A CASE STUDY OF A CHINESE-CANADIAN DAUGHTER CAREGIVING FOR HER MOTHER WHO HAS ALZHEIMER’S TYPE DEMENTIA (AD)

by

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ABSTRACT

The prevalence of Alzheimer’s disease (AD) increases with advancing age. Persons with AD are often being cared for by family caregivers. Spouses, mostly the wives, are the largest group of family caregivers and daughters are the second largest group. With the aging population, family caregiving of persons with AD requires increasing attention and resources. In recent years, although the number of Chinese-Canadians has been increasing, the influences of culture on family caregiving have not been fully explored yet.

To add to the body of knowledge that could lead to interventions that enhance dementia care, I explored the caregiving experience of a Chinese-Canadian daughter caring for her mother who has AD. I used a qualitative secondary analysis case study approach to explore her caregiving experience in-depth. Perry’s (2004) primary data is adequate and appropriate for secondary analysis to explore how Chinese culture in a Canadian context influences caregiving.

This Chinese-Canadian daughter’s caregiving experience had challenged her values and beliefs in gender roles in marriage, filial piety, and family values. However, having her feet in both Chinese and Canadian cultures had offered her more options to resolve the challenges. Caregiving is influenced not only by her cultural background but also by her previous family relationships, socio-economic status, formal and informal support, and the available health care and social services. The research findings of this case study support that caregiving is individual, dynamic, and multi-factorial. To care for the persons with AD and to support the caregivers, a person-centered approach with sensitivity to culture and gender is the key.
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CHAPTER I

INTRODUCTION

Introduction

In this qualitative case study, I examine the case of a Chinese-Canadian woman caring for her mother who has Alzheimer's disease (AD). Using narrative analysis as the analytical approach, I establish why this case study will advance nursing knowledge. Ultimately, the goal of this research is to add to the body of nursing knowledge by providing insights that could support interventions that enhance the quality of life for family caregivers of persons with AD.

The number of people diagnosed with AD has been increasing each year (www.alzheimer.ca, 2003; Bloom et al., 2003; Canadian Study of Health and Aging Working Group, 1994; www.statcan.ca, 2003). Since most persons with AD are being cared for by their families, the number of family caregivers has been increasing as well (www.alzheimer.ca, 2003; Canadian Study of Health and Aging Working Group, 1994; Haley, 1997; Langner, 1995; Lynch-Sauer, 1990; National Advisory Council on Aging, 1996).

Canada is a country with a long history of migration and has a population characterized by social and cultural diversity. In recent years as the social and cultural make up of Canada has shifted, it has been recognized that some population groups' viewpoints are not fully understood and considered in the ways care is provided to patients and their families. Chinese-Canadians are one such group. Since there are a considerable number of Chinese-Canadians who are providing care to family members, it
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is important that we have a better understanding of the ways culture influences caregiving.

Values and beliefs influence but not determine how an individual thinks and acts in response to a situation (McCarty, 1996). People of different cultures have different opinions on how health, social support, socioeconomic status, and functional well-being affect their quality of life (Sterritt & Porkorny, 1998). Ahmad’s (1993) review on health and healthcare undertaken in the UK asserted that culture, history, and socio-economic context influence how a person perceives and acts in a given situation. Nevertheless, the person’s capacity to act is also influenced by the availability and accessibility of resources.

To date, the influences of culture on family caregiving for persons with AD have not been fully explored. The majority of studies on family caregiving have focused on the European-American family caregivers (Farran et al., 1991; Farran et al, 1993; George & Gwythwer, 1986; Langner, 1995; Lynch-Sauer, 1990; Perry, 2002). Although the researchers have begun to explore the caregiving experience of other ethnic groups, most of these studies were done in the US. Moreover, most of these studies were done to compare the caregiving experience of the European-Americans with the African-Americans (Farran et al, 1997; Gaugler et al., 2004; Paun, 2004; Sterritt & Porkorny, 1998), or the European-Americans with the African-Americans and Hispanic-Americans (Clark & King, 2003; Connell & Gibson, 1997). Only a few studies were done to explore the caregiving experience of Chinese-Canadians. Since the Chinese population in Canada, particularly in BC, is large and is increasing, examining the influences of the
Chinese culture on family caregiving is important (Lai et al., 2003; Lilies & McLean, 2000; www.statcan, 2003).

The purpose of this case study is to explore the cultural influences on a Chinese-Canadian daughter’s caregiving experience of her mother who had AD. I examine how this daughter, Sau Ying (pseudonym), dealt with the changes that AD brought to her mother and her family within the Chinese-Canadian cultural context of caregiving. A case study approach allows all sources of influence in a particular situation to be examined by asking how and why things happen in relation to the phenomena being studied (Fritzgerald, 1999; Polit & Hunglar, 1999; Stake, 1995; Yin, 1994). I am interested to examine how Sau Ying became her mother’s primary caregiver, how she managed caregiving, and how she felt about being her mother’s caregiver. I focus on the different aspects of the Chinese culture that had shaped Sau Ying’s decisions and actions when caring for her mother. In addition, I am interested to explore how her caregiving decisions were shaped by this family’s life and life circumstances in Canada.

To place this particular case in a wider context, I discuss what AD is and how culture influences caregiving. To illustrate the significance of this case study, I present statistical information on the population of older adults and Chinese-Canadians. Lastly, I discuss the qualitative secondary analysis case study using a narrative analytic approach as the method of this study.

**Alzheimer’s Disease (AD)**

Alzheimer’s Disease (AD) is a progressive degenerative brain disease that affects predominantly the older population. AD affects the person’s cognition, behavior, and mood (Clark & Karlawish, 2003; Forbes, 1998). Further, AD is the most common
type of the dementias, accounting for about half (48%) of the cases. The course of AD from diagnosis to death is usually eight to ten years (Hall et al., 1995; Sadik & Wilcock, 2003). AD has become the third most common cause of death in the US (Ewbank, 1999).

Studies show that advanced age is the major risk factor of AD. About 10 to 15% of people over 65 and about 25 to 50% of people over age 85 are affected by AD (Clark & Karlawish, 2003; Munoz & Feldman, 2000, National Advisory Council on Aging, 1996; Sadik & Wilcock, 2003). Recent studies also suggest that genetics and environmental factors may increase the risk of having AD (Clark & Karlawish, 2003; Munoz & Feldman, 2000).

Today, a definitive diagnosis of AD can only be made by a post-mortem examination of the brain to determine the presence of neurofibrillary tangles and senile plagues. Usually, medical professionals make a clinical diagnosis of AD based on the inclusion of the clinical presentations of AD and the exclusion of other possible causes (Clark & Karlawish, 2003; Munoz & Feldman, 2000).

Clinical Presentations of AD

AD is an incurable, progressive disease affecting the persons' cognitive function, including memory, judgment, communication, reasoning, and orientation. The short-term memory loss is one of the earliest signs and as the illness progresses, long-term memory will be affected. With the progressive memory loss, the persons with AD may have difficulty in remembering where they live and how to get home (www.alzheimers.org, 2003; Clark & Karlawish, 2003; Long & Dougherty, 2003; Munoz & Feldman, 2000). AD also affects the persons with AD's mood and behavior (Clark & Karlawish, 2003; Forbes, 1998). Incidence of depression is found to be high at the time of diagnosis and
individuals often feel hopeless and helpless (www.alzheimers.org, 2003; Clark & Karlawish, 2003; Long & Dougherty, 2003; Munoz & Feldman, 2000). Persons with AD often exhibit personality changes, such as agitation, irritability, restlessness, aggression, delusion, and paranoia. In addition, persons with AD gradually lose their social skills and consequently are at very high risk of social isolation (www.alzheimers.org, 2003; Clark & Karlawish, 2003; Hall et al., 1995; Long & Dougherty, 2003; Munoz & Feldman, 2000).

Stages of AD

Current conceptualization in the biomedical view of AD suggests that the disease occurs in stages progressing from early to late stages over time (www.alzheimers.org, 2003; Boyd & Vernon, 1998; Hall et al., 1995; Sadik & Wilcock, 2003). During the early stage, persons with AD have mild short-term memory loss. At that time, they and their family often attribute the memory loss to normal aging (www.alzheimers.org, 2003; Boyd & Vernon, 1998; Hall et al., 1995; Rowe, 2003). They do not consider seeking medical advice as necessary until their family or friends perceive the memory loss problematic or dangerous, such as when they get lost in a familiar environment (Tappen et al., 1999) or when they forget to turn off the stove after preparing a meal (www.alzheimers.ca, 2003; www.alzheimers.org, 2003; Boyd & Vernon, 1998; Hall et al., 1995; Rowe, 2003).

As AD progresses, persons with AD will gradually lose their capacity for judgment, abstract reasoning, and language use. Over time, they will lose the ability to manage finances, shopping, cooking, and housekeeping. They will no longer be able to bath, dress, feed, or use the toilet independently (www.alzheimer.ca, 2003;
When AD reaches the end stage, persons with AD will be in a severely debilitated state. They will be susceptible to medical complications, such as malnutrition, pneumonia, urosepsis, and pulmonary embolus, which are the common causes of death (Boyd & Vernon, 1998; Clark & Karlawish, 2003).

**Psycho-social View of AD**

To understand the impact of AD on people’s lives, we need to not only understand the biomedical effects of AD on the brain but also the psychosocial impact of AD on the persons in their family. Although AD affects the cognition and behaviors of the persons with AD, studies show that the degree of cognitive impairment and behavioral changes is related not only to the biological effects of the illness but also to the psycho-social environment (Kitwood & Bredin, 1992; Lyman, 1989; Morgan & Stewart, 1997). The length of time of having AD is not the sole determining factor of the clinical presentations (Adams & Clarke, 1999; Kitwood & Bredin, 1992; Lyman, 1989; Morgan & Stewart, 1997). In addition to the pathological changes of the brain, the psychological, physical, cultural, economic, and social environment have great influences on how persons with AD function (Adams & Clarke, 1999). A positive social environment with optimal stimulation and interactions with others, to some extent, can compensate for the biomedical effects of AD (Kitwood & Bredin, 1992; Little, 2002).

Studies indicate that AD affects all the aspects of lives of both the persons with AD and their families (www.alzheimers.ca, 2003; www.alzheimers.org, 2003; O’Connor, 1998; Sadik & Wilcock, 2003). To ensure that family caregivers have the needed support, the health care and social service providers need to assess the biomedical
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changes brought about by AD, the psycho-social influence on the persons with AD and family caregivers, and how they cope with the situation.

The Senior Population in Canada and Alzheimer’s Disease

The Canadian Study of Health and Aging Working Group (1994) predicts that the proportion of the population aged 65 and over will increase from 14.5% in 2011 to 21.8% in 2030. In British Columbia (BC), out of a total population of 4,141,300, about 551,800 (13.3%) were aged 65 and over (www.statcan.ca, 2003). Lilies and McLean (2000) predict that the proportion of people aged 65 and over in the Vancouver/Richmond area in BC will increase from 11.8% in 2000, to 12.3% in 2010, and to 17% in 2020.

Prevalence studies estimate that 2.4% people aged 65 to 74 and 34.5% people aged 85 and over will have dementia of some kind. With the increasing average age of the population and AD being the most common type of dementia, the number of people with AD is expected to increase as well (Canadian Study of Health and Aging Working Group, 1994; Jackson, 2002; Jellinger, 2003). As this occurs there will be a concurrent increase in the number of family caregivers.

The Chinese Population in Canada

Chinese is now the third largest ethnic group and the largest minority group in Canada (Lai et al., 2003; www.statcan, 2003). In 2001, the total number of people reporting Chinese as their ethnicity was 1,094,700 (about 9.37% of the total Canadian population). In BC, the total population was comprised of 373,830 Chinese (about 9.7%) (www.statcan, 2003). In 1996, about 36% of the seniors in the Vancouver/Richmond region were Chinese or East Asians (Lilies & McLean, 2000).
The two main Chinese languages, Cantonese and Mandarin, are the third most spoken language groups in Canada, trailing only behind English and French. Chinese is the most spoken non-official language in Canada. In 2001, about 853,745 Canadians, or about 2.8% of the total population, claimed that their mother tongue is Chinese. Among them, 307,990 (about 7.9%) lived in BC and 404,250 (about 3.6%) lived in Ontario (www.statcan.ca, 2003).

Lai et al. (2003) report that 91.3% of Chinese-Canadians speak a Chinese dialect most of the time. Although 43.1% of older Chinese-Canadians speak English fluently, 41.1% of them do not speak English at all (Lai et al, 2003). Even if they had lived in Canada for many years, many older Chinese-Canadians have not mastered the English language (Fung, 1998). Chinese-Canadians, particularly the elders, who do not speak or understand English, would choose or prefer involving primarily with the local Chinese communities where language barrier does not exist. They rarely connect with the mainstream Canadian society if their needs are being met. However, when they need to access community services outside the Chinese community, they often encounter language as a barrier (Fung, 1998; Lai et al., 2003; Zhan, 2004).

Although some Chinese-Canadians identify the long waitlists (37.9%) or an unawareness of services as barriers to accessing social and health care services, most of them consider language as the primary barrier. Even if they benefit from utilizing the services, they often choose not to use the community services when the service providers do not speak Chinese. When they find communicating with the English-speaking service providers difficult, they may prefer to coping without any formal support. For those who
have utilized the services, they often choose to stop using the services as soon as they feel that they can manage the situation on their own (Lai et al, 2003).

**Chinese Cultural Influences on Caregiving**

The historical development of the culture and the current socioeconomic context in which people live influence how they view health, illness, and health care delivery (Ahmad, 1993). The family caregivers’ values and beliefs influence, but not determine, how they make decisions and act when caring for persons with AD (McCarty, 1996). In the traditional Chinese society, men usually assume the role as the heads of the families while women usually take on a subordinate role. Women are expected to obey the men. While men usually work outside the house and bring home money, women usually stay home to provide hands-on care to the family and bring up the children (Chiu & Zhang, 2000; Fung, 1998; Lai et al., 2003).

Filial piety, the children’s duty to respect and care for their parents, is a traditional Chinese cultural value. In the traditional Chinese society, in order to show their gratitude to their parents for raising them, the children are obligated to have absolute obedience and respect to their parents and to care for them until death (Choi, 1993; Fung, 1998). Fung (1998) and Lai et al. (2003) found that majority of the Chinese-Canadians still expect their children to be obliged with filial piety to their parents and grandparents.

Lai et al. (2003) have conducted a descriptive research on the health and well-being of Chinese-Canadians living in seven cities across Canada. The study shows that over 80% of the Chinese-Canadians believe that their children are responsible for their care. As with the research findings of other studies, most Chinese have the belief that if they have more than one child, the sons, particularly the first-born son, are responsible
for most of the filial piety duties (Chiu & Zhang, 2000; Fung, 1998; Lai et al., 2003).
Since women are traditionally the caregivers of the family, the daughters and daughters-in-law are expected to provide the hands-on care for the elders. Compared to the daughters-in-law, the daughters are more closely related to their parents. Therefore, daughters are expected to take on most of the caregiving responsibilities for their parents (Lai et al., 2003). As these traditions may continue to exert an influence on how families enact caregiving, subsequently, it is important we gain an understanding of how families reconcile traditional Chinese values and expectations in the new cultural context of Canada. This study explored how a particular Chinese-Canadian family undertook the caregiving role. It aimed to advance the knowledge of the influences on ways Chinese-Canadians provide care for a family member with AD.

**My Own Experience of Cultural Influences on Caregiving**

I have worked as a registered nurse (RN) in both Hong Kong and Canada for almost 26 years. I found that health care providers and family caregivers in both places have different attitudes towards the care of persons with AD. I graduated in nursing in 1980 in Hong Kong and moved to Canada in 1994. When working in Hong Kong, I was not aware that the needs of older patients were different from those of other age groups. I had little knowledge in dementia care because I had no special training or education in this area.

During the 1980's, the society in Hong Kong had associated dementia with mental illness. Most health care providers found that caring for the “demented patient” was difficult and frustrating. When a person with dementia exhibited behavioral problems, such as wandering, agitation, or aggression, the doctors and nurses would
consider administrating sedatives and applying physical restraints as the best and only way for managing the behavior.

When the person with dementia was found wandering on the streets, police officers would take the person to the emergency room (ER) of the hospital, where the person would be admitted to the medical ward. Nurses used physical restraints to keep the person in bed and to prevent wandering. If the person became agitated, nurses would administer a sedative. The person with dementia would stay in the hospital receiving total care until the family came to take them home. In some cases, a number of days might pass before anyone showed up. I remember that one family would deliberately leave the person with dementia to wander on the streets whenever the family needed to go away. Later, the family would come to the hospital to take the "demented" person home. Even though the social worker had told the family that what they did was inappropriate, the family continued doing this until the person with dementia was moved to a government-funded nursing home.

In Hong Kong, it was not uncommon for some family caregivers to call the police to take the person with dementia, who became aggressive, to the ER. Doctors would order sedatives to settle the agitated person with dementia while nurses and security staff would apply physical restraints. If the person calmed down, he/she might be discharged home. Otherwise, he/she would be admitted to the psychiatric unit for further management. The only involvement of the social worker was in arranging financial assistance. With very limited formal health care and social services to support family caregivers, most persons with dementia had repeated admissions to the hospital for re-occurring problems. At that time, social service or health care policy was not yet in place.
to deal with these problems. Families were simply expected to cope. Such examples
draw attention to the challenges individual families face in caring for a family member
with dementia where there is no formal system to support them in their roles or to
recognized the individual’s care needs.

At that time, people with dementia in Hong Kong usually lived at home with their
families. As few government-funded nursing homes were available for those who had no
family, the waitlists were long. In addition, no regulations were in place to standardize
how the care provided by the private nursing homes. Most private nursing homes were
run by only one RN, who was responsible for providing the hands-on care and for
training the staff. Consequently, the residents might not receive the care they needed.
They were often admitted to the hospital for treatment of malnutrition or multiple
pressure ulcers. Although the hospital staff felt sympathetic about the residents’
suffering, little was done to ensure the nutritional status or to prevent pressure ulcers
from reoccurring when they returned to the private nursing homes. At the time, the
society felt that improving the care of persons with dementia was a low priority.

I began working in extended and intermediate care facilities in Canada in 1994. I
was impressed by how Canadians cared for the elderly. Canadian nursing homes were
staffed by health care professionals that included RNs and Licensed Practical Nurses
(LPNs). Most of the resident care aides had formal training in the community colleges
and some even had specialty training in dementia care. The Canadian government and
the public had been paying much more attention to dementia care than the Hong Kong
government. One of my realizations about dementia was that it was not a mental illness.
When I first came to Canada, I noticed that almost 90% of the nursing homes residents were European-Canadians. My colleagues told me that most Chinese-Canadians chose to live in nursing homes near Chinatown because Chinese food was served and the staff spoke Chinese. Over time, I began to notice that more Chinese-Canadians were living in nursing homes that were outside Chinatown. Although most Chinese-Canadian elders only spoke and understood Chinese, most staff members in the mainstream nursing homes did not speak or understand Chinese. Communication between the staff and the Chinese-Canadian residents was a problem. If the family members were not fluent in English, additional challenges were created. Up until now, I find that the situation remains more or less the same.

In my experience the European-Canadian and the Chinese-Canadian families enact their caregiver roles in different ways. While European-Canadian families usually support the persons with AD by being the financial and personal decision-makers, Chinese-Canadian families usually continue their caregiver roles by visiting daily to help with washing, dressing, toileting, and feeding. The Chinese-Canadian families often bring the residents homemade Chinese foods, especially if the elders do not like Western food. On the other hand, only some European-Canadian families help with personal care and feeding. Most of them spend time with the residents by talking to them and taking them out for meals. Many of the European-Canadian families live in other cities, provinces, or countries. They may visit a few times a week, or weekly, monthly, or even less often.

In conclusion, I have found that while the elders in Hong Kong are being cared for at home by family caregivers, the elders in Canada are being cared in nursing homes.
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After the elders are admitted to nursing homes, the manner by which Chinese-Canadian family caregivers continue their caregiving roles differs from that of European-Canadians. Having seen these differences, I am interested in exploring the contributing factors. The goal of conducting this case study of a Chinese-Canadian daughter caring for her mother with AD via a cultural lens is to explore how culture and other factors influence family caregiving. Having lived in both Hong Kong and Canada, my own personal experience may give me more insight into this Chinese-Canadian daughter’s caregiving experience.

**Family Caregiving of Persons with AD**

More persons with AD are being cared for at home by their family caregivers than ever before and family caregivers are expected to take on more and more responsibility (Bloom et al., 200; Hinton, 2002). At the same time, studies support that quality family care provided by family caregivers is important for preventing or delaying nursing home admissions (Bloom et al., 2003; Schulz et al., 2002; Semple (1992). Research shows that family caregivers need education and support for communicating with the persons with AD, managing the challenging behaviors, coping with their own emotions and stress, making legal, financial, and health care decisions, and planning for facility care (www.alzheimers.org, 2003; McCarty, 1996; Shulman & Mandel, 1993).

**Family Caregivers**

Among all the family caregivers, about 24% were wives and 29% were adult daughters (www.alzheimer.ca, 2003; Anderson et al., 1997; Canadian Study of Health and Aging Working Group, 1994; Chiu, 2001; Heok & Tan, 1997; Langner, 1995; McCarty, 1996; National Advisory Council on Aging, 1996). Furthermore, while wives
usually care for their husbands at home, daughters usually care for their parents when they are in institutions (National Advisory Council on Aging, 1996).

Daughter caregivers

Compared to sons, daughter caregivers often take on more hands-on caregiving responsibilities (Fung, 1998; Langner, 1995; McCarty, 1996). Married son caregivers often receive support from their wives in the hands-on care (Fung, 1998; Langner, 1995; McCarty, 1996). In contrast, daughter caregivers tend to struggle to balance their other multiple social roles as wives, mothers, daughters, daughters-in-law, and career women (McCarty, 1996; Fung, 1998; Anderson et al., 1997).

Caregiving Experience

The average time family caregivers spend in care of persons with AD is about six and half years (Haley, 1997). When caring for persons with AD, the family caregivers frequently encounter negative caregiving experiences, such as financial difficulties and problems with personal health status (National Profile of Family Caregivers in Canada, 2002). Nevertheless, some family caregivers have positive caregiving experience (Cohen et al., 2002; Farran et al., 1991; Paun, 2003; Paun, 2004; Ward-Griffth, 2004).

Caring for persons with AD require time and energy. The most frequent problems encountered by family caregivers are financial difficulties and personal health problems (National Profile of Family Caregivers in Canada, 2002). The caregiving responsibilities often leave the family caregivers little time for other obligations in life (Duncan & Morgan, 1994; George & Gwyther, 1986; Walker, 1983). Some caregivers find the hands-on physical care, such as toileting, incontinence care, feeding, transfer, and mobility difficult (www.alzheimers.org, 2003). If the persons with AD exhibit physical
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and verbal aggression, resistance to care, agitation, sleep disturbance, hallucinations, delusions, paranoia, and wandering behaviors, the care will be more problematic for the caregivers to manage (Hall et al., 1995). Although regular support group meetings are helpful to caregivers to learn and adapt effective coping strategies from each other, some caregivers feel that the support they receive is inadequate to meet their needs.

Even though caregiving is often challenging and stressful, some family caregivers choose to be the caregivers despite having other choices (Farran et al., 1991). Paun (2003) found that the wives chose to care for their husbands at home because they felt that home was the best place for their husbands. Studies show that if the family caregivers are able to cope and manage their roles, they can find meaning in caregiving, which enables them to continue with the role (Farran et al., 1991; Paun, 2003).

Cultural Social Influences on Family Caregiving

The health of individuals is influenced by their socio-cultural context, which includes not only their physical make-up but also their life-style, social position, social role, support system, and economic status. Anderson et al.’s (1997) study on family caregiving of persons with chronic illness illustrated ways the family structure, social roles, support network, economic status, demands of paid employment, and surrounding physical environment influence how individuals manage health and illness. For example, caregivers with lower socioeconomic status may not have adequate money for nutritious foods, appropriate clothing, and safe shelter but they may not have the time or money to engage in health maintenance and promotion activities. Since AD is a chronic illness, the findings of Anderson et al. (1997)’s study may be relevant to family caregiving of AD.
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**The Primary Study: Perry's (2004) Research on Daughter Caregivers of Mothers who have AD**

Perry (2004) conducted a qualitative study to explore the process through which daughters became, and continued to be, the primary caregivers of their mothers. The author interviewed 19 daughters and one daughter-in-law who cared for their mothers or mother-in-law with AD at home. Among the interviewees, 16 were European-Canadians and 4 were Asian-Canadians. Perry (2004) used theoretical sampling and recruited participants according to the emerging categories and themes from earlier interviews until data saturation was achieved (Polit & Hungler, 1999). She recruited participants through support groups and adult day care centers in the Pacific Northwest.

Perry (2004) identified mastering the three R's of (re)calling, (re)learning, and (re)adjusting the main themes of caregiving. She found that the previous and current relationships between the mothers and the daughters had influences on the caregiving experience. The daughters felt it natural for them to become their caregivers when their mothers had taken care of them when they were young. During the process of caregiving, the daughters expressed how they positioned their parent-daughter relationships to adjust to their new roles (Perry, 2004).

**Purpose of this Case Study**

The purpose of this case study is to explore how caregiving of a traditional Chinese woman with AD was enacted by her Chinese-Canadian daughter in a Canadian context.
Research Questions

The research questions of this case study are: “How did culture and other factors influence this Chinese-Canadian daughter’s decision of becoming the primary caregiver of her mother who has AD?” “What was her experience and feelings about being the caregiver?” “How did culture and other factors influence the way she managed and coped with caregiving and her other roles in her life?” and “How did the caregiving experience influence her personal values and beliefs and those of her immediate family?”

Significance of the Study

With the aging population, the number of family caregivers is increasing (Canadian Study of Health and Aging Working Group, 1994; Hepburn et al. 2001; Lilies & McLean, 2000; Sadik & Wilcock, 2003). With the constant financial constraints on the formal health care and social systems, the care of persons with AD often relies on the family caregivers (Bloom et al., 2003; McCarty, 1996; Sadik & Wilcock, 2003). To support family caregivers, a more complete understanding is needed about how they respond to and cope with the physical and emotional stress and burden of caregiving.

For a long time, as early as the eighties (Hasselkus, 1988), researchers have been interested in family caregivers’ caregiving experience and evaluating the effectiveness of various interventions in assisting family caregivers. However, most of the studies on family caregivers have not examined how culture influences caregiving (Donaldson et al, 1998; Duncan & Morgan, 1994; Fortinsky, et al., 2002; McCarty, 1996; Mafullul & Morris, 2000). The issues faced by the European-Canadian caregivers of persons with AD are often not applicable to caregivers of other ethnicities (Janevic & Connell, 2001). To date, it is still unclear how cultural context influences how caregivers enacted.
Many studies on family caregivers included spouses and adult children together as a group. Among the studies that explore the caregiving roles of adult children, whether the adult children were sons or daughters were not mentioned in most studies (Farran et al., 1991; 1993; George & Gwythwer, 1986; Hasselkus, 1988; Tarlow et al., 2004). Consequently, the research findings do not provide an adequate understanding of the specific caregiving experience of daughter caregivers. Since daughters are the largest group of women family caregivers for persons with AD, and Chinese-Canadians are the third largest ethnic group in Canada (www.alzheimer.ca, 2003; Canadian Study of Health and Aging Working Group, 1994), this case study will contribute useful information and a needed perspective about the role of Chinese-Canadian daughter caregivers.

**Research Method**

The qualitative case study is conducted to look into and make sense out of the daughter’s caregiving experience. Although the research findings of this case study cannot be generalized to all Chinese-Canadian daughter caregivers of mothers who have AD, transferability is possible if the context of caregiving is similar (Polit & Hunglar, 1999; Yin, 1994). This qualitative case study is a secondary analysis that uses data from Perry’s (2004) study. Secondary analysis is appropriate when the primary data is sufficiently rich and suitable to answer the research questions (McArt & McDougal, 1985). Perry’s (2004) data on the daughter’s caregiving experience is adequate and appropriate to explore in-depth the influences of the Chinese culture on her decision to be her mother’s primary caregiver and on her ability to manage her multiple roles as wife, mother, daughter, sibling, and career woman (Polit & Hunglar, 1999; Yin, 1994).
Narrative Analysis

Perry (2004) used the constant comparative approach to analyze the data from the primary study by constantly comparing the codes and categories that emerged from previous interviews (Strauss & Corbin, 1990). Since this secondary analysis case study is about the caregiving experience of one daughter, using the constant comparative approach is not appropriate. Instead, I use a narrative analysis for the data analysis.

Narrative analysis begins in the person’s story or account to present the life story to the researcher, who then attempts to see this everyday life story in a scientific way (Sandelowski, 1991). Narrative analysis emphasizes understanding the phenomenon from the point of view of the participant (Coffey & Atkinson, 1996; Sandelowski, 1991).

In the methodology chapter, I discuss in more details the purposes, uses, advantages, and limitations of qualitative research, case study, secondary analysis, and narrative analysis. I also discuss how Perry (2004) collected the primary data, how I obtained the primary data for the secondary analysis, how I analyzed the data, ensured the rigor of this case study, and how I adhered to the ethical principles to protect the participant from exploitation.

Summary

This introductory chapter opens the discussion on conducting this case study of a Chinese-Canadian daughter’s caregiving experience of her mother with AD. The purpose of conducting this case study is to answer the why’s and how’s of the situation via a cultural lens (Yin, 1994). The ultimate goal of this research is to contribute to the knowledge of nursing in family caregiving for persons with AD.
To understand the effects of AD on the persons and their family caregivers, I discussed both the biomedical and psycho-social views of AD. In presenting the prevalence of AD, numbers of older adults in Canada, and the numbers of Chinese-Canadians, the significance of the case study is apparent for the care of persons with AD. I presented my own nursing experience with the elders both in Hong Kong and in Canada. In presenting the differences that I noticed in the care of the elders in these two places, I explained why I am interested to explore if the differences are related to culture or other factors.

I discussed briefly the methods of conducting this qualitative secondary analysis case study using narrative analysis as the analytic approach. Since this case study is a secondary analysis with the primary data obtained by Perry (2004)'s study, I presented a brief overview of Perry's (2004) study. The primary data on this Chinese-Canadian daughter is rich and appropriate for answering the research questions of this case study.
CHAPTER II

LITERATURE REVIEW

Introduction

In this chapter, I review the literature relevant to Chinese-Canadian daughters caring for mothers who have AD. The purpose of conducting a literature review is to identify what is already known and the gaps in the current knowledge on the topic. The goal of literature review is to demonstrate how this case study will advance nursing knowledge (Morse & Field, 1995). In reviewing the literature, I appraise the aims, biases, implicit and explicit assumptions, interpretations, research findings, implications for nursing, and suggestions for future study. The areas of literature being reviewed include family caregivers, caregiving experience, and cultural influences on caregiving of persons with AD.

For this study, the Cumulative Index to Nursing and Allied Health Literature (CINAHL) database for nursing and health science research were searched for relevant articles. The Medline database for medicine, social science, and other health science publications were searched. I use the keywords, “AD”, “family caregivers”, “Chinese”, and “culture” when I search these two data base for the relevant literature.

I have found numerous articles on the family caregiving of persons with AD and the influences of cultures on family caregiving. Researchers have begun exploring family caregiving experience in areas other than stress and burden fairly recently, for about 10 years only. Most of the literature I found focused on exploring the negative caregiving experience. At the same time, most of the research on cultural influences of
family caregiving was conducted to compare the caregiving experience of African-Americans or Hispanic-Americans with that of European-Americans. For those studies that explore the influences of Chinese culture on caregiving, most of them were conducted in Asian countries, such as China, Taiwan, and Hong Kong.

To provide a more holistic perspective on family caregiving, I have reviewed literature in areas more than just those of Chinese daughter caregivers and those that explore both negative and positive caregiving experiences. The literature I reviewed was written by scholars and researchers of a wide range of disciplines, with different purposes, and that employed diverse research methods. To gain more insight into the history and changes in family caregiving literature over the years, I have reviewed literature from as early as 1986 and as recently as 2005.

**Family Caregivers**

As discussed in Chapter one, informal caregivers, particularly daughters and wives, are expected to take on more and more responsibilities for the care of their frail elders (www.alzheimer.ca, 2003; Canadian Study of Health and Aging Working Group, 1994; Gallicchio et al., 2002; Langner, 1995; Lynch-Sauer, 1990; McCann et al., 2000; National Profile of Family Caregivers in Canada, 2002). Family caregivers are unpaid caregivers who are related to the persons with AD. Because of their relationships, family caregivers usually have love and compassion toward the persons with AD. They often choose to be the caregivers. Some caregivers continue their caregiver roles even after formal care has been sought (Langner, 1995; Lynch-Sauer, 1990; Mass et al., 2004).

Family caregivers are often subjected to negative caregiving experiences, such as stress, burden, and social isolation. However, when they can find meaning and joy in
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caregiving, they often perceive caregiving as positive (www.alzheimers.ca, 2003; www.alzheimers.org, 2003; Hepburn et al., 2001; Farran et al., 1991; Farran et al., 1993; Paun, 2003).

Who the Family Caregivers are

In response to the ongoing fiscal constraints to health care and social services, the demands placed on family caregivers caring for those with chronic illnesses, such as AD, are increasing (Kelly, 1997). Currently, spousal caregivers, mainly the wives, comprise the largest group of family caregivers of persons with AD. While daughter caregivers make up the second-largest group, son caregivers are the third-largest group of family caregivers. From another perspective, women make up the overall largest group of family caregivers providing about 70% of the family care. Among all the family caregivers, 29% are daughter caregivers and 24% are wife caregivers (www.alzheimer.ca, 2003; Canadian Study of Health and Aging Working Group, 1994).

The Process of Becoming Family Caregivers

Since AD is a progressive disease, caregiving is a process evolving over time in response to the constant deteriorating condition of the persons with AD (Ward-Griffith et al, 2005). Perry and Olshansky (1996) found that the process of caregiving often begins when the family caregivers feel that the persons with AD are acting and communicating differently. Often, the persons with AD and their families seek medical attention only when the increasing memory loss becomes alarming and problematic. After the diagnosis of AD is made, family caregivers usually make afford to adjust to the progressive changes brought by AD. After they have adapted to and accepted the
changes brought by AD, they will try re-connecting with the persons with AD by giving the persons with AD a new identity (Perry and Olshansky, 1996).

Although some family caregivers willingly take on the caregiver role, others provide care to the persons with AD because of obligation. Studies show that family caregivers’ previous relationships with the persons with AD affect their decision to take on the caregiver roles. When the family caregivers described their previous relationships as harmonious, caring, and reciprocal, they often accepted their caregiver roles voluntarily and willingly. On the other hand, when they perceived their previous relationships as difficult and filled with conflicts, they often became the caregivers because of obligation. If other choices are available, they often chose not to be the caregivers (Bontinen, 2001; Choi, 1993; Farran et al., 1991; Perry, 2002; Perry & Olshansky, 1996).

During the process of caregiving, family caregivers often develop a sense of selflessness and humanity (Bar-David, 1999). Bar-David (1999) has identified three phases of caregiving. The first phase begins when the family caregivers care for the persons with AD. The second phase is when the caregivers begin to care for the caregivers themselves. The last phase is when the caregivers extend the care for others.

Influences of Gender and Family Roles on Family Caregiving

To support family caregivers, social and health care service providers need to be aware of the psycho-socio-economic influences on both the family caregivers and on persons with AD (McCarty, 1996). How gender and family roles affect family caregiving also need to be understood (McCarty, 1996; Perry, 2002). Research findings of family caregiving support that wives, husbands, daughters, and sons perceive their
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caregiver roles differently (de Geest, 2003; Gallicchio et al., 2002; Haley, 1997; Sawatzky & Fowler-Kerry, 2003; Walker, 1983, Pucci et al., 2003). In many cultures, including Chinese culture, men are the head of the family while women are the family caregivers. Today, whether the women are working outside the house or not, they are still expected to be the caregivers of the family (Anderson et al., 1997; Fung, 1998; Lai et al. 2003; Langner, 1995; McCarty, 1996; Walker, 1983).

Some studies show that the behavioral and emotional problems of the persons with AD affect the female caregivers more than the male caregivers (Robinson et al., 2001). For example, Almberg et al. (1997) found that the wife and daughter caregivers are more prone to burnout than the husband and son caregivers. Although sons usually consider their duty to care for their parents, they often share the caregiving duties with female family members, such as their wives and sisters. While sons usually provide financial and emotional support to their parents with AD, women often provide the hands-on care (Harris, 1998).

The Needs of Family Caregivers

Usually, family caregivers have no formal training in dementia care. Most of them have no specialized skills or knowledge about caregiving of persons with AD (Kelley et al., 1999). They usually need educational support from the social services and health care professionals to help them to cope with their continuously evolving caregiving roles (www.alzheimers.ca, 2003; Hall et al., 1995; Haley, 1997; Hepburn et al., 2001; Hirst, 2003; Jansen, 2001). Many family caregivers find information about the signs and symptoms of AD, use of pharmacological management, course of the illness, resources available, and methods for providing hands-on care useful in supporting their
caregiver roles. For instance, some family caregivers find receiving general information guidelines on dementia care useful (www.alzheimers.ca, 2003; Hall et al., 1995; Haley, 1997; Hepburn et al., 2001; Hirst, 2003; Jansen, 2001; Wald et al., 2003).

Family caregivers often find caregiving stressful and burdensome. A large volume of studies have explored the stress and burden of caregiving. Other studies have demonstrated the usefulness of various strategies to alleviate the stress and burden of caregiving while improving the lives of caregivers (Forbes, 1998; Graham et al., 1997; Haley, 1997; Hall et al., 1995; Kelley et al., 1999; Ripich et al., 1999; Schulz et al., 2002; Shulman & Mandel, 1993). Examples of some of the interventions include: a standard care plan provided by the health professional as a guide of caregiving (Hall et al., 1995); opportunities for caregivers to narrate their feelings and perceived reality toward caregiving (Clark & Standard, 1997); benefits of involving the person with AD and the family in planning care and interventions (Brodaty et al., 2003; de Geest, 2003); and psychosocial counseling from health professionals (Balwin, 2003; Cassells, 2003; Woods et al., 2003).

Family caregivers often find a negotiable, consultative, collaborative, and participative relationship with the health professionals most helpful (de Geest, 2003). They find that a sense of partnership can be created if the health professionals understand the caregivers’ stress and burden of caregiving (Runciman, 2003). Studies suggest that better health care and social services utilization enhance the care provided by family caregivers and, thereby, delay seeking of institutional care (Schulz et al., 2002). Nevertheless, more studies are needed to compare the effectiveness of different strategies in alleviating the caregivers’ stress and burden.
Caregiving Experience

Caring for the persons with AD includes attending to both physical and emotional needs of the persons with AD (McCarthy, 1996). Traditionally, caregiving experience has been categorized into negative and positive experience. To enable family caregivers to continue their caregiver roles, both negative and positive caregiving experience need to be understood (Tarlow et al., 2004).

While negative caregiving experience is described as unpleasant and difficult to endure, positive caregiving experience is portrayed as satisfying and empowering. Some family caregivers find caregiving so negative and exhausting that they become unwilling or incapable to continue their caregiver roles. However, some caregivers claim that their caregiving experience was so positive that they are powered to get through the negative experience. Positive caregiving experience often enables family caregivers to continue their caregiver roles (McCarty, 1996).

Negative Caregiving Experience

Family caregivers often find caregiving unpleasant and difficult to endure. Negative experience and unpleasant feelings that family caregivers frequently encountered includes stress and burden, coping with constant decline, and social isolation.

Stress and burden

Researchers have long explored the stress and burden of caregiving. Although caregiving is often perceived as stressful and negative, most family caregivers do their best to continue their caregiver roles. As AD progresses, they try to provide care to meet the needs of the persons with AD. They try to adapt to their constantly changing
caregiver roles in response to the constantly changing needs of the persons with AD. They often strive to manage the stress and burden of caregiving by integrating caregiving with their daily lives (Butcher et al., 2001; Sanderson & Meyers, 2004).

To understand how family caregivers cope with caregiving, a range of factors, such as gender, age, socio-economic status, previous relationships, support system, and cultural background, need to be examined (Youn, et al., 2003). Numerous studies have explored the effects of the demanding physical tasks, psychological and mental stress, and financial burdens of caregiving on caregivers (Cassells, 2003; George & Gwyther, 1986; Hall et al., 1995; Tornatore & Grant, 2002). The context of caregiving influences the family caregivers' perception of stress and burden and ability to cope (Clark & King, 2003). The care receivers’ and caregivers’ health status, financial situation, and their personal experiences influence the caregiving experience (Sawatzky & Fowler-Kerry, 2003).

The family caregivers often find dealing with the persons with AD’s altered personality and mood disturbances difficult. Level of stress experienced by the family caregivers is often correlated with the severity of the persons with AD’s disruptive behaviors, such as wandering, restlessness, agitation, resistance to care, and aggression (Dibartolo, 2002; Donaldson et al., 2002; Farran et al., 1993; Mafullul & Morriss, 2000) and severity of cognitive impairment (Donaldson et al. 2002). Behavioral problems of the persons with AD are also correlated with the caregivers’ risk of depression (Beeson, 2003; Clark & King 2003; National Advisory Council on Aging, 1996), which in turns, potentially affects the family caregivers’ physical and mental health (Shulz et al., 1995).
Family caregivers, particularly the spouses, often feel sad, stressed, lost, frustrated, lonely, and emotionally wounded when the persons with AD, whom they love, gradually lose the ability to communicate (Butcher et al., 2001; Narayan et al., 2001; Shulz et al., 1995). They may have a higher risk of depression if they feel that the persons with AD are present physically but absent emotionally. The feeling of losing the lifelong emotional companionship of the persons with AD may lead to depression (Beeson, 2003; Butcher et al., 2001; Narayan et al., 2001; Sanders & Corley, 2003; Shulz et al., 1995).

Family conflicts often result when different family members have contrary opinions on the goals of care and how the care is to be provided. Unresolved family conflicts may result in the primary caregivers having a higher risk of depression and anger (Clark & King, 2003; Semple, 1992). Family caregivers’ perception of the degree of difficulty in caregiving is, in turns, related to their degree of emotional distress and dissatisfaction (Mafullul & Morris, 2000). Family caregivers often have feelings of burden and burnout when they do not have a positive outlook in caregiving (Almberg et al, 1997).

Family caregivers often find increasing demands of physical care, particularly falls and incontinence, difficult to cope with. Eventually, they may consider institutional care as the only way out. Their feeling of burnout often indicates their inability to cope, which in turn, leads to the perception of institutional care as necessary (Sanderson & Meyers, 2004). In some extreme cases, the family caregivers continue to feel stressed and burdensome even after the persons with AD have moved to institutional care.
A Case Study of a Chinese-Canadian Daughter Caregiving for her Mother with AD (Almberg et al., 1999; Lieberman & Fisher, 2001; Monahan, 1995; Tornatore & Grant, 2002).

Caregiving can have a great impact on the socio-economic status of the whole family. To cope with caregiving, some family caregivers find it necessary to lighten their paid work load by taking on a part-time job instead of working full time. To cope with the increasingly demanding and challenging caregiving responsibilities, some caregivers find it necessary to give up their career altogether. Although self-care and home care is believed to be more economic, humanistic, and beneficial in promoting independence, if the family caregivers cannot get by with working less or without paid work, caring for the persons with AD at home may be impossible. Institutional care will then be warranted (McDaid, 2001).

Coping with constant decline

Since AD is a progressive disease, the condition of the persons with AD is expected to decline constantly. Therefore, family caregivers need to cope with multiple losses related to the constant decline (Bar-David, 1999; Haley, 1997; Kuhn, 2001; McCarty, 1996). Study supports that if family caregivers engage in problem-solving strategies to manage the multiple losses, they are more able to cope (Kneebone & Martin, 2003).

Seeing the condition of the persons with AD deteriorating gradually, family caregivers may have the feeling of losing control and hopelessness (Sanders & Corley, 2003). Because of the fear of losing privacy, some family caregivers are reluctant to utilize the formal health care and social services. Incapability to cope often triggers family caregivers to access formal services necessary. However, they may grieve the loss
of privacy when they perceive the service providers, who assess their needs and provide
the service, invading their privacy (Sanders & Corley, 2003; Sawatzky & Fowler-Kerry,
2003).

Social isolation

Family caregivers are prone to social isolation (Duncan et al., 1994; George &
Gwyther, 1986). Social and emotional support from family and friends enable them to
cope with the stress and burden of caregiving (Almberg, et al., 1997; Butcher et al., 2001;
Haley, 1997; Lily et al., 2003; McCarty, 1996; Semple, 1992; Sterritt & Porkorny, 1998).
However, the persons with AD and the family caregivers are at high risk of social
isolation when caregiving leaves them no time to maintain regular social interaction with
other family members and friends (Lily et al., 2003).

Positive Caregiving Experience

Although caregiving is usually described as stressful and burdensome, more
recent studies show that family caregivers also experience positive feelings about
caregiving (Acton & Kang, 2001; Langner, 1995; Perry, 2002). Family caregivers have
expressed that they feel positive about caregiving when they are able to meet the needs of
the person with AD. The feeling of being able to provide quality care to their loved ones
enables them to find meaning in caregiving (Farran, et al., 1991; Narayan et al., 2001;
Langner, 1995).

The ability of family caregivers to find or create meaning in caregiving often
enables them to cope with the stress and burden of caregiving (Butcher et al., 2001;
Cohen et al., 2002; Langner, 1995; Paun, 2003; Farran, 1997; Farran et al., 1991). In
addition, some family caregivers may see the personality and behavioral changes of the
persons with AD a positive gain when the persons with AD become less volatile and stubborn (Ikel, 1998; Langner, 1995; Paun, 2003).

Some family caregivers claim that a positive previous relationship with the persons with AD has enabled them to take on the caregiving roles more willingly (Hoek & Tan, 1997). They indicate that memories of the good old times with the persons with AD lighten their feeling of stress and burden, enable them to create pleasurable moments in caregiving, and allow them to have a more positive attitude toward their caregiver roles (Butcher et al., 2001; Langner, 1995; Paun, 2003; Duncan & Morgan, 1994).

Some wives feel that, after years of marriage, they would understand their husbands so well that they are the best persons to be their husbands’ caregivers (Perry, 2002). They also claim that their love and lifelong friendship with the person with AD enables them to endure the stress of caregiving (Cassells, 2003).

Family caregivers have identified enjoyment, meaning, satisfaction, personal growth, and rewards as positive aspects of caregiving (Farran, 1997). A sense of satisfaction often indicates that their needs to support them to continue their caregiver roles are being met (Cohen et al., 2002). Feeling of satisfaction is often correlated with caregivers’ physical and mental well-being (Tarlow et al., 2004). Family caregivers often find feeling of companionship and a sense of duty lessens feelings of depression, burden, and poor self-rated health (Cohen et al., 2002).

Some family caregivers find spirituality enabling to cope with stress and burden of caregiving. The feeling of being connected to a higher power enables them to find meaning, peace, comfort, and purpose in life (Acton & Miller, 2003; Paun, 2004). Family caregivers’ intrinsic personal quality of self-efficacy and hardness often
empower them to endure the stress and burden of caregiving (Dibartolo, 2002; Fortinsky et al., 2002). They claim that if they can make sense out of the caregiving situation, they are better able to continue their caregiver roles with fewer problems (Duncan et al., 1994; Hasselkus, 1988; Langner, 1995; Paun, 2003).

**Daughter Caregivers**

Between men and women, women are the largest group of family caregivers. Among all the family caregivers, daughters are the largest group of caregivers (www.alzheimer.ca, 2003; Canadian Study of Health and Aging Working Group, 1994). In developing countries, including China, women usually stay home and take care of all members of the family. In developed countries like Canada, many women have paid jobs. However, whether the daughters stay home or work outside the house, often they are still expected to be the family caregivers. Many daughters who work outside the house often struggle to balance their caregiver roles with other competing roles, including wives, mothers, and daughters-in-law (www.alzheimer.ca, 2003; Canadian Study of Health and Aging Working Group, 1994; Gallicchio et al., 2002; Langner, 1995; Lynch-Sauer, 1990; McCann et al., 2000; National Profile of Family Caregivers in Canada, 2002).

To find more effective ways to support daughter caregivers, health care and social service providers need to understand how they cope with caregiving while balancing their other competing social roles (Chumbler et al., 2003; McCarty, 1996; Perry 2002). However, most studies on family caregiving were done on family or adult children caregivers as a group (Almberg, et al., 1997; Balwin, 2003; Berg-Weger, et al., 2003; Farran, et al., 1991; Gallicchio et al., 2002; Graham et al., 1997; Haley, 1997; Hepburn et
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al., 2001; Hirst, 2003; Kelley et al., 1999; Langner, 1995; Lynch-Sauer, 1990; McCann et al., 2000; Perry, 2004; Perry & Olshansky, 1996; Shaji, et al., 2003; Schulz et al., 2002; Wald et al., 2003), not many studies have focused on caregiving experience of daughter caregivers.

Although family caregivers have common caregiving experience, different caregivers may have individual and unique concerns. The concerns of one family member may not be the same as other family members (George & Gwyther, 1986; Semple, 1992). The research findings on one family role and relationship may not be transferable to daughter caregivers. For example, older retired spousal caregivers have the time but not the strength and health to provide care. In contrary, younger daughter caregivers, because of other competing role roles as wives and mothers, have the strength and health but not the time to care for their parents with AD. Daughter caregivers often find caregiving complex and dynamic.

Since AD is a progressive disease, caregiving is a complex and constantly changing process. During the process of caregiving, the needs of the persons with AD change constantly in response to the progressive deterioration of their cognition and condition. To ensure the changing needs of their mothers with AD are being met, daughter caregivers often find their caregiver roles changing overtime and the mother-daughter relationships negotiable (Ward-Griffith et al. 2005).

Daughters are the second largest group of caregivers, only second to spousal caregivers. When separating the spousal caregivers to wives and husbands, daughters are the largest caregiver group. However, studies that focus on exploring the caregiving experience of daughter caregivers have been conducted only recently. Little is known
Influences of Culture on Caregiving

Values and beliefs influence, not determine, how an individual perceives and responds to a given situation (McCarty, 1996). An individual's personal values and beliefs are influenced by the cultural background and the culture of the society. Culture is generally defined as a template for human behaviors and many conceptions of culture equate culture with ethnicity. However, this view of culture is problematic as it leads to the narrow view of culture as limited to the common values and beliefs shared by a particular ethnic group. In fact, evidence shows that considerable diversity of viewpoints, values, and beliefs existed in different ethno-cultural groups. Evidence also shows that people's decisions and actions in a given situation are influenced by ethnicity, life experience, history, and socio-economic context (Kirkham & Anderson, 2002). Therefore, there is a need to adopt a view of 'culture' that considers the historical and socio-economic context.

Influences of Society's General Attitude on Caregiving

The care of persons with AD is partly influenced by society's general attitude toward aging, AD, and caregiving (Chiu, 2001). For instance, studies show that, when they cannot explain the mood change or memory loss, some Chinese stigmatizes AD as a mental illness or as a possession by the evil spirits. With this misconception and stigmatization of AD, they may not consider seek medical attention when the persons with AD exhibit increasing memory loss and behavioral problems (Braun & Browne, 1998; Hoek & Tan, 1997; Zhan, 2004).
Studies show that the behavioral and mood problems exhibited by the persons with AD are often related to how they are being treated (Ikels, 1998; Kitwood, 1997; Kitwood & Brendin 1992). Influenced by the misconception and stigmatization of AD, instead of being seen as human beings with AD, persons with AD are at risk of being seen as the disease itself and being labeled as “demented persons.” When the persons with AD are being seen as the disease and as “demented” persons, their emotional needs are at risk of being ignored. Failure to see the persons with AD as the same persons who had AD, caregivers are at risk of overlooking the persons with AD’s right to choose, make decision, express feeling, and exert control over their own lives. While attending only their physical needs is considered necessary, attending to their psychological needs may be considered as least priority (Kitwood, 1997; Kitwood & Brendin, 1992).

The biomedical view of AD has historically been the predominant view of AD. As a consequence, resource allocations in dementia care has been skewed to finding a cure with much less funding being allocated to the care of the persons with AD (Kitwood, 1997). With comparatively much less funding to the care, the formal and informal caregivers often find it challenging to pay equal attention to both physical and emotional care. When caregivers need to choose, they often choose to attend to the physical care over the psychosocial care (Kitwood, 1997; Kitwood & Brendin, 1992).

*Conditions that Contribute to Inequities in Care*

It has been agreed that it is an obligation for the health care providers to meet the expectations of ensuring equitable care (Stubbs, 1993; Williams, 1996). Language barriers and insensitivity of the service providers have often been identified as barriers to accessing health care and social services. Not receiving the needed services have great
impacts on the nature of care the persons with AD received and the care outcomes (Ahmad, 1993; Anderson, 1990; Aranda, 2001; Lai et al., 2003; Stubbs, 1993; Zhan, 2004).

Braun and Browne (1998) found that Chinese-Americans often preferred having Chinese-speaking service providers. Service-recipients often prefer having services providers who speak the same language and are of the same cultural background to ensure their concerns and needs are being understood accurately and not being misunderstood (Anderson et al., 1997; Braun & Browne, 1998). Even if interpreters are available, they may be worried that their messages may not be accurately translated and lead to inadequate or inappropriate care being provided (Anderson et al., 1997).

Although many people of the same ethnic group have a similar cultural background, they may perceive, make decisions, and act in different ways in a given situation. How people make decisions and act in a given situation is also influenced by their social and material resources (Kirkham & Anderson, 2002). To provide health care and social services to meet individual needs, service providers and policy-makers need to view health and illness from the individuals' perspective, not solely through the eyes of the service providers (Stubbs, 1993).

Currently, most of the Canadian health and social services were developed according to the needs of European-Canadians. With the increasing numbers of different ethnic groups in Canada, their individual needs should be assessed. To promote health, prevent illness, and provide rehabilitation, equity in health and social services is important (Ahmad, 1993). If inequities in resource allocation among the minority groups continue, poorer health and lower socioeconomic status will likely continue (Kirkham &
A Case Study of a Chinese-Canadian Daughter Caregiving for her Mother with AD (Anderson, 2002). Therefore, it is necessary to examine the influences of the ethnicity, culture, and related social processes on health and illness (Ahmad, 1993). To ensure fairness and equity, new insights are needed to reform the service delivery.

Research on Cultural Influences on Caregiving

To ensure cost-effective services are available for family caregivers of different ethnic groups, policy makers, health care providers, and social services providers need to understand the notion of each caregiver having individual needs (Ahmad, 1993). Conducting research on cultural influences on caregiving is useful in exploring how culture influences caregiving of persons with AD (Powell, 2002).

Research that includes participants from different ethnicities, genders, and backgrounds is a systematic way to assess their needs and to evaluate the interventions being provided (Sandelowski, 1995a). For instance, acknowledging the trend of the aging population and the influences of culture on the health and health care of Canadians, the Canadian government has funded a national project to explore culturally-appropriate best practices for educating seniors and caregivers of different ethno-cultural origins on topics of healthy aging (National Advisory Council on Aging, 19996).

Although the number of immigrants from Asia, South America, and Africa is increasing, the volume of research exploring the cultural influences on family caregiving of persons with AD in North America is still limited. Although some studies have included family caregivers from different ethnic groups, most research did not focus on cultural influences on caregiving. Today, most research on family caregiving has focused on the caregiving experience of caregivers who are of European origin (Aranda, 2001; Chiu, 2001; Morimoto et al., 2003; Paun, 2003; Perry, 2002; Sterritt & Porkorny, 1998).
Only a few studies have been cultural-specific (Cox, 1993; Mintzer et al., 1992; Youn, et al., 2003).

To learn more about the needs of the persons with AD and their caregivers, ongoing research is needed to explore the cultural influences (Hinton, 2002). Research is needed to evaluate the effectiveness of existing services and interventions in supporting the caregivers (Youn et al., 2003). Further study is required to assess how socio-economic status and availability of social services influence caregiving (Braun & Browne, 1998; Lee & Farran, 2004).

Instead of the day-to-day caregiving experience, most of the studies exploring the influences of culture on caregiving were done to explore the rare or uncommon phenomena (Sterritt & Porkorny, 1998). However, a number of authors have challenged this notion of ethno-specific approach to understanding cultural influences on health care. This concept of minority groups having special needs is itself problematic as it promotes segregation of the minority groups and rationalizes inequity across different cultural groups (Kirkham & Anderson, 2002; Williams, 1996).

Cox (1993)'s study on Hispanic family caregivers in New York is an example of a cultural specific study that explores the influences of cultural context on caregiving experience. This study shows that Hispanic culture values respecting elders. While men are often authoritative, controlling, and possessive, women are often submissive and caring. Hispanic families often live with extended and multigenerational families. The younger generations are expected to provide physical and emotional support to their elders, who, in turn, are expected to look after the children and grandchildren (Cox, 1993).
With increasing burden from financial constrain, physical tasks of caregiving, lack of time for themselves, and social isolation, family caregivers often experience stress and burden related to caregiving. However, rather than receiving external support, the Hispanic family caregivers often prefer having support from their own family members. Not only they may feel guilty but also they may be reluctant to share familial information with the service providers, whom they see as the “outsiders,” when they seek external help (Cox, 1993).

Influences of Chinese Culture on Cargiving of Persons with AD

In response to the increasing number of older Asian-Americans and Chinese-Canadians, researchers have begun to study the influences of Chinese culture on the care of persons with AD (Chow et al., 2000; Lai et al., 2003; Zhan, 2004). In the US, Chinese-Americans are the largest group of Asian-Americans (Braun & Browne, 1998). In Canada, Chinese is the third largest ethnic group and the largest visible minority group (Lai et al., 2003; www.statcan, 2003). This number of Chinese-Canadians has included all the Chinese from Hong Kong, mainland China, and Taiwan as a group. However, although being considered as the same ethnic group, research shows that Chinese living in different countries, including China, Hong Kong, Singapore, US, and Canada, have different experiences of caregiving (Farran et al., 1997; Gonzalez, 1997; Janevic & Connell, 2001; McCann et al., 2000; Zhan, 2004).

There are nonetheless some influences that can be traced through history. Such influences include the Confucian philosophy that emphasizes harmony, unity, and family survival (Braun & Browne, 1998). Similar to many other cultures, Chinese value the relationships among family members. Members of the whole family are obligated to care
for the ill, the young, and the old (Loke et al., 2003; Mok et al., 2003). Traditionally, the
Chinese culture assigns roles to family members according to hierarchies of gender, birth
order, and age. While women usually take on subordinate roles to look after the
household chores and raise the children, men usually take on authoritative roles to look
after the family affairs and deal with external matters (Chiu & Zhang, 2000; Fung, 1998;
Lai et al., 2003).

Filial piety is a value perpetuated through the organization of Chinese society. It
is the expectation that younger generations are obligated to obey and respect their parents
and grandparents to show their gratitude to them for bringing them into the world and
raising them (Braun & Browne, 1998; Chiu & Zhang, 2000; Fung, 1998; Ikels, 1998; Lai
et al., 2003; Pang et al., 2002). In China, most Chinese with AD live at home with their
family caregivers (Chiu, 2001; Ikels, 1998). In addition to the Chinese government state
policy that requires adult children to look after their aging parents, the cultural values of
filial piety and the extended family living arrangement add on facilitating, enabling, and
demanding the adult children to care for the persons with AD at home (Ikel, 1998).

Chinese culture is characterized as valuing responding to unsolved problems by
enduring the consequences, avoiding further discussion, and not dwelling on the unsolved
issue (Braun & Browne, 1998). Chinese culture often places the whole family’s needs
above individual family member’s needs with the belief that any problem of the family
should be resolved within the family. Asking for external help is often considered as
admitting defeat and dishonor to not only the person asking for help but also the whole
family (Braun & Browne, 1998). Therefore, external help is sought only when absolutely
necessary. For instance, Chow et al. (2000) found that when the Chinese-Americans
asked for formal support, they usually sought financial assistance or case management only.

Lai et al. (2003) found that Chinese-Canadians usually have more than one family caregiver. They often live with or are very close to their extended family. They prefer caring for those who are chronically ill or dying at home (Fung et al., 2003). One of the benefits of an extended family living arrangement is someone is always there to look after the elders or the sick. Thus, even if the persons with AD require 24-hour care, family members may still be able to care for them at home.

Chinese and European cultures often perceive the memory and behavioral problems of AD differently. Instead of acknowledging the memory loss, functional decline, personality changes, and behavioral problems as the clinical presentations of AD, Chinese often normalize these problems as consequences of aging (Braun & Browne, 1998; Chiu, 2001; Zhan, 2004). In addition, if the memory loss and behavioral changes have resulted in the elders with AD loosing their household power and authority, the family caregivers may perceive these changes as positive (Braun & Browne, 1998).

Some Chinese, when unable to explain the behavioral and memory problems exhibited by the persons with AD, attribute the problems to an evil spirit possession. Misconception and unawareness of AD also result in association of AD with mental illness. Influenced by the stigmatization of AD as an evil spirit procession or a mental illness, family caregivers may feel ashamed to seek medical attention resulting in delays in medical assessment and diagnosis. This delay may, in turns, result in the persons with AD not receiving the care they need (Braun & Browne, 1998; Zhan, 2004).
Hoek and Tan (1997) explored the stress levels of Chinese family caregivers of persons with AD in Singapore, where AD is often seen as a shameful mental illness. The Chinese-Singapore family caregivers often consider seeking formal support as a sign of failing in their caregiving capacity. They prefer and rely more on family support than formal support. The hierarchy of family caregivers is: spouses, daughters, daughters-in-law, sons, and then sons-in-law. Similar to other research findings, women are the main family caregivers of persons with AD with daughters being the largest group and wives being the second largest group of family caregivers (Hoek & Tan, 1997).

Institutional care is less common in China than in Western society. Chiu and Zhang (2000) and Ikels (1998) found that family caregivers in China usually live with the person with AD. Spouses, mainly the wives, are the largest group of primary caregivers. Due to illness or death, when a spousal caregiver is not available, adult children usually take over the caregiving responsibility. Family caregivers either move the person with AD to their own home or move in with the person. When the family caregivers are not at home, the neighbors usually help keeping an eye on the persons with AD to ensure their safety and their needs are met (Ikels, 1998).

In China, if the persons with AD have no family and if they had worked in the past, their employers will assume responsibility for their care either by having paid caregivers at their homes or by moving them to institutional care. The government will be responsible only for those who have no family and have never worked outside the house (Ikels, 1998).

Compared to the Chinese in China, the influences of the Western culture is much stronger on the Chinese living in Hong Kong. This may be related to Hong Kong was a
British colony for about 100 years before 1997. In Hong Kong, the number of extended family living arrangement is decreasing while the number of nuclear families is increasing. Instead of living with their children and grandchildren, more elders are living by themselves. The traditional respect for the elders and feeling of obligation to filial piety are fading gradually (Chiu et al., 1998; Chiu & Zhang, 2000; Chung, 2000, cited in Chiu, 2001; Ikels, 1998).

The dense population, small living space, and the trend towards nuclear families have created conditions in which more and more elders with AD live in institutions instead of being cared for at home by family caregivers. Studies show that family caregivers in Hong Kong have a high incidence of caregiver stress. Although the number of persons with AD living institutions is increasing, the percentage of institutional care in Hong Kong is still much less than in the Western countries, such as US and Canada (Chiu et al., 1998; Chiu & Zhang, 2000; Chung, 2000, cited in Chiu, 2001; Ikels, 1998).

In Canada, even though the Chinese population is large and daughters are the largest group of female family caregivers, little attention has been paid to the Chinese-Canadian daughter caregivers. I am interested in exploring the influences of cultural social context on caregiving. Exploring the caregiving experience of this Chinese-Canadian daughter caring for her mother with AD will contribute to examining how ethnicity, culture, history, and socio-economic status influence caregiving.

**Summary**

Research indicates that majority of persons with AD are being cared for by their family caregivers during the course of their illness and that the support of family members is their main source of social support. Cultural values and beliefs influence but
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does not determine the views and actions of family caregivers in caring for persons with
AD. The views of the society on culture and ethnicity have influenced the allocation of
resources for supporting persons with AD and their caregivers. Viewing culture as the
same as ethnicity is a narrow view that has the risk of overlooking the influences of
socio-economic context on caregiving.

In this chapter, I have discussed literature relevant to Chinese-Canadian daughter
caring for her mother with AD. Literature that I have reviewed includes articles on
family caregivers of persons with AD, the experience of family caregiving, and the
cultural influences on family caregiving. By building on the strengths of previous
research and seeing where the case study may fill in the gaps in the current knowledge,
literature review is useful in directing how this case study is conducted.
CHAPTER III

METHODOLOGY

Introduction

Methodology is the theoretical and procedural orientation of a study. The method of the study describes how the researcher plans and conducts the research. In this chapter, I discuss the criteria used to determine why Perry's (2004) primary data is adequate and appropriate for this case study. I also discuss how I used the primary data to conduct a secondary analysis qualitative case study using narrative analysis as the analytical approach. The discussion includes the uses and limitations of qualitative research, secondary analysis, a case study, and narrative analysis. I explain how I obtained the primary data for the secondary analysis. I include a brief description of the primary study on the ethical considerations, recruitment of participants, data collection, data analysis, and research findings (Perry, 2004). I explain how I upheld the appropriate ethical standards to protect the participant from exploitation. I also discuss how I ensured rigor in this secondary analysis case study.

As already discussed in the introductory chapter, although the number of Chinese-Canadian daughter caregivers caring for their mothers with AD is increasing, little is known about their caregiving experience. I used a qualitative case study as this research approach as it is a useful research approach for exploring a phenomenon when little is known about it (Janevic & Connell, 2001; Paun, 2001; Polit & Hunglar; Stake, 1995; Yin, 1994). I chose this particular case to study because this Chinese-Canadian daughter's caregiving experience is complex and special. The examination of her
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caregiving experience allows an in-depth understanding and a greater insight into the care of person with AD (Kearney, 2001; Stake, 1995; Yin, 1994).

Perry's (2004) had not explored the influences of Chinese and Canadian cultures on this Chinese-Canadian daughter’s, Sau Ying (pseudonym), caregiving experience in the primary study. After reading the primary data, I found that the complexity of this particular daughter’s, caregiving experience might be attributed to her cultural and personal values and beliefs, and those of her family (Ahmad, 1993; McCarty, 1996). Sau Ying, her parents, and her siblings are Chinese-Canadians. She and her siblings were born in Hong Kong and the family moved to Canada when she was a teenager. The data on her caregiving experience of her mother who had AD was detailed and in-depth.

After reviewing the primary data, I found that the data is not only adequate but also appropriate for answering the research questions that explored how Chinese culture in a Canadian context had influenced Sau Ying’s caregiving experience (McArt & McDougal, 1985). The primary data had permitted me to undertake an in-depth exploration of how Sau Ying became the primary caregiver of her mother, to examine Sau Ying’s feelings about being her mother’s primary caregiver, and to make visible the ways she coped with her caregiving role while managing other competing roles as wife, mother, daughter, sibling, and career woman.

I used narrative analysis as the analytic approach because it allows for a meaningful, logical, and scientific understanding of the daughter’s caregiving experience (Coffey & Atkinsin, 1996; Poirier & Ayres, 1997; Sandelowski, 1991). Researchers who use narrative analysis, both descriptive and explanatory, insert only minimal influences on the narrators to encourage them to tell their past and present real life experience
A Case Study of a Chinese-Canadian Daughter Caregiving for her Mother with AD spontaneously in a naturalistic setting (Coffey & Atkinsin, 1996; Sandelowski, 1991). The narrators are encouraged to describe the actions, events, characters, settings, and story-lines by asking only open-ended questions to explore the phenomenon (Sandelowski, 1991; Stake, 1995).

**Theoretical Methodological Premises**

The discussion of the methodology of this case study includes the theoretical and methodological premises of a qualitative secondary analysis case study using narrative analysis as the approach for data analysis. The uses and limitations of qualitative research, case study, secondary analysis, and narrative analysis are discussed in details.

*Qualitative Research*

The purpose of conducting qualitative research is not to describe or to summarize the content of the data. Instead, the purpose is to analyze the data meaningfully to construct a theory that explains the events. Qualitative research allows social science and nursing researchers to explore in-depth the human experience of a social phenomenon when little is known about it (LoBiondo-Wood & Haber, 1998; Morse & Field, 1995; Reed, 1992). Using an induction approach, qualitative researcher develops or extends the theory of the phenomenon by analyzing the data obtained from the participants (Sandelowski, 1993).

The context of a qualitative study is part of the phenomenon. To observe how participants act and interact in the natural environment, the researcher usually conducts the study in a naturalistic setting. The data is usually obtained by interviewing and/or observing participants in the naturalistic environment. Sometimes, the researcher
conducts interviews or observation sessions on more than one occasion (Morse & Field, 1995; Stake, 1995; Szabo & Strang, 1997).

Perry’s data on this daughter’s caregiving experience is rich, deep, and meaningful for me to explore and answer the research questions of this case study. Perry (2004) used theoretical sampling to allow the participants to verify the emerging patterns and themes. She had recruited participants according to the themes that arise from previous interviews (Morse & Field, 1995; Sandelowski, 1995b).

During data analysis, qualitative researchers usually perform a member check by asking the participants or experts in the field to verify the emerging themes. From the emerging theme, the researchers construct a theory that describes or explains the phenomenon by induction (Morse & Field, 1995; Stake, 1995). To obtain the essence of all essential features and to gain a full picture of what has happened, what is happening, and what is going to happen, qualitative researchers must immerse themselves in the data (Morse & Field, 1995; Sandelowski, 1995b; Thorne et al., 1997). When I analyzed the data, I began by reading the transcript of Perry’s (2004) primary data line-by-line while assigning codes to the elements of the data. After categorizing the codes, I synthesized the elements into themes that explained the phenomenon.

Data analysis of a qualitative study is inevitably subjective. Researcher’s personal values, beliefs, and life experience unavoidably influences how the participant’s description of events and actions are interpreted. Personal bias of the researchers may be problematic if the bias leads to data misinterpretation and inaccurate research findings. On the other hand, if the researchers’ subjective feelings and thoughts allow for a fuller understanding of the phenomenon, then the researchers’ view will be beneficial to the
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qualitative study (Kearney, 2001). To minimize the possibility for misinterpretation and to prevent researchers from imposing any judgment of the participants’ actions, keeping an audit is a useful strategy (Ayres, 2000a; Poirier & Ayress, 1997; Mathieson & Barrie, 1998; Morse & Field, 1995; Sandelowaski, 1991; Stake, 1995). During the course of data collection and analysis, I have kept an audit trail to record my personal feelings and thoughts to prevent misinterpretation of the data.

Case Study

The purpose of conducting a case study is to explore fully the complexity of a case of special interest. Instead of generalizing the findings to other cases, the intention is to study in-depth a particular case (Stake, 1995). Through a process of inquiry, this approach allows the researcher to gain an in-depth insight into the participant’s thinking, feelings, actions taken, intention of actions, and context of the experience (Fritzgerald, 1999; Stake, 1995; Yin, 1994).

The researcher may select a typical or an atypical case for the case study (Stake, 1995). The case can be an entity or a series of entities. Each entity can be an individual, a family, an institute, or a unit (Hewitt-Taylor, 2002; Polit & Hunglar, 1999; Ragin & Becker, 1992; Stake, 1995; Twinn & Lee, 1997; Yin, 1994). The researcher studies a single entity when the case itself is extreme, unique, or particularly revelatory (Stake, 1995; Yin, 1994).

I chose this case because in the context of this Chinese-Canadian daughter’s family and cultural background caregiving, Sau Ying’s experience represented a unique, extraordinary, and revelatory case of family caregiving of a person with AD (Fritzgerald,
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1999; Polit & Hunglar, 1999; Stake, 1995; Yin, 1994). Studying the complexity of this case has contributed to the knowledge of family caregiving of persons with AD.

Secondary Analysis

I used Perry's (2004) primary data for secondary analysis to answer the research questions of this case study (McArt & McDougal, 1985; Thorne, 1994). Secondary analysis maximizes the use of the primary data (Szabo & Strang; 1997; Thorne, 1994). Without the need to recruit the participant to collect the data, I had saved the time and money for the data collection (Brown & Semradek, 1992; Jacobson et al., 1993; McArt & McDougal, 1985; Rew et al., 2000).

Besides saving the time and money in data collection, secondary analysis has the potential to lessen the burden on participants who may find re-telling their experience stressful (Szabo & Strang, 1997). Although some caregivers have positive caregiving experience (Acton & Kang, 2001; Farran, et al., 1991; Langner, 1995; Narayan et al., 2001; Perry, 2002), some find caregiving stressful and burdensome. They may feel narrating their caregiving experience distressful (Cassells, 2003; George & Gwyther, 1986; Hall et al., 1995; Tornatore & Grant, 2002).

Sources of the primary data depend on the nature and needs of the secondary research (Brown & Semradek, 1992; McArt & McDougal, 1985; Polit & Hunglar, 1999). Before using the primary data for a secondary analysis, the researcher must assess whether or not the primary data is appropriate and adequate to answer the research questions (Brown & Semradek, 1992; Jacobson et al., 1993; Hinds et al., 1997; Szabo & Strang, 1997). Perry (2004) had explored in-depth the caregiving experience of 19 daughters and daughters-in-law caring for their mothers or mothers-in-law who have AD.
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However, she had not explored the influences of cultural values and beliefs on the daughters' caregiving experience. After reviewing the primary data carefully, I determined that the data was adequate and appropriate to explore the phenomenon I was interested to study.

After having determined the primary data is suitable for secondary analysis, the researcher must seek permission to use the data from the primary researcher, archives, or agencies that own the primary data (Herron, 1989; Jacobson et al., 1993; McArt & McDougal, 1985). After I had decided to conduct this case study, I had obtained Perry's permission to use the primary data for secondary analysis.

**Narrative Analysis as the Approach to Data Analysis**

Perry (2004) used the constant comparative approach to analyze her data by constantly comparing the codes and categories emerged from the interviews (Strauss & Corbin, 1990). Since this case study is about the caregiving experience of only one daughter and the data had already been collected, it was inappropriate to use constant comparative as the analytical approach. However, narrative analysis was appropriate to analyze the data to induct a theory to explain Sau Ying's caregiving experience.

The story-telling approach in qualitative studies has become a useful research starting point for narrative data collection, interpretation, and analysis. Story-telling involves participants presenting their life story to the researcher spontaneously. The researcher then interprets the participants' everyday life stories in a scientific way (Sandelowski, 1991). Examples of research that use a story-telling approach are Abma's (1998) evaluation of a vocational rehabilitation project in a Holland mental hospital; Bottorff et al.'s (2000) examination of smoking behavior in postpartum mothers, and
Ayress's (2000a, 2000b) studies that explore the process and meaning of family caregiving.

A narrative analysis emphasizes the importance of understanding the phenomenon under studied from the point of view of the participants (Coffey & Atkinsin, 1996; Sandelowski, 1991). This approach allows the researcher to see the importance of the story from the story-teller's perspective, which would lead to the elucidation and interpretation of a theory (Mathieson & Barrie, 1998; Sandelowski, 1991).

Compared to the other research approaches, narrative analysis emphasizes the spontaneous telling of the stories with minimal influence from the interviewer or listener. The narrator selects the importance and sequences of events and determines how they describe the characteristics of the players (Sandelowski, 1991). Narrative is not a fiction. It is a real life story that has actually happened and been experienced (Sandelowski, 1991). It is a story with actions, events, characters, settings, and story-lines. It can be in the form of an oral or a written story told in words, paintings, sculptures, or performance. It can be gathered from the historical records or by recruiting participants to tell the story (Coffey & Atkinsin, 1996; Sandelowski, 1991).

The narratives arise from the subjective memory of the storyteller that captures the storyteller's past, present, and future experience of the phenomenon (Sandelowski, 1991). The narrators' repetitions and moments of silence in certain topics often indicate their subjective feeling about the topics. Repetitions often indicate a desire to emphasize the importance of events or themes, whereas, silence often suggests an intention to avoid topics that the narrator feels unsure of or uncomfortable to share with others. To gain more insight into the Sau Ying's subjective life experience, I was sensitive to the themes
that she wanted to share and to the topics that she wanted to avoid (Mathieson & Barrie, 1998; Poirier & Ayres, 1997; Sandelowski, 1991).

The story told by the story-teller is affected by the history, culture, and current social context. The story-teller’s present emotion and contextual experience influence the manner in which the story is told. The story-tellers’ life experience, values, beliefs, and perspectives on the life events and characters affect how the life story is narrated. A given story-teller, for example, may tell the same story with different emotions and perspectives each time the story is told (Coffey & Atkinsin, 1996; Sandelowski, 1991). On the other hand, one event, if told by a different story-teller, will be told with a different perspective (Coffey & Atkinsin, 1996; Sandelowski, 1991).

For this case study, after reading the transcript of Sau Ying’s story, I attempted to see how the past, present, future, as well as, the involved players, culture, and social contexts come together to create the narrative (Coffey & Atkinsin, 1996; Sandelowski, 1991). I used narrative analysis to create a meaningful and logical understanding of her story (Coffey & Atkinsin, 1996; Poirier & Ayres, 1997; Sandelowski, 1991). I was sensitive to not only her spoken but also her unspoken and indirect messages by paying attention to her tone of voice, choice of words, and sequence of events being told (Poirier & Ayres, 1997).

Narrative analysis can be descriptive or explanatory. In descriptive analysis, the researcher describes the story as told. In explanatory analysis, the researcher tries to find out why and how the events had happened and are happening (Sandelowski, 1991). Since the purpose of conducting this case study is to gain an insight into Sau Ying’s
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caregiving experience, I used explanatory analysis to explore her reasons for becoming her mother’s primary caregiver and how she managed her caregiver role.

**Method**

After discussing the theoretical premises of the methodology for this qualitative secondary analysis case study using narrative analytic approach for data analysis, I now describe the method of conducting the data for this case study and how I proceeded in carrying out the research project.

**Selection of the Case**

One of the requirements for a Master of Science in Nursing is to conduct a research project as part of my thesis. I discussed my interest in dementia care with Dr. Perry who is the Chair of my thesis committee. Previous research supports having a researcher, who is of the same race, peaks the same language, and understands the needs and experience of the participant, an advantage in research on cultural influences (Ahmad, 1993; Aranda, 2001; Kirkham & Anderson, 2002; Stubbs, 1993). Considering my Chinese-Canadian cultural background and my interest area, we decided to conduct a secondary analysis qualitative case study to explore a Chinese-Canadian daughter’s caregiving experience. Dr Perry gave me permission to use the data from her study of daughter caregivers of mothers (Perry, 2004) to conduct this case study.

After reviewing Perry’s (2004) primary data, I found this daughter’s caregiving experience complex and unique. The data was adequate and appropriate for exploring the influences of the traditional Chinese and the Canadian values and beliefs. In particular, the data was sufficient to understand how this daughter became her mother’s primary
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caregiver, how she managed her caregiving roles and other roles in life, how she kept her family together, and how she felt about being her mother’s primary caregiver.

In considering the context of caregiving, Sau Ying’s caregiving experience is extraordinary and complex. She emigrated from Hong Kong to the Pacific Northwest region of Canada with her parents and siblings when she was in her teens. She and her siblings were educated in both China and in Canada. While her parents held strong traditional Chinese cultural values and beliefs, her values and beliefs and those of her siblings were influenced by both the Chinese and Canadian cultures.

After a preliminary literature review, I found that although the number of Chinese-Canadian daughter caregivers is increasing, little is known about this specific phenomenon. Since Perry (2004)’s primary data is appropriate and adequate to answer the research questions of this case study, I decided to conduct a qualitative case study to explore in-depth the caregiving experience of Sau Ying caring for her mother who had AD via using a cultural lens.

Obtaining the Data

Before using Perry’s (2004) primary data, I had asked Dr. Perry for permission. Only after I had her permission, I proceeded with this case study research. I do not need the ethical approval from the Institutional Ethics Review Board (IERB) because the daughter had previously signed a consent form for giving her permission to use the data for further research and education purposes, thereby meeting the council policy guidelines criteria and standards for research with human study. For more information on how Perry obtained the IERB approval and how she collected the primary data, please refer to the primary study (Perry, 2004).
Ensuring the Quality

Instead of generalizing the findings to all other cases of Chinese-Canadian daughter caregivers, the purpose of conducting this case study is to gain an in-depth understanding of this daughter’s caregiving experience. When conducting a research, strategies must be in place to ensure the quality of the study to ensure accurate interpretation of the data and to prevent inaccurate research findings and conclusions. The four primary determinants of quality in a qualitative case study include: credibility or truth value, transferability or applicability, consistency, and neutrality (Lincoln & Guba, 1985; Stake, 1995; Yin, 1994).

Credibility or trustworthiness

To ensure credibility, every perspective of the daughter’s story must be portrayed fairly (Yin, 1994). When reading the transcript of the primary data, I was sensitive to Sau Ying’s spoken and unspoken messages (Poirier & Ayres, 1997). I was aware that my subjective feeling, life experience, values, and beliefs would inevitably influence my interpretation of the data and, subsequently, the research findings. However, under no circumstances, I could judge if Sau Ying’s caregiving experience was right or wrong. I took steps to prevent my preconceptions from imposing any judgment on Sau Ying’s actions and feelings by keeping an audit trail to record my thoughts and feelings during the course of data analysis (Stake, 1995; Yin, 1994).

As suggested by Acton and Miller (2003) and Stake (1995), conducting member check by presenting the findings to the participants or to experts in the field for affirmation of the findings is an effective way to prevent misinterpretations of the data. Since I had no access to Sau Ying, I presented the research findings to the primary
researcher and the thesis committee for a member check (Sandelowski, 1993; Stake, 1995; Szabo & Strang, 1997).

Transferability or applicability

Transferability or applicability of a study is defined as the limit to which the research findings can be applied to other cases. Transferability of a qualitative case study to other cases depends on the context. The research findings of this case study could only be applied to other Chinese-Canadian daughter caregivers when the context of the caregiving experience is similar (Hewitt-Taylor, 2002; Stake, 1995; Yin, 1994).

Interviewing participants in the natural environment where the phenomenon under studied is taken place is an effective strategy to enhance the transferability. Sufficient information must be included about the participant’s the participant’s occupation, other competing social roles, and socio-economic status to allow the readers to decide if applying this case to another situation is appropriate (Acton & Miller, 2003). Perry (2004) interviewed this Chinese-Canadian daughter caregiver at her home where she lived with her mother who had AD. The primary data also included information about the daughter’s social and family background.

Consistency

Ensuring consistency is important when conducting a qualitative case study (Lincoln & Guba, 1985; Morse & Field, 1995). However, human experience in any situation is unique. The research findings are expected to be different if other researchers repeat the same study with different participants. To ensure consistency, the researcher can keep an audit trail to establish and enhance the consistency of the qualitative research. Keeping a personal journal to record my personal feelings and thoughts during
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Data analysis served as the audit trail to ensure consistency of this case study (Lincoln & Guba, 1985; Szabo & Strang, 1997).

Neutrality

Prolonged contact with the participant is a useful strategy to ensure the neutrality or conformability of the research study as it helps to ensure the research findings are inducted from the data directly. Perry's contact with Sau Ying was adequate as she had interviewed this daughter on two occasions for two to three hours each session. The data on Sau Ying's caregiving experience was in-depth and details.

Credibility and reliability of secondary analysis

Credibility of a secondary analysis depends on the reliability of the primary study's data collection and data entry (Herron, 1989). A well-trained interviewer enhances the reliability and validity of the primary data (Jacobson et al., 1993; Hinds, 1997). To determine if Perry's (2004) primary data was appropriate for this case study, I had reviewed and critiqued the primary study's research method and data collection procedure. I was satisfied of the credibility, validity, and reliability of Perry's (2004) study (Brown & Semradek, 1992; Jacobson et al., 1993; Hinds, 1997; McArt & McDougal, 1985).

Using Narrative Analysis as the Analytical Approach

Perry (2004) used the constant comparative method described by Strauss and Corbin (1990) to analyze the primary study. Perry (2004) began data analysis by reading the transcript line-by-line and assigning codes to the data. She then categorized the codes into common themes. Since this case study is about only one person, the same approach
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for data analysis is not applicable. Instead, I used the narrative analysis approach to analyze the primary data.

During data analysis, my personal values, beliefs, and life experience had inevitably influenced my interpretation of the data (Stake, 1995; Yin, 1991). Although my cultural background is similar to Sau Ying's, we also had many differences in our personal and family backgrounds. We both were born and raised in Hong Kong. Our mothers were housewives who brought us up. Both our fathers worked outside the house to support our families. We both received education in Hong Kong and Canada. However, while Sau Ying came to Canada when she was a teenager, I came to Canada after I had worked as an RN for more than 14 years. While she was the eldest daughter, I was the second youngest. My parents did not have AD. I had not been my parents' caregiver because they both died after a brief illness. Also, while Sau Ying had a supportive husband, I am single.

Because of our differences in life experience and socio-economic backgrounds, Sau Ying and I have similarities and differences in our views and opinions on caregiving (Mathieson & Barrie, 1998; Sandelowski, 1991; Stake, 1995; Yin, 1991). I prevented my own bias from misinterpreting the data by keeping an audit trail to record my thoughts and feeling during data analysis. Constantly reflecting on and recording my feelings and thoughts had helped to prevent my own biases from imposing any judgment on Sau Ying's caregiving experience (Ayres, 2000a; Poirier & Ayress, 1997).

To proceed with the narrative analysis, my first step was to read the story several times. Researchers have termed this first step of narrative analysis as "over-reading". The purpose of over-reading is to gain a full understanding of the plot and to assign
meaning to the events. Over-reading allows the researcher to analyze the narrative
directly from what has been told explicitly and implicitly (Ayres, 2000a; Poirier & Ayres,

The ultimate goal of data analysis is to induct the theory that explains the past,
present, and future events (Bottorff et al., 2000). When re-reading the story line-by-line,
I assigned codes to elements of the data while paying attention to both the spoken and
unspoken message. After I had completed assigning codes to elements of the data, I
categorized the codes to identify important components. I then related and linked the
codes and the categories together to find common themes of the story.

The purpose of conducting this case study was not to describe or summarize the
content of Sau Ying’s story only. Instead, the intention was to interpret the underlying
meaning of her caregiving experience. Using narrative analytical approach, I explored
the complexity of Sau Ying’s caregiving experience by examining in-depth what it meant
to be the Chinese-Canadian daughter caregiver of a mother with AD (Kearney, 2001;

To gain a comprehensive understanding of the situation, I gained an overview of
what had happened and what was happening by paying attention to the content of Sau
Ying’s story and how she told her story. Understanding Sau Ying’s verbal and non-
verbal messages enabled me to have a better insight into her underlying feelings,
thoughts, emotions, and expectations of the events and actions (Ayres, 2000a; Ayres,
2000b; Bottorff et al., 2000; Poirier & Ayres, 1997; Sandelowski, 1991). However, since
I was not the interviewer, I could not assess Sau Ying’s body language in person at the
time when she told her story. Instead, I assessed how she told her story by paying
attention to her choice of words, repetitions, omissions, silence, and inconsistencies of her story. Inconsistencies and conflicting messages of Sau Ying’s story might be indications of her feelings of confusion, uncertainty, or conflicting emotions about the events, actions, and people involved (Ayres, 2000a; Clark & Standard, 1997; Poirier & Ayres, 1997; Sandelowski, 1991).

**Limitations**

Since this case study explored only one Chinese-Canadian daughter’s caregiving experience caring for her mother who had AD, the main limitation is credibility. I ensured credibility of this case study by making sure the research findings arose directly from the data of Sau Ying’s story. As discussed earlier, my own subjective feelings, values, and beliefs inevitably influenced my interpretation of the data of this qualitative case study. However, keeping an audit trail to guard against misinterpretation of the data was a useful strategy to enhance the credibility of this case study (Stake, 1995; Yin, 1994).

Exploring only one daughter’s caregiving experience led to generalization of the research findings to other cases being questionable. However, the purpose of conducting this research was not to generalize the findings to all Chinese-Canadian daughters caring for their mothers. Instead, the intention was to gain an in-depth understanding of this Chinese-Canadian daughter’s caregiving experience (Stake, 1995; Yin, 1994). The research findings of this case study are appropriate for naturalistic generalizations when the context of the phenomenon is similar (Hewitt-Taylor, 2002; Sandelowski, 1996; Stake, 1995). Stake (1995) terms generalization of a case study, instead of a “grand
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generalization”, a “modified or a petite generalization” in which certain findings may be applicable to other cases and situations when the context is similar.

Having no control or involvement in data collection had limited my insight into the data and increased risk of misinterpretation (Jacobson et al., 1993; Szabo & Strang, 1997). However, I had access to the primary researcher who had clarified my concerns and questions about the primary study’s methodology and data to guard against data misinterpretation (Jacobson et al., 1993; Hinds, 1997; Szabo & Strang, 1997; Thorne, 1994). Paying attention to Sau Ying’s spoken and unspoken messages, such as choice of words and sequences of the events being told, had also limited the possibility of data misinterpretation (Mathieson & Barrie, 1998; Poirier & Ayres, 1997; Sandelowski, 1991).

Another limitation of this case study is related to the lack of access to the participant. During data analysis, I would identify different categories that I was interested to explore. However, even if I was interested to explore a particular category, I could not pursue further if the primary data did not have adequate information for the further exploration (Hinds et al., 1997; Liken, 2001; Szabo & Strang, 1997).

**Ethical Considerations**

When conducting research involving human subjects, the researcher must uphold ethical principles at all times to protect the participant(s) from any harm (Kavanaugh & Ayress, 1998; Thorne, 1994). The first step is to submit the research proposal to the Institutional Ethical Review Board (IERB) for review and approval. However, for this secondary case study, no ethical approval is needed from the IERB.
Perry (2004) had the approval of the IERB before recruiting the primary study participants. Participation in the study was completely voluntary. Under the research code, the researcher cannot contact participants directly without the permission of the participants. A third party known to both the researcher and the potential participants is needed. Perry (2004) contacted the participants after they had given their permission to be contacted through the third party.

Before the interviews began, Perry (2004) explained to the participants in details the purposes and process of the research. She began data collection after the participants had signed the written consent. Since the purpose of this case study was to expand the findings of the primary study, the scope of this study was within that of the consent given in the primary study (McArt & McDougal, 1985). Readers can find details of how Perry ensured the ethical considerations from Perry’s (2004) study.

Ensuring confidentiality of the participants is essential for protecting them from any harm or exploitation (Yin, 1994). The means by which Perry (2004) safeguarded the confidentiality of the participants is described in the primary study. For this case study, since the primary data had already been coded, the identification of the daughter was kept confidential to me. Nevertheless, when presenting this case study, I must ensure Sau Ying’s confidentiality by being cautious when disclosing her demographic information. In the report, I have altered some of the demographic and social information of Sau Ying and her family, such as names, occupation, family background, and place of residency.

Summary

Methodology is concerned with the theoretical and procedural orientation of a study. The method of the study involves how the researcher conducts the research. In
this chapter, I have discussed the uses, advantages, and limitations of qualitative research, case study, secondary analysis, and narrative analysis. I have discussed how I ensured the quality and credibility of this case study. I have also discussed the approach for analyzing the data and presenting the case. Lastly, I have discussed the limitations of this case study and how I adhered to the ethical principles to protect the participant from exploitation. In the next chapter, I will discuss the data analysis and the research findings.

As a Chinese-Canadian, my own values and beliefs had enabled me to be more sensitive to the experiences of the Chinese-Canadian daughter caregiver in this case study. My previous experience working with persons with AD and family caregivers in both Hong Kong and Canada permitted me to have more insight and a deeper understanding of Sau Ying’s caregiving experience. However, my values, beliefs, and life experience had also potentially blindfolded me to create biases resulting in misinterpretation of the data and in correct induction of the research findings. To ensure the rigor and accuracy of this case study, I had kept an audit trail to document my subjective opinions, feelings, and biases during the course of conducting this case study research (Morse & Field, 1995; Polit & Hungler, 1999).
CHAPTER IV

DATA ANALYSIS AND RESEARCH FINDINGS

Introduction

In this chapter, I present and discuss the research findings I have examined using a narrative analytical approach. In analyzing the primary data, I examined and explored how culture influenced the caregiving experience of this Chinese-Canadian daughter, Sau Ying (pseudonym). The data is obtained from the transcripts of Sau Ying’s two interviews acquired from the primary study (Perry, 2004). These two narrative interviews were concerned with Sau Ying’s perspectives of how she, her father, her siblings, her husband, and her other family members felt about and coped with issues related to her mother’s care.

I begin this chapter with a brief summary of the process and outcomes of Sau Ying’s caregiving experience of her mother who has AD. An overview of this process is illustrated in Figure 1. Subsequent to this, I discuss how the traditional Chinese and the Canadian cultures influence Sau Ying’s caregiving experience, using quotations from the narrative interviews.

I present the research findings using a narrative story-telling style. In the beginning of the story, I introduce the cultural background of Sau Ying and her family and their relationships. As the story unfolded, Sau Ying and her family began encountering a succession of challenges related to caregiving when her mother’s cognition and abilities to function were affected by AD. These challenges resulted in Sau Ying’s feeling of increasing tension over time as she perceived her father failing to
provide the care that her mother needed. The story reached its climax when Sau Ying’s feeling of tension increased to beyond her tolerance level. Following this point, I present her resolutions of the crisis. To conclude Sau Ying’s story, I discuss how the caregiving experience led her to redefine her personal values and to create a new meaning for the future.
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Figure 1. The Process and Outcomes of a Chinese-Canadian daughter's Caregiving Experience of her Mother who had AD

Confirmation of her father abusing her mother with AD

Redefining personal and family values

Creating meaning for future

Sau Ying introduced herself

Sau Ying described her mother

Sau Ying described her family

Sau Ying's narratives began

Sau Ying's attempts to support her father being the caregiver of her mother who had AD

Mother deteriorating

Sau Ying being the caregiver of her mother with the support of her family and her siblings

Mother improving

Moving toward harmony

Feeling of Tension

Chinese Culture

Filial Piety

Gender Role

Canadian Culture
Interpretation of the Data using the Narrative Analysis Approach

The purpose of conducting this case study is to explore, describe, and explain the influences of culture on Sau Ying’s caregiving experience of her mother who had AD. Narrative analysis is used to analyze the story content and the way in which Sau Ying told her story. In the analysis, I took into account her subjective feelings, as well as her evaluation of the events and people involved. Throughout the analysis, I sought to consider not only her spoken but also her unspoken message when she spoke about her mother, family, other people involved, events, and her feelings. When reading the transcripts, I had paid attention to her unspoken message by considering how she told her story by her use of words, pauses, repetitions, and avoidance of events (Mathieson & Barrie, 1998; Sandelowski, 1991).

I explored Sau Ying’s caregiving experience by reflecting on the influences and limitations of both the Chinese and Canadian cultural values and beliefs on her caregiving experience. Clearly, not only culture but also the socio-economic context had influenced how Sau Ying responded to her mother having AD, how her father cared for her mother, how she made decision to take over the primary caregiver role, how she cared for her mother, how she felt about being the caregiver, how she drew upon her family’s support to cope with caregiving, and what she had learnt from the experience.

An Overview of the Process and Outcomes of Sau Ying’s Caregiving Experience

This case study explored how culture influenced the caregiving experience of Sau Ying, a Chinese-Canadian daughter, in caring for her mother who had AD. The research findings are illustrated in Figure 1.
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When her mother’s cognition was affected by AD and caregiving was needed, Sau Ying and her family experienced the emergence and resolutions of a series of challenges to their Chinese cultural values and beliefs, particularly the gender roles in marriage and filial piety. These challenges resulted in Sau Ying’s feeling of increasing tension from the time when AD was diagnosed, to when her father became the primary caregiver, to the rapid deterioration of her mother’s condition, and finally, to her perception of a crisis situation when her father’s abusive behaviors toward her mother were confirmed.

When Sau Ying confirmed what Lin (pseudonym), her mother’s paid caregiver, said about her father’s abusive behaviors toward her mother was true, her feeling of tension reached to beyond the limits. She perceived her mother being in a life and death situation. Feeling obligated to live up to the Chinese values and beliefs of filial piety to both of her parents, she took over her mother’s care without having any confrontation with her father. After taking over the primary caregiver role, Sau Ying sought to provide her mother with loving care while maintaining her family’s relationship with her father and keeping the family unity intact.

With the support of her own family and her siblings, Sau Ying managed to cope with her primary caregiver role. Her feeling of tension decreased and eventually resolved when her mother’s condition improved and her family relationships became stronger and closer. Influenced by her caregiving experience, Sau Ying had redefined her personal values and beliefs in the gender role in marriage, filial piety, and family values. Not wanting to experience what her mother had been through, she created a meaning for the future to have complete control over her own life with advance planning for the future.
The Beginning of Sau Ying's Caregiving Story

In the primary study, the interviewer began the first interview with Sau Ying by asking her “to start with a little bit of a run down from the beginning” to know more about her family, her mother, and Sau Ying. By knowing who the family was, who her mother was, and who Sau Ying was, a fuller understanding of her caregiving experience could be obtained.

Sau Ying Described the Family

Sau Ying began her story of caregiving from the point when her family immigrated to Canada from Hong Kong. When she was a teenager, her father planned to send her, the eldest of the four siblings, to Canada for secondary education. Eventually, instead of sending one child at a time to Canada, he was convinced by the immigration officer to move the whole family to the new country. When the family moved, her father kept his business in Hong Kong. Thus, he needed to go back to Hong Kong to attend to his business from time to time. This pattern continued for years until he retired.

Sau Ying Described her Mother

Sau Ying described her father as the head of the family, making all of the family decisions. On the other hand, she described her mother as an obedient wife and a devoted mother who had raised Sau Ying and her siblings all by herself:

she did it all, raising the kids, the physical work, my father do other things, every Sunday he take us all out, we appreciate that because we have learned a lot of fathers doesn't do that

After years of being an obedient housewife, her mother had the opportunity to work outside the house. When her father opened a store in Canada, he asked her mother to help with the business. For the first time in her life, Sau Ying’s mother made
independent business decisions whenever Sau Ying’s father attended business in Hong Kong. Sau Ying felt that those were the happiest days in her mother’s life. She felt that her mother had enjoyed her work and social life very much.

When Sau Ying and her siblings finished schooling and left home, her father decided to retire and to enjoy life. He sold his business and moved back to Hong Kong with Sau Ying’s mother. Since he had always made the decisions for her mother, he made the decision without discussing with her to find out if this was what she wanted. Sau Ying felt that her mother would have preferred staying with her and her siblings in Canada. However, she knew that her mother had limited control over her life, “My mum has absolutely no control over things like that,” because her father was “a control freak... always controlled mum.” After her parents retired and moved back to Hong Kong, they began traveling the world spending less than six months in Canada every year.

**Sau Ying Introduces Herself**

Sau Ying had lived and been educated in both Hong Kong and Canada. Her values and beliefs were influenced by both Chinese and Canadian cultures. Having taken up values or practice in the Canadian context, while her parents had strong beliefs and values in the Chinese gender role in marriage, she had a different view about marital relationship. She believed in equality and disagreed with the Chinese cultural view of husbands’ position being higher than that of the wives’. She also disapproved wives’ obligation to obey their husbands. She believed in husbands and wives having equal responsibilities for such things as household chores and bringing up the children together.

Unlike her parents, Sau Ying and her husband were partners and played equal roles in the family. They both had full-time jobs and they provided hands-on care to their
children. They hired a nanny to assist with the household chores and the care of their children, “I would say my husband plays just as big a role as me in the house.” Although Sau Ying felt it unfair and felt sorry for her mother having little control over her own life, as their daughter, she accepted her parents’ marital relationships.

Sau Ying’s Story Continued: Delineating her Dilemma

After being interviewed and having introduced her family, her mother, and herself, Sau Ying continued with her caregiving story. She went on to recite times when she first recalled seeing her mother’s memory, behaviors, and mood changing and deteriorating gradually.

Mother Began to Show Signs of AD

Sau Ying recalled that, after her parents’ retirement, she began seeing her mother’s memory deteriorate gradually. However, no-one in the family had paid much attention to the changes at the beginning, “Mum got a little stop watch… She seemed to get confused… We noticed it but nobody thought much of it.” She also noticed her father’s increasing impatience and rudeness toward her mother, “Dad just picked on her about everything.” She saw her mother fighting back and her parents’ relationship deteriorated. As time went by, she found her mother becoming quieter and quieter. Eventually, her mother stopped fighting back.

Since her father had always been a controlling husband, and her mother had always been an obedient wife, Sau Ying was not surprised to see him become increasingly impatient and rude to her mother. Although she resented the way her father was treating her mother, she was not alarmed that her parents’ marital relationship was different than it was before. Although her mother became quieter and forgetful, Sau Ying
did not suspect that her mother was sick. Sau Ying did not ask her father why he was increasingly impatient to her mother. She had no idea that her father was impatient with her mother’s progressive cognitive deterioration when AD began affecting her cognition.

Although Sau Ying was used to seeing her father treating her mother rudely, she could not help but feel resentful about it. Believing in equality in a marital relationship, she disagreed with the way her father was treating her mother. Eventually, she found her father’s attitude toward her mother intolerable. Although she realized that traditional Chinese couples rarely divorced or separated, she suggested her mother to leave her father. As expected, her mother refused to leave her father, “[Mother] said why do I want a divorce now at this age, that's how your father is and I just fight back and well that's a healthy attitude.”

Over time, Sau Ying noticed how her mother’s memory worsened until she seemed to have no memory at all, “…noticed something is wrong… How come mum cannot remember anything?” She began having increasing concerns of her mother’s progressive cognitive impairment. Since Sau Ying had never heard of AD, she did not suspect that AD was affecting her mother until she read an article about AD in a Chinese magazine.

After reading the article, Sau Ying realized that her mother might have AD. Immediately, she shared the information with her family and they sought medical treatment. Nevertheless, Sau Ying and her family were disappointed when the family doctor, instead of ordering tests and prescribing a treatment, told them that AD was incurable and they should just be nice to her. The whole family found it difficult to accept that no treatment was available. They found it hard to cope with AD.
Father became the Caregiver

Sau Ying’s father had always believed that “if there's a problem, there is a solution to solve the problem.” After her mother was given the diagnosis of AD, Sau Ying found her father unable to accept AD being incurable. He was on a mission to find a cure. When the family doctor told him that the Western medicine had no cure for AD, he made her mother try on herbal medicine.

Sau Ying began feeling some tension when her father dragged her mother to different places to try alternative Chinese medicines and ignored her mother’s response to the therapy, “Drag mum everywhere to look for a cure, oh acupuncture, acupressure, medicine, you name it, father did it for one year.” Although not complaining in words, she felt that her mother was suffering. For instance, her mother was in tears when she went through the testing at the AD clinic. She was upset when her father made her mother swallow the horrible-tasting herbal medicine, even when the medication had made her mother throw up.

Sau Ying’s mother was unable to manage her life independently when her cognition and abilities to function deteriorated gradually. When her mother needed to be cared for, her father took on the caregiver role. However, the Chinese gender role in marriage had a strong influence on his ability and willingness to be a caregiver. Being her mother’s caregiver, he had taken on a role that was usually performed by the females in the Chinese culture. He was not prepared nor expected to be her mother’s caregiver:

father realized he become the caregiver and he try, ...he doesn't really know how to take care of woman ... so mum start to look really bad and he wouldn't put anything color co-ordination.
Consequently, he and the family began encountering a succession of challenges in the care of her mother.

As a Chinese man who upheld the Chinese cultural values and beliefs, her father had always expected to “be served and helped by his mother, and then by his wife.” Sau Ying found him unable to cope with caregiving because “he did not really know how to play the different role.” Although he had tried to cope with his caregiver role by attending Chinese-Canadian caregivers support group meetings, her father did not get the support he needed. He was “the only husband” at the meetings when all the other caregivers were wives, daughters, or daughters-in-law. He had told Sau Ying that no-one in the group understood the issues and concerns he encountered. He continued to believe that caregiving was “a woman's job... What are you [all the other female caregivers] complaining about?”

Sau Ying felt that her father was a selfish man, “He's just a very selfish man ... It's just him, him, him.” She found her father provided care to her according to what he wanted for her, not what her mother needed. Instead of slowing his life down to accommodate her mother’s cognitive impairment, her father continued to travel with her mother constantly. However, Sau Ying felt that the constant traveling and the crowded environment in Hong Kong were too overwhelming for her mother. She found her mother’s condition worsened every time she returned to Canada. In addition, Sau Ying felt that her father was not concerned about her mother’s rapid deterioration, “Father was very selfish, no understanding, he felt that he was already the best husband in the world.” Seeing her mother’s condition deteriorating, Ying’s feeling of tension increased.
Sau Ying felt that culture had influenced her mother’s care. She felt sorry for her mother because her mother was the one who had AD. She had the belief that if her father was the one who had AD, her mother would have taken very good care of him, “With the culture ... people like my mum really suffer.... But mum would have taken care of him.” Moreover, compared to Chinese husbands, Sau Ying felt that Caucasian husbands seemed to be more willing and capable to care for their wives, “I can see more examples of Caucasian... husbands ... trying to take care of their wives.... I don't know of any case... of a Chinese husband.”

**Rapid Deterioration of her Mother**

Sau Ying felt that the inadequate care provided by her father had contributed to her mother’s deterioration. She believed that her father had made her mother worse than AD had, “He's the one contributing to her deterioration... She looked much worse than what she actually is.” Sau Ying’s feeling of tension increased when she saw her father being increasingly rude and impatient with her mother.

Sau Ying felt that her father did not really care about her mother’s miserable, unhappy, and depressed condition. She felt that her father had not done his best to protect her mother and ensure her safety. She was concerned about her mother’s safety when her father had once almost lost her mother in a foreign country during a trip oversea. Her mother had also got lost many times in her own neighborhood.

**Sau Ying’s Attempts to Support her Father’s Caregiver Role**

Sau Ying’s feeling of tension increased when she saw her father having “absolutely no patience and pushing her [mother] around.” With a strong belief in filial piety, however, she found herself facing a dilemma. She felt obliged to “respect and be
good to [her] parents and support [her] parents later on.” On one hand, she felt obliged to respect and obey her father, “never talk back... a blind faith.” On the other hand, she also felt obliged to ensure her mother was being cared for with love and respect. How could she respect and obey her father when he was the one who was ill-treating her?

We all resent him so much by the way he badger mum ... causing so much trouble for her, we already know he's not nice and not good but what can we say... in Chinese you don't talk back to your parents, you're not allowed.

How could she ensure that her mother would receive loving care without having to confront her father?

I would never have a big fight with my father, no matter how, as much as I resent him... I won't tell him, ... I'm not allowed, we're not allowed to do that with your parents ... you kind of keep to yourself...if you want to blow the whole thing out of proportion, what do I get out of it, so mother get ....angry at me.. he won't want to come and see my mum hurting mum... Then I feel guilty, I guess as you get older you learn all these things.

Sau Ying felt obliged to ensure her mother’s safety and receiving the care she needed. Without challenging her father’s caregiver role, she suggested her father to hire a paid caregiver to assist with the hands-on physical care as, she put it, “It’s not working out... We better have somebody take care of her... Mum needs a caretaker just for her.” She told him that, “Mum needs care... Mum needs a caretaker just for her so you can be free.” She indicated that her father was reluctant to hire a paid caregiver initially. He claimed that he did not want to have a stranger at home to invade his privacy.

Nevertheless, when Sau Ying insisted to have a paid caregiver to care for her mother, he finally agreed.

When Sau Ying noticed that all the paid caregivers whom she hired did not stay long, she simply assumed their leaving was because they did not get along with her
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father. She assumed that her father wanted to have control over the hiring. To resolve this problem and to find the paid caregiver whom he wanted and who would stay, she asked him to proceed with the hiring. She felt relieved when he finally hired Lin who really cared about her mother and whom her mother liked.

*Sau Ying’s Perception of a Crisis Situation*

After hiring Lin, Sau Ying’s feeling of tension did not decrease as she had hoped. Instead, her feeling of tension increased when Lin began telling Sau Ying’s siblings how badly her father had been treating her and Sau Ying’s mother. Since the stories that Lin had been telling were too horrible to be true, Sau Ying and her siblings could not believe in what Lin said, “Each time father is away we get stories about how bad it is... It is becoming really bizarre.” Initially, not knowing how to deal with the situation initially, they chose to cope by avoiding visiting their parents. Sau Ying and her siblings visited her mother only when absolutely necessary:

I don’t want to see my mum, I drag myself to see her .... Subconsciously, I know she needs help but I didn’t want to face it, don’t want to deal with it

However, when she saw her mother deteriorating rapidly and she was not doing to do anything to help her, Sau Ying could not help feeling guilty, “I have the guilt that I’m not doing enough.” Eventually, she decided to investigate whether Lin was telling the truth or not, “I had better find out what was the problem... If anything of what she said is true... action must be taken.” After interviewing Lin, Sau Ying confirmed what Lin said was true and that her father had been physically and mentally abusing her mother. Sau Ying’s feeling of tension continued to mount.

Sau Ying’s feeling of tension increased when Lin told her about her father not providing her mother with adequate nutritional food. Her feeling of tension rose when
Lin told her about her father bringing his girlfriend home and ignoring her mother's feelings. This was compounded by Sau Ying's belief in the obligation of a couple to be faithful to each other and to uphold their marriage vows until death. She resented her father for taking his girlfriend home. She felt that he had mistreated her mother mentally by giving her a feeling of insecurity as he made her mother live in constant fear that he would abandon her. According to Sau Ying, "its mental abuse... She's scared that father doesn't want her anymore."

Sau Ying's feeling of tension increased further when she found out her father having two faces. She believed that he was planning to send her mother to a nursing home for care so that he would be free of caregiving. She believed that her father had deliberately made her mother miserable to justify his intention to send her to a nursing home. She felt that he purposely mistreated her mother to give the family the false impression that her deterioration was inevitable. Sau Ying resented him for misleading her and her siblings to believe that nursing home care was the only option:

'I always wonder why is this happening, I can't understand why is my father doing this, like it comes through the diet, the way he control it, I want to make sure mum get really as sick as possibly she could, almost like he knows this lady is taking good care of mum and be bad to her too, I think I finally come to a conclusion between me and my family we talk this, father really want to take her to a home, and we all don't want her to go.

Sau Ying's feeling of tension reached to beyond the limit when Lin told her that she could not tolerate her father any more and gave her notice of leaving:

'I said ... how about we pay you more, ...this woman said I don't want no money, you can pay me two thousand a month, I want my life, I just want to wish you've got to take care of your mum, money is not the issue here.'
Sau Ying could not imagine how her father would treat her mother when Lin left. She could not imagine how he would treat her mother when she was at his mercy completely. She could not imagine how he provided the hands-on physical care to her mother. She was afraid of the possibility that he would mistreat her mother to such an extent that her mother’s life would be at risk. In fact, she perceived her mother in a life and death situation.

As she strongly believed in filial piety, Sau Ying felt obliged to protect her mother. She felt that she had no other choice but to take over her mother’s care immediately, “I don’t have any choice, to me it’s a no choice situation.” Since her mother and Lin were both elders who did not speak English, she did not want to let them live on their own. She believed that moving them to her home was the only option, “Mum cannot live here anymore, she’s going to die... I’m taking mum to my house... Mum’s moving to my house for the rest of her life.”

Resolving the Crisis: Decision to Take Over Mother’s Care

Sau Ying decided to move her mother and Lin to her home before discussing with her husband. Feeling she had no other choice but to move her mother to her home, she did not feel necessary to have her husband’s agreement. Since she had an equal marital relationship with her husband, who was a Chinese-Canadian with similar values and beliefs of filial piety, she was confident that he would support her completely in her decision, “We’d been talking about it for a while anyway... I believe sometimes you don’t need everybody's permission to do things.”

Although Sau Ying was not a son, she was the eldest among her siblings. As the eldest sister, she had always been the decision-maker among her siblings. She felt
obligated to make decisions for them and also felt that they were waiting for her to decide what they should do in fulfilling their obligation of filial piety to both parents. She felt that she was more responsible than her siblings in deciding what should be done to ensure her mother’s care and safety, “I'm the eldest... they expect me to look after things.”

When taking over the caregiver role, Sau Ying found herself in an advantageous situation. Since she and her husband had always prepared to be their parents’ caregivers, they had bought a big house with spare rooms for her mother and Lin. She had a full-time English-speaking nanny to help with caregiving. She worked at home and could be there for her mother at any time, “I work at home ... I have a nanny here who is young and speaks English well... and can help them and watch out for them.”

Although Sau Ying resented her father for what he did to her mother and the family, she still felt that, as the daughter, she was obliged to show an absolute respect to him. She confessed that no matter how old she was and how much she resented him for what he had done, she could never talk back to him or confront with him, “You never talk back.... You could be fifty years old – and your mum can still hit you if she thinks you deserve it.... it’s like a blind faith.” To fulfill her obligation of filial piety to her father, she sought to avoid any confrontation with him.

Not knowing what to say and trying to avoid confrontation with her father, she moved her mother and Lin to her home when he was out of town. When he returned and asked why she had moved her mother, Sau Ying avoided telling him the truth. Instead, she told him that she was concerned for “his” health because caregiving was stressful, “You must be exhausted. My health is okay, I don't mind mum living with me.”
Managing and Coping with her Mother’s Care

Sau Ying had a strong belief in filial piety and felt obligated to care for her mother with respect and love by preserving her personhood and honoring her. Before moving her mother to her home, Sau Ying was worried that her mother might not want to move or she might be shocked by the move. Even though she was unsure if her mother could comprehend, she asked Lin to explain to her mother about the move. Sau Ying hoped that by telling her the move repeatedly, even with cognitive impairment, her mother would understand and accept her new living arrangement, “The move could be terrible for her... I wanted her to know and be prepared for where she was going... [Lin] kept saying it to my mum.” Sau Ying asked Lin to tell her mother because she knew that her mother liked Lin and her mother “know the care taker take care of her... she start to learn to like the care taker and know the care taker take care of her and she understand... care taker explain her.”

Right after her mother’s move, Sau Ying felt greatly relieved that her mother understood and accepted the move. Although her mother had not spoken for a long time, Sau Ying was surprised and happy to hear her mother say, “That would be nice” when Lin asked if she wanted to live there for the rest of her life. Sau Ying was happy to see that her mother’s attitude was relaxed, and that she accepted her move to Sau Ying’s home.

After assuming the role of her mother’s caregiver, Sau Ying sought to preserve her mother’s dignity and respect. She felt relieved that her mother’s condition, mood, and appearance all improved with good care and she was happy that her own children accepted her mother living with them and that they got along with their grandmother,
“Mother looks younger... kids like to play with her more because she looks healthier.”

She felt that her mother was aware of her improvement, “I think my mum feels good about herself, too... She knows she is feeling good.”

As the primary caregiver, Sau Ying sought to ensure that her family was as respectful to her mother as when before she had AD. She felt obliged to show her family, particularly her father, “What mum could be, when she's being properly taken care of... and realize she's not that bad.” To prevent her mother from being in an uncomfortable situation, Sau Ying set a few rules, “Never eat in a restaurant again... Bring back all those memories... Never go to father's house again.”

Influenced by the Canadian culture, Sau Ying accepted that more and more Chinese-Canadian family caregivers were sending persons with AD to nursing homes. She was saddened about this fact. Nevertheless, she would not consider a nursing home to be an option for her mother. She was determined to have her mother live with her even when the care became heavier as AD progressed, “As long as I live she's going to live with me... if... she need a nurse around the clock, we just get her a nurse around the clock.” She told the interviewer that she could not forget how miserable her mother was when her father attempted to move her to a nursing home a year earlier. The move lasted for about three days. They quickly moved her mother back to her father’s place when they saw how much she was suffering.

Sau Ying found her mother’s adequate economic status an advantage for her care. Her mother’s financial access allowed her to pay for 24-hour home care whenever her mother needed round-the-clock care, “My mum herself has enough money to have that, all we have to do is to carry out her wishes for her.”
Sau Ying understood that her mother strongly believed in the Chinese cultural values and beliefs of filial piety, gender role in marriage, and family values. She knew that no matter how bad her father had treated her mother, her mother would want to keep her marriage. She believed that her mother would want them to continue respecting her father. As the daughter, she also felt obliged to maintain her relationship with the father. She confessed that, no matter how much she resented her father for what he did, she could never confront with him, “I would never have a big fight with my father, no matter what, as much as I resent him.”

Sau Ying felt obligated to ensure that her children continued to respect her father as their grandfather. She felt that she needed to preserve her father’s image in front of the family. By not telling her children the truth of how their grandfather had treated their grandmother, she hoped that they would continue to respect him as their grandfather, “I just have to keep saying [to her children] well grandfather … just couldn't handle it, so that's why we have a caregiver, that's why we live with her.”

Sau Ying’s feeling of tension decreased when she found that her father wanted to preserve his image of a respectful father and grandfather in front of the family. He, too, did not want to have a confrontation, “He doesn't want us to resent him… It’s important to him… that's why he had the two faces that we never knew existed.” To maintain the family relationships with the father, Sau Ying allowed her father to visit and to spend time with her mother. Her feeling of tension decreased when she found both her parents responding positively and satisfied with each other’s company:
father's happy too, he lost a burden... always some grandkids here and he get to see all of us a lot more often ... [mother] happy now because father comes home and spends more time with her.

Although they all agreed to maintain their relationships with their father, Sau Ying and her siblings had different feelings toward him and different ways for coping with the situation. She found that her brothers, in general, were glad that the problem was over. They wanted to forget what had happened and did not want to talk about the thing that was in the past:

We share different feeling about father ... I think we all feel what father did is wrong but I think ... my brothers ... seems to want to avoid men's way of dealing with problems, they avoid it, he doesn't want to talk a lot about how bad mum was being treated... Let's not talk about it again ... don't even talk about it again, that's how they handle it.

Nevertheless, Sau Ying, her sister, and sisters-in-law preferred to share their feelings toward their father openly. They liked to talk about how they felt, “Only we will talk about it... We have two feelings, one is, Boy he's bad treating mum like that ... The second feeling is, Uh, it is over.”

Sau Ying, her sister, and sisters-in-law all resented her father for bringing his girlfriend to Sau Ying’s home for the family gatherings. As a woman, she felt strongly against it, “I find it very hard to accept because I'm a woman.” Sau Ying, her sister, and her sisters-in-law resented her father for being unfaithful to her mother as well as disrespectful to her whole family. They were worried that their own husbands might learn from her father and be unfaithful to them.

On the other hand, her brothers had different feelings toward the father having a girlfriend. Kwong (pseudonym, a brother) seemed to be able see things from the point of view of a man and accepted his father more readily than did the other siblings, “...doesn't
have that big of an anger to his father... He’d like to forget the bad things.” Her other brother, however, Hung (pseudonym) and his wife, could not accept what his father had done, “…couldn't handle it... always hated father... he can never look at my father in the eye... He doesn't like father to see his kids.”

Although Sau Ying felt obliged to respect her father and let him visit her mother and the family, she could not help feeling resentment for what he did to her mother and to the family. She considered maintaining the relationship with him as formality and obligation. In her heart, she felt that she did not care about him or his well being, “I still don't really care about him and whatever he's doing now to me is no big deal... He needs a little sympathy... but he doesn’t get it from me.”

Maintaining Integrity of the Family Unit

Sau Ying’s feelings of tension decreased as she found the family relationships stronger and closer following her decision to move her mother to her home, “It seemed to pull us together closer.” When her father was the caregiver, they all avoided visiting her mother because they did not want to see how she was being treated and how miserable she was. After moving her mother to Sau Ying’s home, her siblings and the grandchildren visited regularly. Everybody was willing to contribute to her mother’s care.

Sau Ying’s feeling of tension decreased when she saw her mother responding positively to the regular visits from her father, her siblings, and their families. Although her mother had never actually spoken the name of the families visiting her, Sau Ying hoped that she would remember who they were, “Hopefully mum remembers that they have been here... it’s good for her to see a lot of people.” The whole family adjusted to
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the caregiving arrangement very well. She felt positive that “My mother brought in my sister” and the family relationships became stronger and closer, “It seemed to pull us closer together.”

**End of the Story: Drawing upon the Chinese and Canadian Cultures to Redefine Values and Beliefs and to Create Meaning for the Future**

While coping with caregiving, Sau Ying and her family encountered a series of challenges to the Chinese cultural values and beliefs, particularly in the areas of gender role in marriage and filial piety, in the context of the Canadian culture. These challenges increased Sau Ying’s feeling of tension generated from the differences between the Chinese and the Canadian cultural values and beliefs. To resolve the challenges and to relieve her feeling of tension, Sau Ying drew upon the values and beliefs of both cultures to redefine her personal values and beliefs and to create a new meaning for the future.

**Transformation of Sau Ying’s Personal Values and Beliefs**

Sau Ying told the researcher that she volunteered to participate in Perry’s (2004) study not because she was an expert daughter caregiver:

I’d only had mum for three and a half weeks ... four weeks, (laughs) ... I don’t think my experience can help you a lot, first of all I’m not the major care taker...I’m not the one who do all the detail work for my mum except care taker’s day off, there I am doing everything but that one day I can handle.

Instead, she shared her mother’s experience of being cared for by her father with the hope that other Chinese-Canadian women would not suffer the way her mother had suffered:

one of the reasons I really want to talk to you about all this is I want to tell you not my experience care taking because it hardly exist the experience, its I want to tell you my mum’s experience with her husband as a care taker...I hope that it will help somebody.
After participating in Perry’s (2004) research and being interviewed, Sau Ying felt that she had positive gains. She felt that the interviews had given her the opportunity to explore her own feelings of the whole situation and toward her father:

It kind of put things into perspective.... also help me, I get to get out what I feel about my father...To me that is the biggest block in me that I deal with it and still like this when he comes.

The interviews also gave Sau Ying an opportunity to reflect on what had happened, “I always wonder why is this happening, I can't understand why my father is doing this.” She was able to reflect on what was happening and what she wanted for her mother, her family, and herself:

I kind of wonder if he [father] know everything, what would he do...Maybe he should know, maybe that is the penalty.... I believe in whatever is back here, you come back so what do we do now, it come back to you somehow.

These reflections enabled Sau Ying to see that she had drawn upon the Chinese and Canadian cultures to redefine values and beliefs and to create meaning for the future.

Redefining Gender Roles in Marriage

Influenced by both the Chinese and the Canadian cultures, Sau Ying’s values and beliefs were different from those of her parents. Instead of being an obedient housewife, she believed in equal marital relationships. She strongly believed that the inequality in the Chinese gender role in marriage potentially caused conflicts between the couple:

I ask my husband a question from a man's point of view, why is God so unfair they create woman to reproduce, not the man ... we put so much energy in raising the family ... once you become a mother, sex become like secondary... [men] never lost that ability to engage in sex or lost the interest ... that is such a conflict as the couple get old.
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Although her mother valued and believed in Chinese cultural values and beliefs, Sau Ying felt that her mother had always been dissatisfied with the traditional Chinese gender role in marriage. She felt that her mother would prefer having more control over her life. In fact, her mother had advised her to pursue a university education and a career. Her mother had advised Sau Ying to have children only if she wanted to. She advised Sau Ying that even if her husband wanted to have children, if she did not want to, she did not need to obey her husband to have children.

Sau Ying disagreed with Chinese cultural value of gender role inequality. Instead, she valued a couple's obligations to their marriage vows. She believed in husbands and wives being equal partners, both the husband and the wife were obliged to ensure the happiness and welfare of the spouse. She felt obliged to consider her husband's wishes when she made decision of having children. Although she did not have a strong desire to have children and her husband let her decide having children or not, she started the family with her husband. Knowing her husband had always wanted to be a father and he would be a wonderful father, she could not deprive her husband of having children:

I change my mind, because I wanted to be a good mum ... I think I'm going to feel very bad later on... I also feel guilty for my husband because I know he make a good father...And I'm here ripping him off.

Sau Ying valued a couple's faithfulness to each other. Although she was not surprised to see men being unfaithful to their wives, she resented her father for being unfaithful to her mother. She felt that even though her mother had AD, as long as her mother was alive, her father needed to respect their marriage. She could not accept him bringing his girlfriend to family gatherings. She found his behavior disrespectful not
only to her mother but also to the whole family. She resented him for being a bad role model to the family because she was worried that her husband, her brother, brothers-in-laws, and grandsons would learn from her father to be unfaithful to their wives:

When I find out all these things my father is doing like with women, I think for a long time I was disgusted with men in general ... So it is our society or our culture forces them to stay home with one mate when they need to have a different one everyday and a problem will arise when the couple gets old.

However, Sau Ying was glad that the inequality in gender role in marriage was fading over generations. While men were getting more involved with household chores and raising their children, more women worked outside the house on their own careers, “Things are changing now... our children are seeing their father play... just as big a role as me in the house.” In her family, both Sau Ying and her husband had full-time jobs. Although they had hired a full-time nanny, she and her husband had equal responsibilities in raising their children, “They [my children] are not... surprised to see father do house work... It’s totally accepted... where before it wasn’t.”

Redefining Filial Piety

Sau Ying’s caregiving experience of her mother who had AD prompted her to rethink the traditional Chinese cultural value of filial piety. She found that her closeness to her mother enhanced her willingness to be her caregiver. Not only she felt obliged to care for her mother but also she was willing to provide her loving care that preserved her dignity. On the other hand, although she felt obliged to care for her mother-in-law, she did not have the same degree of willingness, “Even though I’ll do it, I'm not excited about it.”
Sau Ying did not consider taking over the care of her mother as a heroic act because she felt obligated to ensure her mother’s care. In addition, she knew that if she did not take over her mother’s care, her mother would continue to suffer, and then would feel guilty about it for the rest of her life:

It’s almost like somebody is drowning there… It’s not heroic, it’s you better do it… If you don’t do it… I would be guilty for the rest of my life and I don’t like that.

Sau Ying’s Chinese-Canadian husband also valued filial piety. He felt obliged and was willing to care for his own mother. To get ready to be the caregivers of their parents, Sau Ying and her husband had bought a large house with spare rooms. They were ready to move their parents in at anytime. Thus, when Sau Ying took over the role as her mother’s primary caregiver, she was confident that her husband would give her full support:

In the back of our mind we always have to prepare for one or two of our parents might end up living with us so we get a bigger house…with two spare bedrooms.

Sau Ying was aware that more people were sending their parents to nursing homes, instead of caring for them at their own home. With a strong belief in filial piety, however, she felt that sending parents to a nursing home was just like abandonment. She was upset when she learnt that other Chinese-Canadians do not always care for their parents at home:

I was shocked to hear that, I’m not shocked to hear from Canadian families, Caucasian families, Chinese family usually do the best to accommodate the elderly.

Sau Ying admitted that filial piety was fading away over generations and it “starts wearing off and when it comes to our generation of Chinese, it’s fifty percent rubbed
off.” Since her children were born in Canada, she expected that the Canadian, rather than the Chinese culture, would have a stronger influence on their values and beliefs, “We don't talk back… My kids talk back to me even it doesn't matter how mad I am to tell them something… it’s so different.”

Although she did not want to be a burden to her children, she hoped that they would respect and take care of her when she was old and sick. She wanted her children to learn filial piety from her, when they saw her caring for her mother, “I think this is good example, my kids should see this because they will do that for me.”

Since Sau Ying wanted her children to learn filial piety from her, she did not want them to know about her true feeling toward her father. She did not want them to see her resentment of her own father for what he had done to her mother, “I don't want them to say, you know, you used to hate grandfather.” Instead, she wanted them to continue respecting their grandfather. Thus, she never told them what he did to their grandmother or the real reason why their grandmother was living with them.

Redefining Family Values

Sau Ying valued a close family relationship very much. She believed that if her family relationships were stronger, her mother’s problems from abuse would not have happened. She believed that family members who were close to one another would share the caregiving responsibilities willingly. Consequently, the primary caregiver would receive the needed support to cope with caregiving and, in turn, have less stress and burden related to caregiving:

In this society we really have to stress a family value… if that value is very, very strong in this society these things don't happen or if the spouse cannot handle it, the children will step in and share the responsibility.
After taking over her mother's care, Sau Ying was pleased that her family relationship became stronger and closer. Her own family and her siblings fully supported her in her caregiver role. She took advantage of her authority as the eldest sibling to ensure that her siblings contributed to her mother's care. Although Sau Ying was not the eldest son, she had successfully manipulated the Chinese cultural value of birth order and the Canadian culture gender role equality to obtain her siblings' support. She would remind her siblings to visit her mother, “If they don't come, they're going to hear from me... I'm keeping a log book... I'm in charge of that area... and they come a lot more often.”

Creating Meaning for the Future

Sau Ying felt sorry that it was her mother who had AD. She strongly believed that if her father was ill and needed to be cared for, her mother would have taken very good care of him. However, her father had not only failed to look after her but also mistreated her physically and mentally. Sau Ying felt fortunate that her mother had four children who all had strong beliefs in filial piety. She was convinced that if her mother had no children or if her children failed to assume any responsibility as caregivers, her mother would have been sent to a nursing home much sooner than necessary:

When the wife is sick, I think they end up in a home so much faster than the husband .... he looks like he can take care of her, obviously he's not willing to ... when the husband is looking after the wife, the wife goes into care earlier.

Influenced by the caregiving experience, Sau Ying reflected on her plans for the future. She was concerned that a similar scenario as her mother’s situation might happen to her. She was worried that when she was old or sick, her husband and her children
might not care for her according to her best wishes. Instead of being sent to a nursing home, she would want to have control over how she would be cared for. She realized the need to make advance planning for her own future:

They'll send me to a home .... I won't let anybody send me anywhere... I like to control my own life... If I know I'm going that way I'll probably arrange things myself, ....I learned so much from mum, ... I know exactly what I shall do ...Before I hit that bottom so I won't become a burden to anyone.

Summary

Figure 1 illustrates the process and outcomes of Sau Ying’s caregiving experience of her mother who had AD. Her relationships with her mother, her father, her siblings, and her immediate family, as well as, how her father had treated her mother had influenced her caregiving experience. In this chapter, I have presented the research findings of Sau Ying’s caregiving experience with a story-telling style. The plot consists of the beginning of the story with the introduction of the characters and the background, the climax with developing events leading to Sau Ying’s ultimate feeling of tension, and the end of the story with subsequent resolving of the feelings of tension. Each of these three components of the narrative is discussed in greater detail and summarized.

Sau Ying began her narratives by introducing who her mother and her family were. She and her young siblings were born in Hong Kong and the family moved to Canada when she was in her teens. Sau Ying’s parents had strong Chinese cultural beliefs and values. Since Sau Ying grew up and was educated in Canada, her values and beliefs were influenced by both the Chinese and Canadian cultures.

Sau Ying told her caregiving experience from the time she saw the initial changes in her mother’s cognition and behaviors, to the diagnosis of AD, to her father becoming
the primary caregiver, to deciding to take over the caregiving responsibilities, to managing her mother’s care, and finally, to reflecting about her feelings of the caregiving experience. When first encountering the disease, preparing for the caregiving, and then providing the care, Sau Ying, her siblings, and her family experienced a series of challenges to their traditional Chinese values and beliefs, particularly in the areas of gender role in marriage and filial piety.

Sau Ying’s personal values and beliefs were influenced by both the Chinese and Canadian cultures. Her personal values and beliefs had influenced her assumptions about how her mother should be cared for. Sau Ying’s father became her mother’s primary caregiver when her mother’s abilities to function were affected by AD. Her father, strongly influenced by the Chinese gender role, was not prepared to be the caregiver. However, neither Sau Ying nor her siblings had discussed with him their expectations of how her mother was to be cared for, or what support her father would need for a role as caregiver. When her father’s care for her mother failed to meet Sau Ying’s expectations and assumptions, she faced a dilemma that caused her to experience increasing tension.

Seeing her father being increasingly impatient and rude to her mother and her mother’s condition deteriorating rapidly, Sau Ying’s feeling of tension increased. Nevertheless, influenced by the Chinese value and belief of filial piety, Sau Ying not only felt obliged to ensure that her mother was well cared for but also felt obliged to respect and obey her father. Regardless of how much she resented her father for what he had done to her mother, she could not confront him with her view that his care for her mother was inappropriate.
Initially, to fulfill her obligation of filial piety to both parents, Sau Ying sought to support her father without challenging his primary caregiver role. Later, when she saw her mother deteriorate rapidly, she could not help feeling that her father’s failure to care for her mother had contributed to the deterioration. Sau Ying felt guilty about her mother’s condition because she felt that she had not done enough to ensure her adequate and loving care. These issues were causing her feeling of increasing tension.

Sau Ying had hoped that her father would treat her mother with more patience when he was relieved of the physical caregiving responsibilities. She suggested to her father and eventually convinced him to hire a live-in, paid caregiver to help with the hands-on care. When they finally hired Lin, who had taken good care of her mother and whom her mother liked, Sau Ying assumed that her mother would be well cared for. However, Lin began telling Sau Ying’s siblings about her father’s abusive behaviors toward her mother. After interviewing Lin, Sau Ying was convinced of the truth of the stories and perceived that her mother was in a crisis situation. Immediately, she took steps to assume responsibility for her mother’s care, as the only option to ensure her mother’s safety and well-being.

Sau Ying decided to move her mother to her own home without discussing it with her husband. She felt that the situation was so critical that a drastic move was necessary, with or without her husband’s support. Nevertheless, she had an equal marital relationship with her husband who also had a strong belief in filial piety. In the back of her mind, she had the confidence that her husband would give his full support to assume the responsibility for her mother’s care.
When Sau Ying became her mother's primary caregiver, she sought to maintain her family relationships and the relationships between her father and other family members. To avoid any confrontation with her father, she moved her mother when he was out of town. When he came back, she avoided telling him the real reason for moving her mother. Instead, she made up a reason that she was concerned about his health because caregiving can be so exhausting.

Sau Ying managed to maneuver the support of her family and siblings to cope with the caregiving. All her siblings felt obliged to care for her mother. In the Chinese culture, the eldest son holds the greatest authority. Although Sau Ying was the eldest daughter and not the eldest son, she managed to direct her siblings towards her mother's care. She had successfully manipulated the gender role equality of the Canadian culture and the authority of birth order in the Chinese culture to elicit the support of her siblings to care for her mother.

After taking over as her mother's primary caregiver, Sau Ying felt relieved that her mother's condition improved and the family relationships grew closer and stronger. Having learnt from her caregiving experience, she drew upon the Chinese and Canadian cultures to redefine her personal values and beliefs, particularly with regard to the gender role in marriage, filial piety, and family values. She had also created a meaning for the future. She was aware of the necessity in advance planning of her personal and health care needs to ensure what had happened to her mother would not happen to her.
CHAPTER V

DISCUSSION, IMPLICATIONS FOR NURSING PRACTICE, EDUCATION, AND RESEARCH

Introduction

In this chapter, I discuss the insights drawn from the research findings of this case study. The purpose of this discussion is to reflect on how culture and the historical socio-economic context influence caregiving of persons with AD. Exploring Sau Ying’s caregiving experience in-depth via a cultural lens has led to a meaningful understanding of the influences of culture and socio-economic context on how she made decisions, acted on, and felt about being her mother’s caregiver. Currently, most of the health care and social services provided to the persons with AD and family caregivers, including persons of minority ethnicity, were developed under the influences of a number of assumptions of how culture influences the caregiving experience. However, after examining the research findings of Sau Ying’s caregiving experience, I find that some of these assumptions need to be re-examined.

Culture does not determine how a person thinks, decides, and acts in a given situation. Instead, culture is one of the factors that influence how an individual feels and responses (McCarty, 1996). How a person views health, illness, and health care delivery is multi-factorial and is influenced by the personal values and beliefs, historical development of the culture, the socio-economic context, and the resources available and accessible to the person (Ahmad, 1993).
Sau Ying had lived and received education in both Hong Kong and Canada. Both the Chinese and the Canadian cultures had influenced her personal values and beliefs, which in turns influenced her caregiving experience. Having the influences of both cultures, just like having one foot in each of two cultures, had offered Sau Ying more options to resolve the challenges she encountered when caring for her mother. With her understanding of what was important to her own nuclear family, her parents, and her siblings, Sau Ying was able to navigate the situation and find the support to resolve the challenges she encountered. When caring for her mother, she aimed at not only providing the care her mother needed but also preserving the respect and dignity of her mother, coping with caregiving with the support she needed, and maintaining the family unity with her husband, children, parents, and siblings.

Caregiving is individual as well as a familial undertaking. Sau Ying’s caregiving experience was not static but dynamic. Her caregiving experience was influenced by her cultural background, relationships with her family, other competing social roles, support she received from her family, and economic status. The research findings of this case study support that the challenges she encountered and how she resolved these challenges were not identical with other caregivers, even if they are of the same ethnicity. In fact, the literature shows that the caregiving experience of Chinese living in China, Hong Kong, and other countries is not identical either.

I begin this chapter by discussing research findings that are similar to the literature and then research findings that are different with the literature. Following this, I discuss how culture and the historical socio-economic context influence caregiving. The research findings support that caregiving is individual and multi-factorial.
Stereotyping the caregiving experience and needs of people of the same ethnicity is, therefore, inappropriate. To conclude the discussion, I assert that in order to provide the needed support to the persons with AD and their caregivers, health care and social services providers need to consider each individual’s cultural background, values, beliefs, and the historical socio-economic context. To care for the persons with AD and to support their caregivers, an individual approach to meet individual needs is the key of success.

Sau Ying’s Caregiving Experience Similar to the Literature

Traditional Chinese culture values filial piety, gender role in marriage, and family unity highly. Sau Ying was born in Hong Kong, a city that was a British Colony for about a century before 1997 and is now a special administrative region of China. She moved to Canada with her parents and three younger siblings when she was a teenage. She had received education in both Hong Kong and Canada. While the population in Hong Kong is mostly Chinese, the population in Canada is mostly European decedents. Although Sau Ying’s parents’ values and beliefs were predominately influenced by the Chinese culture, hers were influenced by both Chinese and Canadian cultures. Her cultural background and life context in Canada had shaped her personal values and beliefs, which in turns, influence how she felt, made decisions, and acted in a given situation.

Gender Role in Marriage

Chinese culture traditionally assigns hierarchal status to the family members according to the gender, birth order, and age. Traditionally, the oldest man in the family has the most power. While men are usually the heads of the families making all the
family decisions, women usually take on a subordinate role to the men looking after the family's needs and the household chores (Chiu & Zhang, 2000; Fung, 1998; Lai et al., 2003). Today, although women often work outside the house, men are still the heads of most Chinese family with the expectation to be cared for by the women. Very often, men are never taught nor prepared to be the caregivers.

When AD progressed, the cognition and communication skills of Sau Ying's mother continued to deteriorate gradually. When no longer able to care for herself or to make health care decision, her father became her mother's primary caregiver and proxy decision-maker. Strongly influenced by the Chinese gender role in marriage, he was used to be served by her mother and the head of the family. Therefore, he was not taught nor prepared to be the caregiver. As a result, he did not know how to care for her mother.

Moreover, when seeing other women were still serving their husbands, he felt that he was being treated unfairly. This feeling had affected his willingness to accept his caregiver role. Consequently, he failed to provide care that her mother needed. The care he provided was not according to what she needed but according to what he thought was need. He had also failed to assess how she responded to the care. Sau Ying did not feel that he really cared about her mother's rapidly deteriorating condition. In fact, Sau Ying had learned from Lin that not only he had failed to provide appropriate or adequate care to meet her needs but also he had mistreated her to the degree of abuse.

Filial Piety

Most Chinese-Canadians value filial piety. They believe that their children are responsible for their care (Fung, 1998; Lai et al., 2003). Sau Ying and her siblings valued filial piety highly. She felt obliged to respect, obey, and care for her both her parents, no
matter how old she was and what her parents had done. She and her siblings felt obligated to ensure her mother was being cared for appropriately. However, they had not considered the influences of the Chinese gender role in marriage on her father’s ability and feeling toward caregiving. Instead, they accepted and respected her father as the primary caregiver without discussing if he was able to and if he was willing to be the caregiver.

At first, Sau Ying did her best to fulfill her obligation of filial piety to her parents. Although she saw her mother’s condition deteriorating rapidly, she did not confront her father of his inability to provide care that her mother needed. To ensure her mother receiving the care she needed, she tried resolving the problem by hiring a paid caregiver. Eventually, she convinced her father to hire Lin whom her mother liked to help with caregiving. However, when Lin told her about her father’s abusive behaviors toward her mother, Sau Ying found herself facing a dilemma. She felt torn between her obligations of filial piety to both parents of obeying her father and caring for her mother at the same time.

Perceiving her mother in a crisis situation of being abused, Sau Ying could not let her mother continue to stay with her father. She felt that taking over the primary caregiver role immediately was the only option she had. Perceiving her mother in a life and death situation, she felt that she no had other choice but to move her mother to her house, with or without the support from her husband and siblings. Although she made the decision without discussing with them, in the back of her mind, she was confident that they would support her because she understood her husband and siblings very well. She knew that they all valued filial piety. Moreover, her husband being her equal marital
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Partner and Sau Ying being the eldest sibling had enabled her to make instant decision without discussing with them first. I will discuss this argument further when I discuss how culture and historical socio-economic context influence caregiving.

Influenced by the value of filial piety, Sau Ying could not confront her father. She admitted that no matter how old she was and how much she resented him for ill-treating her mother, she still felt obliged to respect him as her father. Since she could not confront her father, she moved her mother and Lin to her house when her father was away. When he came back, she did not tell him the truth of why she took over the caregiver role. Instead, she told him that she was concerned about his health because caregiving was stressful.

Family Unity

While some family caregivers became caregivers because of obligation, most of them volunteer to be caregivers (National Profile of Family Caregivers in Canada, 2002). Previous relationships with the persons with AD influence their caregiving experience (Perry 2002; Perry 2004). Family caregivers who had harmonious, caring, and reciprocal relationships with the persons with AD often claimed that they were willing to be the caregivers. By contrast, if their previous relationships were difficult and filled with conflicts, they often stated that they took on the caregiver roles because of obligation as other choice was not available (Bontinen, 2001; Choi, 1993; Farran et al., 1991; Haley, 1997; McCarty, 1996; Perry, 2002; Perry, 2004; Perry & Olshansky, 1996).

Sau Ying took over her mother’s care not only because she felt obliged to care for her mother but also because she loved her. Although she had described her previous relationship with her mother as a typical Chinese parent-child relationship only, her love
for her mother was strong. Although she had never had a heart-to-heart conversation with her mother, she was more willing to be her mother's caregiver than being the caregiver of her mother-in-law. Her relationship with her mother was much closer than with her mother-in-law because her mother had raised her and her siblings.

Sau Ying could have a few options of caring for her mother. Rather than moving them to her house, she could have found an apartment for her mother and Lin. She could have her mother moved to nursing home care. However, because of her love for her mother, she wanted not only to protect her mother from her abusive father but also to care for her mother with love and respect. Because of her strong desire to provide her mother the best care, she felt that having her mother and Lin living with her was the only option.

Influenced by the Confucian philosophy, Sau Ying felt obliged to maintain a harmonic family relationship. To fulfill her obligation of filial piety to her father and to keep the family unity, she continued to respect him as her father. She let her father visit her mother regularly. She was pleased that both her parents responded positively to this arrangement. Being relieved of the primary caregiver role, her father was more willing to spend time with her mother and was more patient with her. At the same time, her mother responded positively to his visits and seemed to enjoy his company.

To continue the caregiver role and to manage the stress and burden of caregiving, family caregivers need the support from their families and friends (Butcher et al., 2001; Hall et al., 1995; Haley, 1997; McCarty, 1996; O'Connor, 1998). Sau Ying’s husband, children, siblings, and father all supported her primary caregiver role. During the interviews, she did not mention having any stress or burden related to caregiving. She admitted that she had the support she needed. For instance, she mentioned that without
Lin, she would have the stress and burden of providing physical care to her mother. She also appreciated the contribution of her husband and siblings to the care of her mother, particularly on Lin’s day off. She was pleased that the family unity became stronger and her mother’s mood and cognition had improved. Being able to provide quality care to her mother was also a positive caregiving experience that enabled her to continue her caregiver role.

Traditionally, Chinese believe in dealing with unsolved problems by enduring the consequences and avoiding dwelling on them. They believe in dealing with family problems within the family and consider asking for external help admission of defeat and dishonor to the whole family (Braun & Browne, 1998). Initially, when unsure of how to resolve challenges related to caregiving for her mother, Sau Ying and her family tried to avoid encountering the challenges. For instance, when her mother was being cared for by her father and her condition deteriorated rapidly, Sau Ying and her siblings avoided visiting her mother. Also, when Lin told them how their father was mistreating their mother, they did not want to listen to Lin initially because they did not know how to deal with father’s abusive behaviors. Even when Sau Ying had confirmed her father’s abusive behaviors, she could not confront with him either.

After Sau Ying had taken over her mother’s care, her brothers felt relieved that the challenge of their father’s abusive behaviors was over. They stopped dwelling on the issue as soon as Sau Ying became her mother’s primary caregiver. Only Sau Ying, her sister, and her sisters-in-law kept talking about their concerns and fears of what had happened to her mother might happen to them. Sau Ying admitted that she participated in Perry’s (2004) study because she wanted to share her mother’s story with the hope that
other women with AD would not suffer what her mother had suffered, although she was aware of her siblings’ disapproval of her sharing her caregiving experience with outsiders.

**Sau Ying’s Caregiving Experience that Differs from the Literature**

Research findings of this case study show that Sau Ying’s caregiving experience is not reflected in the literature. For instance, Sau Ying’s father taking on the primary caregiver role was not commonly found in the Chinese family caregivers literature.

*Father Became Mother’s Primary Caregiver*

As already been discussed earlier, Chinese culture traditionally assigns hierarchy to family members according to the gender, birth order, and age. Today, although many women are now working outside the house, men are still usually the heads of the families making all the family decisions while women often are expected to be obedient to the men looking after the families and the household chores (Chiu & Zhang, 2000; Fung, 1998; Lai et al., 2003).

Studies show that spousal caregivers, mainly the wives, are the largest group of family caregivers of persons with AD. From another perspective, among all the caregivers, daughters are the largest group of caregivers while wives are the second largest group of caregivers (www.alzheimer.ca, 2003; Canadian Study of Health and Aging Working Group, 1994; Chiu, 2001; Heok & Tan, 2002; Langner, 1995; McCarty, 1996; National Advisory Council on Aging, 1996; Walker, 1983). Although husband are usually not expected to be the caregivers, when Sau Ying’s mother condition deteriorated and needed to be cared for, her father became the primary caregiver.
Although her father had tried to cope with his caregiver role, he did not find attending a caregiver support group meeting beneficial. Since husband caregivers were not common, her father was the only husband caregiver attending the Chinese-Canadian caregiver support group meetings. All the other caregivers were wives, daughters, or daughters-in-law. As a result, he felt that his caregiving issues were not being understood. He did not feel attending the support group meeting beneficial. He continued to feel sorry and unwilling to be the husband caregiver.

Undermining or unaware of the influences of the gender role in marriage on her father’s ability and willingness to be her mother’s caregiver, Sau Ying and her siblings had not considered the influences of the Chinese gender role in marriage on her father’s ability and feeling toward caregiving. As a consequence of not being prepared to be a caregiver and not having the support he needed, her father eventually failed to cope. He began losing patience and ill-treating her mother.

Sau Ying Became Mother’s Primary Caregiver

That Sau Ying became her mother’s primary caregiver and proxy decision-maker also challenges traditional literature. Chinese culture believes that the first-born son is more responsible for the filial piety duties than his younger and female siblings (Chiu & Zhang, 2000; Fung, 1998; Ikels, 1998; Lai et al., 2003). While married son caregivers often receive support from their wives, daughter caregivers often provide the majority of hands-on care (Fung, 1998; Harris, 1998; Langner, 1995; McCarty, 1996).

In this case, although Sau Ying was not the first-born son, she had always been the decision-maker of her siblings. Influenced by the Chinese cultural value of birth order and the Canadian gender role equality, she had assumed the decision-maker among
her siblings without any objection from them. As the elder sibling, Sau Ying felt more responsible to make decision than her siblings to decide how her mother was to be cared for. In fact, her brothers came to her when Lin began telling them their father's abusive behaviors toward her mother. Her siblings were waiting for Sau Ying to decide what to do to ensure her mother receiving the care she needed. Therefore, as soon as she had confirmed her father's abusive behaviors toward her mother, she made instant decision to take over her mother's care, even before she had discussed with her husband and siblings.

Influences of the Culture and Historical Socio-economic Context on Caregiving

Nursing home care is not as popular in China as in Canada. Extended family arrangements are still very common in China. The Chinese living in China often live with, or are very close to, their extended family. They often prefer caring for the chronically ill or dying persons at home (Ikels, 1998). Family caregivers often move the persons with AD into their own home. Or, they move in with the persons with AD (Chiu & Zhang, 2000; Ikels, 1998). Often such decisions further compounded by a lack of other options.

In Canada, however, Sau Ying had more options but was determined to care for her mother at home. Although she was aware that AD was incurable and progressive, she was determined to care for her mother at home with the support of her family and the paid caregiver. Sau Ying and her husband had a large family house and well paid jobs. As such Sau Ying kept her mother at home was not determined solely by the Chinese cultural values of filial piety, gender role, and family unity. The historical socioeconomic context also influenced the caregiving experience and decisions of Sau Ying.
Having One Foot in Each of the Chinese and Canadian Cultures Offered More Opportunities to Resolve the Challenges Encountered

Sau Ying was born in Hong Kong and immigrated to Canada when she was a teenager. She was raised under the influences of both the Chinese and Canadian cultures. These two cultures had influenced how she shaped her personal values and beliefs, which in turns influenced how she perceived, felt, made decision, and acted in a situation. Having two feet in both Chinese and Canadian cultures had offered her more options and opportunities to resolve the challenges she encountered when she cared for her mother.

After Sau Ying had confirmed that her father was abusive toward her mother, she decided to take over the primary caregiver role and moved her mother to her house. She made this decision before discussing with her husband and siblings because she felt her mother’s situation was so critical that she had to remove her mother away from the abusive situation immediately. Although she could have other options of how to care for her mother, she perceived moving her mother to her house the only option. She made this decision even before discussing with her husband partly because she was confident that he would support her.

Sau Ying knew that her husband valued filial piety highly. They had prepared to be the caregivers of their parents. For instance, they had bought a big house with spare rooms for their parents. In addition, she and her husband were equal partners in their marriage. They both believed in equality in gender role in marriage. They had the understanding of supporting each other to take on the primary caregiver roles of their parents. When her father was the caregiver, her husband had already been contributing to her mother’s care. Having no doubt that he would support her decision, she felt it
unnecessary to discuss with him before she made the decision of moving her mother and Lin to her house.

Sau Ying was also confident that her siblings would support her caregiver role and they would contribute to her mother’s care. As the eldest sister, she had always been the decision-maker of her siblings. Although Sau Ying was not the first-born son, she was the eldest sibling. While Chinese culture values birth order in the family hierarchy, the Canadian culture values gender role equality. By maneuvering these two cultural values, Sau Ying had always been the decision-maker among her siblings. She felt more responsible to ensure her mother’s care than her siblings and more obligated to take charge of her mother’s care than her siblings.

How Culture and Historical Socio-economic Context Influenced Caregiving

Sau Ying’s socio-economic context had influenced her caregiving experience. Having a house with spare room for her mother and Lin had enabled her to make instant decision and action to take over her mother’s care. Affected by AD, her mother might find a noisy environment overwhelming when her children were around. Having a room in a quiet area that separated from the main activity areas of the house was helpful to prevent her mother from over-stimulation from the busy activities of her children and other family members. This living arrangement was also helpful in preventing her family from experiencing any stress related to an overcrowded living situation that might affect her family relationships. In addition, with her mother living with her, Sau Ying’s husband and nanny could help with caregiving.

Sau Ying expressed that being her mother’s power of attorney was an advantage to her caregiver role. She admitted that providing hands-on physical care to her mother
would be stressful and burdensome. However, with her mother's adequate financial access, she could afford having Lin to provide the hands-on care to her mother.

Moreover, she also managed to have her siblings to share the caregiving duties with her on Lin’s day off.

Sau Ying was determined to have her mother living with her even when her condition deteriorated to such an extent that around-the-clock care was needed. She admitted that she was able to care for her mother at home because her mother's economic access was adequate to afford 24-hour paid care. She also expressed that having three other siblings to share her caregiver responsibilities was an advantage. She claimed that even if her mother’s financial status was inadequate to afford 24-hour paid care, she was sure that her siblings would share with the cost of around-the-clock care. The shared cost would not be too much a burden to her and her siblings.

**Caregiving Experience and Caregivers’ Needs are Individual**

Stereotyping or generalizing the caregiving experience of family caregivers of the same ethnicity is inappropriate. To provide the needed support to the persons with AD and their family caregivers, a person-centered approach is the key. The research findings of Sau Ying’s caregiving experience support that the family caregiving is not solely determined by ethnicity or culture. The historical socio-economic context also influences caregiving (Kirkham & Anderson, 2002).

Caregiver’s other competing social roles, the informal support from family and friends, the formal support from the health care and social services, and the economic status all influence caregiving experience. Since most caregivers have different personal
values and belief, different access to the formal and informal support, and different socio-economic context, each family caregiver's caregiving experience is unique.

Instead of being static, values and beliefs are evolving over time. Shaping of a person’s values and beliefs depends not only on the cultural background but also on the history and social-economic context (Kirkham & Anderson, 2002). The Chinese living in China, Hong Kong, and Canada have various degrees of Chinese values and beliefs. Compared to the Chinese in China, the Hong Kong-Chinese’s values and beliefs in family values and filial piety are fading gradually. The trend of fading of filial piety in Hong Kong is probably due to the stronger influences of European culture in Hong Kong because Hong Kong had been a British Colony for about a century prior to 1997 (Chiu et al., 1998; Chiu & Zhang, 2000; Chung, 2000 cited in Chiu, 2001; Ikels, 1998).

Being born in Hong Kong and having lived in Canada for many years, Sau Ying’s values and beliefs were different from her parents’. She expressed that she had the expectation of the influence of the Chinese culture wearing off over generations. Therefore, with her children being born and raised in Canada, she expected that her children would not have the same degree of filial piety. She did not expect them to take care of her the way she took care of her mother. Thus, she had decided to plan ahead for her health and personal care to ensure she had some control over her life when she was old or sick.

**Summary**

I have discussed the similarities and differences of the research findings of this case study with those described in the literature on family caregiving and culture. One of the insights I draw from this study is that having a family does not necessarily mean that
family caregiving is readily available. Being a caregiver is a multi-factorial experience. Family caregiving is not the same to all caregivers even if they have the same ethnic background. Caregiving experience is a dynamic process and multi-factorial. Caregiving is not only influenced by the cultural background of the persons with AD and their family caregivers but also influenced by their previous relationships, socio-economic status, education, health care and social services available, and society’s view the persons with AD and their care.

When providing care to her mother, Sau Ying’s values and beliefs in gender roles in marriage, filial piety, and family values were challenged. Both the traditional Chinese and Canadian cultural values and beliefs had influenced how Sau Ying resolved the challenges she encountered. Having each of her foot in each of these two cultures, she had more options and opportunities to resolve the challenges she encountered. With her knowledge about what was important to her own family, her parents, and her siblings, she was able to provide the care her mother needed, dissipate the mounting tension, and maintain a harmonic family relationship. The research findings of this case study support that caregiving experience is individual. No two caregivers, even with the same cultural background, would have the same caregiving experience and the same needs to support their caregiver roles.

**Implications for Nursing Practice, Education, and Future Research**

Based on the research findings of this case study, I put forward a number of implications and recommendations for nursing practice, education, and future research. These recommendations are for enhancing nursing practice, planning appropriate education to support nursing practice, and suggesting future research to fill in the existing
knowledge gaps. To utilize the knowledge learned from this case study in nursing practice, we need an educational plan for the nurses and other health care professionals. By comparing the knowledge gained from this case study and previous research, I identify knowledge gaps that require further study. The ultimate goal is to enhance the quality of care to the persons with AD and the support to the family caregivers.

**Implications for Nursing Practice**

To improve the care of persons with AD, we need to ensure they receive adequate and appropriate care that meets their individual needs. Since family caregivers provide the majority of care to the persons with AD at home and often even after institutional care, they need to receive appropriate and adequate support to meet their needs (Langner, 1995; Lynch-Sauer, 1990; Mass et al., 2004). To continue their caregiver roles, family caregivers need to have appropriate support to prevent them from stress, burden, and burn (Cassells, 2003; George & Gwyther, 1986; Hall et al., 1995; Tornatore & Grant, 2002).

The research findings of this case study support that stereotyping caregiving experience of caregivers of the same ethnicity is inappropriate. Although caregivers of the same cultural background may have similar cultural values and beliefs, individual caregivers have individual set of values and beliefs and unique socio-economic status that affect how they perceive and manage caregiving and what support they need. To ensure caregiving for persons with AD and to support their caregivers, person-centered care is the key (Kitwood & Bredin, 1992; Lyman, 1989; Tappen et al., 1999; Vittoria, 1998). To understand the individual needs of the persons with AD and their family caregivers, cultural-competent practice is a key feature (Gustafson, 2005).
Cultural-competent care

Health care and social service providers, including nurses, must not stereotype or generalize the needs of all persons with AD and their family caregivers even if they are of the same ethnic group. Instead, when providing care to persons with AD and when supporting their family caregivers, a cultural-sensitive approach is necessary. Nurses must have unbiased attitudes and effective communication skills to work within the cultural context of the persons with AD and their families. Nurses must include not only the ethnicity but also the gender, age, education, social class, and religion when assessing their needs and planning interventions (Gustafson, 2005).

Culturally competent nurses must be sensitive to their own potential bias and not to pass any judgment on the persons with AD or the family caregivers. If the cultural beliefs of the persons with AD or their family caregivers are in conflict with those of the nurse, the nurse need to respect their wishes. If, because of potential harm to the persons with AD or to others, it is not possible to integrate these wishes into the care plan, the nurses would help them to explore the sources of tension and possible avenues for addressing them. If the nurses find that their own biases are affecting their practice, they need to participate in educational programs or self-reflection to remediate any deficit in culturally specific knowledge, skills, or attitudes (Gustafson, 2005).

Since Canadian cultural values and beliefs are mainly rooted from the European culture, most formal and informal Canadian health care and social services are designed and operated under the influences of the European cultural backgrounds. Since generalizing all caregivers of the same ethnicity is not appropriate, cultural non-sensitive services often do not meet the needs of all Canadians. To provide care that meets the
needs of individuals with AD and the caregiver, person-centered care with a clear understanding of the individuals’ individual needs is the key for success.

To understand the individual needs, effective communication is essential. Language barrier often contributes to feeling of powerless in advocating their needs (Aoki, 2002). If not able to speak and understand the official languages, Canadians who do not speak or understand English may feel disempowered. For instance, the Chinese family caregivers often identify language barrier and negative interactions with the service providers as barriers to accessing services and support (Zhan, 2004). Therefore, having service providers who are able to speak and understand the languages of the service recipients, instead of ignoring the effects of language barriers, is essential to ensure their needs are met. The demands of the cultural-specific services depend on the number of persons with AD and the family caregivers. Resource allocation should be determined by the number of service users.

**Gender role-sensitive services**

Gender role differences affect the care of persons with AD and the needs of family caregivers to continue their caregiver roles (Chiu & Zhang, 2000; Fung, 1998; Gustafson, 2005; Lai et al., 2003). For instance, even though Sau Ying’s father had attended an AD caregiver support group for Chinese family caregivers, he did not perceive the meetings to be beneficial. Instead, he felt alienated from the other family caregivers when they were women caregivers who were wives, daughters, or daughters-in-law.

To ensure that family caregivers having the support they need for their caregiving roles, not only cultural-competent but also gender role-specific services are needed.
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Nurses, health care professionals, and social service providers need to be sensitive to the gender roles of different cultures.

As with cultural-competent services, the demands of gender-specific services depend on the numbers of service-users. The demands also depend on the degree of differences in the gender role expectations of the culture. For instance, gender role expectations of Chinese-Canadian women as caregivers may be very distinct from those of men as care receivers. Such differences are also more pronounced among the older generations of Chinese-Canadians whose values and beliefs are not much influenced by the Canadian culture. Since Chinese-Canadians are the largest non-European ethnic group in Canada, the demand for Chinese-Canadian cultural and gender role specific health care and social services is much needed.

Implications for Education

To prepare cultural-competent nurses to provide cultural sensitive care, nurses and other health care providers need to be taught of the importance of sensitivity to the persons with AD and their family’s needs. Their preferences and choices should be the primarily consideration when developing a plan of care (Gustafson, 2005). Implications for education include the following aspects:

Cultural-competent educational program

The nursing profession values and promotes individuals to take responsibility for their own health and well-being, informed choice, self-awareness, tolerance, and the ethics of care (Gustafson, 2005). To prepare cultural-sensitive nurses to meet the individual needs of persons with AD and their family caregivers, cultural-competent education is important. The curricula of both undergraduate and graduate nursing
education programs need to incorporate principles and practices to support the preferences and choices of persons with AD and the family caregivers.

Nursing education needs to include the awareness and the approach to practice in working with people of multi-diversities. Because of the differences in age, gender, education, life experience, work experience, and other influences, people of the same ethnicity often have different values and beliefs. In addition, to ensure nursing practice is cultural sensitive and cultural competent, novice nurses need the mentoring of experienced nurses to enhance their cultural competency.

*Gender role-sensitivity in nursing education*

Nursing education needs to be sensitive to the gender role differences in different cultures. The equality between men and women in the Western culture may differ from other cultures. Nursing education needs to include information about different ethnic groups having various degrees of gender equality. For instance, the expectations of the social roles of men and women in the Chinese culture are different from those of the Canadian culture. Nurses need to be aware of this kind of gender inequality and be gender role sensitive. They must not impose any personal judgment on the gender role inequality in different cultures.

Nurses must have sufficient knowledge on the ethical principles to provide them guidance about cultural and gender sensitive care. They need to be taught the ethical principles of justice, fairness, beneficence, and non-maleficence. If nurses find it difficult to work with clients who have values and beliefs that conflict with their own, they need the support from their work and from professional organizations to assist them in resolving such issues. Participation in educational programs and consciousness-raising
education are effective ways to achieve these goals. If resources are available, regular meetings and discussion on ethics with an ethics expert is useful in ensuring cultural-sensitive practice.

Implications for Future Research

Hinton (2004), after conducting a literature review on the care of an ethnic minority of elders who had AD, suggests that more information and knowledge is needed to better understand the impact of cultural influences on the care of persons with AD and to support family caregivers. From the research findings of this case study, I recommend future research to fill in the gaps and to expand the existing knowledge in the care of persons with AD:

Regular demographic data update

The demands of the cultural-specific services depend on demands of the services. Resource allocation should be determined by the number of service users. To obtain accurate number of persons with AD and family caregivers, demographic information should be collected and updated regularly. The demographic data to be collected should include age, sex, cultural background, years in Canada, and language spoken and written.

Influences of culture on a multicultural society

In a multi-cultural country such as Canada, the influence of other cultural values and beliefs on one’s own values and beliefs is inevitable. Daily contacts with people of different cultural backgrounds at work, school, social gatherings, business interactions, and other social activities influence a person’s values and beliefs. The impact of these influences depends on the length of time and intensity of the contacts.
Multi-cultural influences inevitably occur in a multi-cultural country such as Canada. Therefore, ongoing cultural specific research is needed to understand the impact of the ever-changing cultural effects. Future research is needed to develop ways of understanding individuals' experience and needs. With their experience and needs being clearly understood, health care and social services will then be in a better position to plan with the caregivers effective strategies to support their caregiver roles.

Differences of cultural values and beliefs among different generations

The research findings of this case study suggest that different generations of the same ethnic group have different values and beliefs in caregiving of persons with AD. The needs of Chinese-Canadians with AD and their caregivers are also different in different generations. Unless the context is the same, research findings of this case study are not applicable to all Chinese-Canadian daughter caregivers caring for their mothers with AD. Individual needs of the different generations of persons with AD and the family caregivers need to be explored by conducting ongoing research in the context of culture and historical socio-economic influences.

Limitations of the Study

The limitations of this research are mainly related to the limitations of secondary analysis and the case study. Generalization of the research findings is questionable in a case study. However, the purpose for conducting this case study is not to generalize the research findings to all Chinese-Canadian daughter caregivers (Polit & Hunglar, 1999). Rather, the intention is to explore the caregiving experience of this particular daughter caregiver in-depth and the insights that this case study may offer (Sandelowski, 1996).
Transferability of the findings is possible as it depends on the context of caregiving (Polit & Hunglar, 1999).

Since I have no access to this daughter to validate the research findings, the credibility of this case study may be questioned. In order to ensure the credibility, I have read the data carefully to ascertain the fit between the primary data and the new research questions before making the decision to use the primary data for secondary analysis (McArt & McDougal, 1985). Although I cannot discuss my interpretation and research findings with this daughter for validation, I can discuss with the primary researcher (McArt & McDougal, 1985; Thorne, 1994). Having no access to this daughter to collect further data is a limitation of secondary analysis because I cannot explore any category in-depth if the existing data does not provide adequate information for a meaningful analysis (McArt & McDougal, 1985).

Since I am a Chinese-Canadian, I may have more insight into the daughter’s caregiving experience. However, my own beliefs, values, and life experiences will influence how I interpret the data. To ensure the credibility of the case study, I need to be aware of my own biases that can potentially influence the data interpretation and, consequently, the research findings.

Summary

This qualitative secondary analysis case study explores the caregiving experience of Sau Ying, a Chinese-Canadian, who cared for her mother with AD. Because this case study is about one particular daughter’s caregiving experience, the major limitations of this study are the credibility and generalization of the research findings. In fact, any intention to generalize the research findings of this case study to all other Chinese-
Canadian daughter caregivers is inappropriate because transferability is appropriate only if the context the caregiving experience is similar.

The introductory chapter opened the discussion of this case study and established the reasons for conducting the case study and how this case study will advance nursing knowledge. I conducted a literature review to identify what is already known and the knowledge gaps in the area of family caregiving of persons with AD. In the methodology chapter, I discussed the theoretical and procedural orientation of this case study. I explained why I chose a secondary analysis qualitative case study with a narrative analytic approach as the method of conducting this research project. I described how I obtained the primary data for secondary analysis, how I analyzed the data, how I presented the case study, and how I managed the ethical considerations.

Subsequently, I presented and discussed the research findings from the data analysis. The research findings support previous research findings that ethnicity and culture influence but do not determine caregiving experience. In fact, family caregiving is multi-factorial and individual. Factors that affect caregiving include culture and the historical socio-economic context that includes life experience, education, other competing social roles, available and accessible support, and society's overall view on AD. To conclude this case study, I have discussed the implications of the research findings on nursing practice, education, and research.
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