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ABSTRACT

CHINESE WOMEN'S PERSPECTIVES
ON THE TRANSITIONAL PROCESS OF CARING
FOR SPOUSES WITH DEMENTIA FROM HOME TO INSTITUTION

This study describes the caregiving experience of elderly Chinese wives while caring for their spouses with dementia at home and in an institution. Conflict arises between health care workers and family caregivers because of a different perception about role expectations. A good understanding of how the Chinese wives conceptualize their caregiving role and assign meanings to the caregiving relationship in different contexts will enable the nurses to engage in effective care planning for the Chinese patients with dementia.

Phenomenology was the research design chosen for this study because of its unique focus on revealing the participant’s perception about a particular situation or experience. Data were collected through ten interviews with six Chinese women between the ages of 70 - 82 years. These women had cared for their spouses with dementia at home from one and one-half to three and one-half years before their spouses’ admission to a care home.
A reflective data analysis process resulted in a consistent description of the caregiving experience of the Chinese wives. An emotional experience, a sense of conflict, of the Chinese wives throughout the caregiving process, was identified as the predominant theme.

The major conclusions from the findings of this study are: (1) the Chinese women perceived their caregiving role and ascribed meanings to the caregiving process quite differently from that reported in the literature, (2) the context in which caregiving is embedded has to be critically examined in order to understand how caregivers conceptualise their caregiving role. The ascribed meanings to caregiving and its significance to the caregiving relationship have to be explored as they influence role conceptualization, and (3) the Chinese culture and the traditional values held by the Chinese women were major forces in creating the situations of conflict.
# Table of Contents

Abstract ....................................................................................................................... ii

Table of Contents ....................................................................................................... iv

List of Figure ............................................................................................................... viii

Acknowledgements ..................................................................................................... ix

CHAPTER ONE : Introduction ..................................................................................... 1

    Background to the Problem ................................................................. 1
    Conceptualization of the Problem ............................................................. 6
    Problem Statement ......................................................................................... 8
    Significance of the Study .............................................................................. 9
        Scientific Significance ................................................................................. 9
        Practical Significance ............................................................................... 9
    Statement of Purpose ..................................................................................... 10
    Definition of Terms ....................................................................................... 11
        Meanings .................................................................................................. 11
        Dementia ................................................................................................. 11
        Institutionalization ................................................................................... 12
        Primary Caregiver ................................................................................... 12
        Care Home .............................................................................................. 12
        Formal Caregiver .................................................................................... 12
        Informal Caregiver .................................................................................. 13
    Assumptions ................................................................................................. 13
    Limitations ................................................................................................. 13
    Summary ................................................................................................. 15
<table>
<thead>
<tr>
<th>Chapter Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Progression of the Disease</td>
<td>54</td>
</tr>
<tr>
<td>Making Sense of the Progression</td>
<td>55</td>
</tr>
<tr>
<td>Caregiver's Response to the Suggestion of Admission</td>
<td>56</td>
</tr>
<tr>
<td>Summary</td>
<td>57</td>
</tr>
<tr>
<td>The Third Phase -- Dealing with Institutionalization</td>
<td>58</td>
</tr>
<tr>
<td>Changes in the Caregiving Role</td>
<td>58</td>
</tr>
<tr>
<td>Feelings Associated with Institutionalization</td>
<td>59</td>
</tr>
<tr>
<td>Perception about the Institution</td>
<td>60</td>
</tr>
<tr>
<td>The Role of the Nurse</td>
<td>60</td>
</tr>
<tr>
<td>Communication with the Staff</td>
<td>61</td>
</tr>
<tr>
<td>Caregivers' Response to Institutionalization</td>
<td>62</td>
</tr>
<tr>
<td>Summary</td>
<td>66</td>
</tr>
<tr>
<td>The Caregiving Context</td>
<td>67</td>
</tr>
<tr>
<td>Traditional Values</td>
<td>67</td>
</tr>
<tr>
<td>Spousal Relationship</td>
<td>69</td>
</tr>
<tr>
<td>Caregivers' Other Life Stress</td>
<td>70</td>
</tr>
<tr>
<td>Family Support</td>
<td>72</td>
</tr>
<tr>
<td>Summary</td>
<td>73</td>
</tr>
<tr>
<td>Sense of Conflict</td>
<td>74</td>
</tr>
<tr>
<td>Before Admission (The First Phase)</td>
<td>74</td>
</tr>
<tr>
<td>Deciding to Institutionalize (The Second Phase)</td>
<td>75</td>
</tr>
<tr>
<td>Dealing with Institutionalization (The Third Phase)</td>
<td>77</td>
</tr>
<tr>
<td>Summary</td>
<td>78</td>
</tr>
<tr>
<td>Summary</td>
<td>79</td>
</tr>
<tr>
<td>CHAPTER FIVE: Discussion of the Findings</td>
<td>81</td>
</tr>
<tr>
<td>The First Phase -- Before Admission</td>
<td>81</td>
</tr>
<tr>
<td>The Caregiving Role at Home</td>
<td>81</td>
</tr>
<tr>
<td>The Caregiving Stress</td>
<td>83</td>
</tr>
<tr>
<td>The Second Phase -- Deciding to Institutionalize</td>
<td>84</td>
</tr>
<tr>
<td>Progression of the Disease</td>
<td>84</td>
</tr>
<tr>
<td>Making Sense of the Progression</td>
<td>84</td>
</tr>
<tr>
<td>Caregivers' Response to the Suggestion of Admission</td>
<td>85</td>
</tr>
<tr>
<td>The Third Phase -- Dealing with Institutionalization</td>
<td>86</td>
</tr>
<tr>
<td>The Caregiving Role after Admission</td>
<td>86</td>
</tr>
<tr>
<td>Perception and Role Expectation</td>
<td>87</td>
</tr>
<tr>
<td>Response to Institutionalization (Change)</td>
<td>89</td>
</tr>
<tr>
<td>The Caregiving Context</td>
<td>91</td>
</tr>
<tr>
<td>Culture and Traditional Values</td>
<td>91</td>
</tr>
<tr>
<td>Spousal Relationship</td>
<td>92</td>
</tr>
<tr>
<td>Family support</td>
<td>93</td>
</tr>
<tr>
<td>Caregivers’ Other Life Stress</td>
<td>95</td>
</tr>
<tr>
<td>A Sense of Conflict</td>
<td>96</td>
</tr>
<tr>
<td>Conflict as a Predominant Theme</td>
<td>96</td>
</tr>
<tr>
<td>The Concept of Conflict</td>
<td>97</td>
</tr>
<tr>
<td>Conflict as Experienced by the Chinese Wives</td>
<td>98</td>
</tr>
<tr>
<td>Conflict with Spouse</td>
<td>98</td>
</tr>
<tr>
<td>Conflict with Self</td>
<td>99</td>
</tr>
<tr>
<td>Conflict with Staff</td>
<td>99</td>
</tr>
<tr>
<td>Summary</td>
<td>100</td>
</tr>
</tbody>
</table>

**CHAPTER SIX: Summary, Conclusions and Implications**

| Summary and Conclusions | 102 |
| Implications for Nursing Practice | 106 |
| Implications for Nursing Education | 109 |
| Implications for Nursing Research   | 111 |

**REFERENCES**

**APPENDICES**

| Appendix A - Letter of recruitment | 122 |
| Appendix B - Letter to the Agencies  | 124 |
| Appendix C - Consent Form            | 126 |
List of Figure

Figure 1. The Conceptual Framework of the Study:

The Transitional Process of Caregiving
From Home to Institution .......................... 48
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CHAPTER ONE

Introduction

Background to the Problem

Dementia is a syndrome characterised by progressive intellectual deterioration. Cognitive changes include memory loss, disturbance in language use, change in perception, impaired judgement, and/or inability to problem solve and think in abstract terms. Personality changes, symptoms of paranoia and delusion, aggression, agitation and irritability are also evident in some cases (Katzman, 1986).

Dementia is primarily a disorder of the elderly. About 4-8% of those aged 65 and over suffer from moderate or severe dementia (Preston, 1986). The prevalence of dementia increases with age. It is estimated that 3-5% of those 65-79 years of age and 13-22% among those aged 80 and over have moderate or severe forms of dementia (Preston, 1986). These percentages translate to as many as 12,000 victims among British Columbians aged 65-79 and an additional 12,000 aged 80 and over.

The increasing occurrence of dementia in the aged is a serious concern. In Canada, another aspect which complicates the issue is the heterogeneity of the aging population related to rapid demographic change. In 1981, the
proportion of those 65 years old and over was particularly high for certain ethnic groups, such as the Jewish, Polish and Ukrainian (Ujimoto, 1988). In 1984, the immigration trend shifted from the traditionally European countries to predominantly Asian which comprises 47.5% of immigrations to Canada (Ujimoto, 1988). From 1980-1989, Hong Kong and China had the fourth and fifth largest number of immigrants to Canada (Statistics Canada, 1991), and the trend continues. Vancouver ranks third in immigrant arrivals, 65% of whom are Asians (Statistics Canada, 1991). Though most immigrants are young, about 32% are family immigrants (Statistics Canada, 1991). Due to the strong traditional value of extended family among the Chinese, one can assume that a good portion of the family immigrants are older adults.

In 1986, persons who were 65 years old and over accounted for 14% of the total population of the city of Vancouver. This translated to 63,560 males and 93,260 females (Vancouver Health Department, 1986). The estimated number of Chinese over 65 years of age was 75,665 which accounted for 48% of the total elderly population in Vancouver. As cited previously, Preston (1986) suggests that the prevalence of dementia increases with age. Taking a very conservative estimate from Preston's suggestion that 4-8% of elderly persons aged 65 years and over suffer from dementia, about 3000 or more Chinese over 65 years of age in Vancouver might be suffering
from dementia. With the current immigration trend, this number is likely to increase.

Research has shown that elderly people with dementia are frequently cared for at home (Chenoweth & Spencer, 1986; Miller, 1987; Bower, 1987; Hasselkus, 1988 & Lynch-Sauer, 1990). However, as dementia is a progressive disease, it gets to a point when individuals with dementia cannot be adequately cared for at home. The above notion, compounded by the current rapid demographic change in Vancouver, leads to the conclusion that more Chinese elderly people with dementia are likely to be cared for in health care facilities in the future.

At home, care of the individual with dementia may be provided by one primary care giver, usually a woman or, shared among several family members, with women assuming major responsibility for personal care. Usually, by the time the individual with dementia requires continuing care in a health care facility, the caregiving relationship and the caregiving role have been well established. However, the admission of the individual with dementia to a health care facility does not necessarily mean the discontinuation of the caregiving role and the severance of the caregiving relationship. Findings from past research have pointed out that institutionalization should not be viewed as a termination of the family caregiving relationship, but
rather, the continuation of the relationship (York & Calsyn, 1977; Shanas, 1979; Reifler, Cox & Hanley, 1981; Hook, Sobal & Jeffrey, 1982; Johnson & Catalano, 1983; Bower, 1988). Though there is no research to support the continuation of such a caregiving relationship among the Chinese, Chang (1981) suggested that it is not uncommon for hospitalized Asian patients to have many family members visit them.

Women are the prime caregivers of the elderly (Isaacs, 1971; Finch & Groves, 1982; Johnson & Catalano, 1983; Soldo & Myllyluoma, 1983; Cantor, 1983; Miller, 1987; Stone, Cafferata & Sangl, 1987; Hogan 1990) and, because there are proportionately more women then men (Hogan, 1990), this trend will continue. From their study in 1987, Stone, Cafferata & Sangl reported 72% of the informal care givers to the frail aged were women, with adult daughters comprising 29% and wives 23% of the study population (N = 2,201). Husbands constituted 13% of informal caregivers. Similar findings have been affirmed by previous research (Shana, 1979; Fengler & Goodrich, 1979; Cantor, 1983, Soldo & Myllyluoma, 1983).

Wives caring for their frail elderly husbands is not a new phenomenon. Golodetz, Evans, Heinritz & Gibson (1969) termed the female spouses as 'responsors' who provided a special kind of care which involved commitment and sympathy. Within the total caregiver population, 25% of them were 65-74
years and 10% were 75 years or over (Stone, Cafferata & Sangl, 1987) thus supporting the notion of 'the young-old caring for the old-old'. The fact that elderly wives will continue to play a significant role in caring for their spouses cannot be ignored.

For the Chinese, the traditional responsibility of caring for the elderly lies with the family (Lai & Yue, 1990). Age indicates dominance within the families, and it is an expectation that the children respect, support and care for their parents (Li, 1985; Chae, 1987). However, this proves to be difficult for some of the younger generation. Frequently, both husbands and wives from newly immigrated families have to work in order to maintain the family and get established. They may find little time to care for their elderly parents even if it is their wish to do so. Also, the influence of Western culture may have changed the attitude of many younger Chinese; they expect their parents to live independently and take care of themselves (Lai & Yue, 1990). As an Asian wife, a Chinese married woman is expected to devote herself to care of the home, the children and husband (Chang, 1981). Chinese, like most Asians, show their love for their families by caring for them while they are sick (Chang, 1981). It follows then that a Chinese wife will most likely assume the caregiver role when her husband suffers from a chronic illness such as dementia.
For the past two decades, family caregiving for individuals with Dementia has been the focus for research. Recently, researchers have shown some interest in exploring the meaning of caregiving while the individuals with Dementia are cared for at home (Chenoweth & Spencer, 1986; Miller, 1987; Bower, 1987; Hasselkus, 1988 & Lynch-Sauer, 1990). However, there is no study which explores the caregiving role of Chinese elderly wives when their spouses with dementia are institutionalized, and the meaning of caregiving as perceived by the Chinese elderly wives.

Conceptualization of the Problem

The caregiving relationship and the caregiving role are established while the individual with dementia is cared for at home. Within their own context, caregivers conceptualize their roles and establish the caregiving relationship in ways that are meaningful to them. Caregivers may perceive their roles and responsibilities differently depending on the context. Contextual elements may include the environment, the relationship with the individual with dementia, the developmental stage of the caregiver and the individual with dementia, the length of time in a caregiver’s role, ethnic background and many other such variables.

One has to appreciate that the caregiving role is not a static one. As
the context changes, caregivers are required to once again examine their roles. The transition from home to an institution creates a new contextual framework within which the caregivers have to re-conceptualise their roles, and reconstitute the meaning of caregiving.

A phenomenological study will provide an opportunity for the researcher to explore the meaning of caregiving and the caregiving role of Chinese elderly wives caring for their spouses subsequent to their institutionalization. An in-depth understanding of the life experience of caregiving of the Chinese elderly wives will enable nurses, as formal caregivers, to find ways to complement the informal caregiving role of the Chinese elderly wives within the institutional setting.

During her many years of working with elderly patients, the researcher has witnessed many occasions of conflict between the formal and informal caregivers (family members) due to the difference in perception of their roles. At times, such differences in perception placed the nurses and the informal caregiver in an adversarial, rather than a collaborative relationship. It has also been observed that when the caregivers are of different ethnic backgrounds than the nurse, the views of the role are even more discrepant. It is possible that this is due in part to the ethnic groups’ values and beliefs about caregiving, and cultural norms about caregiving practice for their family
members and the elderly persons. But such questions have not yet been examined. Therefore, given an understanding of the meaning of caregiving and the constitution of the caregiving role from the Chinese elderly wife's perspective, nurses may be enabled to work towards the goal of enhancing the quality of life and care of the patients by working effectively with their families.

**Problem statement**

Caregiving is a phenomenon which has received much attention and has been studied exhaustively in the general population, but little is known about how the family caregiving role is enacted, nor its meaning within the Chinese population. This research will focus on exploring what constitutes the caregiving role of Chinese elderly wives within the context of an institution, and how this role compares with the one previously established at home.

It has been well established that elderly wives continue to play a significant role in caring for their spouses subsequent to institutionalization. The nurses and the elderly Chinese wives, as members of the care team, must understand and appreciate how that caregiving role may have changed. Such mutual understanding should facilitate effective care planning and sharing of responsibilities, and consequently will enhance the quality of life and care for the patients.
Significance of the Study

Scientific Significance

Findings from this research will add to the body of knowledge of caregiving. No research topic can be 'overworked' to the extent that there are no quality contributions yet to be made (George, 1990). There have been many studies on the meaning of caregiving for the general aged population, but none of them is related to the perspectives of Chinese elderly wives during their spouses' institutionalization. This study is going to fill the gap of knowledge in this area. This study addressing the caregiving role of Chinese elderly wives will set the stage for further studies of similar nature in other ethnic groups. Comparisons can then be made; similarities and/or differences can also be identified. Research questions such as; 'do different ethnic groups of elderly wives perceive their caregiving role differently while their spouses are cared for in nursing homes?' can then be answered. It is hoped that the results of this study will raise more interest in nurse researchers to explore the rich and complex arena of cultural nursing which has been largely untapped.

Practical Significance

By understanding caregiving as perceived by the Chinese elderly wives,
the nurse will be able to identify the areas of discrepancy and conflict about
care issues for the institutionalised spouses of Chinese elderly women. Due
to the progression of dementia, caring for individuals with dementia becomes
more demanding and complex. The clarification of roles and expectations will
prevent role ambiguity and the overlapping of responsibilities of the formal
and informal care givers. It will also help in timely and effective care
planning, thus facilitating the delivery of quality care to patients with
dementia. Nurses will also learn about the cultural values and other variables
which they have to consider in planning care for the population of Chinese
elderly, and how they differ from those of the Anglo-Canadian elderly
population.

Statement of Purpose

The purpose of the study is to explore the caregiving role of Chinese
elderly wives while their spouses are in nursing homes, and to identify the
changes (if any) they perceive in their caregiving role subsequent to their
spouses’ move from home to institution. The researcher wants to explore the
changes in the role and meaning of caregiving as perceived by elderly Chinese
women upon their spouses’ transition from home to an institution, and how
the caregivers want the role to be changed or remain the same. The feelings
associated with the role changes they experienced will also be examined. The
researcher also wishes to explore how elderly Chinese wives conceptualize their caregiving role in the different contexts of home and institution, and identify the factors which influence the conceptualization.

**Definition of Terms**

**Meanings**

Those values, beliefs, and principles that people use to organise their behavior and to interpret their experience (Hansen, 1979 cited in Hasselkus, 1988).

**Dementia**

A term used to refer to a variety of conditions. "These conditions are characterised by intellectual deterioration in general, and specifically by failing memory, the inability to acquire and retain new information, and a resulting impairment of judgement and orientation" (Coons & Metzelaar, 1990. p.18). The above cognitive impairment can manifest itself in dysfunctional behaviors.

Behaviors exhibited by individuals with dementia may include disruptive and socially unacceptable behaviors such as hoarding, poor table manners, urinating in public, constant pacing etc., and inability to carry out activities of daily living caused by cognitive decline/impairment, not by reason of physical dysfunction/disability. An unawareness of safety for self and
others, and being an elopement risk are also included. For the purpose of this study, behavioral manifestations caused by cognitive impairment are the main determinant of dementia.

**Institutionalization**

The long term admission (more than three months) to any Continuing Care facility.

**Primary Caregiver**

Chinese elderly wife who resides in the same living quarters with her spouse with dementia. She should have been in the caregiving role for at least six months prior to the spouse’s institutionalization. Also, the Chinese wife must perceive herself as the primary care giver. The primary caregiver is responsible for the major part of the care, with or without assistance from others who may include family members, neighbours, friends and health professionals.

**Care Home**

Any continuing care facility, either privately owned or government subsidized. It may include an extended care unit attached to an acute hospital, a free-standing extended care hospital, or any intermediate care facility.

**Formal Caregiver**

Any care aide, nurse or other professional who contributes to the care
of the patient. The formal caregiver is usually an employee of a facility or agency, or receives a fee for service.

**Informal Caregiver**

A relative, a significant other or a friend who participates in the care of the patient.

**Assumptions**

It is assumed that (1) all participants of the study will be able to articulate their experience, (2) institutionalization of individuals with dementia occurs because they can no longer be cared for adequately at home, (3) with the current caregiving trend, wives will remain the largest group of primary care givers who will continue to play a significant role during institutionalization of their spouses, and (4) most Chinese elderly women still hold strongly to the traditional value of devotion to their husbands.

**Limitations**

One of the limitations of this study is related to the translation from Cantonese to English. As the researcher will conduct some of the interviews in Cantonese and translate them to English later, some of the original meanings may be lost. Another concern is related to culture. Due to the
traditional value of the Chinese that "silence is virtue" and inner feelings should not be exposed to strangers, the researcher may find it difficult to gain the trust of the participants such that they will talk freely about their feelings and experiences.

"...The artistic approach to qualitative inquiry emphasizes the irreplicability of the research process and product." (Sandelowski, 1986. p.29). Findings from this study cannot be generalised to the population of elderly wives in general as it relates to the unique experience of each Chinese elderly wife in an unique context. A qualitative approach obtains information about the meaning of a construct (Morse, 1986) and making sense of the setting. Unlike a quantitative study, it does not tell the distribution of a phenomenon.

Participants are chosen because they have experience related to the phenomenon under study. From a qualitative approach, the purpose of this study is to offer a new perspective of caregiving in a nursing home as conceptualized by the Chinese elderly wives, and the creation of new knowledge about caregiving. "The qualitative research reports on a setting pertain only to that point in time, the research may not be replaceable" (Morse, 1986. p. 188).
Summary

With the rapid demographic changes, the immigration trends, the prevalence of dementia among the elderly, and the lack of research in caregiving related to the Chinese elderly population, there is an urgent need to know about caregiving related to Chinese elderly with dementia. The literature review and the researcher's experience indicate that there is always discrepancy surrounding the caregiving role as perceived by the formal and the informal caregivers. This study, using a qualitative approach, has been designed to explore the meaning of the caregiving role as perceived by Chinese elderly wives while caring for their spouses with dementia. Findings from this study will help nurses to gain a better understanding of how Chinese elderly wives conceptualize their caregiving role. Such an understanding is going to help in identifying cultural variations and other factors which nurses need to consider when developing nursing interventions for other institutionalized elderly Chinese males with dementia.
CHAPTER TWO

Literature Review

In this section, the current state of knowledge about the meaning of family caregiving for the frail elderly and individuals with dementia while they are cared for at home will be reviewed. The frail elderly is a term frequently used to refer to elderly persons with physical disabilities or limitations, whereas dementia is a term which is often used to refer to the behavioral manifestations of mental/cognitive impairment. The meaning of caregiving in caring for the two populations—one with physical disabilities, and the other with cognitive impairment, can be quite different. It is important to review the literature in these two areas so as to identify any differences or similarities about the conceptualization of caregiving for the two populations.

Following the above, a literature review of the meaning of caregiving after institutionalization as perceived by the family will be presented. A good understanding in this area will enable the researcher to appreciate the similarities or differences about caregiving at home and in an institution as perceived by the caregivers. The knowledge gained in this area sets the stage for further discussion and comparison of the caregiving role as perceived by the Chinese elderly wives and the nurses. To be addressed also are the ethno-
cultural norms of the Chinese that influence patterns of caregiving, and the continuing debate of the impact of both modernization in Hong Kong and migration on these norms.

**Knowledge of Caregiving**

**The Meaning of Caregiving**

Caregiving can be defined as the activities and experiences involved in providing help and assistance to relatives or friends who are unable to provide for themselves (Pearlin, Mullan, Semple, & Skaff, 1990). "Whereas caring is the affective component of one's commitment to the welfare of another, caregiving is the behavioral expression of this commitment. Giving care to someone is an extension of caring about the person" (Pearlin, Mullan, Semple & Skeff, 1990, p.583).

On reviewing the caregiving literature, it is clear that family members/friends who are caregivers conceptualize or define caregiving in terms of behaviors or tasks performed. Care can range from one instance of assistance to long periods of full-time commitment (Barer & Johnson, 1990). The activity components of caregiving range from regular shopping, emotional reassurance, telephone contact, and running of errands to more or less
continued assistance with basic activities of daily living (ADLs) (Horowitz, 1985; Scharlach, 1987; Stone, Cafferata & Sangl, 1987; Hays, 1988).

Using a grounded theory approach, Bowers (1987) studied caregiving of middle aged women to their aged parents. Interviews were conducted with 27 parents and 33 daughters. Caregiving activities were conceptualized by purpose rather than by tasks. The five categories of caregiving were anticipatory, preventive, supervisory, instrumental and protective. The caregivers concluded that protective care was the most difficult and most important type of caregiving. The purpose of protective care was to protect the parent's self-image, rather than physical well being. In this research, caregivers saw themselves working to maintain their parents' identity. For example, they allowed their parents to repeat an activity even though it might cause physical harm. It is suggested that this emphasis on protective caregiving can cause conflict between the caregivers and the health professionals who have identified preventive or instrumental care as more important (Hogan, 1990).

Senses of self, of managing, of future, of fear or risk, and of change in role and responsibility were the five organizing themes of meaning in family caregiving identified in Hasselkus' (1988) study. Using an ethnographic approach, non-structured interviews were carried out with fifteen family
caregivers of the frail elderly at home. The care-receivers’ ages ranged from 63-99 years and they all required personal or instrumental care, or both, every day. The fourteen female caregivers included eight wives, four daughters and one daughter-in-law.

There is a distinct difference in how family caregivers conceptualized caregiving in Bower’s and Hasselkus’ study. In Hasselkus’ study, the meaning of caregiving focused on the impact of the experience on the caregivers--now and in the future. With Bowers’ study, the meaning of caregiving revolved around the care receivers’ well being. As noted, Bower interviewed both the caregivers and the care receivers (daughters and parents), whereas Hasselkus collected data from the caregivers only.

The experience of caregiving is interpreted as strain by Cantor (1983). In her study of family caregivers (N = 111) of the frail elderly, it was evident that all four groups of caregivers (spouse, children, relatives and friends) suffered from varying degrees of financial, emotional and physical strain. The cause of caregiving strain was also multifactorial (Isaac, 1971). The three common problems--immobility, incontinence and mental abnormality, and the constant presence of the individual with dementia in the home were all causes of strain. The caregiver’s age, physical/mental health and personality, and the competing demand for the caregiver’s time by the individual with dementia
and others (such as children and spouse) were also causes for strain (Isaac, 1971).

**The Meaning of Caregiving for Individuals with Dementia**

Financial, emotional and physical strain described by Cantor are synonymous to 'caregiver burden' in the caregiving of demented adults. Caregiver burden is defined "as the extent to which caregivers perceived their emotional or social life and financial status as suffering as a result of caring for their relative" (Zarit, Todd & Zarit, 1986, p. 261). A similar definition is used by George and Gwyther (1986) in their study of caregivers' well being.

Chenoweth and Spencer (1986) explored the experiences of families from the time of the earliest recognition of symptoms of dementia throughout the course of the illness by asking 413 families to complete a questionnaire. Of the 289 respondents, 130 (45%) were caring for their relatives at home, and 159 (55%) had relatives in nursing homes or other institutions. For the caregivers at home, the caregiving experience as stress or burden was similar to the findings discussed above. However, some stated that the caregiving experience had been positive.

In a study of 30 demented adults and their family caregivers, Hirschfeld (1983) identified mutuality as the main theme. Mutuality is defined
as the caregivers’ ability to find gratification in the relationship with the impaired person and assign meaning to the caregiving situation. It also involves the caregiver’s ability to perceive the impaired person as reciprocating by virtue of his/her existence.

Miller (1987) explored the perception of caring for cognitively impaired spouses through in-depth, semi-structured interviews with six husbands and nine wives. With the exception of two males, the other thirteen caregivers indicated that it was important to treat their spouses as normally as possible. Such perception of caring is similar to the protective caregiving as identified in Bower’s (1987) study. Caregiving also means taking control over most details of their impaired spouses’ lives.

Through the constant comparative method, Wilson (1989) explored the experience of family caregiving of twenty family caregivers for relatives with dementia caused by Alzheimer’s disease. The caregiving experience was described as the coping with negative choices wherein all possible alternatives are undesirable. The three stages of 'surviving on the Brink' consisted of (1) taking it on, (2) going through it, and (3) turning it over. The caregivers felt a deep sense of desperation throughout the process. Caregivers in this study were characterized as not being able to see beyond their present situation into the future.
Lynch-Sauer (1990) described the experience of caregiving for a family member with dementia caused by Alzheimer's disease by reviewing seven published works of family caregivers about caregiving experience. Change was identified as the meta theme. The core themes included the constant attempt to stay ahead, the loss of mutuality and reciprocity of the relationship, a progressive diminution of diversity in the relationship, the narrowing of the horizon for the caregivers, and an ever-present search for personal connectedness. Mutuality and reciprocity are similar to the findings of Hirschfeld (1983). However, the study is limited as the method would have made it impossible for the researcher to validate any of the data with the family caregivers. Also, the editing done before the publication might have taken away some of the original meanings.

**Perception and Meaning of Caregiving during Institutionalization**

Reifler, Cox and Hanley (1981) noted that families and staff members frequently disagreed on the severity of problems of the patients. Such findings imply that perception of caregiving can be different too. Shuttlesworth, Rubin and Duffy (1982) identified that the families and the staff had different perceptions as to whose responsibility it should be in the carrying out of certain tasks for patients in nursing homes (1982). Both families and staff saw some tasks as their responsibilities. It was further
suggested that such discrepancies in perception and role expectation could lead to role incongruence and affect role performance, and consequently affect patient care. The above researchers supported their findings in a subsequent study in 1983 (Rubin, Guy, & Shuttlesworth). The same task inventory used in the 1982 study was sent out to 64 staff members in two nursing homes with about one hundred residents in each home. Relatives were surveyed by mail. A total of 189 inventories were mailed, and 137 (73%) were returned. Seventeen items were identified as being significant in both studies. Role incongruence between the relatives and the staff member was seen to arise due to disagreement in defining the 17 tasks as the staff’s or the family’s responsibility. From the findings of the two studies, the researchers suggested the following five categories as the most problematic: (1) personalizing care, for example, making the room attractive and providing special food, (2) monitoring and ensuring the provision of care, (3) clothing needs, (4) grooming, and (5) providing reading material.

The above studies concentrated on differentiating the tasks carried out for patients in nursing homes while Bower’s study (1988) explored the meaning of caregiving in nursing homes. Bower (1988) used a grounded theory approach to study the family perception of 28 family members who had relatives in a nursing home. Her findings revealed that family members
perceived themselves as the monitors for quality of caring tasks carried out by the staff. Besides providing direct care, they were also there to 'fill in the gaps' and to teach the staff how to care for their relatives.

Preservative caregiving was identified as the most important by the family members. It included maintaining family connectedness, maintaining their relative's dignity, maintaining their relative's hope and helping their relative to maintain control of the environment. Families perceived maintaining family connectedness as their primary responsibility whereas the other three types of caregiving required collaboration between family members and staff. Preservative caregiving in this study is similar to protective caregiving as identified in Bower's (1987) earlier study on intergenerational caregiving. It is evident that the importance of preserving the relatives' self image is carried through from the home to institutional care setting. The family members' perception that they have specialised knowledge is supported by findings in two other studies (Chenoweth & Spencer, 1986; Hasselkus, 1988).

**Cultural Norms of Caregiving of the Chinese**

The Chinese from Mainland China, Hong Kong and Taiwan constitute the largest proportion of Chinese immigrants to Canada (Lai & Yue, 1990).
Therefore the discussion will centre on these three subgroups.

In Mainland China, the civil code of marriage states that children have the obligation to support and help their parents (Li, 1985). "The idea that when old, one has to depend on his or her children is still prevalent" (Li, 1985, p. 88). Despite the fact that many elderly people have a pension and other sources of income, they still prefer to stay close to their children. It is more common for elderly people to be cared for at home in the rural villages than in the cities. According to Li, the rate of hospitalization for the Chinese elderly persons is extremely low, as most elderly persons are cared for at home, and hospitalization is the last option.

Filial piety, a term used to refer to the duty of a child to respect and care for his/her aged parents, is also emphasized within the family structure of Taiwan. According to Chang (1981), this specific obligation has been translated into a specific law in Taiwan. However, research has shown that young people’s respect for elderly people is on the decline (Chang, 1981). Such findings imply that the contemporary younger generation may not be as eager to take care of their elderly parents at home.

"Until the mid-1960s, the care of the elderly in Hong Kong was seen primarily as the sole responsibility of the family" (Chow, 1983, p. 584). However, the rapid industrialization and modernization in Hong Kong for the
past two decades has eroded this traditional function (Wong, 1975, cited in Chow, 1983). According to Chang, findings in a study conducted by Hong Kong University (1982) concluded that the family remained the main source of support for elderly people. In this research, a total of 794 elderly persons were interviewed. For the 312 elderly persons who needed help with household chores, the source of support came mostly from the family--spouse (34%), children (22.4%), children-in-law (23.1%), and friends (19.6%). Formal community support was used only by two elderly persons.

Race (1982) conducted a study on residential and institutional services for the elderly people in Hong Kong which reaffirmed the fact that the family was the most prevalent means of providing support to elderly persons. Most of the elderly people admitted to an institution were individuals without a home, living alone, or had lost the support of the family. Unfortunately, the trend of supporting the elderly persons at home is not likely to continue as the elderly people experience a gradual decline of importance in the family structure (Chow, 1983). In a study about attitudes towards the elderly in 1982 by Lau, more than 90% of the sample agreed that elderly people should be cared for at home. However, the same high percentage felt that the government, as well has the responsibility of taking care of the elderly people.

Chang (1981) conducted a study in the United States to examine how
the elderly are perceived by young people of Chinese descent. A total of 400 college-age students were non-randomly selected (male = 225; female = 175). The three main subgroups included (1) American born (N = 108), (2) those from Taiwan (N = 149) and (3) those from Hong Kong (N = 121). The fourth group was "other" (N = 22) which included students from the other parts of South East Asia. The Hong Kong group scored significantly higher than the American-born group in recognizing the practical needs of the elderly people and felt that they were entitled to care by the family. However, there were no significant differences between the America-born group and the two other subgroups. Most of the American-born Chinese and those from Hong Kong stated that they would not live with the elderly people if they had a choice. However, the majority of those from Taiwan stated that they would prefer to live with the elderly. The above suggests that one cannot apply the traditional values and cultural norms of caregiving across the board, as diversity also exists within ethnic groups.

The Impact of Modernization and Migration on Cultural Norms

As discussed previously, modernization could also influence cultural norms. "The ability and desire to adhere to traditional values and behaviour
will depend to a great extent on the socio-cultural environment of their country of origin" (Chang, 1983, p. 258). Chow’s study (1983) identified that the Chinese’ cultural norms of caring for the elderly persons at home no longer held true for the younger generations in Hong Kong. It was partly due to the Western influence and the process of modernization.

As well as the impact of modernization in the home country, the process of migration over the years has had a profound impact on cultural norms. Migration is the process by which an individual or group moves from one physical and social environment to a new one (Morrissey, 1983). The Chinese emigrated to Canada as early as 1800’s. The greatest influx of Chinese, however, was between 1881 and 1884, 15,000 men came from China to work as railway workers (Lai & Yue, 1990). This group of immigrants left their families in China, had very little or no education, could not speak English, and worked long hours for poor wages. Their reasons for migrating to Canada were to earn money to support their families in China.

The group of Chinese who emigrated to Canada in 1800’s worked as railway workers and was isolated from the rest of the Canadian society by language barriers and their low social status. They brought with them very strong cultural values, and they socialized only with their fellow countrymen. This group of Chinese was also discriminated against by the Canadians.
In 1923, the passing of the Exclusive Act virtually stopped the entry of Chinese into Canada (Starkin, 1986 cited in Lai & Yue, 1990). Immigration slightly increased after World War Two, and relatives of the Chinese residents were allowed to come to Canada. From 1962 to 1967, the creation of the 'point system' in the Canadian immigration law and the riot in Hong Kong (1967) again attracted a large number of immigrants. The 'point system', still in effect, was based on specialized/professional skills of the applicants, age of the applicants, and the prospect of finding a job in Canada. If the applicant has enough points, he/she is then allowed to emigrate. Immigrants from the period of 1962 to 1967 included young professionals, skilled labourers, and dependent family members which include elderly parents. Some of the older immigrants brought with them some of their cultural values, beliefs and norms. However, the younger immigrants may not have had the same value system as the older Chinese. It would be fair to suggest that the immigrants from World War Two to 1967 were a diverse group; age differences, attitudes and educational/family background being some of the characteristics.

fourth in number of immigrants to Canada \( (N = 7,752) \) followed by the People’s Republic of China \( (N = 69,093) \). Vancouver was the third most popular metropolitan area chosen by immigrants, and 65% of Asians settled here (Logan, 1991). This group of immigrants is mostly the young labour force (Kalbach, 1990), with 56% under the age of 30 (Logan, 1991).

In anticipation of the imminent take-over of the Hong Kong Colony by China in 1997, another wave of immigrants from Hong Kong swept into Canada in the late nineteen eighties. This group includes skilled workers, professionals, individuals with investment money and individuals who are retired (Lai & Yue, 1990). They bring with them money and wealth. Though their financial situation may not be as favourable as the investors and the retired people, most professionals have brought along some assets to Canada.

In 1989, 45% of the total immigrant population were family immigrants (Logan, 1991). This pattern has not changed for the past decade with family members accounting for 39% of the total immigrants to Canada (Statistics Canada, 1991). Family members include spouses, dependent children and parents. The large percentage of family immigrants suggests that the Chinese still value the family structure/system. However, Lai and Yue (1990) argued that Western culture has also changed the traditional values of
some younger Chinese in Canada. In order to get established in the new
country, it is sometimes a necessity for both husband and wife of a newly
immigrated family to work outside the home. Even if it is the younger
generation's wish to take care of their elderly parents at home, it may not be
possible as there will be nobody at home to assume the responsibility. From
the above, one can appreciate that cultural norms are not static, but can alter
due to changes in environment and circumstances.

**Summary**

From the above discussion, it can be concluded that family members
conceptualise caregiving differently depending on the caregiving context.
Caregivers perceive caregiving in a different light when caring for their
relatives with dementia at home and in an institution. When caring for their
relatives in nursing homes, caregivers perceive themselves in a monitoring and
a teaching role; while their role when caring for their relatives at home is one
of preserving dignity and independence, despite the risks of physical harm to
the person(s) receiving care. Caregiving is conceptualized in terms of tasks
performed for the care receivers with emotional experiences attached to it.
The caregiving experience is one of strain and burden, and there is much
negativity attached to the experience of caregiving. Most of the studies have
concentrated on the caregiving experience while the individuals with dementia are cared for at home. In the few studies which addressed caregiving in nursing homes, role incongruence between family and staff members is an area of great concern. To the researcher’s knowledge, there is no study yet which addresses elderly wives’ perceptions of caregiving subsequent to the institutionalization of their spouses with dementia.

There is no specific mention of the ethnic make up of the study population in most studies related to caregiving of individuals with dementia. As most studies were done in the United States, the researcher assumes that the study groups could (but likely did not) represent a cross section of all ethnic groups. There is no study which specifically addresses the meaning of care giving from the perspectives of a certain ethnic group of elderly persons.

The Chinese is an ethnic group with a rich heritage and culture. The family system is important and the family’s responsibility to take care of the elderly parents is emphasized. However, the process of migration and modernization has had a mitigating effect on this cultural norm. Therefore, it would be fair to suggest that, during the time of sickness, most Chinese elderly people may have to depend on their spouses to care for them, as support from their children may not be readily available. Due to the progression of dementia and the strain it poses on caregivers,
institutionalization of the individual with dementia eventually becomes a necessity. As most elderly Chinese wives still hold strongly to the traditional value of devotion to their husbands, it is most likely that they will continue with the caregiving role after their spouses’ admission to an institution. As the elderly Chinese population in Vancouver is increasing, it is important for health care professionals to gain more knowledge about the caregiving experience of the elderly Chinese wives in a specific context, as such knowledge will facilitate care planning. However, there has been no study which explores the caregiving role of elderly Chinese wives subsequent to the institutionalization of their spouses with dementia.
CHAPTER THREE

Methodology

The focus of this study is to explore the lived experience of Chinese wives while they care for their spouses at home and in the institution. A phenomenological approach is used. This chapter describes the phenomenological approach, in addition to the criteria and selection of participants, the ethical considerations, the process of data collection, and the data analysis.

Research Design

The research design chosen for this study is phenomenology which is the study of human experience. The goal of this design is to describe the total systematic structure of lived experience of individuals in relation to the phenomenon under study (Omery, 1983). In order to describe lived experience, the natural attitude prescribed through one’s biography must be set aside (Merleau-Ponty, 1964 in Munhall & Oil, 1986). 'Bracketing' is the process whereby any presupposition about the experience under study is set aside as the aim of phenomenology is to explore the perception of the
participants about a particular situation or experience.

In order to achieve the goal of having the participants relate their experience openly and fully, the researcher needs to immerse herself in the physical world of the participant, "by attending to the realities constituted in individual experiencing" (Munhall & Oiler, 1986). Trust and active interaction are keys to obtaining valid data. The researcher must show genuine interest in the subject under study and in the participants, so that the participants will feel free to discuss their experience and feelings.

Selection of the Study Group

Criteria for Participation

All Chinese women recruited for the study had to be over 60 years old. The Chinese women must have perceived themselves as primary caregivers of their spouses with dementia at home and continue to carry on the caregiver role subsequent to their spouses' institutionalization. The Chinese women recruited for this study included immigrants and women who were born and raised here. Both English and Cantonese speaking Chinese women were included in the study.

In evaluating samples, Morse (1986) suggested the criteria of appropriateness and adequacy. "Appropriateness refers to the degree in which
the method of sampling "fits" the purpose of the study as determined by the research question" (Morse, 1986, p. 185). For qualitative research, an appropriate sample will provide understanding and insight (Morse, 1986). Therefore, Chinese women who are caregivers of their spouses with dementia is an appropriate sample to provide understanding about the experience of caregiving.

**Process for Soliciting Participants**

The directors of care of a number of extended care units and intermediate facilities in the Lower Mainland were contacted to identify elderly Chinese wives who, subsequent to their spouses' admission to the institution, still carried on the caregiving role. The researcher met with the prospective group of Chinese wives individually to ascertain that they met the criteria. The researcher explained the study to each of the prospective participants. The verbal explanation was accompanied by a letter of recruitment, in both Chinese and English (see appendix). The letter described the purpose of the study, the procedure and time involvement. The researcher ensured that the prospective participants fully understood the process through clarification of points and answering questions.

The number of participants was not pre-determined at this stage as the adequacy of qualitative research is evaluated by the quality, completeness,
and the amount of information from the participants, rather than by the
number of cases (Morse, 1986). "... sampling ceases when the researcher
gains understanding of the situation or setting, obtains coherence, does not
collect any new information, and cannot locate negative cases" (Morse, 1986,
p.186). At the end of the data collection phase, a total of six participants had
been interviewed for the purpose of this study as no more new themes
emerged after the interviews with the last participant, and the researcher had
gained a good understanding of the topic under study.

Data Collection

Ethical Considerations

The rights of the participants in this study were ensured through the
use of informed consent and the maintenance of confidentiality. In keeping
with the requirements of the University of British Columbia, the research
purpose, process and the benefit of the research were explained to the
participants. All participants signed a consent and understood that they could
withdraw from the study at any time they wished.

All participants were assured that confidentiality would be maintained
throughout the whole research. Any data deemed sensitive by the participants
were not included. In order to maintain confidentiality, taped recordings and
subsequent transcripts did not identify the participants. Individual code numbers were assigned to the participants. No one had access to the list of code numbers except the researcher. The participants were assured that the collected data would be used only for the purpose of this study, and would be shared only with the faculty members on the Thesis Committee. The participants were also informed that none of the data would be released to the institutions where recruitment took place.

Discussing and revealing one’s life experience can sometimes be very trying and may rouse deep-rooted and concealed feelings. The researcher was sensitive to the reaction of the participants to the whole process. Two participants expressed sadness during their first interview, but were able to regain their composure and carried on with the interview.

Data Collection Procedure

The researcher conducted and transcribed all of the interviews. The researcher is a Chinese person who emigrated to Canada from Hong Kong in 1975. She is fluent in both Chinese and English, and has been working with the elderly for the past fifteen years. Six participants were interviewed. Two interviews, each lasting about one hour, were carried out with four participants. One participant refused to be interviewed again; another participant was in the hospital when the second interview was requested. The
aim of the first interviews was to provide opportunities for the Chinese women to describe their experience from their own perspectives. The second interviews were for clarification, for validation of identified concepts with the women, and for further exploration of the areas which were significant and pertinent to the women.

Data collection was done through unstructured, face to face interviews with the participants. With four participants, the interviews took place at the participants' homes. For the other two participants, interviews were conducted in the conference room of the care home, which was the choice of the participants. Two of the participants spoke fluent English and they requested the interviews to be conducted in English. Interviews with other participants were conducted in Cantonese.

Two of the participants refused to have their interviews tape recorded. The process was difficult for the researcher as she had to take notes and listen to the participants at the same time. For the interviews conducted in English, the tape recording was transcribed verbatim by the researcher. For those interviews conducted in Cantonese, the tape recording was transcribed verbatim before the translation to English took place. The data collection process was terminated when the researcher had gained an in-depth understanding of the phenomenon under study, recurring themes were
identified, and no more new themes evolved.

During the interview process, the researcher took a holistic approach to the subject under study. The intent was to preserve the natural spontaneity of the participants' lived experience (Oiler in Munhall & Oiler, 1986). The researcher tried not to interrupt, and only asked questions when it was necessary to clarify what the participants were relating. The researcher assumed a posture of unobtrusive presence with the participant (Oiler in Munhall & Oiler, 1986), as the researcher wanted the participant to feel that she could relate her experience and feelings freely. Some trigger questions were used to begin the interview. During the process, the researcher was aware that she had to use the technique of 'bracketing' as discussed earlier. The researcher found that validating the participant's feelings during the interview was important as the demonstration of empathy by the researcher enabled the participants to relate their experience more freely. One of the participants stated, "it is nice that somebody is asking me how I feel, trying to understand and listening to me."

Data Analysis

The data analysis follows Reimer's method which is based on methodology developed by Colaizzi (Munhall & Oiler, 1986). It includes:
(1) the reading of the entire transcript in order to get a sense of the whole, (2) a second reading to extract significant statements about the phenomenon, (3) the elimination of redundancies; any repeated statements are not included, (4) the formulation of meaning units from the significant statement, (5) clustering of the meaning units into emerging themes, and (6) the formulation of an exhaustive description through synthesizing and integration of the essential themes. In analyzing the data, there were two concerns which the researcher had to bear in mind, (1) to characterize the essential meaning of what the participant’s description reveals about the subject under study, and (2) to remain as faithful as possible to the participant’s original characterization (Reimen in Munhall & Oiler, 1986). Thus, objectivity and 'bracketing' were the techniques that the researcher used throughout the process.

The researcher transcribed each interview immediately afterwards, and read the interview a few times in order to get a sense of the whole. Significant statements were identified, coded and clustered into meaning units. Subsequently, four major concepts emerged from the clustering. The four major concepts are (1) before admission (the first phase), (2) deciding to institutionalize (the second phase), (3) dealing with institutionalization (the third phase), and (4) the caregiving context. The findings also suggested that there was a sense of conflict as caregivers went through the three phases. A
conceptual framework has been developed to enhance the reader's understanding of the caregiving experience of the Chinese wives and to facilitate the presentation of findings.

Summary

Phenomenology, a qualitative research approach was chosen to explore the lived experience of Chinese wives while caring for their spouses with dementia at home and in an institution. The method provided direction for the selection of participants, ethical issues to be considered, data collection, and data analysis.

Reimer's method enabled the researcher to use a systematic approach to data analysis. Four major concepts, each with a number of meaning units, emerged after the completion of the process.
CHAPTER FOUR

Presentation of Findings

Based on the methodology presented in Chapter Three, the researcher interviewed six elderly Chinese wives who met the criteria. The researcher asked these women to describe their lived experience of caring for their spouses at home and in the institution. The unstructured interviews provided a rich bank of data from which four major concepts emerged. Presentation of the findings is organised to follow the conceptual framework developed by the researcher which encompasses the four identified concepts: (1) before admission (the first phases), (2) deciding to institutionalize (the second phase), (3) dealing with institutionalization (the third phase), and (4) the caregiving context. Conflict, an emotional experience of the caregivers when going through the three phases, is also discussed.

In order to familiarize the readers with the participants, a brief description of their demographic characteristics will be presented. For purpose of clarity, the Chinese wives will be referred to as caregivers in the report of findings.

A Description of the Participants

The six participants were recruited from three different care homes;
two of them were from an extended care unit attached to a small acute care hospital, three of them were from a private intermediate care facility and one was from a government subsidized intermediate care facility. All three facilities are located in the Greater Vancouver Region.

The Chinese wives who participated in this study ranged from 70 to 82 years old. The length of time these women took care of their spouses with dementia at home before institutionalization ranged from one and one-half years to three and one-half years. Two of the participants were born in Canada, and the other four emigrated to Canada with their spouses during the last two decades. Two participants emigrated in 1980 with their families; one woman came to Canada in 1982, and the other arrived in Canada in 1977. The native born women are fluent in English and the other four speak only Cantonese. Among the four women who emigrated from Hong Kong, three have only elementary school education while the fourth is more educated. This woman had a high school education and obtained a teaching certificate from a vocational college in Hong Kong. She had been a teacher for many years before her retirement. During their years in Hong Kong, the other three women were housewives, carrying out the traditional duties of taking care of the household, the husband and the children. The two Canadian-born women both had a high school education. One woman spent all her married life
helping her husband run his restaurant, and the other devoted much of her time to volunteer work besides raising her children.

All four women who emigrated to Canada came here through sponsorship by their children. Three from the group have accustomed themselves to Canadian life (though they can not speak any English) as their families are always there to support them. The other woman, though she has been in Canada for ten years, still feels isolated and wishes that she could go back to Hong Kong. She stated that she could not do anything as she had to stay to take care of her sick husband. Family support is evident in this case, but not as strongly as the others.

Three of the Chinese women have severe health problems; one has rheumatic heart disease, one is still going through rehabilitation after recurring strokes and falls, and a third one has heart disease and chronic renal failure which requires haemodialysis four times daily. The other three, except for minor ailments, are in relatively good health.

Five of the six participants had a good relationship with their spouses and definitely saw themselves in the role of the primary caregivers. The sixth participant was not quite certain whether she was the primary caregiver. This woman watched her spouse while he was cared for at home. She did not participate in any physical care as she had to cope with a very serious health
The homemaker or the son were the active caregivers. It could not be clearly established whether this woman was the primary caregiver. However, the researcher decided to include her experience in the study as she presented a very different perspective on caregiving.

**The Conceptual Framework for the Study**

The conceptual framework developed for this study includes the four major concepts of (1) Before admission, (2) Deciding to institutionalize, (3) Dealing with institutionalization, and (4) the caregiving context.

The first three concepts form the temporal phases which describe the transitional process of caregiving from home to institution. The fourth concept 'the caregiving context' affects all three temporal phases and how the caregivers conceptualize their caregiving role. Figure 1 depicts the three temporal phases, the contextual framework in which caregiving is embedded, and the predominant and mixed feelings of conflict experienced by the caregivers as they went through the different phases.

Under the concept 'before admission', the meaning units include, (1) doing care at home, (2) the feelings associated with the care process, and (3) the caregivers’ response to the care process. (1) Progression of the disease, (2) making sense of the progression, and (3) the caregivers’ response to the
suggestion of admission (of spouse to care home) form the meaning units for the concept 'deciding to institutionalize'. The meaning units used to formulate the concept of 'dealing with institutionalization' are (1) changes in the caregiving role, (2) feelings associated with institutionalization, (3) perception about the institution, and (4) the caregivers’ response to institutionalization. Traditional values, spousal relationship, the caregivers’ other life stress and family support are the context within which caregiving is embedded. They affect how the caregiver conceptualizes her caregiving role for all three temporal phases.

Using the conceptual framework developed for the study, the researcher will describe the experience of the Chinese women while caring for their spouses with dementia at home and subsequent to their admission to an institution. The description of the caregiving experience and the associated emotion--a sense of conflict will be presented following the identified meaning units of each temporal phase. In order to depict the experience of the Chinese women accurately, quotations will be used throughout the presentation of findings.
Fig 1. The Conceptual Framework of the study

The Transitional Process of caregiving
from Home to Institution
The First Phase--Before Admission

The meaning units included in this concept are (1) doing care at home, (2) feelings associated with the care process and (3) the caregivers' response to the care process.

Doing Care at Home

Cooking, feeding, washing and bathing were the major aspects of physical care identified by the Chinese women. At first, the caregivers were able to care for their spouses on their own. Eventually, as their spouses' condition deteriorated, the caregivers found that they had to seek help, either from their family or from other sources of support. All of the caregivers got help from the home care services of the local health unit. Usually, homemaker services ranged from two hours every other day to two hours everyday. Two of the caregivers received some respite as their spouses went to an adult day program three times a week. When the caregivers were alone with their spouses and they encountered certain crisis situations, for example, the spouse falling or the spouse going missing because of wandering, they usually sought outside help by calling the police, firemen or ambulance.

The demand for more care increased according to the progression of dementia. Instead of just preparing the meals and giving the necessary supervision, three of the caregivers had to start feeding their spouses, and in
one case, the caregiver had to take over an hour at each meal to feed her spouse. In all six cases, the repeated cleaning up required by the spouses because of incontinence of bowel and bladder took a major part of the caregiver's day. It is one of the care aspects with which the caregivers had difficult coping. Due to the presence of family support in all cases, the Chinese women did not have to run errands outside the home. They all seemed to concentrate very much on maintaining the physical well being of their spouses.

Besides the physical care, the caregivers also took on a protective role. They were always worried about the safety of their spouses at home. The constant fear was that the spouses would hurt themselves because of the frequent falls. One of the women was so concerned about her spouse's safety that she had him restrained in a wheelchair.

The caregivers also had a "monitoring" role. Wandering and lack of judgement are common manifestation of dementia. Four of the caregivers had the experience of having to watch over their spouses all the time, as the spouses tended to wander away from their home. As one caregiver said, "you have to keep an eye on him all the time...you turn around and he's gone!" There was a continuous demand on the caregivers as the wandering behavior did not stop during the night.
One of the elderly Chinese women carried out her monitoring role in an interesting way. She was physically in the house with her spouse all the time, but she could not give any physical care to her spouse due to her poor health. She watched over her husband, and asked for help from her son who lived in the basement when necessary. If her spouse soiled himself, she would ask her son to clean him up. If her spouse fell, she telephoned the fire department for help.

With the exception of one, all caregivers attempted to take a preventative role in caring for their spouses at home. However, one caregiver had a 'take it as it comes' attitude and dealt with the crises when they occurred. However, this caregiver had good reasons for doing so which would be discussed later.

**Feelings Associated with the Care Process**

As related by the caregivers, the sense of frustration was paramount. They felt frustrated for various reasons. One caregiver was frustrated because her spouse was 'a picky eater'. One was frustrated because her spouse would not follow instructions when she was dressing him. She was also frustrated about herself. This woman had just recovered from a stroke, and she required two hours to complete a daily task which would normally have take half an hour. When monitoring their spouses’ wandering behavior, the caregivers
were frustrated because their spouses "just won't listen", and they never knew what was going to happen next. As one of the caregivers put it, "you will get a phone call from a stranger, and then you will have to trot all the way down to China Town to pick him [the spouse] up." Words like frustration, burden, trouble, worry, being scared, difficult, kept surfacing when the researcher asked the caregivers about the caregiving experience. As one caregiver described her feelings when her spouse was missing from home, "It was worrisome...whenever the phone rang, my heart jumped." The stress felt by the caregivers was immense as one caregiver described her experience,

I got very scared; he had a bad temper and wanted to hit me all the time. There was nothing I can do about it, I had to carry on. I worried about him all the time. It was a burden...it was just getting too much, not just his incontinence but everything. I kept on saying that if it carried on, for sure I would die before him.

From the above, the researcher sensed the notion of desperation and powerlessness which was validated by the caregivers in the subsequent interview.

The woman who did not give the physical care to her husband expressed her feeling in a very different way. She used, what the researcher termed, the 'block off' technique. This woman has a severe health problem
and her own health needs frequently competed with those of her spouse. Consequently, she did not participate actively in the care of her spouse at home. In order to cope with the situation, she blocked herself from the illness of her spouse by making statements such as "I can't remember," and "I don't really know."

The Caregivers' Response to the Caregiving Process

Physical manifestation of strain was identified by all caregivers. It took various forms ranging from loss of appetite, loss of sleep, loss of weight to palpitations. One of the women had a second stroke and one had to be admitted to hospital for a week due to a flare up of her heart condition. Emotionally, the caregivers felt drained and exhausted. The worries, the fear and the frustration were constant elements in their lives, and there was no sense of relief. All the women, except for one, believed that it was their responsibility to take care of their spouses when they were sick, and they would do everything they could to keep their spouses at home. It is this belief which helped them to carry on as long as they did before the spouses' admission to a care home.

Summary

Maintaining the spouses' physical well being was considered the most important aspect of care as perceived by the Chinese wives while taking care
of their spouses at home. The caregivers also carried on with a monitoring role and preventative role in order to safeguard the physical safety of their spouses. Strain and stress, both physical and emotional, were associated with the caregiving process. As the care demand increased due to the progression of dementia, caregivers felt more frustrated and a sense of desperation and powerlessness prevailed. The length of the phase before admission ranges from one and one-half to three and one-half years.

**The Second Phase--Deciding to Institutionalize**

Progression of the disease, making sense of the progression, and the caregivers' response to the suggestion of admission form the major meaning units of the second phase.

**Progression of the Disease**

The disease process started about seven or eight years prior to institutionalization for all the spouses of the women in this study, and the deterioration in mental and physical function had been progressive. The deterioration in cognitive function included increased confusion, loss of judgement, inability to follow instructions, and loss of short term memory. The decrease in cognitive function affected the physical function of the spouses, and in some cases led to the manifestation of inappropriate behaviors.
Some of the spouses lost the ability to carry out the activities of daily living, such as ambulation, feeding, dressing and grooming. The spouses of two women in the study were urinating everywhere in the house, and the spouses of four women had a history of wandering. Physical aggression was evident in only one case. Due to the lack of judgement, perception and co-ordination related to the progression of dementia, falls seemed to be a common occurrence in all six cases. The demand for physical care, monitoring and protection rose according to the progression of the disease.

The women made the decision to admit their spouses to a care home only when the condition of the disease was so severe that they could not manage any more. None of the women in this study had considered admission of their spouse to an institution as an option. They did not realise that they were not coping until somebody pointed it out to them. In all six cases, the consideration of admitting the spouse to a care home was at the suggestion of the family or health professionals.

**Making Sense of the Progression**

It was interesting to note that all the women attributed the manifestation and the progression of the disease to the spouses’ personality. Without exception, all the women viewed their husband as being stubborn and chauvinistic all their lives. All the women felt that their spouses should know
better and behave properly. Some quotes to substantiate the above are: "he should sit still when he was told to do so, but he never listened. He has always been like that". "He has always been very fretful, very chauvinistic." "If he listens and doesn’t act up, then he is not going to fall. He asked for it sometimes...he never listens to me anyway." Initially, I thought that the women lacked knowledge about the disease when I received the above information from the first interviews. In subsequent interviews, I took the time to explain the disease process and the behavioral manifestation. The information did not change the women’s perception about their spouses’ behaviors.

**Caregivers’ Response to the Suggestion of admission**

The decision for seeking admission of their spouses to an institution was difficult for five of the women. Some of the comments from the women were, "I don’t really have much choice as my health is bad," "I don’t really want him to go but I know I cannot take care of him any more," "it was a hard decision for me. I lost a lot of weight and I was worried."

One woman suffered from depression for about one year after her spouse’s admission to the care home, as she stated, "there was no spark in life...only a sense of hopelessness...I was very depressed." Immediately after her spouse’s admission to the care home, she put her name on the waiting list.
At that time, she felt that there was no purpose in life, and she might as well go to a care home.

In retrospect, all the women felt that they had made the right decision. In one case, the woman felt that her spouse was better cared for after his admission to the care home. The woman who suffered from depression has changed her mind about wanting to go to a care home. She stated, "time is the best medicine, I don't feel so bad now when I see him."

Before the decision to seek admission, none of the women would have considered sending their spouses to a care home as an option. At the time of this study, which was about one and one-half years after their spouses were admitted, all except one woman would consider the option of caring for their spouses at home, given the current mental and physical condition of their spouses.

Summary

Progression of the disease was characterized by the deterioration of mental and physical function. Wandering and inappropriate social behaviors were evident in most cases. Frequent falls, wandering and incontinence of bowel and bladder were common occurrences. Caregivers attributed the cause of the inappropriate behaviors to the spouses’ personalities, rather than the progression of dementia. The caregivers never considered the admission of
their spouses to an institution as an option until the suggestion was made by the family or health care professionals. Making the decision had been a difficult process for most of the caregivers. However, in retrospect, all caregivers felt that they had made the right decision.

**The Third Phase -- Dealing with Institutionalization**

The meaning units that comprise the concept of 'dealing with institutionalization' are (1) changes in the caregiving role, (2) feelings associated with institutionalization, (3) perception about the institution, and (4) the caregivers’ response to institutionalization.

**Changes in the Caregiving Role**

There was a definite change in the caregiving role as perceived by the caregivers. Instead of concentrating on giving physical care, the role for one woman had shifted to one of giving emotional support. Besides keeping their spouses company, the wives did extras for their spouses, such as tidying up their drawers, helping the nurse to transport the spouse from one place to the other, and washing the spouses’ hand and face after meals. Two of the women carried on with their monitoring role -- not to monitor their spouses wandering behavior, but to monitor the consumption of food and fluid. One woman stayed until supper time just to ensure that "he [the spouse] has at
least one decent meal." The other woman, who visited almost every day, kept on feeding jello to her spouse as she was worried that he did not have enough fluid.

Two women felt that it was important to maintain their spouses' dignity and identity. One woman was still very much concerned with the safety of her spouse. She wanted her spouse to be restrained as "it is worse if he falls."

The woman who never gave any care to her spouse at home did not visit, but ensured that her spouse was taken care of financially, as his pension was not adequate to cover the care home charges. With all the other women, their visiting pattern varied from visiting every day, two to three times a week to once every week. The visits of most of the women became more infrequent and their length of stay became shorter when they were satisfied that their spouses had settled in to the new environment. As one woman stated, "He is settled now. It eases my mind and I am quite settled now."

The elderly Chinese wives showed their caring through food. With no exception, the wives brought soup, tonic, home made meals, fruit and Chinese tea to their spouses when they visited.

**Feelings Associated with Institutionalization**

The women all agreed that life was much easier after their spouses'
admission to the institution. All stated that they were still worried about their spouses at times, but were quite content that their spouses had finally settled down in the institution. However, all the women felt that they still had an obligation to visit.

**Perception about the Institution**

**The role of the nurses.** The caregivers believed that the nurses and the care professionals have the knowledge and that they would do their best to care for the sick. One woman stated, "I have complete trust in the nurses as they are professionals, and they know what they are doing." All caregivers saw it as the role of the nurses to give the physical care to their spouses as it was the main reason for their spouses' admission. The caregivers also felt that the staff should be responsible for monitoring the wandering behaviours of their spouses and ensuring their safety. Two women felt that it was the care aides' responsibility to help in maintaining their spouses' self identity through proper dressing and grooming.

The caregivers saw it as the role of the nurses to communicate to them immediately if there should be any change in their spouses' condition. Also, the caregivers stressed that it was the responsibility of the nurses to communicate the care needs of their spouses to the care aides, as "they [the
nurses] should ensure that the care aides know what they are doing." When asked about the importance of meeting the emotional and psycho-social needs of the spouses, one woman saw it as her role to give emotional support. When asked about the need for social stimulation such as attending activity programs, the answers received were, "My husband thinks that they are childish any way." "He has always been very self centred, he does not like to socialize any way." "He doesn’t really know any difference." All of the caregivers felt that the staff had enough to cope with just trying to meet the physical needs of the residents. "It is difficult for the nurses as they have so many residents to take care of."

**Communication with the staff.** As identified by two of the women, communication with the staff was not optimal. One woman attributed it to the fact that the care aides rotated around too much, and there was no continuity of care. She felt that the care aides might not have been aware of her spouse’s routines and her expectations. All the women who did not speak English had to rely on their children to express their concerns (if any) to the nurses when there were no Chinese nurses on duty. One woman who placed her spouse in a facility with an all Chinese-speaking staff felt that having staff of the same nationality who understood the language was beneficial for herself and her spouse as communication was
made easier. The woman who could speak both English and Chinese found it an asset as she could talk to the nurses directly when there was a concern. With the women who did not speak English, communication with persons in the facility occurred only when there was a concern on both sides as translation aids were not readily available in the facilities. All caregivers agreed that a Chinese speaking staff would be beneficial for the caregivers and the Chinese residents. One of the women summed it up as follows:

I guess it helps a bit [that I can speak fluent English]. The primary nurse is not Chinese, so I guess it is an advantage that I can speak English. It would be nice if the nurses speak the same language. Some of them [the residents] cannot make their needs known when there are no Chinese nurses around. The nurses [who can not speak Chinese] cannot understand them, and they sometimes just let it go.

It was obvious that communication among the spouses, the caregivers and the nurses was impeded because of the language barrier. Concerns of the caregivers could not be addressed immediately as communication would have to be through a third person.

**Caregivers’ Response to Institutionalization**

As the frequency and duration of the visiting diminished, the women started to engage themselves in some form of leisure activities. Two women helped to take care of the grandchildren. One woman started to get back to
volunteer work, music and watching television which she gave up when she had to take care of her spouse at home. One woman started helping with Sunday School, going to English class twice a week, reading and knitting. This woman put it all in perspective as she stated, "I have to occupy my life and structure my life a bit, otherwise it is going to be very boring." One woman enrolled herself in lawn bowling, Tai Chi and fitness classes. Sharing time with the family and enjoying the grandchildren were the two activities most valued by the women in this study.

Every woman used a different strategy to cope with the change. Self growth was evident in two women; they tried to improve their skills by enrolling in classes; they became very active with volunteer work; they learned to be self sufficient and become more independent. One of these women related her experience and feelings as follows:

My daughter wanted to buy me an apartment, but I refused. I want to be independent; I want to be alone; I do not want to rely on anybody ... I try to help the seniors in this complex, I relate my experience to them and help them to establish themselves and become more independent. I told the kids that their father has settled down now for almost two years, it is time for me to think about myself.

For another woman, it was the sense of hope which helped her to carry on. She had a number of strokes and she was still trying to regain her mobility at the time of the interviews. This woman was barely managing with
the help of a walker, and she was still having considerable pain in her hips and knees, but she had a very strong will, "I am very positive. If I can walk and manage better, I'll take him home one day...I'll never give up, he will be home one day."

'Being contented' is the strategy used by one woman to cope with the change. The admission of her spouse to a care home was a relief for this woman, and she was just very happy that she could now have more time to take care of her two younger children who are still at University and living with her, and spend the rest of her time helping her other son by taking care of the grandchildren.

The woman who did not participate in the care of her husband took a 'take it as it comes' attitude. She stated "I have so much to cope with myself that I cannot worry about anything else too much." However, she was not impeded by her chronic illness. Since her spouse's admission, she has engaged herself in a lot of leisure activities and a volunteer program for helping the seniors.

The response to the transition from home to institution has been positive for five of the women in this study. However, the outcome for the sixth woman was not as desirable. This is the woman who had never got used to life in Canada. She took care of her spouse for three and one-half years
before her spouse’s admission to the care home, and she visited every day after her spouse’s admission though she had a very bad heart. She became very dependent on the caring relationship, and at times, risked her own health in order to maintain it. For example, she would still go to visit her spouse when she was very sick. She has ended up in hospital several times because of her insistence.

The admission of her spouse to the care home has created a void in her life. Her spouse had been in the care home for two and one-half years when the interview took place, but she still was unable to let go. As she stated, "It has been very difficult, very difficult. I wanted to go back to Hong Kong, but I can’t leave now...I have to stay to take care of him." It seemed that the family support for the father was there as the children went to see him regularly, but family support for the woman was not evident. When asked whether her children spent any time with her, the reply was, "the kids are always busy; they have to spend the time with their children when they have time off." This woman’s inability to 'let go' was partly due to her unhappiness related to the resettlement in Canada. She identified some of the barriers she faced, such as being unable to speak English, and not being able to travel on a bus. However, these were barriers experienced by some of the other women too.
Summary

The caregivers assumed a different caregiving role after their spouses' admission to an institution. Instead of giving physical care, some changed their role to one of emotional support; some still maintaining their monitoring role, not about the spouses' safety, but their spouses' consumption of food and fluid. Some felt that maintaining the dignity and identity of the spouses were important. However, there was a lack of emphasis on meeting the psycho-social needs of the spouses. Five women felt that they still had the obligation to visit and they showed their love by bringing food whenever they visited.

The caregivers perceived the role of the nurses as one of giving physical care, communicating with the families, and educating the care aides on how to meet the needs of the residents. Communication among staff, caregivers and the residents was impeded because of language barrier. All caregivers agreed that a staff who understands the Chinese language would be beneficial as communication would be improved and the residents’ needs could be made known and met more readily.

After the admission of their spouses to an institution, the caregivers went through a phase of re-structuring of life. They started to engage themselves in different leisure activities. Spending time with the family and enjoying the grandchildren were the two activities valued by the caregivers.
However, this was not possible in one instance. The caregivers developed different strategies to cope with the institutionalization of their spouses. They included: self growth which encompasses learning new skills, doing volunteer work, helping others and becoming more independent and self sufficient, a sense of hope, just being content, and a 'take it as it comes' attitude.

**The Caregiving Context**

Traditional values, spousal relationship, the caregiver's other life stress, and family support constitute the caregiving context. As pointed out earlier, the researcher identified three temporal phases for the transitional process of caregiving from home to institution as follows: (1) before admission, (2) deciding to institutionalize, and (3) dealing with institutionalization. This section will describe how the caregiving context influenced the three temporal phases.

**Traditional Values**

All the women in this study carried out their responsibility as dutiful wives as soon as they were married. They took care of the household, their spouses and raised their children. One of the women worked as a teacher and another helped her husband to run a restaurant, but they still carried on their duties as wives. All six women have very strong traditional values, they took
it as their duty to cook and take care of the spouse all the time, in wellness and in sickness. One of the women who was born and raised in Canada stated, "I do carry a lot of the Chinese values mainly because of the way I was raised by my parents." This was the probable reason why the wives carried on as long as they did before the decision for institutionalization was made.

Because they saw it as their obligation to take care of their spouses, the idea for admitting their spouses to an institution never occurred to these Chinese women, as one of them said, "It has never occurred to me as an option, but the social worker suggested it to me, I am a Chinese and I wanted to take care of my husband at home." Getting relief for themselves was not the primary intent for these women. Their utmost concern was the well being and safety of their spouses.

All women, except one, felt that they have to continue to visit after their spouses' admission to an institution. They were very much aware of their spouses' feelings and their values. One women said,

My feeling is that he came from China; his thinking is that the wife should take care of the husband...If I don't come every day, he would think that I have deserted him...I look at it as part of my duty as a wife."

One woman was really scared when she went to visit her spouse at the care
home as there was a lot of confused residents who wandered around and 'do weird things'. Despite her fear, she went to visit her spouse at least twice a week.

The strong traditional value of family connectedness had enabled most of the women to add some meaning to their lives after the spouses' admission. As mentioned earlier, enjoying the grandchildren and sharing time with the family were two activities most valued by the women in this study. However, the above was not evident in one case. For this woman, her spouse was her strongest social link.

**Spousal Relationship**

Five women had a good relationship with their spouses, some closer than the others. The decision to admit the spouse to a care home was more difficult for some than others. It seemed that the closer the relationship, the harder it was for the woman to make the decision. One of the women who had a very close relationship with her spouse made the following statement:

I wish that he could stay. I miss him very much. We have been together for fifty years. We have gone through a lot together. When I recall the old days, I feel sad.

The relationship with the spouse definitely affects how the caregiver conceptualises her role. One of the women who stated "I haven't missed him
for thirty years!" clearly did not have a good relationship with her spouse. Consequently, she carried out her caregiving role differently than the others. This woman claimed that she had never gotten along with her spouse. Her spouse stayed in the house for over one year after developing symptoms, and her caregiving role was defined as 'watched over him'. The decision for admission seemed easy for her. She did not suggest it but she welcomed the idea. After her spouse’s admission, her role was mainly to take care of him financially. She never visited as she said, "it is no use anyway, as he doesn’t recognise me...I haven’t missed him for the past thirty years!"

**Caregivers’ other Life Stress**

Besides dealing with their spouses’ illness, the women were faced with different life stresses which inadvertently affected their caregiving role. Three of the women had severe chronic health problems. Two of them carried on their caregiving role like the other wives, but their poor health had impeded them in many ways. Because of her stroke, one woman found that doing a simple task for her spouse, for example, dressing him, took about two hours. As her own functional ability decreased, she had to give up a lot of things she used to do for her spouse, and gave that responsibility to a homemaker. One woman carried on with all the chores and care functions at home despite her poor state of health. One woman felt that she had enough on her hands
coping with her own chronic illness, and assumed the role of monitoring the spouse's behaviors.

One other woman had financial burdens as her two younger children were still in University. One of the major concerns of this woman was the safety of her spouse. She insisted on restraining her spouse while he was at home and at the institution, partly because she was concerned for his safety, but mainly because of the extra financial burden (the ambulance fee) she would have to bear if her spouse was hospitalized. Another woman suffered a number of losses after her spouse' admission to the care home. One sister-in-law and a brother died within a year, and her sister became seriously ill. For awhile, she found it very difficult to visit her spouse, as seeing her spouse in his present condition did not make things any easier. She reflected upon her experience by stating "You try not to think about it too much, but you can't help it. You sit down, and all of a sudden, they all come to you."

The women in this study are at a developmental stage when they are most likely to be faced with life stresses such as death and ill health of close friends and family. Such issues are illustrated by the experience of the caregivers in this study. Without exception, every woman in this study was faced with at least one other life stress.
**Family Support**

From the account of the Chinese wives, it was obvious family support was conceptualised in terms of 'doing things' and financial assistance. Emotional support or expression of feelings were not mentioned.

Family support, of varying degrees, was evident in all six cases. In this study, family members refers to the children of the caregivers and their spouses. During the phase before admission, the caregivers concentrated on maintaining the well-being of their spouses, while the children would assist in the caregiving process by running errands, taking care of financial matters, taking their fathers to the doctor’s office and buying groceries. In one case, it was the son who gave the physical care to his father and took care of all the other related matters.

All the family members were instrumental in initiating or assisting with the process of admitting their fathers to a care home. In some cases, the suggestion was first made by the health professionals who were involved in the care of their fathers. From the caregivers’ accounts, it was clear that the family members made the suggestion out of concern for their parents, some were concerned with their mothers, while the others were more concerned with their fathers.

The family members continued to give support to their parents after the
admission of their father to the care home. Again, the degree of support varied. Some of them showed equal support for their parents. They went to visit their fathers regularly and carried on the mothers’ caregiving role if the mothers were unable to visit. They also ensured that they spent some time with their mothers on the weekends. Other showed more support to their fathers. The son who was involved in caring for his father at home still visits his father every day. One son and his wife went to visit his father regularly but could not spare any time to spend with his mother.

Summary

Traditional values, spousal relationship, other life stress and family support are the context in which caregiving is embedded, and affects all three temporal phases. The firm belief in the duties of a wife to care for her husband, a good relationship with the spouse, and strong family support had enabled the caregivers to carry on as long as they had before their spouses’ admission to an institution. The caregivers were faced with other life stresses; some were able to carry on with their role despite the adversity, and some had to reconceptualize or give up their caregiving role.
**Sense of Conflict**

The conceptual framework denotes that the sense of conflict is interwoven into the three temporal phases and it is a predominant theme which best describes the feelings of the Chinese women in this study. From the findings, the researcher has identified the source of conflict of each temporal phase, and the strategies used by the caregivers to resolve or to avoid the conflict. The type of conflict experienced by the Chinese women changed according to the phase.

**Before Admission (The First Phase)**

The collected data indicated that the spouses’ behavior or non-compliance was a source of conflict between the caregivers and the spouses in this phase. One woman was really annoyed at her spouse’ wandering behavior and she stated,

I tried to hide all the money, all the shoes, and all the jackets, but he still went. I tried many ways to stop him, but he still found a way out of the door...I couldn’t remember how many times I told him [not to run away], but he never listened.

Another woman related her experience as follows:

I could not work as fast as before [after the stroke]. It would have been easier if he just listened...he unbuttoned his shirt as soon as I put it on...you know, I can’t remember how many times he left the stove on, and let the kettle boiled dry...I keep on reminding him, he keeps forgetting!
One women blamed her spouse’s frequent falls and wandering behavior on the spouse’s non-compliance. She stated,

If he would have just listen and sit down, then he would not fall...I have to chase after him all the time...he has always been like that, never listens to me anyway.

These conflicts, caused by the spouses’ behaviors, became harder to deal with as the dementia progressed. The frequency of these conflicts was also increased as time went by. The women in this study internalized these conflicts, and they became very frustrated. The strain and stress, both physical and emotional, experienced by the women were the results of these unresolved conflicts.

**Deciding to Institutionalize (The Second Phase)**

'Conflict with self' would be the best term to describe the feelings of the women at this phase. In the discussion earlier, it was identified that the women attributed their spouses’ behaviors to the spouses’ personalities, rather than the progression of dementia. It seemed as if they were trying to preserve the previous image of their spouses. The women were trying to protect themselves too. The denial about the disease and the rationalization might well have been the mental defense mechanism used by the Chinese wives in order to put things into perspective and carry on with life.

None of the wives in this study had considered the admission of their
spouses to a care home as an option, until the suggestion was brought forth by somebody else. As noted in the discussion earlier, the wives had strong traditional values and viewed it their responsibility to take care of their spouses, and that responsibility remained when the spouses were sick. As the care demand increased, the wives had a sense that they could not carry on any more, which was clearly demonstrated by the following:

There was nothing I could do about it, I had to carry on. I worried about him all the time. It was a burden...it was just getting too much, not just his incontinence but everything. I kept on saying that if it carried on, for sure I would die before him.

However, they saw themselves as having to carry out their role as wife because giving up their caregiving role would be a conflict with the traditional values, as one women said, "it was a real struggle for me. I am a Chinese, and I would prefer to take care of my husband at home." Again, the internal conflict manifested itself in physical and emotional strain. The wives went through a period of emotional turmoil before they made the decision to admit their spouses to an institution. The presence of family support and the advice from the health professional had offered a way out for the women and eased the process of conflict resolution. Not initiating the process of institutionalization made it easier for the women.
Dealing with Institutionalization (The Third Phase)

Once the decision regarding admission was made, the wives went through a period of uncertainty. One woman who had a very close relationship with her spouse described her initial feelings about the admission:

I was very unhappy. I felt that he was not properly cared for in the beginning. I always worried that he was not going to get the best care. Things are a lot better now.

At the time of the interviews, the caregivers were generally satisfied with the care received by their spouses at the care home. However, there were times when the caregivers were unhappy about certain aspects of care which were a source of conflict with the nurses. One woman said:

My husband always like to have his shirt and tie on, when the aides don't dress him properly, I got upset and he got upset too...Sometimes the care aides did not put his underpants on, and I got really upset.

The woman saw the primary nurse and identified her concerns. The woman attributed the cause of such conflict to the lack of communication between the nurses, the care aides and herself, and to the lack of staff. She stated:

There are so many residents yet only so many workers. There are only so much they can do for each resident...May be they [the staff] did not know what were his routines and my expectations.

Another woman stated, "it made me very unhappy when he was wearing somebody else clothes." When asked by the researcher how she resolved it, the comments were:
It is no use anyway, I didn’t really want to mention it. You can’t help it any way when you are in a care home. Something like this is going to happen. I mentioned it once or twice, but I could not see that anything has been done.

Another women said, "you cannot expect too much anyway, there is not much the nurses can do." One caregiver blamed it on her spouse for not telling the nurses what he wanted, without realising the fact that her spouse was unable to do so because of the decline in his cognitive function.

Initially, the caregivers took an active role in communicating to the nurses when they were unhappy about certain aspects of care. Eventually, the caregivers reached a stage of resignation--resigning to the fact that it was no use to complain. They did not state their concerns--as according to some of the caregivers, ’it is no use anyway’.

**Summary**

The caregivers were faced with different types of conflicts as they went through the three temporal phases. The sources of conflict were with: (1) the non-compliance behaviors of the spouses in the first phase, (2) the traditional values and beliefs of oneself in the second phase, and (3) incongruence of expectations between the caregivers and staff in the third phase. For the first and second phase, inability to resolve conflicts resulted in physical and emotional strain for the caregivers. However, conflict resolution led to a
sense of relief. For the third phase, inability to resolve the conflict led to resignation (to the fact that it was no use to complain) which could undermine the advocacy role of the caregivers. For unresolved conflicts, internalizing the frustration and rationalization were identified as the coping strategies used by the caregivers. When caregivers were able to face the problems head-on, conflicts were resolved.

**Summary**

The presentation of findings in this chapter reflects the lived experience of six Chinese women when caring for their spouses at home and in the institution. The data have been organized under the conceptual framework of 'the transitional process of caregiving from home to institution' as developed by the researcher. Findings from the three temporal phases: (1) before admission, (2) deciding to institutionalize, (3) dealing with institutionalization, and the predominant theme -- a sense of conflict were discussed. The rich data has provided a vivid picture of the caring experience, the feelings of the caregivers, and how the caregivers responded to the experience as they went through the three phases.

The findings indicate that there was a definite change in the caregivers' role after their spouses' admission to the care home, and the conceptualization
of the role was very much influenced by the caregivers' own life circumstances, her own value system and family relationship.

The caregivers faced different types of conflict as they went through the three temporal phases. The sources of conflict and the coping strategies used by the caregivers were identified and discussed.
CHAPTER FIVE

Discussion of the Findings

The purpose of this chapter is to discuss the findings of this study by comparing and contrasting with related literature. The findings in this study will be used to further support or refute previous findings as discussed in Chapter Two. The discussion will follow the organized format as presented in Chapter Four so that no area will be overlooked.

The First Phase—Before Admission

The Caregiving Role at Home

The Chinese wives of this study identified their caregiving role as one of 'maintenance of physical well being'. It was a task-oriented focus and involved a long period of full time commitment. The components of caregiving concentrated on the activities of daily living (ADL) which are similar to those identified in previous caregiving literature (Horowitz, 1985; Scharlach, 1987; Stone, Cafferata & Sangl, 1987; Hays, 1988). However, due to the rapid progression of dementia, caregivers in this study had to devote almost all their time to such activities, and did not see themselves as having time for anything else.
Bower's study (1987) of middle aged women caring for their aged parents identified protective care as the most difficult and most important type of caregiving. Protective care in Bower's study referred to the protection of the parent's self image rather than the parent's physical well being. The caregivers in the research being discussed here agreed that protective care was the most important aspect of care of their spouses at home, but their definition of protective care was quite different from that of Bower's study. The difference in opinion could be due to different nature of the samples involved, one group being the middle aged daughters caring for aged parents, and the other group being elderly wives caring for spouses with dementia. The two groups of caregivers might have a different perception about their caregiving role. Or, the different role definition might be related to the different care needs required by the care receivers in the two studies.

Miller (1987) explored caregivers' perceptions regarding caring for cognitively impaired spouses. The caregivers included six husbands and nine wives. Most caregivers indicated that it was important to treat their spouses as normally as possible. Such perceptions of caring are similar to the protective caregiving as identified in Bower's (1987) study. However, the meaning of protective care was perceived differently by the Chinese wives in this study. As discussed earlier, the Chinese women viewed the maintenance
of physical well-being as most important while caring for their spouses at home, and some perceived the preservation of dignity and identity equally important only after their spouses' admission. Caregivers in Miller's study suggested the preservation of dignity and identity was the most important role while caring for their spouses at home. There is a similarity between the samples used in Miller's study and the current study; participants were either husbands or wives caring for their cognitively impaired spouses at home. However, the term protective care, had different meanings for the two groups of caregivers. The researcher suspected the assignment of a different meaning to the term of protective care could have been related to the difference in cultural values between the two groups.

**The Caregiving Stress**

The caregiving burden and strain identified by the women in this study are similar to findings in previous studies (Cantor, 1983; Hirschfeld, 1983; Chenoweth & Spencer, 1986; George & Gwyther, 1986; Zarit, Todd & Zarit, 1986). Physical, financial and emotional strain related to caregiving are all evident in this study.

Wilson (1989) explored the experience of family caregiving through interviews with twenty family caregivers for relatives with dementia. The caregivers in Wilson's study were characterised as not being able to see
beyond their present situation into the future. The Chinese wives were going through the same experience while caring for their spouses at home. Like the caregivers in Wilson’s study, the care demands were overwhelming and the Chinese wives felt a deep sense of desperation. With one exception, the Chinese wives also felt a powerful sense of responsibility to provide the care needed by their spouses.

The Second Phase--Deciding to Institutionalize

Progression of the Disease

Issac (1971) Identified immobility, incontinence and mental abnormality as the three most common problems when caring for individuals with dementia. The caregivers in this study had the same perception. According to the Chinese wives, frequent falls, incontinence, wandering and inappropriate social behaviors were common occurrences associated with the progression of dementia. The above perhaps had made the Chinese women more receptive to suggestion by others that they should seek care for their spouses in an institution.

Making Sense of the Progression

These Chinese women attributed their spouses’ inappropriate behaviors to the spouses’ personalities, rather than the progression of dementia. As
Senile Dementia of the Alzheimer Type is still considered a psychiatric disease, and that its manifestation leads to the exhibition of socially unacceptable behaviors in some cases, it is probable that the Chinese women in this study purposefully put themselves in a state of rationalization. Mental illness is highly stigmatized in Chinese cultural settings (Kleinman, Eisenberg & Good, 1978), and "The Chinese are more likely to explain the causes of mental illness in terms of external factors or events..." (Lai & Yue, 1991, P.81).

As stated earlier, the women’s behavior appeared to be related to lack of knowledge. However, even when they had accurate information about the disease and its manifestation provided in their own language, the women continued to attribute the spouses’ inappropriate behaviors to the spouses’ personalities. It can be argued this was a way the women could make sense of the spouses’ behaviors without taking on the stigma of the disease.

Caregivers’ Response to the Suggestion of Admission

Except in one case, the Chinese women in this study found that making the decision to admit their spouses to an institution was a difficult process. It seems that the closer the spousal relationship, the harder it was for the woman to make the decision. The above is similar to the finding of Gilhooly (1986) who conducted a study to identify the factors associated with the caregivers’
preference for institutional care in Senile Dementia. She stated that the closer the blood/role relationship and the better the quality of the relationship, the lower the preference for institutionalization.

Findings from two studies (Colerick and George, 1986; Zarit, Todd & Zarit, 1986) suggested the subjective perception and experience of caregiver well-being were the main determinants for seeking institutional care for individuals with Alzheimer’s disease. However, the well-being of the spouse was identified by the Chinese women in this study as the reason for seeking institutional care, though the burden of the caregiving experience was very evident. In this research, the close spousal relationship and the women’s strong view about their responsibility to provide care in most cases had delayed the seeking of institutional care.

The Third Phase--Dealing with Institutionalization

The Caregiving Role after Admission

With one exception, the Chinese wives continued to visit their spouses and to participate in various aspects of care after their spouses’ admission to the care home. The above supported findings from previous research which pointed out that institutionalization should not be viewed as a termination of the family caregiving relationship, but rather, the continuation of the
relationship (York & Calsyn, 1977; Shanas, 1979; 1982; Johnson & Catalano, 1983; Bower, 1988). Also, it is not uncommon for hospitalized Asian patients to have many family members visit them (Chang, 1981). The continuation of the caregiving relationship after institutionalization among Chinese is evident.

Once spouses were admitted however, the Chinese women no longer needed to provide the physical care required by their spouses, and they were able to shift the focus of attention to other aspects of care. Whenever they visited, the Chinese wives always brought special food such as home-made soup, tonic, and Chinese tea. Soup is a vital home remedy, it is taken almost every day to maintain health and for dietary balance (Lai & Yue, 1991). Food and diet therapy has long been considered by the Cantonese speaking community as a means for maintaining health and treating disease (Lee, 1980). Also, food has very special social meaning for the Chinese (Lai & Yue, 1991), and it is a way of showing love and caring. Two of the caregivers had taken on the role of monitoring food and fluid consumption of their spouses in the care home as food is important in maintaining health.

**Perception and Role Expectation**

Shetllesworth, Rubin and Duffy (1982) identified that the families and the staff had different perceptions as to whose responsibility it should be to
carry out certain tasks for patients in the nursing homes. They suggest that discrepancies in perception and role expectation could affect role performance and consequently affect patient care. A subsequent study yielded similar findings to support the above (Rubin, Guy, & Shettesworth, 1983). The current study supports the above findings as the caregivers in this study also perceived that, in some cases, the nurses were not aware of the women's care expectations for their spouses.

Shuttleworth et al. (1982) and Rubin et al. (1983) also suggested that there was disagreement between the staff and the families in five major categories which were most problematic: (1) personalizing care, for example, making the room attractive and providing special food, (2) monitoring and ensuring the provision of care, (3) clothing needs, (4) grooming, and (5) reading material. In the research being discussed here, the Chinese women viewed personalizing care as the wife’s responsibility whereas monitoring and ensuring the provision of care should be a shared responsibility between the wives and the staff, depending on what was being monitored. For example, most of the Chinese women took on the responsibility of monitoring food and fluid intake, but viewed it the responsibility of the staff to monitor their spouses’ safety and wandering behaviors. However, the women felt that it should be the staff’s duty to ensure that their spouses receive proper dressing
and grooming.

The previous studies involved both family caregivers and the staff, but the focus of the present study is only on the perspective of the wives who are primary care givers. The perception of the staff about their role and the caregivers role was not explored in this study. However, the experience of the caregivers suggested that there might be different role expectations between the staff and the caregivers.

Maintaining the spouse’s physical well being was still the main concern for the Chinese women. However, the caregivers felt that it should be the staff’s responsibility after the spouse’s admission to the care home. It is not surprising that the Chinese women downplay the importance of meeting their spouses’ psycho-social needs as Chinese are very pragmatic people and their first priority is the satisfaction of practical needs like food and clothing (Lai & Yue, 1991).

**Response to Institutionalization (Change)**

Social stress occurs when there is a disruption in the social system (Monat & Lazarus, 1977). A related concept to stress is coping which refers to "the process of managing external and/or internal demands that tax or exceed the resources of the person" (Vingerhoets & Marcelissen, 1988). Lazarus and Folkman (1984) emphasized that coping should be viewed as an
process which described the relationship between the person and the environment.

In this study, the spouse's admission to a care home was a disruption in the family system previously shared by the caregiver and the spouse. Without the presence of their spouses, the Chinese women had to change the relationship between themselves and the environment.

Lazarus and Folkman (1984) identified distancing, seeking social support, accepting responsibility, self-control (Keeping feelings to self), and positive reappraisal (finding meaning) as some of the coping mechanisms. The coping strategies used by the Chinese women in this study reflected the above. Most of the women sought support from their families and the community. They accepted responsibility by doing volunteer work and enrolling in classes. Positive reappraisal was evident as they tried to find some meaning in their activities. For example, one woman wanted to stay alone as she wanted to be self sufficient. Another woman, hoping that she could take her spouse home one day, was inspired to carry on with her own rehabilitation.
The Caregiving Context

Culture and Traditional Values

According to Chang (1981), an Asian woman becomes integrated into the man's family once married, and the woman has the defined role of devoting herself to care for the home, children, and husband. Also, family members show their love for a person by caring for that person during times of sickness (Chang, 1981). "One of the characteristics of traditional Chinese culture is the strong emphasis on the family system" (Tseng & Wu, 1985, p.83). The family is the basic social unit through which the element of culture is transmitted (Tseng & Wu, 1985). These are traditional values which have been carried through many generations, and the researcher who is a Chinese person, supports the above notion.

The Chinese women in this study carried out their traditional role of taking care of the household, the husband, and the children as soon as they were married. They assumed the caregiving role through their spouses' illness and found it difficult to give up that role because of the strong traditional values they held. Love, devotion, and loyalty are often cited as the motivational factors in caring for individuals with Alzheimer's disease (Stevenson, 1990). The above also held true for the Chinese women in this study. They were somewhat magnified due to Chinese women's strong sense
of duty and obligation to their spouses.

Cantor (1983) suggested that the more caregivers valued and felt committed to family cohesiveness, the more likely they would be involved in the caregiving process, and the more likely they would feel the strain. As the family structure and family connectedness are highly valued by the Chinese women in this study, they must have felt incredible strain. This is supported by the data which revealed that three of the caregivers were hospitalised at different times while caring for their spouses at home.

The Chinese culture and traditional values had a strong impact on how the Chinese women conceptualized their caregiving role. Also, the strong beliefs in their obligation as wives had enabled the Chinese women to carry on the caregiving role as long as they had (up to three and one-half years), and explained why they had never considered institutionalization as an option. Even when the decision about admission was made, the intent of the wives was not to have relief for themselves, but rather for the well being of their spouses.

**Spousal Relationship**

"In the case of spouse caregivers, the quality of the marital relationship prior to the disability of one partner may influence the healthy partner’s willingness or reluctance to assume the role of caregiving" (Given, Collins, &
Given, 1988, p.71). Gilhooly (1986) observed that the caregivers who took their marriage vows seriously wanted to take care of their spouses at home despite the imposed burden. Findings from the current study support the above. The Chinese women who saw themselves as having a good marital relationship carried out their caregiving roles at home (cooking, feeding, monitoring wandering behaviors, bathing, dressing and grooming) despite the adversity of bad health, and continued to visit after the spouses’ institutionalization. The woman who described her relationship with her spouse as a poor one, passed the caregiving role to her son, and assumed only the role of financial assistance after her spouse’s admission, and she never visited him at the care home. She however maintained an aspect of the caregiving role out of obligation, but not out of caring and concern as identified by the other women.

**Family Support**

According to Chang, findings in a study conducted by Hong Kong University (1982) concluded that the family remained the main source of support for elderly people. Race (1982) conducted a study on residential and institutional services for elderly people in Hong Kong which reaffirmed the fact that the family was the most prevalent means of providing support to elderly persons.
The four Chinese women who emigrated to Canada with their families arrived between 1977-1982. It would be fair to suggest then that the notion of family support for the elderly persons should prevail within this group. The findings of this study revealed that family support of varying degrees was present in all cases.

For the past decade, family members accounted for 39% of the total immigrants from Hong Kong to Canada (Statistics Canada, 1991). Family members include spouses, dependent children and parents. The large percentage of family immigrants suggests that the Chinese still value the family structure/system. However, Lai and Yue (1990) argued that Western culture has also changed the traditional values of some younger Chinese in Canada. In order to get established in the new country, it is sometimes a necessity for both husband and wife of a newly immigrated family to work outside the home. Even if it is the younger generation’s wish to take care of their elderly parents at home, it may not be possible as there will be nobody at home to assume the responsibility. The situation with the families of the four Chinese women who were immigrants reflected the above scenario. The Chinese wives carried out the caregiving role as the children had to work. However, the children continued to support the parents in many other ways.
Caregivers' Other Life Stress

"The overall loss of physical capacity, decreased resilience and lowered capacity to resist stress cause most elderly people to view any illness as a potential major crisis in life...temporary or permanent loss of contact with those who could give support -- spouse, friends, relatives may cause anxiety" (Murray & Zentner, 1985. p.592). It would be fair to suggest then that the Chinese women in this study who had chronic illness and faced the permanent loss of their loved ones had immense strain. They were in a position of 'double jeopardy' as the sickness and institutionalization of their spouses compounded the problem.

Central to Lazarus' (1977) theory on stress, there are two major concepts -- cognitive appraisal and coping. Cognitive appraisal refers to the evaluation of the situation. It answers the questions 'what is at stake?'' and 'what can I do about it?' (Vingerhoets & Marcellissen, 1988). A state of stress develops when there is a discrepancy between the current demand and the person's capabilities. Coping occurs when the person tries to manage the demand behaviorly and emotionally (Vingerhoets & Marcellissen, 1988). For the two women who had chronic illness and still maintained their caregiving role, they might not have realized that they themselves were enduring substantial stress, thus they did not change their behaviors, or they might not
have seen other options. One woman who suffered many losses stopped visiting her spouse for a while. It was obvious that this woman realized that she had to change her caregiving role temporarily in order to deal with the stress. A third woman who had a severe health problem coped with the situation by giving up her caregiving role permanently.

A Sense of Conflict

Conflict as a Predominant Theme

In a study of 30 demented adults and their family caregivers, Hirschfeld (1983) identified mutuality as the main theme. Mutuality is defined as the caregivers’ ability to find gratification in the relationship with the impaired person and assign meaning to the caregiving situation. Lynch-Sauer (1990) described the experience of caregiving for a family member with dementia caused by Alzheimer’s disease by reviewing seven published works of family caregivers about caregiving experience. Loss of mutuality was identified as one of the core themes.

The findings of this study support Lynch-Sauer’s finding but not that of Hirschfeld. As discussed earlier, the Chinese women always felt a sense of conflict which equated to the loss of mutuality as suggested by Lynch-Sauer as they went through the three phases of caregiving from home to institution.
The Concept of Conflict

Conflict is a major source of psychological stress (Monat & Lazarus, 1977). "Conflict involves the presence simultaneously of two incompatible goals or action tendencies, and so in conflict, frustration or threat of some sort is virtually inevitable." (Monat & Lazarus, p.4). According to Booth (1979), there are two types of conflict. Intrapersonal conflict exists in the affective and cognitive domain of the individual. The individual may not display any overt behaviors to indicate that there is a problem, but eventually emotional or psychological stress will result. Interpersonal conflict occurs when the relationship between individuals is being affected by incompatible goals and actions.

Direct actions and palliative modes are the two major categories in the taxonomy of coping as developed by Lazarus (Monat & Lazarus, 1977). "Direct actions are behaviors, such as fight or flight, which are designed to alter troubled relationship with one’s social or physical environment. Palliative modes of coping refer to thought or actions whose goal is to relieve the emotional impact of stress…" (Monat & Lazarus, p.8). Direct actions lead to resolution and make the situation and/or relationship better, whereas the palliative methods do not actually change the threatening event, but just make the person feel better.
Use of defense mechanisms such as denial is a palliative mode of coping which was viewed traditionally as dysfunctional or pathological (Monat & Lazarus, 1977). However, it is argued by some that it can be a useful mechanism in many situations, especially when it is used on a short term basis to deal with negative life circumstances. Such an approach may help to sustain a hopeful attitude, thus preventing the feeling of giving up (Cohen, 1975 cited in Monat & Lazarus, 1977). It can be concluded then that palliative modes of coping may prevent direct actions to deal with the conflict, but may be extremely useful in helping a person to maintain a sense of well-being, integration and hope.

Conflict as Experienced by the Chinese Wives

Conflict with spouse. The Chinese wives experienced interpersonal conflict with their spouses in the phase before admission. The women identified and articulated the conflict as the non-compliance behaviors of the spouses. The Chinese women wanted to achieve the goal of caring for their spouses properly, but the spouses would not co-operate and follow directions. Frustration was the emotional stress resulting from the conflict. The current findings revealed that the Chinese women attributed the spouses' non-compliance behaviors to their spouses' personalities, rather than the progression of dementia.
**Conflict with self.** The Chinese women experienced intrapersonal conflict in the second phase of deciding to institutionalise. The women were physically and emotionally exhausted because of their caregiving role at home, yet they had never considered seeking institutional care as an option as they felt strongly that it was their obligation to take care of their spouses. In this case, the Chinese women experienced conflict with their strong traditional values. As one woman described it: "It was a real internal struggle..."

**Conflict with staff.** As discussed in Chapter Four, it was not uncommon for conflict to arise due to difference in perception of role expectations between staff and the caregivers. Some of the Chinese women related that they had the same experience subsequent to their spouses’ admission to a care home. Interestingly, different approaches were used to deal with the conflict. One woman went to the primary nurse and discussed her concerns with her. This woman who was born and raised in Canada, used the direct action approach and resolved the conflict. Another woman who was a recent immigrant from Hong Kong, used the palliative mode approach. She mentioned her concerns about her spouse’s care to the nurse a couple of times, but the situation had not changed. The woman used the coping mechanism of resignation as she stated, "it is no use to complain...you cannot expect too much any way..." It was possible that this woman used the palliative approach in order to maintain
harmony. In dealing with conflict, the Chinese do not like to use the approach of confrontation (Lai & Yue, 1991).

As suggested by the researcher earlier, this style of coping can work against the women’s goals as it undermines the advocacy role of the caregivers. Advocating for quality of care by family members is important, especially in the care of elderly individuals with dementia.

**Summary**

In this chapter, the findings of the current study were compared with related literature for the purpose of demonstrating the knowledge generated by this study in the area of caregiving, focusing on the experience of elderly Chinese women.

Some of the findings of the current study supported results of previous findings as discussed. In addition, this study contributed to new knowledge in the area of caregiving in four areas:

First, like caregivers in other studies, Chinese women conceptualized the caregiving role in terms of tasks carried out for the individual with dementia. However, the role of the caregiver, the purpose of caregiving and the areas of most concern while caring for their spouses with dementia were perceived in a different way by the Chinese women.
Second, the Chinese women in this study experienced caregiver strain and burden as identified in previous studies, but the findings suggested that elderly Chinese women might feel the strain and stress even more due to a strong commitment to traditional values.

Third, culture and ethnicity play an important part in the shaping of the caregiving role and the caregiving process in different context, an area which needs further exploration.

Fourth, conflict has been identified as the emotional experience of the Chinese women during the transitional process of caring for their spouses with dementia from home to institution. A good understanding of the culture, beliefs and values of the caregiver group is important in order to identify the source of conflict and to help the caregivers to prevent or resolve conflict.
CHAPTER SIX

Summary, Conclusions and Implications for Nursing

This chapter will present the summary and conclusions of the current study. Also, the implications for nursing practice, nursing education and nursing research will be discussed.

Summary and Conclusions

As the prevalence of dementia increases with age, and more elderly Chinese persons are migrating to Canada, the number of Chinese elderly persons who will suffer from dementia will increase accordingly. Because of the Chinese culture and the fact that women still remain the largest group of caregivers, it is very likely that the elderly Chinese wives will assume the caregiving role of their spouses with dementia at home.

As dementia is a progressive disease, and the care demand increases accordingly, there is usually a point when institutionalization becomes inevitable as the individual with dementia can no longer be adequately cared for at home. Also, the caregiving role may change related to the transition from home to institution.

The literature review indicated that caregivers for elderly persons (with
or without dementia) at home conceptualized their role in terms of tasks performed, but they assigned different meanings to the purpose of caregiving. For the Chinese, the caregiving role could be affected by context such as migration trends, modernization, and cultural values. The literature review identified that differences in perception between the caregivers and the staff existed at the time of institutionalization and that these differences could affect role performance, and consequently patient care. Due to the reasons identified above and the lack of research in caregiving related to the elderly Chinese population, there is an urgent need to establish a knowledge base on caregiving related to elderly Chinese with dementia.

The purpose of the study was to explore the caregiving experience of the elderly Chinese wives during the transitional process of giving care to their spouses with dementia from home to institution, how the caregiving role may (or may not) have changed, and how the Chinese wives want the role to change or remain the same. The researcher also wanted to explore whether the Chinese women would have the same caregiving experience as identified in the literature. A good understanding of how the Chinese wives conceptualize their caregiving role and assign meanings to the caregiving relationship in different contexts will enable nurses to engage in effective care planning for the Chinese patients with dementia.
Phenomenology was the research design chosen for this study because of its unique focus on the lived experience as perceived by the participants. The six Chinese women who participated in this study were recruited from three different facilities in the Greater Vancouver Region. They were Chinese women between the age of 70 - 82 years. Two of them were Canadian born, and the other four immigrated from Hong Kong in the last two decades. They had cared for their spouses with dementia at home from one and one-half to three and one-half years before their spouses' admission to a care home.

Two in-depth unstructured interviews were done with four participants, and only one interview was conducted with each of the other two. One woman refused to be interviewed again and the other one was in hospital when the second interview was requested. Data were recorded and transcribed verbatim. Data collection and data analysis proceeded concurrently. Continuously, the researcher reviewed the transcription and reflected on her own thoughts. Throughout the interviews, the process of validating and clarifying of thoughts, feelings, relationship and significant statements was carried out. The process of analysis and synthesis resulted in a description which contains the major concepts formed from the meaning units -- a result of the clustering of significant statements. The description accounted for the caregiving experience as perceived by the Chinese wives in the three temporal
phases: (1) before admission, (2) deciding to institutionalize, and (3) dealing with institutionalization. It also examined the caregiving context. The context of spousal relationship, traditional values, family support and the caregivers' other life stresses were found to have influenced the conceptualization of caregiving by the Chinese women.

A sense of conflict, an emotional experience of the Chinese wives throughout the caregiving process, was identified as the predominant theme. The sources of conflict were with (1) the non-compliance behaviors of the spouses, (2) the traditional values, and (3) the nurses because of different role expectations. Unresolved conflicts manifested themselves in emotional and physical strain, whereas resolved conflicts led to a sense of relief.

The three major conclusions from the findings of this study are: (1) the Chinese women perceive their caregiving role and ascribe meanings to the caregiving process quite differently from that reported in the literature, (2) the context in which caregiving is embedded has to be critically examined in order to understand how caregivers conceptualize their caregiving role. The ascribed meanings to caregiving and its significance to the caregiving relationship have to be explored as they influence role conceptualization, and (3) the Chinese culture and the traditional values held by the Chinese women are major forces in creating the situations of conflict, and help to explain the
different approaches used by the Chinese women in dealing with the conflict.

**Implications for Nursing Practice**

The findings from this study have many implications for nursing practice, and the application is not restricted to nurses who work in long term care facilities, but in all settings including acute care and community nursing.

In order to effectively care for the Chinese individuals with dementia at home and in an institution, nurses must explore the caregiving role of the spousal caregivers, and the meanings ascribed to it. As most Chinese spousal caregivers get involved in the caregiving process at the onset of the disease, the nurse should start the above process on the first encounter with the caregivers.

The home care nurse, instead of just determining how many homemaker service hours are required to help the caregivers in completing the care tasks, should devote some time to explore the feelings of the caregivers and give them some emotional support. The Chinese do not open up easily to strangers, and the nurse must first try to gain the caregiver’s trust. Asking about the family and the grandchildren is always a good place to start.

The socially unacceptable and inappropriate behaviors of spouses created frustration and conflict for the caregivers. When the caregivers
attribute the behaviors to causes other than the progression of the disease, the nurse should not try to correct that misconception too hastily. The nurse should reflect on what she knows about the Chinese culture and the Chinese' perception and stigma about mental health. In reflecting, the nurse should consider that there is always a reason behind a certain behavior and seek to understand 'why is the person behaving in such a way?' Caregivers also need information about the progression of dementia and the reason for the inappropriate behaviors.

As noted, the Chinese women did not view institutional care as an option. The nurse therefore must be very observant and closely monitor the progression of the disease and the behaviors exhibited by the clients with dementia. The nurse should consider when institutionalization is appropriate, for both the client and the caregiver, and suggest it to the caregivers. When approaching the caregivers, the nurse should identify her reason for suggesting institutional care, which is for the well being of the caregivers and the clients with dementia.

Upon institutionalization, the hospital nurse should arrange to meet with the caregiver as soon as possible. The findings of this research suggest that caregivers continue with their roles as defined. Those who have been involved in their spouses' care at home may continue to be involved. The
nurse may want to discuss with the caregiver how she wants her caregiving role to change (or not to change). In relation to specific aspects of care, the nurse could discuss her own roles and responsibility in caring for the patient with dementia, and see if the caregiver shares the same perception about role expectations. Orienting the caregivers to the routines of the facility or unit would allow them opportunities to see how they could be involved in care. An assessment should include information from the caregiver regarding the most important aspects of care for her spouse. Negotiation and clarification of roles and responsibility between the nurse and the caregiver will need to be ongoing. The information and the decision of the negotiation process should be incorporated in the nursing care plan.

In order to resolve conflict between the caregivers of Chinese patients with dementia and the nurses, and effectively care for the patients with dementia through collaboration with families, the nurse must explore the caregiving role and its meaning as ascribed by the caregivers, the context in which caregiving is embedded and have a good understanding of the caregivers’ culture, traditional values and personal beliefs.

The nurse may also consider 'care for the caregiver ' by giving them support. Formal support groups can be organised for the Chinese caregivers. However, this may not be an acceptable approach for the Chinese as they are
very private about their feelings; they have learned from a young age to control their emotions (Chang, 1981). They may not want to share their feelings with a group of people who are not related to them. The nurse can try to counsel the caregivers on an individual basis, or try to involve the immediate family members, as the Chinese tend to express their feelings more readily to a family member (Chang, 1981).

The findings suggest that language could be an impediment for effective communication among the caregivers, nurses and the patients with dementia. In caring for patients with dementia, the nurse has to observe the patients’ non verbal communication such as body language and facial expressions. Picture cards may help in some cases but would be futile if the patient is severely demented. For communication with caregivers who do not understand English, the use of an interpreter can be beneficial, usually another staff member who speaks Chinese or a family member can help.

**Implications for Nursing Education**

In recent years, attention has been drawn to the need of including cultural nursing in the curriculum for the baccalaureate and diploma nursing program, but some more emphasis is needed. Canada is a multicultural country and the number of immigrants of different ethnic group are on the
rise. Nurses will care for people from different ethnic origins at some point in their career. Nurses need to have a good understanding of the patient’s culture and beliefs, and the relationship of culture, health and illness in order to plan for effective and quality care.

Nurses should also be educated to take a holistic approach when carrying out the nursing process. The focus on assessment should extend beyond the patients and include the context of family, environment, relationship with others, culture and traditional values. Student nurses who have their training in Canada have some orientation to this approach, but somehow the teaching and reinforcement must continue in the work setting. Nurse administrators and educators have to ensure that it is part of regular in-services.

There has been an influx of foreign-trained nurses in recent years. In some countries, nursing is still very task oriented; nurses tend to concentrate on the physical aspect but downplay or do not realise the importance of addressing the psycho-social aspect of care. Special classes or seminars should be set up for these nurses. They should be taught effective communication skills and how to explore and address the feelings of the patients and their families.

The caregivers in this study identified that Chinese speaking staff
would be beneficial both for the families and the patients. However, one must not assume that because the nurse speaks Chinese, that she understands the needs of the Chinese patients. Each nurse, no matter what her nationality, has to be assessed individually in regards to her educational needs.

Nurses should also be taught not to fall into the trap of stereotyping. People from the same ethnic group do not necessarily behave in the same way. Nurses must be careful not to explain every behavior of the ethnic patients by their cultural norms or traditional values. Nurses have to be educated to treat each patient as an individual, with culture and ethnicity to be examined as part of that individual’s context.

**Implications for Nursing Research**

From the findings, there are some areas where further research or inquiry is warranted. To the researcher’s best knowledge, this is the first research on the caregiving experience of elderly Chinese wives for spouses with dementia. The data generated raise many questions, and validation by further research is required to determine or reaffirm the significance.

Further research can be done to see if other Chinese women share the same caregiving experience as identified in this study. This study used a sample of two Canadian born women and four immigrant women. Further
study can be done using two samples, one group of Canadian born Chinese women, and the other of immigrant Chinese women. Comparison between the two groups can be done to see if they share the same perspective, and/or if it is different from the findings of the current study. Also, research on the caregiving experience of Chinese men taking care of their spouses with dementia should yield interesting findings. The findings from such research can be compared with the findings from the current study, and new knowledge will be generated.

The conceptual framework developed for this research can be used for other research related to caregiving by other ethnic groups, to see if other ethnic groups have the same kind of caregiving and emotional experience as identified in this study.

The emotional experience of conflict was identified as the predominant theme for this study. Further exploration of the conflict experienced by family caregivers is required. An in-depth study can be done to identify the type and the source of conflict and the coping strategies used by family caregivers throughout the stages of caregiving from home to institution. Findings from such research may help other caregivers to cope with conflict more effectively and thus minimize caregiver strain and burnout.

In conclusion, this research has only opened the door to caregiving
issues for the elderly Chinese population. More information and new knowledge are urgently needed to help the increasing number of elderly Chinese persons who will carry on the caregiving role for their spouses with dementia, and to help the nurses to care for the Chinese patients with dementia and their families more effectively.
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Appendix A

Letter of Recruitment

Date:

Dear ,

I am a registered nurse who emigrated to Canada in 1975. I was born and raised in Hong Kong, and I am fluent in both Cantonese and English. I received my diploma nursing training in Hong Kong and obtained the Baccalaureate Degree of Nursing from The University of British Columbia (UBC) in 1988. Currently, I am a student in the M.S.N. program of UBC, and I am conducting this study as part of the requirement for completing the program.

I would like to talk to you about what it is like for you to care for your husband with dementia at home and since his admission to the nursing home. I would like to meet with you two to three times, for up to an hour each time. I would ask a few questions, but most of the time, it would be for you to talk about your caregiving experience.

I will be the only person who knows who you are. However, the information I collect from you will be shared with the Thesis supervisors at UBC. In order to help me to concentrate on what you are saying in the interview, I would have to tape record the interviews. Again, your name will not appear in any of the taped conversations. In order to help other Chinese wives who may be in the same situation as you are, the findings of this study may be published, but your name will not appear in any of the papers.
If you would like to help me out with this study, you would have to give your permission by signing a form. HOWEVER, YOU RETAIN THE RIGHT TO REFUSE TO PARTICIPATE OR WITHDRAW AT ANY TIME. YOUR WITHDRAWAL OR REFUSAL TO PARTICIPATE WILL NOT AFFECT THE TREATMENT, THE MEDICAL AND NURSING CARE YOUR SPOUSE RECEIVES AT THE NURSING HOME.

If you need more information or explanation about the study, please feel free to contact me at 521-7764 (Monday to Friday, 8am - 4pm), or at 591-7077 at any other time. In turn, if you leave your name and phone number with the staff of the nursing home, I would be happy to talk to you personally about the study.

yours truly,

______________________________
Alice Choi, R.N., B.S.N.

Thesis supervisor : Dr. Joan Anderson
School of Nursing, UBC

Phone Number: 822-7455
Appendix B

Letter to the Agencies

Date:

Dear ,

I am a student in the M.S.N. program at the University of British Columbia, and I am doing a thesis as part of the requirement for completion of the program. I would like to have your permission to carry out the study with the spouses of your residents with dementia.

The title of my research is "Chinese women's perspectives on the transitional process of caring for spouses with dementia from home to institution." The purpose of my study is to explore the changes in the meaning of caregiving as perceived by the Chinese wives when the spouses they have been caring for move from home to an institution, and also to explore what constitutes the caregiving role of the Chinese wives while their spouses with dementia are cared for in nursing homes. Information from this study will help to clarify role expectation, and to prevent the overlapping of responsibilities between the Chinese wives and the nurses. It will facilitate effective care planning, and subsequently enhance the quality of life and care for the patients.

I am looking for six to eight Chinese women 60 years of age or older to participate in this study. They must have been the primary caregiver for their spouses with dementia at home, and carry on with the caregiver role following the admission of the spouses to a nursing home. Only Chinese women who perceive themselves as primary caregivers will be included in the study. The primary caregiver must have resided in the same living quarters with her spouse with dementia for at least six months prior to her spouse’ admission to a nursing home. Both English and Cantonese speaking participants are included.
For those who meet the above criteria, I would appreciate your brief explanation about the purpose of the study to them, and give them a letter of recruitment (enclosed). If they would permit me to see them personally or phone them, I would be happy to explain the study to them in more detail.

Except for the initial contact, I shall be personally responsible for obtaining consent and arranging the interviews. All interviews with the participants will be done off the premises, usually at the participant’s home. Please be assured that the research process is not going to interfere with the facility’s operation and impose on staff time.

If you have any questions, I can be reached at 521-7764 (Monday to Friday, 8 am - 4 pm), and at 591-7077 at any other time. I shall contact you in about two weeks’ time to see if there are any prospective participants. Thank you for your assistance and support in this research.

Yours truly,

Alice Choi, R.N., B.S.N.

Encl.

Thesis supervisor : Dr. Joan Anderson
School of Nursing, UBC

Phone Number: 822-7455
Appendix C

Consent Form

I, Mrs. ______________________ hereby agree to participate in the research project "Chinese women's perspectives on the transitional process of caring for their spouses with dementia from home to institution " as conducted by Alice K. M. Choi, R.N., B.S.N. (telephone no. 591-7077)

I understand that the researcher would like to find out what it is like for me to care for my husband at home and since his admission to the nursing home. The researcher will have two to three interviews with me, up to an hour each time. I have the right to ask the researcher questions about the procedure at any time if I do not fully understand the process.

I further understand that my identity shall not be made known to anybody, except the researcher. However, the information from the interviews will be shared with the Thesis supervisors at UBC. Also, the researcher will tape record the interviews, but my name will not appear in any of the taped conversations. In order to help other Chinese elderly wives who may be in the same situation as I am, I understand that the findings of this study may be published, but my name will not appear in any of the papers.

I RETAIN THE RIGHT TO REFUSE TO PARTICIPATE OR WITHDRAW AT ANY TIME. MY WITHDRAWAL OR REFUSAL TO PARTICIPATE WILL NOT AFFECT THE TREATMENT, THE MEDICAL AND NURSING CARE MY SPOUSE RECEIVES AT THE NURSING HOME.

Signature of Participant: ____________ date: ____________

I, ______________________ acknowledge receipt of a copy of the above consent form on ____________ 1992.

Signature: _________________