ideas freely without the fear of being identified. To demonstrate the comfort level expressed by the participants during interviews, seven participants expressed enjoyment during the interviews and asked the researcher to visit again. In other words, the participants did not see the researcher as a threat. In addition, the spot-check of assigned codes performed by the bilingual nurse also adds to the credibility of this study.

Fittingness refers to the transferability of the results to other contexts (Lincoln & Guba, 1985). The study was explorative in nature involving a small number of participants, however, considerable detail is reported. Thus, the results of the study may be cautiously used in other contexts. Only subsequent studies in these contexts can attest to the fittingness of these data.

Triangulation refers to methods utilized to ensure the validity of qualitative research (Miles & Huberman, 1994). In the present study, triangulation could only be partially applied. In terms of research methodology, observations were made during the interviews of the participants reactions and of the interviewing environment. Also, spot-
checks of translation and subsequent queries were carried out to ensure the quality of the data. However, although participant recruitment was attempted at three community agencies, all caregivers but one were from the same facility. Thus, a heterogeneous sample could not be obtained.
Chapter 4

Findings

Common themes were drawn from the in-depth interviews and will be presented according to the components of the model of caregiver stress as put forward by Pearlin, Mullan, Semple, and Skaff (1990). These components include background and context of stress, primary stressors, secondary role strains, secondary intrapsychic strains, mediators, and outcome of stress. Within each component, main themes and sub-themes will be presented. The main themes in each component as reported by the caregivers are incorporated into the conceptual framework and shown in Figure II below. All themes will be presented within the context that only six participants in this study stated that they were ready to institutionalize their relatives although all caregivers had applied for nursing home placements.

Figure II. Conceptual model of Alzheimer’s caregivers’ stress for Chinese Female Caregivers with main themes incorporated.
Throughout the presentation of themes, quotes used are direct translations of what the participants said. To retain the authenticity of the data, changes in the sentence structures were minimized during translation. As a result of the differences between the English and the Chinese language, some sentences may seem awkward. For example, arrangement of noun and verb orders and usage of definite and indefinite articles are different between the two languages.

Culture had influenced the participants’ views on caring for their relatives

In this study, caregivers indicated that culture, as a “background and context” variable (Pearlin et al., 1990), was associated with the various aspects of caregiving. Caregivers perceived their caregiver role as an obligation and viewed the option of institutionalization negatively. They attributed their views to their traditional values which motivated them to provide care for the care-recipients.

Caregiving was perceived as an obligation determined by their culture

All caregivers, with no exception, mentioned that they felt obligated to provide care because of their cultural values. Assuming such a role was viewed as appropriate and the natural course to take. This sense of obligation appeared to be based on family relationships and family loyalty.

All caregivers reported the sense of responsibility irrespective of the particular relationships of the caregiving dyads. They perceived care provision as part of the proper conduct defined by their culture. By taking on the caregiver role, they fulfilled their “names” of being a wife, a daughter, or a daughter-in-law (see p. 7, discussion of the importance of the family relationships). In other words, they felt responsible for the
afflicted person’s care because of their relationships to him or her. As mentioned by a wife caregiver:

The responsibility is mine. I can take care of him like this only because I am his wife. If it was the daughter or the daughter-in-law, it will be different. They are not as close so they cannot take care of him like this. The relationship between husband and wife is the most important. I am the closest to him, I ought to take care of him.

Eight caregivers were explicit about certain responsibilities being attached to their relationships with the care-recipients according to the Chinese tradition. As a daughter caregiver said, “In the thinking of Chinese people, one needs to take care of her mother. She is old now, she took care of me when she was young, now that she is old, I ought to take care of her”. The emphasis of filial obligations was apparent in comments of five participants who mentioned experiences of anticipation of the caregiver role. A daughter-in-law caregiver said:

I think this change is only a short period in my life. I have to face it. I have my father-in-law, my mother-in-law, and my own children, so I have to go through a period of time when I cannot go out or have other social life. It is something I have to face.

In addition to their recognition of the influences of culture on their perceptions of their caregiver role, four caregivers compared the Chinese culture with the Western culture regarding the responsibilities that adult children have in providing care for their aging parents. According to one participant, they felt that “Chinese people truly feel that they have the responsibility to take care of their parents, this is different from the Western
family values". One daughter further expressed appreciation for the traditional values. When asked of the influences of culture on her caregiving experience, she said:

I think the part of our Chinese culture that one has to take care of and to respect the elderly people is right. Conversely, I do not know how the Western countries justify this, explain this. I think it really is culture…. Our elderly people are not like that. They speak of bringing up children to prepare for the future, etc. Our generation of baby boomers has already adopted the values. That is, being filial to our parents is right, or take care of them is what we ought to do. We ought to live with them and hope that we can do more than what she is getting now.

In addition to the fulfillment of their filial obligations, caregivers also mentioned that they felt obliged to provide care for their relatives with Alzheimer’s disease because they belonged to the same family. They felt responsible for helping their family members and taking care of them. When asked of her feelings towards her caregiver role, a daughter-in-law caregiver said, “We are a family, of course I have to do it. My husband has to go to work, so I feel that I ought to do it.”

This sense of belonging also contributes to some caregivers’ efforts to keep the family together. Six caregivers said that being a member of the family, they should try to overcome the difficulties and should not avoid the responsibilities. As mentioned by a daughter caregiver:

No matter what happened, she is a member of the family. I take care of her the same way I always have and our lives are the same. I have never thought of sending her to the nursing home. Therefore I have never applied or filled out forms, our lives are as usual. [Note: This comment is inconsistent information.
regarding intention to institutionalization as the participant said she filled out application forms. However, she made it clear that she filled out forms only under pressure from her family and service provider.]

In addition to being physically together, one daughter caregiver felt that it was important for the care-recipient to have a sense of belonging. She believed that as the care-recipient was unable to adapt to the outside society, her social circle was limited within the family. Thus, she should provide the care-recipient with a sense of family.

She said:

There are a lot of elderly persons who need care from other people. I have also seen too many families who do not care for their elderly relatives and send them to nursing homes. I personally think that doing this is not right. So I try my best to care for her. Let her feel that she still has a family and is still a member of the family.

Culture had influenced the caregivers' perceptions of institutions

When the caregivers were asked to express their opinions on placement, eight of them expressed strong negative feelings towards institutions. They disliked the idea of institutions and thought them inappropriate as they are against family values and would be considered against the care-recipients’ wishes.

For the eight caregivers who mentioned negative feelings towards institutions, the traditional value of family unity was often given as the main reason. They felt more comfortable with the afflicted relatives staying with them since they would be able to provide care when necessary. This value is illustrated by a daughter caregiver’s
expression that, "I still have some old Chinese mentality, for sure I want to be together with my parents. I will not worry as much."

Three caregivers mentioned their relatives’ preference of staying at home. They often took their relatives’ wishes into account when considering the option of placement. When asked if the care-recipients had had previous experience with nursing homes, a daughter caregiver replied:

She has never been in a nursing home before. Although she does not know anything now, she has mentioned before that “even the best nursing home is not comparable to being at home, not comparable to being cared for by one’s own children”.

This preference of staying with one’s family is further captured by a care-recipient’s fear of being abandoned by her family. The caregiver recalled that when she first brought her mother to the daycare program, she had to explain to her mother that she would not be left at the centre. The caregiver said:

When she first came here, I had to fool her. She thought that I wanted to leave her here and leave her alone. Coming to things like daycare, she thinks I want to abandon her, to leave her alone. I told her that is not it, it is just like going to school…. If she comes here, her first impression is, the image given to her is that I want to leave her here, right? Chinese people have those thoughts.

In addition to stressing family unity, six caregivers just could not accept the idea of nursing homes. They described nursing homes negatively and thought that residents at the nursing homes were being treated badly. As mentioned by a daughter caregiver,
“Chinese people always think that when elderly persons are being sent away from their families, they will be treated like nothing.”

This negative impression is further demonstrated by a daughter caregiver’s reactions to her visit at a nursing home. As she recalled, “I have been to the nursing home before. There was one time during Christmas when I went there. When I saw them, I just could not stop my tears. I felt really sorry for those people living there”.

Just as institutions themselves were being perceived negatively, so was the act of sending a relative to a nursing home also being labeled negatively. As described by a daughter caregiver:

Up to this point, I still cannot accept the option of sending her to the nursing home. I mean the environment. Also, going to the nursing home, I do not want to use the word “abandon”, but isn’t that sort of isolating her? I feel this way in my heart.

She further described her feelings towards institutions and attributed her feelings to her traditional values. As she said, “Everyone of us think that way. If she goes to a nursing home, in our traditional mentality, we feel that nursing homes are difficult to accept. Sending one’s family member to a nursing home is a heart-breaking thing.”

Similar feelings were reported by another daughter caregiver. While influencing her own decisions regarding placement for her mother, she also reported influence of cultural values on her expectations for the other caregivers. She said,

I am a traditional person. I very much dislike those people who leave the elderly people alone. Let them live on their own, cook and eat by themselves, live and
die on their own, and visit them only when they have time. I do not like those people. I am very traditional.

Participants reported stressors in relation to caregiving demands differently

Participants reported various sources of stress as resulting from the conditions of the care-recipients and the caregiving demands. These sources of stress correspond to the "primary stressors" in the model put forward by Pearlin et al. (1990). These stressors are considered primary in nature because they arise from within the caregiving tasks and demands. For example, difficulties in activities of daily living, behavioral problems, continence, and mobility were either referred to by the participants or observed by the researcher. These characteristics were noted in order to indicate a level of burden experienced by the caregivers. The characteristics of the individual care-recipients are summarized in Table 2.
Table 2. Characteristics of the care-recipients

<table>
<thead>
<tr>
<th>Case</th>
<th>Level of independence in activities of daily living</th>
<th>Behavioral problems/physical aggression</th>
<th>Continence</th>
<th>Mobility</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td>Independent</td>
<td>Hiding belongings, repetitive questioning</td>
<td>Continent</td>
<td>Mobile</td>
</tr>
<tr>
<td>4</td>
<td>Independent</td>
<td>Repetitive questioning</td>
<td>Continent</td>
<td>Mobile</td>
</tr>
<tr>
<td>3</td>
<td>Independent</td>
<td>None</td>
<td>Continent</td>
<td>Mobile</td>
</tr>
<tr>
<td>1</td>
<td>Required assistance with some activities</td>
<td>Frequent physical aggression</td>
<td>Incontinent</td>
<td>Mobile</td>
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<td>2</td>
<td>Required assistance with some activities</td>
<td>Occasional agitation, verbal inappropriateness</td>
<td>Borderline</td>
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<td>7</td>
<td>Required assistance with some activities</td>
<td>Occasional verbal abuse</td>
<td>Continent</td>
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<td>11</td>
<td>Required assistance with some activities</td>
<td>Verbal inappropriateness</td>
<td>Continent</td>
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<td>12</td>
<td>Required assistance with some activities</td>
<td>Verbal inappropriateness</td>
<td>Incontinent</td>
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<td>8</td>
<td>Required assistance with most activities</td>
<td>Frequent physical aggression, repetitive questioning, verbal inappropriateness</td>
<td>Borderline</td>
<td>Mobile with aid</td>
</tr>
<tr>
<td>9</td>
<td>Required assistance with most activities</td>
<td>Frequent physical aggression, repetitive questioning, verbal inappropriateness</td>
<td>Borderline</td>
<td>Mobile with aid</td>
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<td>5</td>
<td>Required assistance with most activities</td>
<td>Occasional physical aggression</td>
<td>Borderline</td>
<td>Mobile with aid</td>
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<tr>
<td>6</td>
<td>Required assistance with most activities</td>
<td>Occasional verbal abuse, crying</td>
<td>Continent</td>
<td>Immobile</td>
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While the care-recipients varied in their behaviors and levels of independence, the various characteristics led to different levels of stress for individual caregivers. Their response to demands varied according to their own personal subjective appraisal of their discomfort in dealing with the demands. For example, although six care-recipients were incontinent or borderline continent, only one caregiver whose care-recipient was borderline continent reported the particular problem to be the most difficult aspect of caregiving. When asked about the most difficult aspect of caregiving, three caregivers reported that the care-recipients' behavioral problems (e.g., hiding belongings, repetitive questioning) were the most troublesome part of their experience. A daughter caregiver said:
Actually he [her father] is not that difficult to take care of. The worst part is that he did something and did not know it. He did it, I told him not to do it again, and he would just insist that he did not do it. I just told him not to turn the tap on, he often turned the tap on and forgot to turn it off.... That is why whenever I hear something wrong, I would go to his room to check. Otherwise, it will be awful. Using the water is not a problem, but he may flood the house! So sometimes when I have to go out that is the hardest part.

Besides behavioral problems, physical aggression also led to high levels of stress. Among the four care-recipients who exhibited physical aggressiveness, two of their caregivers reported that their relatives’ aggressive behavior was the most difficult aspect of their experience. A wife caregiver said:

When he [her husband] hits me, that is the hardest. I would close the door and let him hit the door. Wait till he has calm down, I would open the door and come out. Him getting agitated and hitting people is the most difficult. I do not care about the other things. I take care of him like this everyday, the work is the same. The only thing is hitting people, that is the hardest.

In addition, three participants mentioned the various aspects of the care-recipients’ dependency as the most difficult part of caregiving. While one caregiver found her mother’s attention seeking during the night difficult, two other caregivers considered the physical care provision problematic. A daughter caregiver said, “What I dislike the most is her being incontinent. Even though I just changed her, she would be all dirty again. To be honest, nobody would want to do the dirty job, but it must be done.”
Caregiving interfered with other life roles

Besides the primary stressors just described, participants also reported other strains caused by the caregiver role. To assume the caregiver role and meet the caregiving demands, previous life roles were affected and compromised. Caregivers experienced increased family conflicts and discontentment, conflicts between the caregiver role and the occupational role, and reduced social and recreational life.

According to Pearlin et al. (1990), these strains are called “secondary role strains”.

Family conflicts and discontentment were a source of strain

Family was reported to have ambiguous effects on different caregivers or even the same caregivers. While the negative aspect of family will be presented in this section, another aspect of it will be presented in a later section. In terms of family conflicts, four caregivers expressed discontentment with the amount of support they got from their families. One daughter caregiver made the distinction between requested support and offered support. Although her children would assist her when she sought help, they would not take the initiative to offer support to her. As she said:

If my children will, for example, when they go out to get groceries, ask me what I need, initiate to ask me, I will feel better. So that it is not me who has to call them and ask them to get the things for me. This is different. One is I have to ask, the other one is they actively show they care about me.

Another caregiver further mentioned the feeling of helplessness related to other family support. Although she wished that her sister, being an insider within the family, would be involved, her sister was not willing to take responsibility. Her feeling of helplessness was intensified when she discussed with her sister the issue of
institutionalization. When she raised the issue, her sister did not respond with an answer
but asked for her opinion on the subject matter. This lack of emotional response
disappointed and confused the caregiver. As she recalled:

At the beginning I wanted to discuss it with her, but when she answered me like
that, how could I not feel helpless? I wanted to have an answer, I could disagree,
but we could still discuss.... Because that was a huge decision for me, I was
crying at home everyday, I really did not want her [her mother] to leave. All I
wanted was to discuss it with someone in the family, to find a support. Whatever
she [her sister] did, it would have been a support. But after I knew she acted like
that, forget it then. I decided myself.

In addition to discontentment with family support, family conflicts regarding care
 provision were mentioned to be a major source of stress. Six caregivers reported
disagreement with other family members with respect to what should be done for the
care-recipient. This is evident in a daughter caregiver’s experience:

I try my best to do it, to raise her [her mother’s] standards, I could really feel the
pressure. Where did the pressure come from? It was actually very complicated.
If it was only the mother and the daughter, I feel it would be a lot simpler. My
sisters often give me troubles, but not help. They think that they have the right to
express their opinions, but they have not thought that they also have the right to
take care of her. Besides my sisters there are also their children, they are also
very messy.

Seniority and status in the family further complicated the conflicts among family
members. This is demonstrated by the case in which the care-recipient’s wife, but not the
care-recipient himself, was reported to be the biggest source of stress for the daughter caregiver. The care-recipient’s wife often disagreed with the caregiver’s suggestions, the caregiver found the situation very difficult since she could not ignore her mother’s ideas. As she recalled:

Right now, the stress does not come only from my father, but from my mother. In our family, everyone’s stress is from my mother. Thus, every time we see that expression on her face, we know she does not like something. Then we have to do something else. While we think something is beneficial for our father, she does not think so.

Besides one’s status in the family, culture also complicated family conflicts in other ways. For example, a daughter caregiver mentioned conflicts with her sister as a result of the difference in culture. While she considered herself as very traditional, she viewed her sister as very much Westernized:

Sometimes I have conflicts with my sister as a result of caring for my mother. Why? Because she is very much Westernized. Her mentality is very Western. She would actually go beyond her own seniority and status in the family and open up to talk to you. But after failing for so many times, she knows it is not going to work.

**Caregiving caused role strains related to other occupational roles**

Besides the conflicts with one’s family, four caregivers reported role conflicts related to their employment. While two of them worked for a paid salary, two of them had their own businesses. These participants had made occupational choices as a function of their caregiver roles and had to arrange their work so that care provision
would not be affected. A daughter caregiver reported that although she had a helper to stay with her mother, she had to arrange her work so that she could cover her mother’s care when the helper was on holidays. She said:

When I arrange my work, I have to consider and match the helper’s schedule. For example, if Saturday is the helper’s day-off, I will not work on Saturday. Or if I have to look after her [her mother] at night, I have to arrange my schedule so that I can have more sleep the next day.

While the aforementioned caregiver worked for a paid job, a daughter caregiver who had her own business with her husband thought that she was lucky to be working for her own company. This arrangement allowed her the flexibility to provide care for her father. She said:

Because this is my own business, I can leave at any time. If this is not my own company, I will not be able to do that. That will be more troublesome…. Also because my husband and I work at the same company, it is easier. If he has a regular job, it will be more difficult.

Caregivers reported decreased social and recreational life

Three caregivers reported that as they spent most of their time providing care for the care-recipients, they had little time to spend with their families. While going out to meet with their families was difficult, having their families to visit was also troublesome. A daughter caregiver said:

It [caregiving] has affected my relationship with my children to a certain extent, because I cannot spend time with them. I cannot go anywhere. It is the same if
they come home. He [her father] will get agitated. Little kids [her grandchildren] do not know anything, what if they push him down by accident?

All of the daughter and daughter-in-law caregivers but one reported reduced social life. Due to the time constraint, they found it difficult to socialize with friends or engage in other activities. A daughter-in-law caregiver said, "I do not have time to socialize with the others. I am not that old, I want to socialize with other people, but now I cannot. I cannot do that because I do not have the time.”

**Caregivers reported psychological strain due to appraisal of issues related to caregiving**

Caregiving also had a deeper effect on the participants such that it influenced the caregivers’ psychological state in an enduring manner. Their caregiving experiences and related issues led them to reflect on their situations which caused additional strain. These strains are comparable to the “secondary intrapsychic strains” described in Pearlin et al.’s model (1990).

**Caregiving led to a loss of self**

As a result of the caregiver role, three participants reported a loss of self. They thought that they had changed their lifestyles because of the care-recipients to such an extent that they no longer had a sense of their own selves. A daughter caregiver said:

Because I wanted her to be happy, I will do it when I know what she wants, I will do it naturally. Sometimes I think about it myself, she is now over ninety years old, basically I live with her, I do whatever she does, in other words, I live a life of a ninety year-old. Basically, except for being able to drive, I live the life a ninety year-old person. I will get really upset if I think about this. I might be
wrong, but I have thought about that before. My life is no different from hers, I accommodate her in everything. She is the center of everything, because I can adjust myself.

In addition to the loss of self as a direct result of the caregiver stress, a daughter-in-law reported loss of self because of the other family members. She said:

Sometimes I know obviously that her [her mother-in-law] method is not good, but I will still take her approach to do it. Because I do not want her to be upset since I am not going to live with her for a long time. And then I think that she is living towards the end of her life, even if she live for another twenty years, that is only twenty years, I do not want to upset her. Because of these reasons, I accommodate her in a lot of things, so I have to give up my own self. For example, I have my own ideas for a lot of times, but I feel that I do not have to insist. I will do whatever she likes.

**Constant care led to psychological burden**

Five caregivers reported psychological burden as a result of the constant care required by the care-recipients. As much supervision was required by these care-recipients, their caregivers were worried constantly and were unable to relax psychologically. The magnitude of this burden was reported by a caregiver to be even greater than the stress resulting from direct care. A daughter caregiver said:

My feeling is being very tired, very tired and extremely stressed. Because I know that she can be in danger anytime, she does not know what she is doing.

Suddenly, she would do something that she is not suppose to do which is dangerous…. That is, she is changing everyday, there is something different
everyday. Suddenly something would happen, almost like accidents. She would be in danger, so I have care for her a lot, I have the invisible pressure.

Four caregivers further suggested that the ongoing nature of caregiving was very stressful. They found caregiving energy-draining psychologically as they did not know when the situation would end. A daughter caregiver said,

I think the hardest part is that you do not know how long that is going to last. I can anticipate what will happen by reading books and the doctor has told me. How will it be like in the future and what will she do. There are examples to show and procedures to follow. But how long that will last, I do not know.

Sometimes I want to relax, but I have no time, I have to arrange a lot of things.... There is no timeframe, it is like I have to wait till she dies, which I do not know when will happen.

One daughter caregiver further reported psychological burden indirectly related to the caregiver role. Her mother’s condition led to her insight about life and made her think about her own self. She was worried about her own future and said:

I think that when a person gets old, living towards the end of her life, the pathway is like this. I am a senior person myself, I will think, “the pathway is like this, will my own future be like this?” So I get upset.

**Participants felt captive in their caregiver role**

Due to the level of supervision required by the care-recipients, four caregivers reported role captivation. They were afraid to leave the care-recipients alone and would not leave their houses unless necessary or if they arranged in advance for someone else to stay with the care-recipients. A daughter-in-law caregiver said:
If there are only my mother-in-law and my father-in-law at home, I will not dare to go out. Really it is not daring to go out. Because if I go out and he [her father-in-law] becomes aggressive, she will not be able to handle him.... So I do not dare to go out, according to my own timetable, I will not go anywhere.

Another daughter caregiver was explicit about her discontentment towards the caregiving needs required by her mother. She thought that she had to perform the tasks and could not avoid them. She said, “Actually I think it is quite painful, because she never needed my care before. Also it is something that I must do now, I cannot escape from it”.

A daughter caregiver further mentioned the feeling of being trapped and being unable to lead her own life as a result of care provision. Her resentfulness towards the caregiver role was apparent. She said:

Because I am a senior person myself, at this stage when I do not have to work, it should be my golden time. I should expand my social life outside. But starting from 1994, after she [her mother] got Alzheimer’s disease, my life has been very limited. My life is limited to the home. I rarely interact with other people. If I have to go out with my friends, I have to find someone to take care of her, then I can leave.

Caregivers were concerned about intergenerational changes in culture

When the daughter and daughter-in-law caregivers were asked about their opinions on family caregiving, three of them expressed expectations for their children to take on the caregiver role in the future while five others did not assume that would happen. For those who did not expect home caregiving in the future, changes in family
values were given as the main reason. Such changes were attributed to the advancement of time and of the society, and to their belief that the Western culture had diverted their children’s traditional values.

Advancement of time was often given as the main reason for the observed intergenerational changes in cultural values. Caregivers thought that their children no longer retained the traditional values that they maintained, as they belonged to two different generations. As a result, they could not expect their children to behave the same way as they did. This thought is evident in the following statement from a daughter caregiver:

But the present society is different from that before. I have thought about it before. When I grow old, like their [her parents’] situation now, my children may not take care of their parents like I am doing now…. The present society is not like before, but now I am like a piece of sandwich, being stuck in the middle. Only our generation is like this, there will be nobody like us in the future.

Another daughter caregiver further extended her view on intergenerational changes in values to broader aspects of the Chinese community. In her opinion, the younger generation of Chinese is not aware of the issue of family caregiving for the geriatric population. As she expressed:

The younger generation in our society is not too concerned about the problem of the aging of the population, but this situation will become more and more serious. This is more so in the Chinese tradition, because there are more elderly people, if this problem is not solved, the impact will be huge.
In addition to the advancement of time, four caregivers believed that being in a Western society has influenced the values of the younger generation. They thought the value of independence upheld by Western society has diverted the younger generation from the Chinese tradition. As expressed by a daughter caregiver:

I think the mentality in the younger generation of Chinese has diverted from our [the older generation’s] traditional views. Of course it has gotten closer to mainstream thinking, but they still have retained some Chinese family concepts. It is already not like the way we look at the Chinese family-valued society. It is already different…. I think that although the younger generation has to merge with the overall Canadian culture, they should still retain Chinese values regarding the area of family relationships.

Similarly, another caregiver believed that peer socialization would influence the values which the younger generation adopt. She further mentioned the importance of family education in maintaining traditionalism in the younger generation.

We cannot expect too much here in Canada. That is, I cannot demand that he takes care of me like that…. He may not have the heart to do it. Because all the people around him think that ‘we will move out when we reach a certain age, we will not take care of our parents, we will be independent’. That is, it depends a lot on his peers at that time, what kind of people they are….Also I think family education is very important. Because when he is older, this society and his family will fight for his mind.
Caregivers utilized different resources to mediate the caregiver stress and stains

In reaction to the caregiver stress, participants reported various ways to deal with their burden or negative feelings. They adopted different approaches to cope with the stress and obtained support from various sources. These resources are comparable to the "mediators" in Pearlin et al.'s model.

Caregivers used various approaches to cope with the caregiving situations

Caregivers reported various coping approaches taken to cope with and face the difficulties. While some caregivers mentioned the use of emotion-focused coping such as tolerance and positive reappraisal, others reported using problem-focused coping to lessen their caregiving burden.

Caregivers felt that they had to tolerate the situation despite its stressfulness

Although difficult, caregivers felt that they had to tolerate the situations because of the sense of obligation. They felt that they had to try their best to handle the situation despite great difficulty, since that was part of their responsibilities. When asked about the stresses of caregiving, a daughter caregiver said:

Whether it is stressful or not, it does not make a difference. Since that is my mother, I cannot complain about her, right? The bottom line is that she is my parent. Even if that is my father-in-law or mother-in-law, they are still part of the family, I cannot complain about those things.

This caregiver’s determination to provide care also extrapolated to her opinions on acquiring assistance from the others. In response to the question on caregiving responsibilities, she expressed reluctance in asking others for help and stressed ownership of the responsibilities. She said:
I do it [caregiving] because that is what I should do. There is no solution to this, since that is my mother…. That is, I will not push the responsibilities to the others. What I have to do, the steps I need to take, I try my best so that it is good for both me and her [her mother]. It is my responsibility, I think it is my own responsibility, I cannot give it to someone else.

Another caregiver viewed family caregiving as something that must be accomplished. She had a strong will to maintain her caregiver role and thought that her siblings also felt the same way:

The thing that is supporting us is that our siblings all feel that ‘we must do it’.

That is, we must do this thing. It is just a matter of who is doing more and who is doing less…. This attitude supports me to continue on, I have to do this job. I think that being her children, we cannot leave her alone.

**Positive feelings about caregiving alleviated the caregiver burden**

On the other hand, seven participants reported experiences of positive feelings which helped to alleviate the caregiver burden. For example, a daughter-in-law caregiver reported a sense of accomplishment. She viewed caregiving as a duty assigned to her and her goal was to complete her duty. She said:

If his [her father-in-law’s] condition does not get worse, I will already feel very happy. That is, I have fulfilled my assignment. Right now, I am like being on duty. During this period when he is not being taken care of by my mother-in-law, he is totally under my care. So, when I hand him over by the end and he has not lost weight, has not fallen when she [her mother-in-law] is not around or there has been no major mistake, I will be very happy.
While the above caregiver described caregiving as an assignment to be fulfilled, four other caregivers experienced an intrinsic sense of accomplishment. They found that it was very rewarding when they observed improvement in the care-recipients. A daughter caregiver said:

I often say that my mother is like my flower. If I cherish her well, I will be very happy. I have this feeling, that I will be very happy if she is well. Because I have put in my effort. I do not mean that she has to give whatever back to me, the bottom line is that I did all that because I wanted her to be healthy.

Positive feelings towards care provision were also reported by a daughter caregiver to be related to the assumption of the caregiver role. When asked about her positive feelings or views towards caregiving, she said:

Up to this point, I think this is a responsibility. This is reciprocity. She [her mother] is now sometimes like a child. Sometimes during the night, I need to soothe her to make her sleep. When I think back, when I was little, she did the same thing for me.

*Caregivers suggested the importance of having the right attitude*

To sustain their caregiver roles, seven caregivers felt that having a positive attitude was very important. They thought that one should take it easy and should not be too up-tight. As mentioned by a daughter caregiver, “one cannot take it too seriously when taking care of these people [persons with Alzheimer's disease], otherwise she [the caregiver] will get more and more upset as it progresses. Sometimes, if one [the caregiver] thinks too much, she will feel more miserable.”
Similarly, another caregiver thought that the stressfulness of the situation depended on the person’s perceptions and that it was crucial for one to be optimistic and be able to view the situation positively. As she mentioned:

There are no likes or dislikes. As I said, one’s attitude is the most important. If one [the caregiver] is able to take it easy, she will not see anything as a problem. But if one is unable to take it easy, she will not be happy even if he [the care-recipient] smiles at her. Because she thinks he is a burden.

In addition to the relaxed approach, two of the seven caregivers mentioned above suggested the importance of having a sense of humor. A daughter-in-law caregiver recalled:

When taking care of him [her father-in-law], you have to be happy yourself. You have to be able to comfort yourself. Do not remember that he was a very bright person, so smart, but now he is like that. Do not think about how he was in the past, otherwise you will be very upset. You have to try to think about something happy. If he gets agitated, we would just laugh about it like a joke and that is it. Last time we even videotaped his behavior when he got agitated.

Another daughter caregiver suggested that it is crucial for one to deal with the circumstances objectively. She thought that as Alzheimer’s disease is progressive in nature and the care-recipient will not get better, one should just focus on the tasks at hand. She further explained her attitude of being task-oriented:

Whether I complain about it or not, I still have to do it, so why don’t I just do it. My personality is that I will just do the job, without feeling that it is a big deal. I will do it if I think that it is my duty to do it. Complaining after doing it is not
going to help…. Thus, I know that clearly. Just do the job, I have to do it whether I complain about it or not. Work on whatever is not looking right, there is no way out.

Meanwhile, two caregivers stressed the importance of understanding. They thought that if one were able to think from the care-recipient’s point of view, they would be able to accept the situation. A daughter-in-law caregiver mentioned:

I think that while we feel uneasy, she [her mother-in-law] may actually be very unhappy. That is, you have to look at it from both sides. You are not happy yourself, but she may feel worse than you do. Otherwise she will not be getting agitated…. It is mainly because I know that she has this disease, her personality will change. This way, you will accept her, accept what she says and what she does. Even though it is very unreasonable, you can still accept it.

Social support had influenced the caregiving experience

When questioned on the area of social support, caregivers reported various sources of support. These include informal sources such as families and friends and formal service providers such as paid helpers. In addition, two caregivers emphasized the importance of spiritual support. From these sources, caregivers received tangible, informational, and emotional support. They had different opinions regarding the amount of support they received and also the benefits of such support.

Family support had influenced the caregiving experience

Although family conflicts were perceived as a source of strain, all caregivers but one reported great support from their families, in general. In fact, nine caregivers reported regular assistance from their families with the care of their relatives with
Alzheimer’s disease. Their families not only assisted them with the physical caregiving demands, but also helped to lessen their psychological burden. Family support was perceived as important and was appreciated.

When organizing the care for the afflicted person, family members often worked with the primary caregiver to create a network so that care was ensured. They perceived this arrangement as necessary because “You cannot be non-cohesive, if you all put the burden on a family during crisis, it will be quite difficult, it will be quite stressful”. The family was being viewed as a unit and care was coordinated among family members. This arrangement is demonstrated by a daughter caregiver’s case in which she shared the primary caregiver role with her sister-in-law. She said:

Since my father is now living at my brother’s place, if my brother thinks he is doing the right thing, he will do it. But he will ask for my opinion on everything and discuss with me. Sometimes when I hear something, something that can help my father, I will tell him about it. Let him apply for it or do it, or I will do it and then tell him about it. We do not have any conflict since we all do it in the best interest of our father.

While the importance of the family was reflected in their care planning, it was also evident in the caregivers’ evaluations of the amount of support provided by their family members. They compared their families’ levels of support with their expectations for their own caregiving and considered themselves as the most appropriate one in the family to take on the caregiver role. When asked about her family’s help, a daughter caregiver expressed that although her siblings did not provide tangible support for her on a regular basis, they did so when it was necessary. She was content with the arrangement
and her siblings' passive role. As she mentioned, "It is alright, I understand that everyone has his or her own job. They are busy, so I cannot ask for too much. Comparatively, I have more time than they do."

Seven caregivers took the particular relationships of their family members into account when evaluating the support they received. Expectations were set as a function of the relationship between the care-recipient and a particular supporting person. This is illustrated by a daughter-in-law caregiver’s appreciation for her sister-in-law’s help. She thought that her sister-in-law had done enough and she did not expect her sister-in-law to do more. She said:

I think the bottom line is that she has her own family. She is married outside the family and has her family. If my husband is living here, my in-laws of course prefer to be taken care of by their son.

In addition to physical support, emotional support provided by one’s family was also reported to be crucial. The importance of it is highlighted by a daughter caregiver. She emphasized the perception of being supported by her husband and that feeling was critical in sustaining her in her role:

My husband treats elderly persons very well and he has accommodated a lot. Otherwise, the family would have fallen apart a long time ago. Because the most important thing is that there is no use if I am in this on my own. My husband has to work with me. It would be impossible if our opinions were different and we would not be able to live together for so long.
The supportive role of her family was further reflected by her expression that “If my family did not support me like this, I would not be able to hang in for so long, I would have placed him [her father] in a nursing home a long time ago.”

While overt emotional support was perceived as valuable by the caregivers, the more covert support was also viewed as important. A daughter-in-law caregiver expressed the importance of being approved of by the family:

'It is lucky that the people around understand what we are doing and are supportive. My sister-in-law knows completely what is being done. She understands. Therefore, sometimes she would turn around to comfort my mother-in-law or provide us with more support. This makes me feel easier. If everyone says that I am doing the wrong thing, I may feel like giving up…. Therefore, I am lucky that the people around with clear minds can understand. I think that is enough, what else can I ask for?'

*Support from friends had made the caregivers feel better*

Informal support from families was valued by all caregivers. Seven of them also noted the importance of support from friends. Among these caregivers, only one reported tangible support from friends. As the friends she mentioned were her neighbours, they were readily available to assist her with tasks such as grocery shopping when her children were unable to do so. Emotional support from friends was also mentioned. They appreciated their friends’ support and thought that a show of affection could be encouraging and soothing. As expressed by a daughter caregiver:
On the other hand is the support from friends. At least when I cannot go out, they would call to see how I am doing, what I need, what is going on. They would ask. I think that encouragement from friends is also very important.

A wife caregiver suggested that sharing her negative feelings with her friends made her feel better. As they were from a similar background, they were able to share with her their experiences. As she recalled:

When I am very upset, I would call my friends. They would comfort me and say, ‘If you take care of him for another month, he will live an extra month. You still have a companion. If he died, you cannot even see him when you want to.’ So my friends explain to me that I have to take care of him nicely. A lot of my friends’ companions have died, they all say that they cannot even see their loved one, and I still have him by my side.

In addition, spending time with friends was reported by five caregivers to be an effective way to relieve stress. It was viewed as some time off from the caregiving demands when they could relax. When asked about her ways of handling negative emotions, a daughter caregiver said:

I will find my own entertainment. Once a week, I like to get together with my friends. We call each other sisters. We have potlucks, play mahjong, tell jokes, have gatherings.... All the way through, I have emphasized the ways to entertain oneself and to spice up one’s own life.

Support from community service agencies had made caregiving easier

Eleven caregivers were grateful for the formal support they received. They reported that the formal helpers had lessened their burden both physically and also
psychologically. While all eleven caregivers were thankful for the particular service providers, four caregivers further extended their appreciation to the Canadian government.

The caregivers were appreciative of the formal support they received. They often viewed the tangible support as assistance for the care-recipients. As some of the caregiving tasks were delegated to formal helpers, the caregivers' burden was in turn lessened. This situation is especially true for the two caregivers whose care-recipients were living in retirement homes. Although nursing care was not provided in the facilities, the caregivers were glad that their relatives received help in instrumental activities of daily living such as doing laundry and boiling water. This perception is illustrated by a daughter caregiver who, while viewing the caregiver role as her obligation, was grateful that the staff at the retirement home provided services for her mother. She said, “The bottom-line is that I need to take care of her. I cannot leave her alone. Now she is lucky that the workers from the _____ can help her, so my burden is lessened a lot.”

Similarly, a wife caregiver who reported great caregiver stress was very appreciative of the homemaking services provided through the CCAC. She further extended her appreciation to the Canadian government and was thankful for the support offered to her:

I am so thankful for the good government. Since there is someone coming to help him [her husband] with the shower, I do not have to worry about giving him a shower…. I am so thankful for the government, it has helped me a lot. He [the
homecare worker] helps him with the shower, also does the house cleaning for us, so my burden is not as heavy.

Informational support was also deemed important by nine caregivers. These caregivers found the information provided during the caregiver support groups very useful. Information regarding the disease such as possible problem behavior and management strategies helped the caregivers in providing care for the afflicted relative.

As mentioned by a daughter caregiver:

I did not know at first, but then I learned at the caregiver support group, so I go to the meeting every time. I go whenever they have topics about elderly persons, because I want to know more. I have never heard about these things. I often talked about it, talked about it like a joke. But now my mother has Alzheimer’s disease. So I want to know more about her situation.

In addition, emotional support from formal services was reported by ten participants to be important in lessening the caregivers’ burden. Although the caregivers perceived the caregiver role as their obligation, support helped them to feel more positively about their situation. Caregivers found formal support helpful in lessening the negative feelings caused by caregiving. It was being viewed as a source of identification and encouragement. A daughter caregiver said:

The social workers at the _____ were supportive in a lot of things and have given me a lot of support. Although I was having a difficult time, having these people give me support for sure made me happier.

In addition to lessening their caregiving stress in general, caregivers found the formal support helpful in lessening their negative feelings regarding the area of
caregiving and institutionalization. A daughter said she felt “bad” when she got upset about her mother and was relieved when the social worker explained to her about her feelings at the caregiver support group. She said:

I have thought about it myself before. I was taking care of my grandchildren at that time, I treasured them, I did everything for them, and was concerned about everything. But why is that when I saw that this elderly person [her mother] did not know how to do things, I scolded her when I helped her? Was that very bad, I asked myself? Why did I treat the grandchildren so well but treated the elderly person like this? Sometimes I got quite upset. They [the social workers] explained to me that it was not bad…. When I saw her regressing which was not good, I got upset.

Similarly, a caregiver discussed her experience in which the social worker explained to her the nature and reason for admitting her mother into a retirement home. After her mother was sick and was discharged from the hospital, it was obvious that her mother should not return home. However, she was extremely distressed about the move. As she recalled:

The social worker at the hospital explained to me that actually I can still visit her [her mother] and take her out. It is the same, the main difference is that they have people to take care of her there…. So I think that it is not really some physical support, but it is still some sort of support. By giving me that information, she made me feel better, in other words lessened my psychological burden.
Private arrangements of paid helpers had made in-home care possible

In addition to the formal support from professional service providers, three caregivers hired private helpers to provide care for the care-recipients. These caregivers perceived hiring additional help as necessary, since around-the-clock care was required and the caregiving demands were too difficult for them to manage alone. A daughter caregiver said:

Since we [she and her husband] have to work, so there is no way that we do not hire a helper to take care of her. Because she is very dependent. Also, she has to use the wheelchair now, she cannot walk, so there has to be someone supervising her with everything.

A daughter-in-law caregiver described her role as a coordinator of the paid helpers. As she knew that she would not be able to tolerate the personal care required by her father-in-law, she was grateful to have help for providing the hands-on care. As she recalled:

My role is only to monitor what they are doing. If they are not doing it right, for example if they are not treating him [her father-in-law] well enough, I will speak up, but if they are doing the job right, I will not. Because the bottom line is that I have to depend on the others for the dirty work. To be honest with you, if you tell me that I have to do that dirty work everyday, I could not take it.

Besides the physical relief from care provision, some caregivers also mentioned that hiring helpers had lessened their emotional burden. For example, a daughter caregiver suggested that having a helper had prevented her from feeling captivated by her role. As she said, “Taking care like that will make you lose your own life. Therefore, I
very much recommend that people hire a person to share the burden. Really, you cannot
be with him [the care-recipient] seven days a week.”

For caregivers who did not have hired helpers, two of them considered paying
someone to provide care an option to pursue in the future. They thought that they might
need to hire helpers when care becomes too difficult and paid attendants were viewed as
a reasonable alternative to institutionalization. This is evident in a daughter caregiver’s
expression:

I think it depends on the situation. When the time comes that I cannot manage the
care, I might hire a special person to come here to take care of her. Since we have
to spend money anyway if he goes to a nursing home, we will both be more
comfortable if we can hire someone, and he can also stay at home.

Some caregivers felt negatively towards the support they received

Although all caregivers received some forms of support, they perceived the
influences and effectiveness of it differently. When asked about their opinions on the
support they received, three caregivers did not perceive the support as important as the
others did. While being appreciative of what they received, they did not perceive the
support as being too useful. This perception is demonstrated by a daughter caregiver who
said:

I think people around cannot give us too much support, because we still have to
deal with the problems ourselves. Other people are unable to help us. Verbally, it
is like when you tell other people, ‘my son is sick, my children have whatever
illness’. So they say, ‘alright, so you take whatever medication then’. You still
have to deal with it yourself. You have to take care of him, take him to the
doctor, take the medication, those are all done by you.

While the above caregiver referred to the support offered by her friends, another
daughter caregiver had similar feelings towards the support that she could get from the
formal service provider. With respect to the caregiver support group, the caregiver
mentioned:

Maybe the resources do exist, but one needs to spend time to find them. For
example, the support group at the _____ may be good, but that requires me to be
working not much or not working.... But that is only information, etc. When it
comes to providing care, I still need to do it myself.

_Spiritual Support was deemed crucial by two caregivers_

It is of interest that two caregivers reported that God was one of their major
sources of support. These two participants thought that the formal services were not
particularly useful since they could not take away the caregiving strain itself.
Conversely, they relied much on God to overcome the problems and the negative
emotions they experienced as a result of caregiving. As one of the daughter caregivers
said:

I am a Catholic, so when I feel very helpless, I pray.... Because there cannot be
someone by my side all the time, I think that when the power is from a higher
entity, that support is the best. Even when there are people around, they cannot
always give me help, and their support cannot be ever-lasting.
Caregivers had different plans for institutionalization of the care-recipients

As a result of the caregiver stress and strains, some participants reported decisions to discontinue in-home care for their relatives. This decision is comparable to the "outcome" in Pearlin et al.'s model. When asked about plans for institutionalization of the care-recipients, all participants indicated that they had applied for nursing home placements. Yet, only six participants reported that they were ready to institutionalize the care-recipients at the time of data collection and said that they would place their relatives in an institution if a bed became available. Among these caregivers, four of them attributed their readiness to the existing or future possible aggressive behaviors of the care-recipients and two of them thought that in-home care was no longer appropriate. A daughter caregiver said:

Actually, the facilities at the nursing homes are more appropriate for her. For example, for bathing, they have the equipment to help her, but we cannot do that. All we can do is use our hands to support her. That is actually very dangerous.

Of course that is not as safe as their equipment.

On the other hand, the other six caregivers applied for placements only as backup plans. These caregivers were either not emotionally ready to send their relatives to nursing homes or did not perceive institutionalization as necessary at the present time. As there were long waiting lists for nursing homes, they thought it was appropriate to apply in advance since placement may be needed in the future. This advance planning is demonstrated by a daughter-in-law who said:

When you think about it, people at the final stage of Alzheimer's disease usually end up going to the nursing home. But right now, we do not need this kind of
service.... I have visited those nursing homes, most of the people there are at the final stage. Going there really is waiting for death to come. They are all like that, so it is not suitable for her. I think that is not the place for her. But we have applied for one nursing home anyway. Since she has to wait for so many years, maybe it will be suitable for her by then.
Chapter 5

Discussion

The model of caregiver stress put forward by Pearlin, Mullan, Semple, and Skaff (1990) provided a framework for data analysis and interpretation of results for this study. The feelings and experiences reported by the caregivers in this study fit well within Pearlin et al.'s framework. The caregivers' culture, being a background and context variable, was associated with the various aspects of their caregiving experiences. They also reported experiences that could be seen as stressors and mediators. Among the findings presented, several ideas are of interest and require discussion.

Throughout the interviews, the notions of obligation fulfillment and familialism were reported repeatedly by the participants. This finding is consistent with a study of Chinese and Filipino American female caregivers conducted by Jones (1995) who suggested that the caregivers had been "raised to accept responsibility" (p. 394) and to see caregiving as an obligation and a "cultural and moral mandate" (p. 394). Findings of filial obligation have also been reported in studies of family caregivers of Western origin (Allan, 1983; Finley, Roberts, & Banahan, 1988). However, contrary to Allan's suggestion that secondary kinships are "normally too shallow" to form long-term caregiving relationships, the daughter-in-law caregivers in the present study took on the caregiver roles and were willing to provide care. This was likely due to the participants' cultural emphasis on filial obligation as in the son's responsibility to his parents and on family as the basic social unit. This inclusion of the extended family unit (i.e., daughter-in-law) was identified as one of the themes in Goodman's (1990) study with Chinese and Japanese American caregivers.
In addition to acceptance of the responsibilities, participants in the present study also mentioned their anticipation of the caregiver role; they had expected that sometime during their lives they would have to provide care for the care-recipients. This anticipation was likely a direct result of their traditional views of caregiving as a normative experience with care provision as a stage in one’s life. Haley et al. (1996) reported that Black but not White caregivers in their study of family caregivers of people with Alzheimer’s disease anticipated the caregiver role because of their cultural values and as a result, care provision was not viewed as a disruption in their lives. Similarly, caregivers in the present study were able to view the situation positively and had a clear view of what they had to do. This perspective is demonstrated by a daughter-in-law caregiver who said:

I think that I am pretty lucky, because for a lot of the things, my husband has already told me that it will end up like this. Therefore, for a lot of the times I know what will happen and I am mentally prepared for it.

Another explanation for readiness to give care may relate to ideas about longevity. For example, a wife caregiver mentioned that it was important for her to continue to provide care for her husband so that he could live on. Although this idea was suggested by only one participant, it appears to be important as elderly people are particularly revered in the Chinese culture. As this idea was not fully explored in the present study, future studies could examine this notion more closely.

Despite their acknowledgement of their obligation to fulfill their caregiver role and being prepared for it, nine of the 12 participants seemed, nonetheless, unhappy about it. They appeared to feel trapped and saw the role as unwanted to a certain extent. This
view is reflected in their often repeated comment, “there is nothing I can do about it”, referring to the management of the caregiving demands and the care-recipients’ problematic behaviors. Even though they did not appear to be strongly resentful about the role, they appeared sad about their situations. As such feelings might lead to negative health outcomes, future research could explore these somewhat hidden negative reactions to the caregiver role.

Most of the families of the caregivers in the present study were seen as supportive. Three quarters of the participants reported regular assistance from their families. Their experience is very different from that of the sample in the study conducted by Aneshensel et al. (1995). In their study, only one in three participants reported regular family help. This may have been a result of the traditional family values of helping one another in the Chinese culture. Although some families did not provide active tangible support, they were emotionally supportive in general. As in other studies on Chinese caregivers (Jones, 1995; Mackenzie & Holroyd, 1996), the participants in the present study relied on and valued their families’ support. For caregivers who reported limited assistance from family members, reasons were given to explain and defend their family members’ low involvement. This reaction is similar to the finding in Mackenzie and Holroyd’s study on family caregivers in Hong Kong. In their study, the caregivers reported that other family members should not be overtaxed as “they had their own lives to lead” (p. 8).

While the literature refers to family conflicts in caregiving as generally stressful (Chenowenth & Spencer, 1986; Rabins, Mace & Lucas, 1982), in the present study, two caregivers found these conflicts to be particularly upsetting and even more stressful than
the stress of caregiving itself. For caregivers who received much support from their families, disagreement was often reported. Similar to Jones’ (1995) findings on Chinese and Filipino caregivers, family conflicts reported in the present study were often related to differences in cultural expectations and authority and control. However, participants who received only limited support from their families also reported discontentment as their expectations for their families were unmet. Supporting Fiore, Becker, and Coppel’s (1983) suggestion, these caregivers found their unmet expectations for support to be stressful.

Unlike other studies on Chinese family caregivers where participants received little help from formal service providers (Jones, 1995; Mackenzie & Holroyd, 1996), caregivers in the present study reported high utilization of formal services, such as caregiver support groups, homemaker services, some homecare nursing (e.g., bathing), and daycare programs. As they were appreciative of the services they received, caregivers may have perceived their caregiving experience as less burdensome. Their positive feelings may have lessened their stress and may in turn have helped them to sustain their caregiver role.

Differences in the healthcare systems in Hong Kong and in Canada may have been a legitimate cause for intensifying the caregivers’ positive feelings about their situations. As reported by Chi and Wong (1994), services for the geriatric population in Hong Kong are limited. Thus, the participants, who were all immigrants from Hong Kong, may have been unduly impressed by the availability and comprehensiveness of the services offered in Canada. In fact, one daughter caregiver mentioned that her parents
were staying in Canada because of the comprehensiveness of the healthcare system. She said:

They actually have a choice, they can choose to leave and go back to Hong Kong. They can still choose to do that at this point. But the problem is that my mother has so much medical problems now, she has diabetes. They think that the medical system here is better than that in Hong Kong, so they chose to stay here.

In addition to the support from families and from formal service providers, five caregivers in the present study mentioned hiring private helpers to assist them. Based on the researcher’s observation of the participants’ living environments, the present sample appeared to consist predominantly of caregivers from families that were relatively well off. Being able to hire helpers may have lightened the burden further. This condition is different from that in Aneshensel et al’s (1995) study where a quarter to a third of their sample reported at least one source of financial stress. Meanwhile, their willingness to hire helpers can be seen as a continuation of a practice common in Hong Kong, where paid caregivers are hired to look after children and elderly persons so that the adult female in the household can have paid employment. As such an arrangement is relatively cheap in Hong Kong, families may do so even if they are not well off.

Of interest in the present study is the fact that two caregivers reported God as a major source of support. The importance of spirituality is supported by Zarit, Reever, and Bach-Peterson’s (1980) study on White family caregivers of people with Alzheimer’s disease and also by Jones’ (1995) study on Chinese and Filipino caregivers. The two participants who valued spiritual support actually perceived support from other sources as less important. This is especially true for the caregiver who stopped obtaining support
from the formal service provider because she thought that such services were helpful but not necessary.

Caregivers realized that their children had acquired values different from those they held and may not be willing to care for them in the future. They said they tried to be role models for their children so that their children would do the same thing for them when the time comes, however, they did not expect their children to follow their example. The intrapsychic strain of intergenerational changes in culture and the ambivalent feelings experienced by the participants is demonstrated by a daughter caregiver who said:

Of course I hope that my children will be good and will take care of me. People always wish that their children will be good to them. But even if they are not good, there is nothing I can do about it, they are still my children.

Caregivers realized that changes in values were inevitable, yet, they expressed that view in a pessimistic manner. During the interviews, there was a general sense of sadness and the caregivers seemed to be resentful. While they expressed appreciation for their children’s assistance as secondary caregivers in the current situation, they were unsure about their children’s willingness to be primary caregivers in the future. Although they did not appear to be emotionally disturbed by the issue, they appeared concerned and felt uneasy about their lack of control over their own future care.

The caregivers’ eagerness to share their experiences with the researcher also deserves attention. Participants were all very friendly and open to the questions and seven of them even invited the researcher to visit again. Although the interviews were not designed to be therapeutic in nature, the caregivers appeared to value the opportunity to
share their experiences with a professional person. In fact, three participants mentioned that they liked to talk with professional people working in the field because these people could understand them better. Their wishes to talk were also shown by the fact that three of the interviews lasted over two hours. Caregivers shared not only their experiences but also their personal views and feelings which they might have considered inappropriate to share with their peers. Thus, the interviews gave them the opportunity to freely express their personal views and vent their feelings. This situation has implications for service providers in that professional workers may wish to provide opportunities for caregivers to share their personal feelings.

In contrast to previous findings that being cared for by a spouse reduced the risk of institutionalization of the care-recipient (Colerick & George, 1986; Lieberman & Kramer, 1991), both wife caregivers in the present study reported readiness for placement of their husbands. This may be due to the excessive physical aggression exhibited by the care-recipient in one case and the old age of the wife in the other case. Due to the fact that there were only two wife caregivers in the present study, the experiences of the wives cannot be compared with those of the daughters and daughter-in-laws. Future studies could include caregivers of the two generations so that their caregiving experiences and readiness to institutionalize may be compared.

It should be noted that as all caregivers were living in a community where comprehensive services were provided by Chinese organizations, their cultural ties were maintained and values were perpetuated. Thus, the participants in this study may have had a stronger emphasis on cultural tradition than immigrant Chinese female caregivers living in a more integrated environment. In addition, the fact that the researcher was a
Chinese Occupational Therapist should be noted. Participants may have tried to identify with the researcher by making more references to the Chinese culture, thinking that such references were desirable.

Lastly, it is worth noting that a large proportion of caregivers’ responses fitted into Pearlin et al.’s (1990) framework as mediators, that is, coping and social support. Although they felt resigned to their caregiver role and were under great stress, caregivers realized that the way they approached their problems could make them feel better. They also mentioned that their situations would be worse if their social support did not exist. Their views are actually contrary to the researcher’s previous, and perhaps stereotypical, beliefs that Chinese persons are often reluctant to seek outside help. The caregivers’ willingness to utilize these resources may have implications for both researchers and practitioners. Future research could explore service utilization in relation to needs of this population and practitioners could promote greater use of and education on social support and coping strategies.

In summary, the caregivers’ Chinese culture appears to have influenced their feelings about their experiences. Their perceptions of their caregiver role, the stress and strains they perceived, the mediators they utilized, and their plans to continue in-home care were all affected. In addition, caregivers’ appreciation of Ontario’s comprehensive health care system, their residence in a well-established Chinese community, their active coping strategies, and their financial resources may have lessened the stresses and strains they perceived.

The caregivers who participated in the present study varied greatly in terms of their individual characteristics and also their level of traditionalism. As the level of
traditionalism was not examined in the present study in any depth and as it may strongly influence caregiving practices, future studies could be conducted to analyze traditionalism more specifically.

One limitation of this study relates to the sample and to the depth of the interviews. To compare themes with other populations, studies involving larger samples need to be conducted and to delve more deeply into emerging themes, more in-depth interviews (or second interviews) are needed. By involving caregivers with various religious affiliations and levels of traditionalism, the issue of spirituality could be examined more thoroughly. Also, the present study utilized a convenience sample of caregivers recruited primarily from one service provider, thus, the service utilization reported by the participants may be over-represented. Future studies could obtain samples consisting of caregivers both in and not in contact with service providers so that the sample is more representative of caregivers in general. Lastly, the present sample consisted of participants with similar geographical locations of residence and financial background. Future studies with more heterogeneous samples could examine the influences of these variables on the caregivers’ experiences.

Despite the above limitations, this study has raised a few points which may be of interest to healthcare professionals, especially Occupational Therapists. As caregivers were receptive of social support provided by community agencies and recognized the benefits of such services, more services for Chinese caregivers could be offered. Provision of services at locations where the Chinese community is not as well-established as it is in some areas of Toronto may be especially important. By providing such services, stresses and strains experienced by caregivers not readily in contact with
community agencies may be alleviated. Particularly, individual supportive counseling may be offered as an opportunity for caregivers to express their feelings and to discuss personal issues. The area of spirituality could be incorporated into services offered so that the caregivers’ needs may be met in a more holistic manner.

The population of Chinese immigrants living in Canada is large and growing rapidly. They will make up a sizable proportion of the elderly population and of the population of persons with Alzheimer's disease. As many Chinese persons with Alzheimer’s disease will continue to be cared for at home, understanding of Chinese female caregiving experiences is valuable.
References


Appendix A
Are you caring for a family member with Alzheimer's disease?

If so, then we need your help!

This is a good chance for you to contribute to the knowledge of caregiving for persons with Alzheimer's disease.

My name is Bertha Ko and I am a graduate student at the University of Toronto. I am doing a study on the caring experience of Chinese female caregivers of persons with Alzheimer's disease.

Now, please ask yourself the following questions:

1) Am I caring for a family member with Alzheimer’s disease?
2) Do I speak Cantonese?

If you answered yes, and if you are a female, then you are qualified to be part of this project.

If you wish to participate or want further information on this project, please contact me at (416) 818-4949.

This is an excellent opportunity for you to contribute your knowledge of persons with Alzheimer's disease and what is it like to be a caregiver. Please consider this request yourself and tell anyone else who you think maybe interested. Please do not hesitate to contact me if there are any questions or concerns. Your involvement is greatly appreciated.

Thank you.
Appendix B
Are you caring for a family member with Alzheimer’s disease?

If so, then we need your help!

This is a good chance for you to contribute to the knowledge of caregiving for persons with Alzheimer’s disease.

You are being invited to be part of a study of caregivers of persons with Alzheimer’s disease.

My name is Bertha Ho and I am a graduate student at the University of Toronto. I am doing a study on the caring experience of Chinese female caregivers of persons with Alzheimer’s disease.

Now, please ask yourself the following questions:

1) Am I caring for a family member with Alzheimer’s disease?
2) Do I speak Cantonese?

If you answered yes, and if you are a female, then you are qualified to be part of this project.

If you wish to participate or want further information on this project, please contact me at (416) 818-4949.

This is an excellent opportunity for you to contribute your knowledge of persons with Alzheimer’s disease and what it is like to be a caregiver. Please consider this request yourself and tell anyone else who you think maybe interested. Please do not hesitate to contact me if there are any questions or concerns. Your involvement is greatly appreciated.

Thank you.
Chinese Female Family Caregivers of Persons with Alzheimer’s Disease
Information Letter
Student: Bertha Ho, BSc (OT)
Supervisor: Prof. Judith Friedland, Ph.D.

I am a student in the Master’s of Science program in Rehabilitation Science, University of Toronto, and am conducting a study on social support for caregivers of people with Alzheimer’s disease who are living in the community. The purpose of the study is to explore the impact of culture, caregiver stress, and social support on caring for persons with Alzheimer’s disease.

You are being asked to participate in this study because you are a Cantonese-speaking female caregiver of a person with Alzheimer’s disease and have come from Hong Kong after the age of 18. The study involves an interview that will take approximately 1 hour and 30 minutes. You will be interviewed at a location of your choice and you will be asked about topics pertinent to the study such as your relationship with the person with Alzheimer’s disease, your caregiver role, and the kind of support you receive from others. You will be free to refuse to answer any specific question.

The entire interview will be tape-recorded. The information will be put into written form and then the tape will be destroyed. Any information obtained in connection with this study will be confidential. Your identity and all information gathered in the interview will be held in strict confidence. Individual cases will not be presented and any material that is published will protect your anonymity.

You will receive no direct benefit from participating in this study but your involvement will contribute to our understanding of the factors influencing caregiving for relatives with Alzheimer’s disease. There will not be any payment and you will receive no financial compensation for participating in this study. There are no risks involved, however, during the interview you might become a little upset because the topic is emotional.

Participation in this study is voluntary. Your decision of whether or not to participate in this study will not affect the service you receive from _______________. If you do decide to participate, you may withdraw from the study at any point without fear of any negative consequences.

This is a good chance for you to contribute to the knowledge of Alzheimer’s disease. If you wish to participate or want further information, please call me at (416) 818-4949.

Yours truly,

Bertha Ho, BSc (OT)
華人女性老人痴呆症家庭護理者
研究計劃資料書
學生: Bertha Ho, BSc (OT)
監督者: Judith Friedland, Ph.D.

我是一名在多倫多大學攻讀碩士的學生。我正準備做一個關於華人女性老人
痴呆症護理者的研究。這項研究的主要目的是探討文化、護理經歷、和護理者所
得到的支持對其照護老人痴呆症患者的意見的影響。

因為你是一位家庭成員中患有老人痴呆症的女性護理者，而且由於移民來自
香港的關係，故此你被邀請參與這項研究計劃。研究過程將包括一個大約一小時
三十分鐘的訪問，而地點將會由你決定。訪問內容將會圍繞著一些有關研究的主題，
例如你與老人痴呆症患者的關係，你身為護理者的經歷和你所得到的幫助或支持。

整個訪問過程將會被錄音然後用文字記錄下來。當文字記錄完成後，你的訪問
錄音帶將會被毀滅。所有的資料包括你的身份和訪問內容等亦會絕對保密。任何
被發表的資料將會保護你的隱私和身份。

你將不會得到任何直接的利潤，然而這個研究的結果將可能加添我們對這方
面的了解和認識。你也將不會得到任何金錢上的補償或利益。這項研究並無任何危
險性，而且由於題材敏感的關係，當訪問進行時，你可能會感受到一點不安的情緒。

參與是出於自愿的。無論參加与否，你的決定絕對不會影響到你原先從
(機構名稱，例如顧問中心)所得到的服務。倘若你決定參與，你也有隨時退出研究
的權利，而這亦絕對不會引起任何不良的後果。

如有任何問題，請致電(416)971-3088，與我接觸。請收下這份資料書以作記
錄。

研究員，

Bertha Ho, BSc (OT)
Study: Chinese Female Family Caregivers of Persons with Alzheimer's Disease
Student: Bertha Ho, BSc (OT)
Supervisor: Prof. Judith Friedland, Ph.D.

Consent Form

I HAVE READ THE INFORMATION LETTER AND HAVE HAD AN ADEQUATE OPPORTUNITY TO DISCUSS THIS STUDY WITH THE RESEARCHER. ANY QUESTIONS I MAY HAVE HAD HAVE BEEN ANSWERED TO MY SATISFACTION. I AM VOLUNTARILY MAKING A DECISION TO PARTICIPATE IN THIS RESEARCH STUDY. I WILL BE GIVEN A COPY OF THIS CONSENT FORM TO KEEP.

__________________________________________  _________________
Signature of Participant  Date

研究项目：华人女性老人痴呆症家庭护理者
学生：Bertha Ho, BSc (OT)
监督者：Prof. Judith Friedland, Ph.D.

参与同意书

我已仔细阅读和了解有关这项研究的资料，并亦有足够时间与研究人员讨论有关这项研究的问题。我所有关于这项研究的疑问亦得到满意的解答。我现在自愿决定参与这项研究。我将会收到这同意书的副本以作记录。

__________________________________________  _________________
参与者签名  日期

256 McCaul Street Toronto, Ontario M5T 1W5 Telephone (416) 978-0300 Facsimile (416) 978-4363
Appendix C
University of Toronto

OFFICE OF RESEARCH SERVICES

PROTOCOL REFERENCE #3837
October 1, 1998

Professor J. Friedland
Graduate Dept. of Rehabilitation Science
Faculty of Medicine
256 McCaul St.
University of Toronto

Dear Prof. Friedland:

Re: "Chinese Female Family Caregivers of Persons with Alzheimer's Disease" by Professor J. Friedland, supervisor; B. Ho, student

We are writing to advise you that a Review Committee composed of Ms. K. Yoshida, Ms. L. Chu and Professor A. Colantonio has granted approval to the above-named research study.

The approved revised consent form is attached. Subjects should receive a copy of their consent form.

During the course of the research, any significant deviations from the approved protocol (that is, any deviation which would lead to an increase in risk or a decrease in benefit to human subjects) and/or any unanticipated developments within the research should be brought to the attention of the Office of Research Services.

Best wishes for the successful completion of your project.

Yours sincerely,

[Signature]

Susan Pilon
Executive Officer
Human Subjects Review Committee

SP/mr Enclosure
cc: Prof. M. Verrier, Ms. B. Ho
Appendix D
Consent Form

I HAVE READ THE INFORMATION LETTER AND HAVE HAD AN ADEQUATE OPPORTUNITY TO DISCUSS THIS STUDY WITH THE RESEARCHER. ANY QUESTIONS I MAY HAVE HAVE BEEN ANSWERED TO MY SATISFACTION. I AM VOLUNTARILY MAKING A DECISION TO PARTICIPATE IN THIS RESEARCH STUDY. I WILL BE GIVEN A COPY OF THIS CONSENT FORM TO KEEP.

______________  ______________
Signature of Participant       Date

研究項目：華人女性老人痴呆症家庭護理者
學生：Bertha Ho, BSc (OT)
監督者：Prof. Judith Friedland, Ph.D.

參與同意書

我已经阅读和了解有關這項研究的資料，而我也有足夠時間與研究員討論有關這研究的問題。我所有關於這項研究的疑問也得到满意的解答。我現在自愿决定参与這個研究。我将會收到這同意書的副本以作記錄。

______________  ______________
參與者簽名       日期

256 McCaul Street Toronto, Ontario M5T 1W5 Telephone (416) 978-0300 Facsimile (416) 978-4363
Appendix E
I am a student in the Master's of Science program in Rehabilitation Science, University of Toronto, and am conducting a study on social support for caregivers of people with Alzheimer's disease who are living in the community. The purpose of the study is to explore the impact of culture, caregiver stress, and social support on caring for persons with Alzheimer's disease.

You are being asked to participate in this study because you are a Cantonese-speaking female caregiver of a person with Alzheimer's disease and have come from Hong Kong after the age of 18. The study involves an interview that will take approximately 1 hour and 30 minutes. You will be interviewed at a location of your choice and you will be asked about topics pertinent to the study such as your relationship with the person with Alzheimer's disease, your caregiver role, and the kind of support you receive from others. You will be free to refuse to answer any specific question.

The entire interview will be tape-recorded. The information will be put into written form and then the tape will be destroyed. Any information obtained in connection with this study will be confidential. Your identity and all information gathered in the interview will be held in strict confidence. Individual cases will not be presented and any material that is published will protect your anonymity.

You will receive no direct benefit from participating in this study but your involvement will contribute to our understanding of the factors influencing caregiving for relatives with Alzheimer's disease. There will not be any payment and you will receive no financial compensation for participating in this study. There are no risks involved, however, during the interview you might become a little upset because the topic is emotional.

Participation in this study is voluntary. Your decision of whether or not to participate in this study will not affect the service you receive from . If you do decide to participate, you may withdraw from the study at any point without fear of any negative consequences.

This is a good chance for you to contribute to the knowledge of Alzheimer's disease. If you wish to participate or want further information, please call me at (416) 818-4949.

Yours truly,

Bertha Ho, BSc (OT)
Appendix F
華人女性老人痴呆症家庭護理者
研究計劃資料書

學生:Bertha Ho, BSc (OT)
監督者:Judith Friedland, Ph.D.

我是一名在多倫多大學攻讀碩士的學生，我正準備做一個關於華人女性老人
痴呆症護理者的研究。這項研究的主要目的是探討文化，護理經歷，和護理者所
得到的支持對其照料老人痴呆症患者的意見的影響。

因為你是一位家庭成員中患有老人痴呆症的女性護理者，而且由於移民來自
香港的關係，故此你被邀請參與這項研究計劃。研究過程將包括一個大約一小時
三十分鐘的訪問，而地點將會由你決定。訪問內容將會圍繞著一些有關研究的主題
，例如你與老人痴呆症患者的關係，你為護理者的經歷和你所得到的幫助或支持。

整個訪問過程將會被錄音然後用文字記錄下來。當文字記錄完成後，你的訪
問錄音帶將會被毀滅。所有的資料包括你的身份和訪問內容等亦會絕對保密。任何
被發表的資料將會保護你的隱私和身份。

你將不會得到任何直接的利益，然而這個研究的結果將可能加添我們對這方
面的了解和認識。你也將不會得到任何金錢上的補償或利益。這項研究並無任何危
險性，而由於話題敏感的關係，當訪問進行時，你可能會感受到一點不安的情緒。

參與是出於自愿的。無論參加与否，你的決定絕對不會影響到你原有從
(機構名稱，例如頤康中心)所得到的服務。倘若你決定參與，你也有隨時退出研究
的權利，而這亦絕對不會引起任何不良的後果。

如有任何問題，請致電(416)971-3088，與我接觸。請收下這份資料會以作記
錄。

研究員，

Bertha Ho, BSc (OT)
Appendix G
Chinese Female Family Caregivers of Persons with Alzheimer’s Disease
Initial Guideline Questions

Note: The following list of questions was only used a guide for the interviews. The interviewer during each interview decided the exact wording and order of the questions.

1) Please tell me about your relationship with your relative with Alzheimer’s disease.
   Probe: What is your ______’s living arrangement like?
   How does that affect your other life roles such as being a wife, a worker, a mother, etc.?

2) How do you feel about it?
   Probe: Some people feel obligated to take on the caregiver role, what do you think about that?
   What do you like and dislike about it?
   What makes you feel better?

3) Please tell me about your experiences in caring for your ______.
   Probe: What are the positive experiences or feelings?
   What are the difficulties?
   Do these experiences have any effect on the different aspects of your life such as your family, marriage, and social life?
   If positive responses are given, interviewer will ask if there are any negative effects and vice versa.

4) Have you ever felt that this situation is too much for you to manage?
   Probe: What alternatives have you considered?
   Some people I have spoken with have told me that they have considered placing their ______ in a home, where they can receive ongoing nursing care. Is this something that you would ever consider?
   How do you feel about it?
Chinese Female Family Caregivers of Persons with Alzheimer’s Disease
Guideline Questions with Subsequent Changes

Note: The following list of questions was only used as a guide for the interviews. The interviewer during each interview decided the exact wording and order of the questions.

1) Please tell me about your relationship with your relative with Alzheimer’s disease.
   Probe: What is your _______’s living arrangement like?
   Do you have brothers or sisters?
   How does that affect your other life roles such as being a wife, a worker, a mother, etc.?

2) How do you feel about it?
   Probe: Some people feel obligated to take on the caregiver role, what do you think about that?
   What do you like and dislike about it?
   What makes you feel better?

3) Please tell me about your experiences in caring for your _______.
   Probe: What are the positive experiences or feelings?
   What are the difficulties?
   Do these experiences have any effect on the different aspects of your life such as your family, marriage, and social life?
   If positive responses are given, interviewer will ask if there are any negative effects and vice versa.

4) Have you ever felt that this situation is too much for you to manage?
   Probe: What alternatives have you considered?
   Some people I have spoken with have told me that they have considered placing their _______ in a home, where they can receive ongoing nursing care. Is this something that you would ever consider?
   What do you think would convince you that you must send your _______ to a home?
   How do you feel about it?

5) In what ways do you think being Chinese has influenced your experience as a caregiver?
   Probe: Some people I have spoken with view caregiving as a duty, what do you think about that?
   Has being Chinese influenced your thoughts, or behavior, or decision-making?
   What do you think your children will do in the future when you grow old?
Chinese Female Family Caregivers of Persons with Alzheimer’s Disease  
Level of Intention to Institutionalize one’s Relative with Alzheimer’s Disease

You said that you have thought about placing your _______ in a home.

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>
| 1)   | Yes | Have you thought about it seriously?  
If interviewee says yes, then ask |
| 2)   | Yes | Have you discussed it with family members?  
If yes, then ask |
| 3)   | Yes | Have you acquired information on institutions?  
If yes, then ask |
| 4)   | Yes | Have you made a list and visited the institutions?  
If yes, then ask |
| 5)   | Yes | Have you requested applications for placement?  
If yes, then ask |
| 6)   | Yes | Have you made applications for placement?  
If yes, then ask |
| 7)   | Yes | Are you waiting for available opening? |
| 8)   | Yes | If a bed became available tomorrow, would you place your _______ in the institution? |
Appendix I
March 17, 1999

To: Professor Judith Friedland
Re: Translation Spot-Checks for Materials Contributing to the Thesis of Bertha Ho

I am a registered nurse in Ontario who was approached by Ms. Mary-Ann Chang, Executive Director of the Alzheimer’s Society, Toronto branch, to help Bertha Ho, a master student at the University of Toronto, with checking her translation of materials collected for her thesis from Chinese to English.

Bertha suggested a random spot-check of ten sentences. They are:

<table>
<thead>
<tr>
<th>#</th>
<th>Page</th>
<th>Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>10-21</td>
<td>immigration background</td>
</tr>
<tr>
<td>2</td>
<td>9-83</td>
<td>worries that husband has this disease</td>
</tr>
</tbody>
</table>
| 3 | 2-3 | father cannot respond to emergency  

  *suggested:* father fails to deal with emergency |
| 4 | 1-8 | patient fell and broke the scalp |
| 5 | 1-15 | injured because of providing care |
| 6 | 8-25 | feelings towards his changes |
| 7 | 9-80 | mind is traditional, doesn’t want to give pressure to husband  

  *suggested:* her thinking is traditional, doesn’t want her husband feeling the stress |
| 8 | 7-49 | cannot accept sending her away |
| 9 | 1-7 | taking care of husband is difficult  

  *suggested:* it is difficult to taking care of husband |
| 10 | 9-50 | positive aspects |

Her translation of the above ten sentences appeared reasonable. If you wish to contact me for further information, please call me at office hours: (416) 493 3333, extension 271.

I wish Bertha every success in her future endeavors.

Best regards

Linda Wu R.N.
Appendix J
Field Notes of Interviews with Caregivers

Case #1

Mrs. A was a wife caregiver and she lived with her husband, the care-recipient, in a senior’s apartment in downtown Toronto. Mrs. A spoke in Cantonese with a slight accent as she had lived in China for most of her life.

The interview took place in a morning at Mrs. A’s apartment while Mr. A was at the daycare program. The interviewer arrived approximately ten minutes early. Mrs. A appeared to be ready for the interview and offered the interviewer a cup of tea.

Mrs. A was very pleasant during the interview and appeared to be willing to share her experience. She began to tell her story before any question was asked. She asked if the interviewer had anything in particular to ask her and then she told the interviewer that she would like to start with the time when she got married. Although her answers were tangential at times, she was very patient and tried to answer all the questions.

Mrs. A seemed to feel sorry for her husband that such misfortune happened to him during this time of life enjoyment. She thought that Mr. A had worked hard to support the family and it was a pity that he could not enjoy life during old age. She thought that their situation was determined by fate so they had to accept it.

Mrs. A seemed to be uncertain about the option of sending Mrs. A to the nursing home. She reported past discussion with her children regarding the issue and she seemed to be more receptive to the option than her children were. It appeared that she was willing to try although her children insisted not to send their father to a nursing home.

Mrs. A saw the caregiving role as an obligation. She thought that she was responsible for providing care for her husband since she was the closest person to him,
followed by their children. As a result, she rather took on the caregiving burden than to bother her children. She thought that she should not interfere with her children’s lives since they all had their own families. She thought that she could only blame her own life for her situation.

Mrs. A seemed to be quite traditional and believed that one’s life script is predetermined by fate. She attributed their situation to fate and felt that it should be accepted if that was part of her life script. She stressed that she was just doing her job and that she had to do it, whether she liked it or not.
Case # 2

Mrs. B was the daughter of the care-recipient. She lived with her husband and her parents in a two-storeyed house. She was the only child and all her children had grown up and left home. She was the primary caregiver of her father while her mother provided some care, too.

The interview took place in a meeting room at the recruiting agency. Mrs. B had requested to have the interview carried out at the agency since it was more convenient for her. The interview was conducted during the time when her father attended the daycare.

Mrs. B seemed to be managing the caregiving tasks quite well and the interviewer suspected the situation to be related to Mrs. B’s past professional experience as a nurse. She seemed to have no major difficulties in providing care for her father. During the times when she reported minor difficulties, she said that she did not perceive the situations to be too troublesome as she was used to them already.

She also seemed to be accepting her father’s disease and his behavior reasonably well. She appeared to be able to react to her father’s behavior objectively without personalizing it. Her attitude was very positive throughout the interview and there was no trace of resentment. She was able to talk about her father’s problem behavior at ease that they were almost like jokes.

Mrs. B appeared to be a very traditional person and she respected her parents so much that she had always let them take the master bedroom in her house. She saw the provision of care for one’s parents as a duty to be fulfilled by adult children. She thought of the caregiver role as a positive experience that she was able to help her father during the final stage of his life.
However, Mrs. B thought that her generation would be the last one maintaining this traditional Chinese mentality. She described her generation as the “sandwich generation” that it was in the middle of two very different generations. She did not foresee that the next generation would have the same traditional family values, since the society had changed.
Case # 3

Mrs. C was the wife of the care-recipient. The couple lived together in a retirement apartment housing complex. Mrs. C spoke in Cantonese with a heavy Shanghainese accent although she had lived in Hong Kong during most of her life.

The interview took place in a morning at Mrs. C’s apartment with the presence of Mr. C. Prior to the interview, Mrs. C confirmed with the interviewer regarding the possibility of conducting the interview with the presence of Mr. C. The interviewer reassured her that it was of her choice.

Both Mr. and Mrs. C were very pleasant and Mrs. C smiled very often during the interview. Being an eighty-year-old lady, Mrs. C was very bright and healthy-looking. During the interview, the researcher and Mrs. C sat at the dinner table and Mr. C sat in a couch nearby to watch television. Mr. C gained interest in the conversation towards the end of the interview and joined in for approximately five minutes. At the end of the interview, Mr. and Mrs. C invited the interviewer to visit again in the future and Mrs. C even said that she would make some dim sum for the interviewer the next time she visits.

During the interview, Mrs. C was concerned that the interviewer might not understand her speech due to her heavy Shanghainese accent. She asked the interviewer on several occasions whether she was speaking clearly enough. On several occasions when the interviewer had difficulty understanding Mrs. C’s speech, she was patient to repeat and tried to paraphrase what was said.

Mrs. C seemed to be able to manage the caregiving tasks and she appeared to be in good spirits. She reported no major difficulties and services were in place otherwise. After the interview was conducted, the recruiting person from the agency asked the
researcher if the interview went smoothly. The researcher told the recruiting person that it went very well and that Mrs. C seemed to be at ease during the interview. The recruiting person then told the researcher that Mrs. C was under tremendous stress previously due to the caregiving responsibilities. The situation was thought to be improving since she had joined the caregiver support group.

Mrs. C appeared to be content with her present life. She thought that her children were treating her very well and that she was receiving the assistance she needed. She thought that it was her responsibility to take care of her husband and she was willing to take on the role. She added that they should take care of themselves at this point in their lives since their children had their own family responsibilities.
Case # 4

Mrs. D took care of her mother with Alzheimer’s disease. Although not living together, she was responsible for her mother’s meals and for arranging her mother’s affairs. Mrs. D’s mother lived by herself in a senior’s apartment with staff from the senior’s housing complex providing minimal assistance.

The interview took place in a morning at Mrs. D’s home. As Mrs. D worked for her daughter on a part-time basis, the interview was conducted on a day when she could spare some time from work. The interview was carried out in a relaxed manner and Mrs. D initiated some informal conversation with the interviewer. She told the interviewer about her family and her son.

Mrs. D seemed to feel obligated to assume the caregiver role as she believed that it was her responsibility as a daughter. However, she seemed to feel ambiguous about the role, since her sister had always been closer to her mother than she was. Her sister got married and moved to the United States several years ago prior to their mother’s diagnosis of having Alzheimer’s disease.

Throughout the interview, Mrs. D stressed the impact of the caregiver role. Although she did not appear to have strong negative feelings towards this role, her spirit seemed to be quite low. She mentioned repeatedly that the caregiving tasks were something that she must do that she could not put off till later.

Mrs. C seemed to be managing the caregiving tasks quite well when she described her situation. Also, she seemed to be willing to carry out the caregiving tasks although she was not too enthusiastic about them. The interviewer had the feeling that it was the time constraints but not the tasks themselves that Mrs. C disliked.
Contrary to the researcher's personal view that families always prefer in-home care, Mrs. D did not show any intention of providing care for her mother at home. She did not express past consideration of bringing her mother home and stressed the comprehensiveness of the services that her mother was getting at the senior's apartment. When questions about institutionalization were asked, she maintained that she would send her mother to a nursing home when the staff members at the senior's apartment could no longer manage her mother's care.
Case # 5

Ms. E took care of her mother with Alzheimer’s disease. They lived together in an apartment with no senior support services. They had always lived in the same apartment since they immigrated to Toronto from Hong Kong. Ms. E had lived with her mother for over twenty years even before her children grew up and left home.

The interview took place in an afternoon at Ms. E’s apartment while her mother was at the daycare program. The interviewer was approximately five minutes late due to difficulty finding the building. Upon arrival, Ms. E put away the jacket for the interviewer and gave her a pair of slippers to put on. The researcher felt that Ms. E was very traditional as a result of the way she treated the researcher.

Ms. E sounded very capable and seemed to be able to manage the caregiving tasks. However, she seemed to be under stress and was upset about her own situation. According to her description, she seemed to be very uptight about her mother’s care. It appeared that she wanted to do so much for her mother that she was almost overdoing it. For example, her mother was incontinent very often but she insisted not to let her use pads. As a result, she had to spend a lot of time doing laundry.

Ms. E appeared to be quite discontent with her family’s support. She complained about her sister and also her children. She thought that her family was paying all the attention on her mother and was neglecting her needs and feelings. She felt that although she may have appeared to be strong, she had her own problems and issues as she was a senior person herself. She mentioned that although she did not really need her family’s assistance, it would be nice if they could care more about her or show some affection.
However, the interviewer suspected that Ms. E might have been so capable and independent in her family's eyes that they thought she did not need them.

Ms. E was quite upset about her role as a caregiver. Although she agreed that it was her duty to provide care for her mother, she felt that the expectations had been placed on her with no other options or choices. She felt that her sister had expected her to be the sole caregiver for their mother because she was the eldest daughter and she had always lived with their mother. She thought that her sister was placing expectations on her without offering any help and she was never being thanked for what she did.

Ms. E seemed to be a very traditional lady. The decoration in her apartment was quite old-fashioned with many Chinese paintings hung on the walls. She had family values that were very traditional, some of which even the interviewer was surprised to hear. Her traditional mentality may have had great influences on her experience as a caregiver that she felt strongly obliged to take care of her mother. She also felt that the traditional Chinese values had their merits and therefore should to be maintained.
Case # 6

Mrs. F took care of her mother with Alzheimer's disease who lived with her in a bungalow. She had hired a helper to assist her with the care for her mother. Her mother was current not attending any activities offered by the community agency.

The interview was carried out in a morning at Mrs. F’s home. Mrs. F worked on a part-time basis and she went to work after the interview was completed. As she was afraid that she would be late for work, she put a small clock nearby to remind herself of the time. Towards the end of the interview, she checked the time quite frequently and her answers to the questions were brief when compared to her answers at the beginning of the interview.

It seemed that Mrs. F felt that having a hired helper was necessary since she had paid employment. She thought that having a helper to stay with her mother at night was very important. As her mother had disturbed sleeping patterns, someone needed to be there to calm her down and to take care of her. She thought that it was impossible for her to take this responsibility because her performance at work would be affected if she could not sleep at night.

Throughout the interview, Mrs. F appeared to be an organized person who liked to maintain a routine very much. The interviewer observed her interaction with her helper and felt that her daily routine was very well-planned. It was suspected that her personality had contributed to her perception of the necessity of having a helper to stay with her mother at night. The interviewer personally felt that having a helper at night might not have been as important as perceived by Mrs. F since she mentioned that there
had only been three to five times so far that she could not sleep at night because of her mother.

Mrs. F seemed to be very understanding and considerate for both her mother and also her friends and family. Throughout the interview, she expressed no negative feelings or resentment towards the other people. When she talked about some negative experiences with the others, she tried to explain why they behaved in such manners. She tried to understand people’s behavior by putting herself in other people’s shoes. The interviewer thought that Mrs. F’s reaction may have been related to her strong religious affiliation that she tried to understand the others and not to blame anyone.

Mrs. F seemed to have put much thought into her caregiver role. She was able to analyze her mental pathway during the different stages of the caregiving process. She mentioned that as her mother’s condition changed and the demands of care altered, she had to adjust to the situation mentally. She described to the interviewer the transitions of her perceptions of her mother and also of the caregiving situation at the various stages.
Case # 7

Mrs. G was the daughter of the care-recipient. They were not living together at the time of data collection since her mother had just moved to a retirement home a few months ago due to difficulty in mobility.

The interview took place in an afternoon at Mrs. G’s home. Although her mother was no longer living with her, she went to visit her mother almost everyday. She was eager to share her experience and the entire interview was approximately four hours in duration. She began to talk about her experience of sending her mother to the retirement home right after the question about her mother’s living arrangement was asked.

Mrs. G appeared to have a very strong bond with her mother. Throughout the interview, she described repeatedly how difficult it was for her to send her mother to the retirement home. She mentioned that she would have kept her mother at home if her husband did not object her suggestions. She was very emotionally involved in this issue and she cried recurrently when this topic was touched upon. She told the interviewer that the decision was so difficult for her that she would cry whenever she talked about it.

The interviewer was quite overwhelmed by Mrs. G’s emotional reaction to the changes in her mother’s living arrangement. The interviewer felt quite uneasy at first and did not really know how to handle the situation. Luckily, Mrs. G was very considerate and she told the interviewer not to worry about her. She said that she had cried many times in reaction to the topic and she reassured the interviewer that she would be fine. The interviewer was very surprised because of the fact that Mrs. G was caring about the interviewer’s feelings while she was crying herself.
Mrs. G did not seem to be too traditional. She said that she wanted to keep her mother at home because of the love and passion she had for her mother. Although she agreed that it was the responsibilities of the children to take care of their aging parents, she thought that this was not the only reason for her wish to keep her mother at home. In fact, she felt that the main reason was the bond developed between them since they had lived together for the past thirteen years.
Case # 8

Mrs. H took care of her father with Alzheimer’s disease. They did not live together at the present time and her father was living with her brother. Due to the fact that Mrs. H used to live with her father prior to her brother’s immigration, she knew her father’s condition and the caregiving demands very well.

The interview took place in an afternoon at Mrs. H’s office. She had her own business with her husband and she invited the interviewer to go there to conduct the interview. Although the environment was a little bit distracting, it was nevertheless quiet enough for conducting an interview. The atmosphere during the interview was very relaxed and Mrs. H appeared to have expressed her thoughts freely. She even told jokes at times.

As Mrs. H was no longer living with her father, she was not responsible for most of his direct care. As a result, most of the interview content was not related to the direct caregiving responsibilities. Rather, she focused on her interactions with her parents.

Mrs. H seemed to have more difficulty in dealing with her mother than in taking care of her father. As she did not provide much direct care for her father, the demands of her father were not bothering her to a great extent. On the other hand, she found it difficult to satisfy her mother since she was very demanding. She thought that her mother was inconsiderate that she was only concerned with providing her husband with what she thought was the best. For example, her mother thought that her father liked to go for dim sum, so she insisted in going out everyday for dim sum. However, Mrs. H thought that this was unnecessary because this may not have been the best for her father at all.
Mrs. H seemed to be adjusting very well to her father's disease and his conditions. As her father had only been diagnosed of having Alzheimer's disease approximately two years ago and his rate of decline had been quite rapid, the interviewer was surprised by Mrs. H's ability to cope with the changes. She appeared to have accepted the fact that her father's deterioration was inevitable. She was very realistic about the situation and was able to look at the situation objectively. She mentioned that she was used to her father's behavior already and she just thought of them as jokes.

The interviewer thought that Mrs. H's ability to cope with the changes may have been related to her personality. Throughout the interview, Mrs. H sounded very positive and she seemed to be an optimistic person. She often downplayed the negative components of the events and looked at the positive aspects of them. In fact, she made jokes out of many incidents of her father's problem behavior and was able to just laugh them away. The interviewer thought that her attitude had helped her in finding ways to enjoy herself even during the bad times.
Case # 9

Mrs. I lived with her father-in-law with Alzheimer's disease. She was the sister-in-law of Mrs. H in the previous case. She had never attended any caregiver support groups and Mrs. H had referred her to the interviewer.

The interview took place in an afternoon at Mrs. I's home. Her father-in-law was at home at the time of the interview but he was having a massage in another room. The atmosphere of the interview was very relaxed. The interviewer suspected that Mrs. I had asked Mrs. H about the interview questions since she was very prepared for the interview. Her answer to the first question covered most the issues that the interviewer would like to ask her about. Her gestures during the interview reflected ease with the interviewer and she had some informal conversation with the interviewer at the end of the interview.

Mrs. I seemed to be satisfied with her situation at the present time. Although she was the primary caregiver of her father-in-law, she was not responsible for most of his direct care. She was glad that her husband had hired some helpers for her to lessen her burden. Furthermore, as her husband had other siblings in Toronto who were willing to take care of their parents, she felt that she could always quit being the primary caregiver for her father-in-law if she did not want to do so. She seemed to be glad that her husband had told her about the situation before she actually took on the role so that she was prepared for the responsibilities involved.

However, Mrs. I seemed to be very discontent with her mother-in-law. She felt that the most difficult aspect of her caregiver role was satisfying her mother-in-law. She thought that her mother-in-law was often unreasonable and inconsiderate. However, due to respect and the Chinese tradition, she had to accept her mother-in-law's ideas and
requests. She found that she often had to ignore her own ideas or points of view because her mother-in-law did not agree with her suggestions. Although unwillingly, she had to take her mother-in-law’s suggestions even when she knew that it was not the best way to perform the task.

Mrs. I’s family appeared to be very traditional. She mentioned about a hierarchy existing in her family. She said that as she was at the very bottom of the hierarchy, she did not have a strong voice in the family. This was especially true in the eyes of her mother-in-law since she had the highest seniority in the family after her father-in-law. As a result, her mother-in-law always got upset if Mrs. I did not follow her suggestions. As her husband was very traditional that he treated his parents very well and respected them very much, she tried not to upset her mother-in-law.

Mrs. I seemed to be feeling a little bit bitter about her situation. Although she repeated during the interview that she had choices of being the caregiver for her father-in-law or not, the interviewer felt that Mrs. I thought that she had to take on the role. She said that while her husband could not choose his parents, he could always choose his wife and it would not be difficult at all. The interviewer had the impression that she was doing what she did to please her husband. Her expression that she had to be satisfied with her situation also made the interviewer question whether she was feeling as positive as she sounded.
Case # 10

Mrs. J took care of her mother-in-law. Although not living together, they lived in very close proximity. Mrs. J’s mother-in-law lived with her father-in-law just next door to her.

The interview took place in a morning at Mrs. J’s home. Mrs. J did not have paid employment and she spent most of her time taking care of her children. Being a caregiver, she did not actually spend too much time providing care for her mother-in-law. She was mainly responsible for her mother-in-law’s meals and transportation to go to different activities. At the time of the interview, she had already dropped her mother-in-law off at the daycare centre. The interview did not take too long and most of her answers were brief when compared to those said by other caregivers.

Mrs. J seemed to be very understanding and rational. Throughout the interview, she maintained repeatedly that she was willing to take on the caregiver role and that her mother-in-law’s behavior did not bother her because she understood that her mother-in-law was sick and needed help. She mentioned that she did not feel burdened at the present time because her mother-in-law was not requiring a lot of assistance at all.

Mrs. J did not seem to be too clear about the future for her mother-in-law. This appeared to be true both in terms of her mother-in-law’s condition and also the possible arrangements. When questions regarding those areas were asked, she replied that she could not predict what would happen or that she had not thought about those issues seriously. However, she did not seem to be prepared to provide too much care for her mother-in-law. The interviewer felt that maybe she was not planning to do so because her mother-in-law lived with her father-in-law.
Case # 11

Mrs. K was the daughter of the care-recipient. Living together in a house, she was responsible for all of her mother’s care including medical care such as insulin injection.

The interview took place in an afternoon at the recruiting agency while Mrs. K’s mother was at the daycare. Since the daycare activities finished early sometimes, Mrs. K was afraid that she would miss her mother. She was concerned about the time towards the end of the interview and asked the interviewer how many more questions were there to be asked. Her answers for the last few questions were quite brief and the interviewer felt that she was rushing through to finish up the interview.

Mrs. K seemed to be very close to her mother. As her mother had been living with her since immigration, she felt natural to take care of her mother. Although she had two brothers in Toronto, she said that they did not really care about her mother that much. They were never involved in her mother’s care and she had always been the primary caregiver for her mother. She thought that it was her responsibility to take care of her mother and she was willing to do it.

During the interview, Mrs. K appeared to be quite positive about the situation. She always had a smile on her face and she laughed at times. However, from the content of some of her answers, the interviewer thought that she may not have felt the same deep inside her heart. For example, when asked of the positive feelings towards her caregiving role, she said that there was nothing positive at all since her mother would only cause her trouble. In addition, she expressed that the worst aspect of her situation was that her responsibilities would not end until her mother dies and she did not know when that
would happen. Mrs. K’s answer gave the interviewer the impression that she would like the situation to end soon even if it meant the death of her mother.

Mrs. K seemed to be discontent with her brothers. The interviewer felt that she did not mind taking on the caregiver role since she had always been close to her mother. However, she was unhappy about the fact that her brothers did not seem to care at all. She said that they would never thank her for what she did no matter how well she was managing the situation. She mentioned that when she informed her brothers of her mother’s condition, they did not seem to be interested in hearing the news. She thought that if her mother had to be admitted to a nursing home in the future, she would ask for her brothers’ opinions just for the sake of respect since she doubted that they would have anything to say.
Case # 12

Mrs. L took care of her mother with Alzheimer’s disease. As her mother lived with her sister, she was not involved in her mother’s personal care. She was mainly responsible for taking her mother to doctor’s appointments and also for some of the indirect care such as getting and refilling her mother’s medications.

The interview took place in an afternoon at Mrs. L’s home. The interview was to be conducted at a coffee shop initially since Mrs. L would like to bring her children out. However, she contacted the interviewer just before the scheduled time to request the interviewer to go to her house because her daughter was not feeling well. The interview was interrupted on several occasions by Mrs. L’s children but it was resumed shortly after the interruptions. She appeared to be at ease during the interview and she initiated informal conversation with the interviewer on several occasions.

Mrs. L described herself as having a busy life being a mother of two young children. She said that she had to work non-stop from the time her husband got up till the time after he went to bed. She mentioned that she could not be committed to her mother’s care too much because she was so busy with her other responsibilities. However, the interviewer thought that Mrs. L’s view was a little bit exaggerated. As she was not working at the present time, she should have a lot more time to take care of her family when compared to other working mothers. Yet, she sounded as if she was too busy for anything else.

Mrs. L seemed to be willing to admit to her own shortcomings. She was very honest in telling the interviewer about her own problems. She mentioned that her driving was very bad and she was afraid to go to places where she had never been to. As a result,
she could only drive her mother to certain places and she would ask her sister to do it otherwise. She also admitted that she had problems managing time. She found herself in a hurry all the time and rushing led to a higher chance of having accidents.

However, Mrs. L did not seem to be too eager to overcome her problems. Although she mentioned that she had been trying to change her habits to improve the situation, she did not seem to be too enthusiastic about it. She said repeatedly that she could not be too involved in her mother’s care because she had her own problems and that she was not capable of doing it. The interviewer had the feeling that Mrs. L was actually quite content with her situation at the present time and that she tried to convince the interviewer of her reasons of being not committed to her mother’s care.