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FAMILY-BASED CAREGIVING OF COGNITIVELY IMPAIRED MEMBERS: THE CASE OF CHINESE IMMIGRANTS IN TORONTO

BY

Carrie, Hor-Yau LEE

A Thesis Submitted in Conformity with the Requirements for the Degree of Doctor of Philosophy
Faculty of Social Work
University of Toronto

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Family-Based Caregiving of Cognitively Impaired Members:  
The Case of Chinese Immigrants in Toronto  

Doctor of Philosophy, 1999  
Carrie Hor-Yau Lee  
Faculty of Social Work  
University of Toronto

ABSTRACT

This study explores the caregiving process of eighteen Chinese immigrant families whose older relatives were afflicted by Alzheimer’s Disease and related disorders. The carers and their relatives were all ethnic Chinese who had immigrated to Canada and had settled in Toronto. The study is qualitative in nature and the long interview method was chosen to examine how family carers perceive, interpret and derive meaning from the care commitment. This in-depth analysis enables the researcher to uncover the intricacies of the process of caregiving. The sample was drawn from those living in the community as well as those residing in institutions.

The carers’ experience revealed a paradox consisting of five recurrent themes: learning to value the new, impaired character of the care recipient; accepting the altered relationship with the relative; managing their own emotional responses; maintaining a balance between caregiving and their own life demands; and, finally, developing the capacity to absorb stress while appreciating the rewards of the caregiving process.
Other broad themes which emerged from the findings included: the significance of family identity, rules, themes, and constructs in care apportioning decisions; the gradual evolution of functional and dysfunctional family care patterns; the mediating role of family and kinship support resources and the positive aspects of care.

The study also examined the respondents’ utilization of informal and formal support systems. They acknowledged that their own immediate family members and close kin provided a great variety of support assistance. Respondents would, however, turn to formal help when informal assistance was deficient or when the caring demands exceeded their capacity to care.

To address effectively the needs of family carers, the study suggests that intervention strategies should be developed at the micro, mezzo and macro levels. But for social work professionals, the greatest challenge is to transform the way dementia care is conceived, so that both caregivers and recipients maintain their distinctive individuality in the face of a cruel and exhausting affliction.
ACKNOWLEDGEMENTS

With deep appreciation and heartfelt gratitude, I acknowledge:

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and whose countless hours of personal involvement, has stretched me to reach beyond myself;

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The eighteen family caregivers participating in my research,
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and whose prayer support and tangible assistance enabled me to survive the darkest moments of the thesis journey;
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who provided me with a combination of companionship and loving encouragement;

The Lord and Master of the universe,
who created man in His own image and when the frail elderly person pleads,

"Do not cast me away when I am old;
do not forsake me when my strength is gone" (Psalms 71:9, New International Version).

and who tenderly promises,

"Even to your old age and grey hairs,
"I am he who will sustain you, I have made you and I will carry you;
I will sustain you and I will rescue you" (Isaiah 46:4 New International Version).
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Alzheimer's Disease: A Characterisation

Alzheimer's Disease represents one of the major sources of impairment in later life. This degenerative disease is characterized by an insidious onset and is accompanied by a variety of cognitive and behavioral symptoms that typically manifest themselves over a span of five to ten years (Garwick, Detzner & Boss, 1994; Gwyther & Matheson, 1983; Marshall, 1997; Quayhagen & Quayhagen, 1988). An illness with unknown origins and an unpredictable course, its early symptoms are often difficult to detect, preventing an accurate diagnosis. As the illness progresses, the older adult's sense of judgement and memory become impaired, leading to a diminished capacity for self care that may place insuperable burdens on significant others who are expected to provide care (Burton, Chapman & Myers, 1997; Morycz, 1990; Noelker & Poulshock, 1982; Oxlad, 1996; Shaw et al., 1997; Teusink & Mahler, 1984). Indeed, the eventual failure even to recognize a life-time spouse or adult child, together with accompanying destruction of personality, is a terrifying testimony to the ravages of this illness.

Incidence of Alzheimer's Disease

Many studies have concurred that the prevalence of dementia of the Alzheimer's type increases with age, from less than 1 percent of persons under 65 to about 5 to 7 percent
of those aged 65 to 74, 8 to 10 percent of those 75 to 84, and 25 to 40 percent of those aged 85 and older (Burton, Chapman & Myers, 1997; Chenoweth & Spencer, 1986; Dhooper, 1992; Evans, Funkenstein & Albert, 1989; Pratt, Schmall, Wright, & Cleland, 1985; Smith, 1987; Zarit, Pearlin, & Schaie, 1993). In view of the rapidly increasing number of older adults reaching the oldest category (85 and above), it is projected that the number of persons with Alzheimer’s in Canada will multiply dramatically in the decades ahead. In 1994, the Canadian Study of Health & Aging Group (CSHA) conducted a large scale study to assess patterns of providing care for people with dementia. Data were drawn from a national representative sample of elderly people, selected from the community and from institutions in the ten provinces of Canada. Interviews were held with the caregivers of people diagnosed with dementia, and with a comparison group of caregivers for non-demented persons. The study found that 8 percent of Canadians over 65, and 35 per cent of those over 85, suffer from dementia and one half of all cases live in the community (Canadian Study of Health & Aging Group, 1994a, 1994b). Indeed, in most developed countries, Alzheimer’s Disease has been recognized as the fourth or fifth leading cause of death, following cardiovascular, cancer and cerebrovascular diseases (Biegel, Sales, & Schulz, 1991; Fox, 1989). Similar concerns about the growing epidemic of dementia within older populations have been expressed in some industrialized Asian countries such as Japan and Singapore (Phillips, 1992).
Family Care: The Major Source of Support

Alzheimer's is a family disease. Research evidence consistently supports the conclusion that the majority of persons affected by the illness live at home and receive care from relatives (Brody, 1985; Cantor, 1983; Horowitz, 1985b; Kane & Penrod, 1995; Niederehe & Fruge, 1984; Pruchno, Burant & Peters, 1997; Shanas, 1979a, 1979b; Stoller, Forster, Duniho, 1992). In the national study conducted in Canada (Canadian Study of Health & Aging Group, 1994b), it was found that the great majority of elderly Canadians with dementia in the community have a caregiver and most have more than one. Only less than 2 percent of demented seniors have no caregiver. In addition, 92 percent of the participants had two or more relatives beyond the primary caregiver who also provided assistance. The study confirms the widespread involvement of the informal network in providing care and assistance to seniors (Chappell, 1992; Antonucci, 1990). Yet, attending to the needs of a demented family member can be an overwhelming experience that affects virtually all aspects of a caregiver's life (Haley, Levine, Brown, Berry, & Hughes, 1987; Lyman, 1993; Montgomery, 1995). Significant caregiving problems identified by researchers include: coping with disruptive behaviors (Haley et al., 1987), physical demands (George & Gwyther, 1986), restrictions on social and leisure activities (Archbold, 1983), disruption of household and work routines, (Montgomery et al., 1985), conflicting multiple role demands (Semple, 1992), and disruption of family relationships (Horowitz, 1982a; Mellins, Blum, Boyd-Davis, Gatz, 1993). In addition, coping with the devastation of the disease severely taxes the family resources (Gwyther & Matheson, 1993; Williamson &
Schulz, 1993). Ory and colleagues (1985) declared that “perhaps more than any other disease of old age, Alzheimer’s Disease affects the family as much as the patient” (p. 629). Families are even considered the “hidden victims” of the disease (Zarit, Reever, Bach-Peterson, 1980).

Increase of Interest in Family Care

Over the past decade, there has been an increasing awareness of the significant role that families provide in caring for dependent family members (Albert, 1984; Caserta, Lund, Wright, & Radburn, 1987; Fox, 1989; Oxlad, 1996; Suitor, & Pillemer, 1996; Zarit, Pearlin & Schaie, 1994). Several reasons explain this striking growth of interest (Aronson, 1985; Biegel, Sales, & Schulz, 1991; Rosenthal, 1997; Treas, 1977). The first concerns the changing demographic landscape of contemporary societies. Life expectancy and the percentage of the elderly population has increased dramatically during this century. The oldest cohort, those aged 85 years and over, are at the greatest risk for Alzheimer’s Disease. Additionally, as a result of medical advances and skilled nursing care, impaired people survive for longer periods of time despite their health status. With diseases such as Alzheimer’s type dementia, early cognitive and behavioral symptoms ultimately lead to increasingly severe deficits in functioning until independent living is impossible at the terminal stage (Mace & Rabins, 1991). However, since most families are committed to caring for their demented relatives, they will continue their commitment despite the
overwhelming burden. Informal caregiving will surely be a typical experience of many families in the decades to come.

The second factor that has attracted the attention of policy makers to the issue of long term care for the cognitively impaired elderly persons is that as the need for care grows, so do its costs and the demand for service (Kane, 1986; Kane & Penrod, 1995). Public and private expenditures for nursing home care have been increasing at a rapid rate. Concern about the increasing costs of institutional care has led to the development of a number of community-based program initiatives to support caregivers. The last social change that helps explain the growing interest in family caregiving concerns the traditional caregivers - the women, who are working in the paid labour force in increasing numbers. Whether by choice, or economic necessity, more females (wives, daughters, or daughters-in-law) are in the labour force. These female carers, frequently identified as the “women in the middle”, are often trapped with multiple role responsibilities of wife, mother and caregiver to an elderly parent and parent-in-law (Aronson, 1985; Neysmith, 1981; Rosenthal, 1997). Brody (1981) once observed, “such women are in middle age, in the middle from a generational standpoint, and in the middle in that the demands of their various roles compete for their time and energy” (p.473). If the woman is employed, work becomes another responsibility. The situation of these caregivers poses unresolved issues: how can they manage work and yet continue to provide care? What assistance must be introduced to give them the incentive for continuous commitment? What impact would this change have on the redefinition of roles and responsibilities of other family carers?
Family Caregiving Among Minority Ethnic Groups

Earlier research findings on family care of older persons with Alzheimer’s Disease and related disorders indicate that the caregiving experience tends to vary with factors such as socio-demographic features, (see, for example, Scharlach & Boyd, 1989; Treas, 1977) and health characteristics of the impaired relative and caregiver (see, for example, Cantor, 1980, 1983; Stoller, 1983), degree of caregiver’s involvement (see, for example, Montgomery, Gonyea, & Hooyman, 1985; Zarit, Todd & Zarit, 1986), caregiver’s attitude toward caregiving (see, for example, Picot, Debanne, Namazi, & Wykle, 1997; Poulshock & Deimling, 1984; Zarit & Zarit, 1982), and informal and formal resources available to caregivers (see, for example, Zarit, Reever, & Bach-Peterson, 1980). However, these studies are conducted within the context of western culture where individualism, independence and reciprocity of social exchange are construed as social norms and values in shaping caregiving behaviour. Whether the findings of these studies hold across different cultures is largely unknown. Minority ethnic groups tend to be profoundly under-represented in empirical studies (Henderson, 1994; Segall & Wykle, 1988; Ujimoto, 1987; Valle, 1981, 1989; Wood & Parham, 1990). In the Informal Caregivers Survey (part of the national long-term care survey) conducted by Stone and associates (1987) in the United States, the respondents were predominately White (79.5%). The sample included 1924 caregivers of frail elderly persons, representing a population of 2.2 million. Other ethnic groups comprised the remaining 20.5%, but no further breakdown by ethnic composition was shown. Similarly, in Poulshock and Deimling’s survey (1984) of 614 families, 75% were
White while 25% were Black. Again, in Cantor’s study (1983) of strain among caregivers, two-thirds (73.9%) of the subjects were White. Black (23.4%) and Hispanic (0.9%) populations were only marginally represented.

To date, there is a serious dearth of data on how ethnic and racial groups manage to cope with the caregiving demands of relatives with dementia (Shaw et al., 1997; Yu et al., 1993). A review of the literature confirmed that most studies of family care either concentrate exclusively on the White sector (see for example, Johnson, 1980, 1983b; Johnson and Catalano, 1993) or do not specify at all the ethnic background of their samples (see, for example, Chappell & Havens, 1985; Pratt et al., 1985; Quayhagen & Quayhagen, 1988; Zarit, Todd, & Zarit, 1986). In 1990, Pearlin and his group examined 555 caregivers residing in San Francisco and Los Angeles to develop a conceptual model of stress. Caregivers of Asian origins were explicitly identified in their study, but unfortunately, they only comprised a low 2 percent (n=6) of 326 spousal caregivers and 3 percent (n=7) of 229 children caregivers. It is difficult to generalize the findings to the Asian population when the data base is so small. Even less is known about the caregiving situation of specific Asian groups, such as the Koreans, Japanese, Chinese, and Vietnamese who are often subsumed under the umbrella term of “Asian origins”, which fails to acknowledge that these groupings are not homogeneous. Another more recent study released by Connell and Gibson in 1997 confirmed the same observation. Connell and Gibson provided a review and analysis of the empirical research published in 1985 that has examined the impact of care, culture, and/or ethnicity on the dementia caregiving experience. Ten out of twelve
studies included in the review focused on comparisons between Black and White caregivers, one examined differences between Black and Hispanic caregivers and one focused on White and Hispanic caregivers.

Nevertheless, minority ethnic groups are growing in size and in importance in many big cities in Canada (Disman, 1988; Saldov, 1996; Saldov & Chow, 1994; Samuels, 1992). On the national level, the Chinese community is the eighth largest ethnic group in Canada (MCC, Multiculturalism and Citizenship Canada, 1991, 1993; Statistics Canada, 1986 Census). Further, Chinese is the mother tongue of 308,905 Canadians (Statistics Canada, 1986 Census). It is second only to English as a mother tongue in British Columbia, for example. By the same token, the ethnic elderly made up approximately 9 percent of the Metropolitan Toronto population in 1986 (Statistics Canada, 1986). Among this group, 15 percent were from the top three non British or French origins, that is Italian, Chinese and Jewish (Saldov & Chow, 1994). There has been a tendency for the Chinese ethnic elderly to join family and community members in the two main areas of ethnic concentration in Canada, namely, Greater Vancouver and Metropolitan Toronto. With a growing elderly population occurring naturally from the aging process and through immigration policies that allow sponsoring of dependent older family members, the proportion of Chinese elderly may well continue to increase in the foreseeable future. Given these trends, it is likely that many more aged and demented Chinese persons will begin to surface. Unfortunately, there is an overall lack of preparation for this situation within the aging research and caregiving
establishment. This study focuses on the Chinese experience of caregiving and should, therefore, contribute to the knowledge base of ethnicity and aging.

Purpose of the Study

The purpose of the present study is to investigate the caregiving process of Chinese immigrant families whose older relatives are afflicted by Alzheimer’s Disease and related disorders. I will explore how their immigrant status, family network characteristics, use of social support and cultural beliefs influence their coping responses. The focus of the study is on exploring how caregivers perceive, feel, interpret, and indeed derive meaning from the care commitment. It is hoped these data will shed light on the coping and adjustment of caregivers and subsequently inform us about how society can enhance its efforts and provide more effective service programs.

Subsumed under the broad research question of exploring the process of caregiving, the following specific concerns will be addressed:

Caregiving Experience

- Who are the caregivers in these immigrant families which have relatives with Alzheimer’s Disease and related disorders and what are their relationships to the care recipients?
- What is the history of their caregiving and to what extent are they involved?
- What motivates the caregivers?
• What kinds of help are these caregivers providing? Can we identify patterns and styles in the caregiving activities?

• Do the Chinese caregivers experience the same manifestations of distress as reported by their counterparts in the dominant culture?

• How has the caregiving experience been affected by gender, age, marital status, and the quality of prior relationships?

• How do carers make sense of their experience?

Family Processes

• In which way have family rules and cultural norms affected apportioning of care responsibilities?

• What tend to be the functional and dysfunctional family patterns of coping and how can we identify them?

• How does the family's prior coping repertoire affect current caregiving decisions and situations?

• In which ways have social, psychological and material resources available from within the family system and its kinship network mediated the caregiving process?

• What role, if any, does an attitude of filial responsibility play in shaping coping responses?
Organization of the Thesis

This thesis is divided into nine chapters. Chapter one presents an introduction and provides an overview of the purposes of the study. In chapter two, literature pertinent to family caregiving with persons affected by Alzheimer's Disease and related disorders is reviewed. Both existing knowledge and gaps in that knowledge are identified. Chapter three summarizes the conceptual framework and I explore the cultural context of family care and discuss how social forces often intertwine in shaping caregiving outcomes. Chapter four discusses the research methodology used in data collection. It also presents the justifications for choosing the qualitative approach. The research steps involved in the long-interview method are also explored. This is followed by the presentation of the major research findings and analysis in chapters five through eight. Chapter nine returns to the research questions originally articulated in the first chapter and examines the implications for social work intervention modes and future research initiatives. The thesis concludes with a discussion of the scholarly significance of the findings and a reflective evaluation of the strengths and weaknesses of the study.
CHAPTER TWO
LITERATURE REVIEW: STATE OF THE ART

Overview

The development of scientific and systematic inquiry into family caregiving has progressed through several successive but overlapping phases. Each phase reflects a dominant theme of its own in its conceptual and empirical literature. The goal of this chapter is to summarize the essential contributions and the major criticisms of each theoretical framework on dementia family care.

In the late seventies, scholars such as Brody (1977, 1985) and Shanas (1979a, 1979b) drew our attention to the role of the family in caregiving. Findings continued to accumulate regarding the extent of family care and patterns of caregiving in the eighties (Archbold, 1983; Horowitz, 1982a, 1982b, 1982c; Ikels, 1983; Matthews & Rosner, 1988). However, these pioneering attempts shared one common characteristic - they were exploratory and descriptive in nature and did not adhere to any explicit theoretical framework (Biegel & Blum 1990; Biege, Sales, & Schulz, 1991). Also, important constructs such as “stress and coping”, “burden”, and “social support” were seldom rigorously defined. It is also important to note that these studies were often drawn from small and nonrepresentative samples, an approach which introduces a significant selection bias. As a consequence, generalization to other populations was difficult. Furthermore,
the methodological designs were usually unsophisticated. Relationships between variables were therefore hard to establish.

The second phase of research on family caregivers was theoretically guided by a stress and coping paradigm. This paradigm suggested that caregiving was stressful. Caregivers coped with their situations in different ways and mediating variables influenced caregiving outcomes. The individual stress and coping model (see, for example, Folkman and Lazarus, 1980; Pearlin & Schooler, 1978; Pearlin & Turner, 1987) was later supplemented by the family stress and crisis theory (McCubbin, 1979; McCubbin, Joy, Cauble, Comeau, Patterson, & Needle, 1980). Expanding beyond the individual "microsystems", family stress theorists proposed that families must adapt to stressors by initiating coping strategies within the family to decrease family vulnerability.

During the third phase of knowledge development in family care, both the individual and family stress approaches were strongly criticised for neglecting the developmental component in caregiving responsibilities. Supporters of the family developmental theory argued that families passed through life cycle transitions. Studies conducted by Famighetti (1986) testified to the importance of appreciating caregiving impacts within the perspective of family developmental tasks and functioning.

The last theoretical framework which has inspired research in recent years stemmed from the interpretive tradition. The symbolic interactionist perspective (see, for example, Boss, 1988, 1993; Boss & Greenberg, 1984; Finch & Mason, 1993; Fisher & Lieberman, 1994; Garwick, Detzner & Boss, 1994) provided a more optimistic outlook.
for the caregiving families. According to the symbolic interactionists, these families, rather than seeing the future as predetermined and hopeless, can at least determine some aspects of the caregiving situation. They can shift the way their families are constructed by negotiating roles and responsibilities with others. Similarly, celebrations and rituals can be adapted to include the cognitively impaired family members and the meaning that families give to their loss can be adapted over time as the illness progresses (Boss, Caron & Horbal, 1989; Boss, Caron, Horbal & Mortimer, 1990).

Initial Exploration Stage: The Pre-Theoretical Era

This first phase of caregiver research focused on the caregiving process and studies conducted during this early period described the roles, needs and burdens of family caregivers, often without the utilization of a sound theoretical framework (Biegel, Sales and Schulz, 1991). The data simply identified the caregivers and noted the extent of their caregiving commitment.

Who are the Caregivers?

Pioneer researchers including Cantor (1983), Horowitz, (1982c), Johnson & Catalano (1981), and Noelker & Poulshock (1982) have consistently confirmed that one family member occupies the role of primary caregiver. Other family members or friends, if involved at all, play secondary roles and shared responsibility between two or more members of the informal support system is very much the exception to the rule. There is
also almost universal consensus about the identity of the primary caregiver, with selection following a hierarchical pattern. Simply the primary caregiver will be a spouse, if there is one available and capable, and a child, if there is not. In the absence of both spouse and children, other relatives such as siblings, nieces and nephews will take on the responsibility of primary caregiver. Only for the minority of older people lacking any functional kin, are friends and neighbours identified as the primary caregivers (Shanas, 1979a, 1979b; Stoller, 1983).

The relationship between the caregiver and frail older person has also been identified as a primary predictor of the pattern of care provided and the stress associated with caregiving (Horowitz, 1982b, 1985b). Spouses are usually found to provide the most extensive and comprehensive care. These spousal carers also maintain the caregiving role longer and tolerate greater levels of cognitive and behavioral deficits than other caregivers. While adult children also tend to be extensively involved in and affected by caregiving, their involvement is less when compared with spouses. Other relatives, friends and neighbours are not only less likely to occupy the principal role, but when they do, they provide less intensive or intimate types of assistance, and, as a result, experience far less stress in the process.

Caregiving Commitment And Behaviour

Earlier studies also explored caregiving commitment and behaviour. Stone, Cafferata, & Sangi (1987) revealed that 80 percent of the respondents provided unpaid
assistance, 7 days a week. Virtually all spousal caregivers provided assistance daily, approximately 75 percent of the daughters and 71 percent of the sons devoted part of each day to caregiving activities.

Caregiving activities vary widely among families and can range from occasional errands to round-the-clock care. Caregiving behaviour includes emotional support (Chenoweth & Spencer, 1986, Cirirelli, 1983), direct service provision (Horowitz, 1982b), mediation with formal organizations and providers (Rankin, 1990), and financial assistance (Horowitz, 1982c). In addition, sharing a household was considered to be a special form of caregiving.

To summarize, research evidence offered in the pre-theoretical era consistently confirmed the central role of family in providing care to relatives with Alzheimer's disease. However, caregiving activities may vary widely among families as patterns of care are related to the characteristics of the caregivers as well as that of the care recipients. The first phase of scientific study on family caregiving has furnished us rich descriptive data but many important questions remained unanswered. A keen awareness of this knowledge gap later became a motivating force to pave the way for the next phase of theory development.
The Individual Stress and Coping Theory: 
An Emerging Explanatory Model

Investigations carried out in the first phase of family care studies have helped us identify the caregivers and their commitment. In the second phase, distinction between the subjective and the objective components of caregiving burden was delineated. Objective burden is related to concrete activities and events resulting from caregiving (Montgomery, Gonyea & Hooyman, 1985; Marycz, 1985). Researchers and practitioners alike began to ask the following questions: what accounts for the wide differences in caregiving effects? How does existing literature define and operationalize measures of caregiving burden? To what extent is a caregiver’s strain related to gender differences, health status and coping style? During this second stage of theory building, attempts focused on better conceptualization and quantitative measures of the concept of burden. Various burden scales were developed and burden was correlated with a variety of caregiver and care recipient variables as age, labour force participation, health and mental health outcomes (Montgomery, Gonyea & Hooyman, 1985; Marycz, 1985; Zacit, 1989b). More sophisticated longitudinal designs and multivariate data analysis techniques were also used during this stage.
Predictors of Stress and Burden

Two predictors of stress are associated with caregiving outcomes. The first predictor is pertinent to the characteristics of the dementing relative while the second is related to the characteristics of the caregiver.

Characteristics of the Care Recipient

Cantor (1980, 1983), Noelker & Poushock (1982) and Stoller (1983) have shown that as the relative's severity of functional and mental impairment increases so does both the amount of assistance provided by the caregiver and the degree of stress experienced. But Montgomery, Gonyea, & Hooyman (1985) suggested that the type of help provided was a more salient factor than either the total number of tasks or the total number of hours involved in caregiving. They argued that personal care tasks such as lifting and transferring, and dealing with incontinence appeared to be both physically and emotionally draining for caregivers. These tasks call for physical resources that older spouse caregivers might not have. As for adult children, they required an intimacy that is often considered inappropriate to lifelong roles. Similarly, mental impairment constitutes the major source of burden to families (Mace & Rabins, 1991). Furthermore, specific disruptive behaviours such as sleep disturbance, physical violence and social embarrassment were found to cause the greatest strain and depression in dementia care (Fisher & Lieberman, 1994; Rabins, Mace, & Lucus, 1982).
Characteristics of the Caregiver

Gender, age and employment status of the caregiver stand out as critical factors in determining caregiving experience. Research data confirm consistently that most caregivers are women (Miller & Cafasso, 1992; Morycz, 1985; Skaff & Pearlin, 1992; Zarit, Todd & Zarit, 1985). However, men can be found in the role of primary caregiver too (Horowitz, 1981; Stoller, 1983). Once in the role, how do they differ from women in their behaviour and experiences? Horowitz (1981) and Stoller (1983) concluded that when male and female caregivers were compared, males were found to offer lower levels of overall assistance. The differences were most pronounced in those tasks requiring “hands-on” assistance such as domestic and personal care tasks and were less apparent in areas such as decision making and linkage functions. As for the experiences associated with caregiving, wives reported higher levels of stress even when the amount of care provided and/or level of impairment was controlled (Cantor, 1983; Fitting, Rabins, Lucus & Eastham, 1986). Brody (1981) explained that the greater stress came from being the “the women in the middle”. The caregiving daughters are of the middle generation, usually middle-aged and subject to competing demands on their time.

The age of the caregiver is a further predictor of burden (Barusch & Spaid, 1989; Zarit & Zarit, 1982). Advanced age might suggest greater difficulty in managing some physically demanding aspects of caring. In addition, Fitting et al. (1985) found that younger caregivers were more unhappy and resentful of the role than were older
caregivers. This may reflect role overload among younger caregivers who had multiple responsibilities.

Figure I below summarises the predictors of caregiving:

<table>
<thead>
<tr>
<th>Characteristics of The Demented Relative</th>
<th>Characteristics of the Caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>• severity of functional impairment (ADL, IADL dependencies)</td>
<td>• age</td>
</tr>
<tr>
<td>• extent of mental impairment (cognitive status, problematic behaviour)</td>
<td>• gender</td>
</tr>
<tr>
<td>• type and amount of assistance required</td>
<td>• marital status</td>
</tr>
<tr>
<td></td>
<td>• health status</td>
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<tr>
<td></td>
<td>• employment status</td>
</tr>
<tr>
<td></td>
<td>• living arrangement</td>
</tr>
<tr>
<td></td>
<td>• caregiving experience</td>
</tr>
</tbody>
</table>

Figure I: Predictors of Stress

Consequences of Caregiving

The most significant contribution that the individual stress and coping perspective has made to the scientific inquiry of family care concerns the conceptualization of caregiving consequences. Several domains of life are potentially affected by being a caregiver.
Objective Burden

Earlier studies emphasized the physical health aspect and henceforth elaborate measures were established by researchers to evaluate the objective stress as manifested by sleep disturbance, physical fatigue and poor health (George & Gwyther, 1986; Niederehe & Fruge, 1984).

Subjective Burden

This trend was followed by studies on mental health indicators - the subjective burden of poor morale, depression and anxiety (Haley, Levine, Brown, Berry & Hughes, 1987; Pearlin, Mullan, Semple & Skaff, 1990). Emotional stress associated with caregiving is the most pervasive and the most difficult for the majority of carers. Later studies introduced more comprehensive measures embracing various facets of caregiving responsibilities (see, for example, Niederehe & Fruge's (1984). Texas Research Institute of Mental Sciences Behaviour Problems Checklist - TRIMS). Similarly, Zarit and Zarit (1982) developed their Memory and Behaviour Problems Checklist to operationalize the burden experienced by family carers.

Other consequences of caregiving include negative changes in family relationships and adverse effects on social participation (Archbold, 1983; George & Gwyther, 1986; Poulshock & Deimling, 1984; Williamson & Schulz, 1990). Caregiving activities often require extensive readjustments in previous daily schedules. Disruption of domestic routines, decreased personal time, less time for social and leisure activities and restricted mobility are all common indicators of this pervasive problem. Horowitz (1982a) further
suggested that restrictions could go beyond daily life and affect changes in long-term plans for retirement or/and relocation.

Caregiving stress in adult children, according to the individual stress and coping perspective, is also attributable to marital strain (Horowitz, 1982a; Suior & Pillemer, 1996). Spending time away from their own family members and neglecting other family responsibilities emerges as a common concern for a substantial number of caregivers.

Economic strain can also be formidable consequence for aging spouses who must draw from a joint and often meagre financial pool. However, the economic impact of caregiving is more indirect for other caregivers. Horowitz (1982c) reported that 21 percent of the non-working caregivers studied had left the labour force to provide care to an older parent. Many caregivers either gave up jobs, had to forego job opportunities or reduced their work schedules (Cantor, 1980; Horowitz & Dobrof, 1982, Zarit et al., 1986).

Caregivers' Perception of Demands

Perception or “appraisal” is another central concept in the stress and coping literature (Lazarus & Folkman, 1984; Pratt et al., 1985). Appraisal has been defined as the “cognitive process through which an event is evaluated with respect to what is at stake (the primary appraisal) and what coping resources and options are available (the secondary appraisal)” (Lazarus and Folkman, 1984, p.223). Stressful appraisals can be classified as: (1) harm or loss; (2) threat; or (3) challenge. Further, the degree to which a
person experiences psychological stress is determined both by the evaluation of what is at stake and the assessment of coping resources and options.

The notion of "perception of demands" or "appraisal", when applied to the caregiving situation of Alzheimer's Disease, serves to expand our understanding beyond the structural parameters of static characteristics. Perception as an intervening variable in determining caregiving outcome has been explored by several researchers (Poulsbock & Deimling, 1984; Zarit & Zarit, 1982; Zarit et al., 1986). Changes in this dimension will affect caregiving outcomes. Firstly, caregivers' experiences of the stressfulness of the illness will change if they adopt more effective strategies for managing the problem, or alternatively, if they receive periodic relief from the demands of care. Re-appraisals can also take place. Different caregivers may appraise the same problematic behaviour in different ways. For example, many find incontinence a distressing problem, while others can take it in their stride. Similarly, some caregivers change their appraisals over time and are better able to tolerate impairments that previously were upsetting, for instance, severe memory disturbance.

**Coping Response**

A fair evaluation of the contribution of the stress theory to our existing knowledge base of family care cannot be completed without addressing the role of coping and social support which has been identified in the stress theory. In Lazarus and Folkman's (1993) framework, coping and social support are the vital mediating variables. Coping has been
defined as “the constantly changing cognitive and behavioral efforts used to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus and Folkman, 1993, p.19).

Coping strategy in dementia care literature has been classified into two categories (Johnson & Catalano, 1983). The “distancing technique” involves establishing greater physical and psychological distance between the relative and caregiver. “Enmeshing technique”, on the other hand, involves intensification of relationship between the relative and caregiver, usually spouse, to the exclusion of other relationships. It results in social regression for spouse and role entrenchment for adult children. An investigation specifically addressed to the correlation between coping strategies and the subjective sense of burden was conducted by Pratt and colleagues (Pratt et al, 1985). They found that three internal coping strategies, namely, maintenance of confidence in problem-solving; reframing of the problem; and the upholding of a positive outlook, were related to lower burden scores.

**Social Support**

As with the case of coping response, social support was positively associated with better caregiving outcomes (Cicirelli, 1983). Scott and associates (1986) recruited 23 primary caregivers whose relatives were diagnosed with Alzheimer’s Disease. The study examined the instrumental and socio-emotional support provided by families to the primary caregivers. It was found consistently that the more adequate the support
provided by the families, the less sense of burden and the better the coping effectiveness of the caregivers.

Figure II (see p.27) has been prepared to show the interrelationships among the various components contained in the individual stress and coping perspective.

Limitations of the Individual Stress and Coping Perspective

As a beginning schema and an analytical tool, the individual response approach is a good starting point for enhancing our understanding of the family caregiving process. Nevertheless, it has not given us sufficient clues as to how families as functional units face the caregiving challenge. Because the focus of attention is on the individual carer, normally the primary caregiver, the relationship is often perceived as a dyadic one. This narrow focus creates the “care equation” postulated by Gubrium and Lynott (1987). The equation hypothesized co-variations between perceived burden, felt stress and outcome measures. Yet, the need to advance theoretical concepts and methods for studying caregiving families beyond the level of individuals is crucial because the family is greater than the sum of its parts. Niederehe and Fruge (1984, p.24) suggested that:

... dementia can be viewed as a marker for a process occurring in a social context affecting all members of the family unit, not just the patient.

Broadening the research focus to include characteristics and dynamics of the family system will provide a more holistic perspective.
A further inherent weakness in the individual stress and coping theory is related to its methodological design. Most studies tend to focus almost exclusively on the individual as the object of study and not on the family as a unit (see, for example, Miller and Cafasso, 1992; Morycz, 1985; Quayhagen & Quayhagen, 1989). As an example, Archbold (1982, 1983) interviewed 15 “care providers” and 15 “care managers” so that the two styles could be compared. These 30 respondents were all primary caregivers. Quayhagen and Quayhagen (1988) studied 58 adults from a large metropolitan area who had responsibility for a family member with a medically verified diagnosis of probable Alzheimer’s Disease. Among this group, 17 were husbands while 26 were wives. The rest (n=15) were daughters responsible for a parent. Following this approach, the individual is generally the sampled unit and data are collected from individuals. Pruchno (1989) offered the criticism that “research that has sampled individual family member’s perception and then generalized results to families as a whole has not been sensitive to the issue of “unit parity” in research” (p. 178). In most cases, the unit of study was shifted from the family (at the theoretical level) to the individual primary carer (at the empirical level) and then back to family. This has created profound design flaws and subsequently undermined data reliability and validity.
Figure 2: Caregiving and the Stress & Burden Process

<table>
<thead>
<tr>
<th>Stressor</th>
<th>Care Demand Characteristics</th>
<th>Mediating Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer's Disease</td>
<td>• cognitive symptoms</td>
<td>• coping response</td>
</tr>
<tr>
<td></td>
<td>• behaviour deficits</td>
<td>• social support</td>
</tr>
<tr>
<td></td>
<td>• physical impairments</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• emotional changes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• actual tasks carried out by the caregiver</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• tasks involving vigilance</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• amount of time devoted</td>
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</tbody>
</table>

Consequences for the Caregiver

- physical well-being
- mental health
- family relationship
- social participation
- employment-caregiving conflict
- financial impact
The Family Stress Perspective: Nature of the Family Response

This section discusses both the theoretical and empirical domains of informal care using the family as the unit of analysis.

One pre-eminent theory with the family as its foundation of analysis is Hill’s (1949, 1958) classic ABCX model of family stress based on war-induced separation and reunion. Modification of the classic ABCX theory was later made by McCubbin and Patterson (1983a). Their version, known as the Double ABCX model, predicts the longitudinal changes that families are expected to experience over time in crisis situations. While the original model focused primarily upon the pre-crisis variables that account for differences in families’ abilities to cope with the impact of a stressor event and transition, the Double ABCX model (McCubbin et al., 1980; McCubbin & Figley, 1983a; McCubbin & Patterson, 1983b) added post crisis variables to capture the dynamic process (see Figure 3 on p. 31). Three variables, namely the A, B and C are identified as interacting in defining caregiving consequences.

The Double A Variable: Accumulation of Stress

In a crisis situation, two sets of stressors exert impact on the family. The first is the initial stressor event - the onset of dementia (the A Factor in the pre-crisis stage) which plays a role in moving the family to the crisis state. The second stressor represents the “pile-up” of family changes resulting from family transitions. Three types of stressors and strains contribute to the “pile-up” in the family system of Alzheimer’s.
McCubbin & Patterson, (1983b) suggested that prior strain was the first factor to be considered. Most family systems carry with them some residue of strain, which may be the result of unresolved hardship from earlier stressors. Usually, these prior strains are not discrete events which can be identified as occurring at a specific point of time. Rather, they emerge more insidiously in the family. Covert disagreement between two adult children on who should do what in parent care is a typical example. Such disagreement could be attributable to life-long unresolved sibling rivalry.

The second type of stressor aggravating the "pile-up" stems from the consequences of the family’s efforts to cope. A wife carer may have to withdraw from cherished social activities in order to take care of the impaired husband and she might feel isolated and lonely.

The final stressor of the Double A Factor is related to the concept of "boundary ambiguity" (Boss, 1988). Since a system needs to define its boundary, physically and psychologically, uncertainty constitutes a major stressor. Due to deterioration in cognition, often a demented relative may still be present physically in the family, but his/her emotional presence is very much undermined. This great uncertainty creates distress within the family system. At the same time, various "outsiders" including remote kin and health care professionals may intrude on the family boundary in an attempt to provide help. It is also possible that friends and neighbours may be fearful or upset by changes in the family and avoid contact (Cotrell, 1996; Gonyea, 1988; Lawton, Brody, &
Safeastein, 1989; Mace & Rabins, 1991) so that the hierarchical structure of the family within the community also changes.

**The Double B Variable: Family Adaptive Resources**

The Double B Factor denotes the adaptive resources found in the family unit. Adaptive resources consist of two general types – existing resources and expanded family resources. Existing resources include those repertoires that are already possessed by the family. McCubbin & Patterson (1983b) identified five categories. They are: (1) personal resources of family members, for example, financial asset, health, self-esteem and a sense of mastery; (2) family system internal resources; (3) collective social support; (4) intergenerational support and (5) family's prior experience with coping. Expanded family resources, on the other hand, denote those that the family has developed in order to cope.

Learning to communicate with other family members in drawing up a care plan for the impaired relative is an example.

Some researchers express similar views on the nature and function of family internal resources (Bonner, 1986; McCubbin, 1979). Family cohesion or integration and family adaptability are the two most important family resources in the management of crisis. Pratt et al. (1976) described the “energized” family in her sample as being endowed with a fluid internal organization characterized by flexible role relationships and shared power. Similarly, McCubbin and his team (1983b) advanced the hypothesis that too much cohesion could create enmeshment while too much adaptability was chaotic for
Figure 3: Caregiving & Family Stress

- Prior Family Strains
- Variable A: Stressor (AD), Hardship
- Variable B: Existing Resources
- Variable C: Family Definition of AD and Demands
- Experience of AD and Initial Adjustment
- Outcome
- Adaptation
- Maladaptation

Adjustment Phase

- Variable X: Crisis
- Pile Up
- Definition of Situation
- Existing & New Resources
- CAREGIVING PROCESS AND OUTCOME
  - Negotiation
  - Restructuring
the family system. Conversely, they contended that too little cohesion would lead to disengagement of family members and too little adaptability would result in a rigid family system.

The construct of social support is not entirely new to those interested in the stress theory. Social support can either protect families against the effects of stress (buffering effect) or promote quicker recovery from stress. Nevertheless, social support in the family context represents an added dimension. Intergenerational support is frequently found in Alzheimer families. A married adult daughter may move in to live with the widowed mother when obvious signs indicate that the latter can no longer manage on her own. The mother, in turn, would share financially in the newly formed household. Scott, Roberts and Hutton (1986) recruited 23 primary caregivers whose relatives were diagnosed with Alzheimer’s Disease from an adult activity centre. Complete data were obtained from the primary caregivers and 10 other family members. The study examined the instrumental and socio-emotional support provided by families to the primary caregivers. It was found consistently that the more adequate the support provided by the family, the less sense of burden and the better the coping effectiveness of the caregivers.

The family’s past history in handling stressful situations is the last component in the Double B Factor. Past patterns would dictate current performance and thus this should be a salient consideration in assessing a family’s current coping approach.
The Double C Variable: Family Definition And Meaning Attached

In Hill’s (1949) original model, Factor C is the meaning attached to the event itself and its impact on the family system at the pre-crisis stage. The post-crisis stage involves a re-definition of the crisis by the family and of the meaning they attach to it, for example, it may be considered as God’s doing, or a form of punishment. When the family is able rationally to redefine the situation and give it a purpose or value, this will help them clarify the hardship issues and tasks so as to render them more manageable. It also works to decrease the intensity of the emotional burdens. Generally, family efforts to redefine a situation as a “challenge”, or an “opportunity for growth”, or to endow the illness with a special meaning, such as believing that the illness brings every one together, appear to facilitate family coping and adaptation. Viewed in this way, the family’s definition and meaning form a critical component in family coping.

Merits of the Family Stress Perspective

Two distinctive contributions have been made by the introduction of the family stress perspective. Firstly, the family framework has broadened our vision to embrace family characteristics as a valid context for understanding care provision. Research evidence utilizing the familial formulation has repeatedly confirmed the significance of family history, familial ties and emotional bonds, intergenerational support, previous coping pattern and family resources in influencing caregiving behaviour (Famighetti,
1986; Finley, 1989; Fitting et al., 1986; Matthews, & Rosner, 1988; Stoler, Forster, & Duniho, 1992).

Furthermore, the familial perspective has served to strengthen some basic concepts addressed in the individual model. A ready example of this kind of conceptual enrichment is related to the enhanced understanding of “perception and appraisal” of stress and demands. In the family perspective paradigm, perception of demands and the availability of social support are mediating variables affecting caregiving outcome.

The second merit brought forth by the family perspective concerns the methodological advancement made in caregiving research. Earlier, I discussed the problem of “disparity in unit of analysis” which is commonly found in studies adopting an individual stress orientation. The introduction of the family stress theory has helped to overcome this methodological flaw. Within this theoretical framework, the sampling unit is the family. The term of “family” may be defined by the researcher in a number of ways. For example, researchers can include the spousal carer and the adult daughter carer in the caring dyad. Similarly, the family constellation in which care is shared between siblings is another type of potential sample pool.

Data collection will also use the family unit. Data are collected separately from the spousal carer and adult child using standard interview or questionnaire formats. Another technique, used frequently by clinicians is to gather data from the family collectively. In this manner, an interviewer might pose questions to the family and record
only those answers agreed upon by the family. Similarly, one questionnaire could be given to a family along with instructions for them to record the “best answer” as a family.

A further approach to explore variation in the family experience of caregiving has been used by Noelker and Poulshock (1982). They purposely sampled the population to obtain a representative number of one, two, and three generation households. Poulshock and Deimling (1984) found that the three-generation households had felt the worst stress. They postulated that the presence of more persons in the household provided greater opportunities for conflicts and that the carers were hampered by multiple roles. Methodological techniques of this nature have been of great value to researchers concerned with understanding the dynamics of family care.

**Critique of the Family Stress Perspective**

Family care of dementing older family members is best understood in the context of family dynamics, family histories of care patterns, prior coping styles and support resources available to the family and its network. Variations in functional characteristics, such as adaptability, family cohesiveness, and the extent to which family roles are defined, all appear related to caregiving outcomes. The family stress formulation has clarified some theoretical constructs which have been dealt with only superficially by the individual stress approach.

In addition, the improved methodological design of the family stress model has made it possible to study caregiving demands in the context of the entire family. Research
based on a family perspective requires data from all members of the family, rather than from a single informant. Studies emerging from a family perspective often put the emphasis on role allocation and renegotiations (Globerman, 1994; Matthews & Rosner, 1988). However, though the family perspective has broadened our unit of analysis, it has not yet been particularly successful in registering changes over time. This is a real challenge to researchers who aspire to understand a more dynamic caregiving phenomenon. Such an opportunity is provided by the developmental perspective which will be explored in the next section.

Family Coping: the Developmental Perspective

Family response to the caring demands of Alzheimer’s depicted in Fig. 3 on p. 31 can be further examined at two stages: the initial adjustment stage and the adaptation stage. Utilising a unique perspective, the adaptation stage takes us through the caregiving process over a longer period of time so that changes in care commitment can be more clearly perceived.

The Adjustment Phase

At the period of time preceding the stress event (onset of Alzheimer’s Disease), family functioning is assumed to be relatively stable. However, this stability does not preclude the possibility of some disturbing patterns of family interaction, for instance, marital conflict of the aging couple or parent-adult child disharmony. In reality, the
family could be “anywhere along the adaptation continuum from adaptation to maladaptation” (McCubbin and Patterson, 1983b, p.19). Thus, the continuum is indicated by broken lines in Fig. 3. When cognitive and behavioral deficits begin to affect the sick member’s normal functioning, the family is confronted with a cluster of demands. Certain tasks, such as household budget must be taken over by the other spouse. In addition, the well spouse also needs to learn new caring tasks and responsibilities. In the usual course of events, the family attempts to make adjustments in its pattern of interaction with minimal change or disruption.

Therefore, most families manage to cope in one way or another during this adjustment stage. Nevertheless, as the disease progresses, structural change in the family system becomes necessary, for example, the demented parent moving into the household of an adult child’s family. The nature, extent and duration of demands may also deplete the family’s existing resources. Persistent prior unresolved strains may also tax the family’s resources. Consequently, as the demand-capability imbalance persists and increases, the family moves toward a state of crisis (Variable X in Figure 3). When this takes place, the family will need to make further adaptation. This is displayed in the bottom row of Figure 3 (p. 31).
The Family Adaptation Phase

The family soon comes to realize that in order to restore some functional stability, it needs to restructure - make changes in its existing structure which may include modifying established roles, rules, goals and patterns of interaction. Additionally, family members are called upon to bring the entire family into a coherent unit working together around and in support of the newly instituted change (McCubbin, 1979). Case histories of Alzheimer's families show that it is not uncommon for these families to attempt to "close-out" the emotionally absent family member's role (Oxlad, 1996; Suitor & Pilleman, 1996; Williams & Kay, 1995). Another option that a family might adopt is to seek an institutional placement when it becomes clear that the relative needs 24-hour care (Morycz, 1990; Smith & Bengston, 1979). Yet, institutionalization may precipitate a new crisis in the family. In order for the family to survive, members need to identify new roles to replace the old ones subsumed in the care of the relative. The primary caregiver needs to establish some outside contacts while spending long hours visiting the sick spouse. On the other hand, the family unit has to deal with intense feelings of guilt, anticipatory grief and separation (Pratt et al., 1985). Formal support resources, in the form of self help groups, and education program are frequently sought at this stage to facilitate adjustment.

A further body of research which has accumulated during this stage of knowledge refinement draws our attention to the family life developmental cycle and I shall discuss this in the following section.
The Family Developmental Cycle

Duvall (1977) contended that the family life cycle comprises the formation, expansion, contraction and dissolution stages. A primary strength of the family developmental approach is its emphasis on the family as a growing and changing system. This perspective has been helpful in enhancing our understanding of family stressors in relation to specific family stages, such as those associated with the childbearing, parenthood, and retirement family stages.

Carter and McGoldrick (1980) argued that the family’s current developmental stage determined its patterns of response. For instance, the “pile-up” effect of other stress-producing demands, and the family’s previous stress history would all be qualitatively and quantitatively different at various stages of the family life cycle. A family in the retirement stage tends to lack the financial and human resources to cope with the 24-hour care of the Alzheimer’s victim. This has partially explained why old spousal caregivers found the care demands very stressful (George & Gwyther, 1986; Morycz, 1990). The retirement stage family will have contracted in numbers. There tends to be little, if any, support outside the immediate household. At this particular stage of the family cycle, the older spouse may have little choice but to rely on formal governmental intervention. The absence of a reliable caregiver is the single most important predictor for institutional care (Brody and Spark, 1981).

The family developmental theory also helps us understand the hardship experienced by offspring carers in lending support to their own parents. Frequently, they
have to “suspend” their own developmental tasks in order to fulfill the caregiving roles (Globerman, 1994). For an adult child who is at the childbearing stage of his/her family of procreation, the increased demand for support by the demented parent aggravates the “pile-up” effects (Barusch & Spaid, 1989). Dual commitments and multiple demands often give rise to role strain and role overload in the carers.

Critique of the Developmental Perspective

The developmental frameworks of the family stress theory and that of the family cycle have provided us with a useful tool for analysing family coping responses over time. They have stressed the importance of examining the developmental stages of families to determine their response effectiveness. Despite its usefulness in explaining care response over time, the developmental perspectives suffer considerably from their relatively weak empirical support. Caregiving research based on this paradigm is, then, rather limited (Biegel and Blum 1990; Biegel, Sales, Schulz, 1991). The key critique is related to the deterministic normative assumptions that inform this perspective.

The Constructivist Stance:
An Alternate Paradigm to Caregiving Study

In previous sections, the focus of the discussion has been on the structural and developmental factors which affect caregiving activities. In this section, attention will be given to the constructivist perspective of family care.
Constructivists assume that actions are structured social encounters, based on shared interpretations of the situations (Berger & Luckman, 1990; Boss, 1988; Boss et al., 1989; Boss, et al., 1990; Garwick, Detzner, & Boss, 1994). Responses to particular situations can only be understood in terms of the meaning that persons attach to these situations. Central to the concept of personal definition of the situation is the person's beliefs about the reciprocal manner in which they should act with regard to particular others, at particular times, and in particular situations. It is this special focus on understanding the situation from the perspective of each family member which makes symbolic interactionism unique in the analysis of caregiving responses.

Alzheimer's Disease and Ambiguous Loss

Stress and coping theorists have deliberated long and hard on the predictors of stress in family caregivers. However, Boss and associates (1990) identified family boundary ambiguity as the most critical predictor of high stress and family functioning. Demented elderly persons are “missing” family members in Boss’s analysis. They are physically present but psychologically absent. They no longer perform the same roles that they previously performed as they become less and less emotionally involved with the family. In addition, the degree of ambiguity increases as the sick relative becomes unable to interact emotionally with the caregiver(s) and other family members. As a result, the caregiver cannot mourn adequately. Although the family has lost its loved one as surely and permanently as in death, since the physical body remains, society neither recognizes
the caregiver’s grief, nor provides the support and comfort that surrounds those bereaved by physical death.

Renegotiating Responsibilities in Alzheimer Families

While the structural-functional perspective advocates network supports, the symbolic interactionist views “restructuring” reality as the focal point of intervention. Therefore, defining the situation is the cognitive prerequisite for coping and managing. Boss (1988, 1993) contended that though families could not change the physical reality of the disease, they could shift the way they were constructed. For example, responsibilities could be negotiated with others, and celebration and rituals could be adapted to include the ill person.

In concrete terms, Boss et al. (1988) suggested practitioners must assess three variables in the family system to determine its vulnerability to ambiguous loss. The first factor examined was the value and belief system prevalent in the family. Case studies showed that if caregivers valued mastery over fatalism, action over passivity, or control over acceptance of “the way things are”, they would rely more on action plans and technological assistance to resolve their problems. By contrast, passive care providers were less likely to set limits on demands for their time and energy because they believed a supernatural power would help them.

Other variables studied by Boss et al. (1988) were the belief system of family rules on gender roles, intergenerational exchanges and communication processes. The more
flexible the gender rules, the better the family was found to be in adapting to role changes. Rigid male and female role divisions had been a source of stress in Alzheimer’s families (Boss et al., 1990). Similarly, conventional rules on intergenerational exchanges had deterred aged parents from seeking help from children carers when help from the latter was obviously needed. A further aspect of family rules was related to communication. In Boss’s view, the more restrictive rules about communication were, the more difficulty the family had in coping with the stress of ambiguous loss. In families where excessive “taboo” dominated the family’s communication process, members could hardly share and face the pain of change and loss.

Caregiving Obligations And Responsibilities

The function of family obligation and responsibility received scant attention in family care until Finch and Mason (1990, 1993) published the findings of their study. They used both quantitative and qualitative research methods to explore the nature of obligation and responsibility within kin groups in the North East of England. The researchers argued that relationships between parents and children were founded on a sense of obligation up to a point but such obligations had definite limits. They found that obligations and responsibilities did not structure family patterns, but rather that “responsibilities build up incrementally over time through complex processes in exchange relationships (1993, p.79). A process of negotiation was shown to be operating in families to decide who does what and when. There were some underlying principles which tended
to shape the negotiation. Notions of “equal shares” and “prior commitment” helped to shape the guidelines. The notion of “prior commitment” entailed that it was important to see one set of obligations, for example, of adult children caregivers of aged demented parents, as locked into a broader set of duties, for instance, mother to young children and wife to marital partner. In other words, some obligations can legitimately take precedence over others. The importance of “prior commitment” was also supported by Gubrium (1988) whose study followed an interpretative tradition. Gubrium maintained that kinship priority centred on the configuration of family rules that any one member had with others. In the matter of caring for an elderly person of Alzheimer’s Disease, the issue of who the caregiver was, “may require a decision about, say, whether one is an adult child to one’s parents first or a parent to one’s children before all” (Gubrium, 1988, p. 204).

In addition to normative obligations and family rules, other more dynamic factors, such as family history, habits and expectations also influence decision-making on family care. This pattern was confirmed again in Globerman’s research (1995). Globerman argued that family legacy and prior reputation explained why one child was called upon, chosen and ended up as the designated primary caregiver while others of the same gender, proximity, or employment status were exempted from the tasks. In a similar vein, Finch and Mason (1993) discussed the “excuses” made by the uninvolved children. Such legitimation of “excuses” was in fact negotiated in their family of origin. The family
granted legitimacy to the unencumbered child's excuses because of some shared knowledge about the person's reputation in the family of origin.

Positive Rewards And Satisfactions of Caregiving

As noted in earlier sections, the research emphasis has been on the negative aspects of providing care to persons with Alzheimer's Disease. Research studies conducted to date have given much less attention to documenting any positive consequences perceived to come from the caregiving role. Yet, when asked directly in face-to-face interviews, some caregivers can identify at least one positive aspect associated with providing care. These potentially positive caregiving outcomes primarily involve feelings of gratification and increased self-respect stemming from the knowledge that one is successfully fulfilling a responsibility and coping with a personal challenge (see, for example, Abel, 1990; Bar-David, 1992; Gubrium & Lynott, 1985). Utilizing an existential theoretical framework to guide their qualitative study of 94 family caregivers, Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken (1991) asserted that caregivers grew and found meaning through the caregiving experience.

Information on the positive aspects of caregiving has been made more available by the interpretative approach because the design allows us to gain access to the raw data - the day to day experience of caregiving which includes the process of changing identity over time.
Additionally, caregiving may result in an improved relationship with, and understanding of, the aging relative, especially when the relative is a parent. Other positive effects that have been reported include putting other stresses into proper perspective and relief from worry that the older relative is being properly cared for (Gubrium, 1987, 1988).

Significance of the Constructivist Perspective

In summary, over the past decade, research on dementia stress effects has been theoretically guided by a stress and coping paradigm. An alternative paradigm has been used in the last decade to guide research which examined caring relationships. The symbolic interactionist perspective asserts that outcomes are socially constructed, based on shared interpretations of the situations. Themes such as family boundary ambiguity, family values and beliefs, filial obligations and the negotiation process have been explored to account for the differences in findings on caregiving experience. In addition, research studies based on the symbolic interactionist approach have illuminated the positive aspects of caregiving, a dimension which was grossly ignored in the stress and coping perspectives. The interactionist approach also informs us how family members become designated caregivers, perceive their involvement and experience the new role relationships with the impaired relatives.
Summary

In this chapter, I have examined four theoretical models which have contributed significantly to our present understanding of family care in dementia disease. The individual stress and coping theory is aimed at exploring the predictors of stress and burden and the impact of caregiving at the individual level. However, the individual stress perspective has failed to enlighten us beyond the dyadic caring relationships to embrace the total family network though research data consistently confirm that often multiple carers are involved. To broaden my analytical base, the family stress perspective was then included. Attention was given to the various key concepts of the model, such as family perception and appraisal of demands and the availability of network resources and social support. A critique of the family stress model naturally leads me to the next phase of conceptual sophistication and methodological advancement. Towards this end, the developmental approach fills the knowledge gap in informing me how families adjust and re-adapt when older relatives further deteriorate in social functioning.

The developmental approach has also persuaded me to examine more closely the family life cycle dynamics to appreciate the trajectory of care. Finally, I discussed the constructionist paradigm. Symbolic interactionists postulate that in a caring relationship, lives of the carers and the recipients are mutually affected by the activities. We must seek to understand the nature of that bond and the family interaction patterns which have persisted over time. That bond also has far reaching consequences for the way in which current situations may be handled.
CHAPTER THREE
THE CONCEPTUAL FRAMEWORK
TOWARDS AN ETHNO-SPECIFIC MODEL OF FAMILY CAREGIVING:
A REFINED CONFIGURATION

In Chapter Two, I conducted an extensive and critical review of the caregiving literature. In this chapter, however, I shall propose a new theoretical framework and examine closely the cultural and family contexts of dementia care. The key questions raised include: What role has immigrant status played in shaping the caregiving behaviour of these ethnic care providers? What strategies were useful to them in negotiating roles and relationships in the host country of Canada? Were motives for care provision influenced by cultural values and obligations such as filial responsibility and reciprocity? The new configuration begins with a survey of the changing nature of Canadian society and an analysis of the immigrant status of ethnic Chinese seniors and their carers.

The Changing Nature of Canadian Society

Henry, Tator, Mattis & Rees (1995) contend that Canada's population has become increasingly racially diverse. While in the past, Canada was a country largely inhabited by Caucasians, it has changed and now includes immigrants from more than 70 countries. Samuels (1992) for example, projects that by 2001, about half of the population of Toronto and two fifths of the population of Vancouver are expected to be visible minorities. In addition, the source countries from which immigrants come have dramatically altered. In
1961, 90 percent of Canada's immigrants came from European countries (Henry, Tator, Mattis, & Rees, 1995, p.78). This figure declined to 25 percent between 1981-1991. Almost half of all immigrants who came during this period were Asian born (Statistics Canada, 1996 Census) and Chinese comprised the most numerous group (1.3 million). In Vancouver, British Columbia for example, between 1991-1996, the three biggest immigrant groups were from Hong Kong (n= 44,715, 36%), China (n=27,005, 18%), and Taiwan (n=22,315, 15%) (Kootnikoff, Purvis, Rehnby, Sieger, & Ward, 1997). Kootnikoff and associates (1997) further maintain that Toronto has actually received more Hong Kong immigrants than Vancouver, but because of its larger size and the fact that it welcomes a steady flow from other parts of the world, the change is less visible.

There has been a tendency for Chinese ethnic seniors to join family members in the two main areas of ethnic concentration in Canada, Greater Vancouver and Metropolitan Toronto. With a growing elderly population deriving naturally from the aging process and through family unification programs that allow for sponsoring of aged parents and dependent grandparents, the proportion of Chinese elderly may well continue to increase for the foreseeable future.

A schematic diagram of the new model is given in Figure 4 on (pg. 50).

**The Impact of the Immigrant Status**

Attending to the needs of cognitive impaired older members is a tremendous burden to families (Cantor, 1980; Chenoweth & Spencer, 1986; Cohler et al, 1989; Cotrell, 1996; Fitting et al, 1986; George & Gwyther, 1986; Gubrium, 1988; Mace &
However, coping with relatives diagnosed with a dementing illness and who are recent immigrants to Canada poses additional challenges to the minority ethnic groups. Elderly immigrants often suffer from multiple losses.

Figure 4: Caregiving Experience of Ethnic Chinese Families with Cognitive Impairment
The first loss is associated with the loss of culture among the minority ethnic Chinese. For the purpose of this study, ethnicity is defined as a state whereby “individuals identify themselves with and are identified by others with a shared culture, language, religion, nationality, region and race” (Auger, 1989, p.156). Culture here refers to “a group’s way of life: the values, beliefs, traditions, symbols, language and social organisation that become meaningful to the group members” (Aranda & Knight, 1997, p.342). This shared way of life is based on a distinctive social and cultural heritage passed on from generation to generation (Gordon, 1964). According to Maclean & Bonar (1993), an ethnic group’s cultural heritage “represents the accumulation of tried and tested methods for adapting to life with its particular world view, life values, language, humour or wit, and religious observances” (p.53). It is not uncommon to witness how older immigrants mourn over the loss of favourite food and drinks, cherished songs, literature, newspapers and folklore. Therefore, connection to one’s heritage is important to the ethnic seniors in adjusting to the major task of settling down in the host country.

Yet, immigrant status often incurs a deep sense of uprootedness, isolation, alienation and powerlessness (Pinderhughes, 1995). Ethnic seniors are frequently seen wandering aimlessly in the shopping malls during the winter or casually chatting with each other in the public parks in the summer. Due to language barriers or other access difficulties, very few of them can fully participate in the mainstream social life. In addition, these ethnic seniors are often marginalized in the health care delivery system (Maclean and Bonar, 1986). To further complicate the situation, the beginning signs of dementia such as memory loss, spatial disorientation and withdrawal are mistaken by family members as common
responses to the adaptation requirements in a foreign land. In this way, accurate diagnosis of
cognitive decline can be further delayed.

As for the ethnic Chinese caregivers, the loss of a community of origin is a painful
setback. Departure from the home country inevitably implies bidding farewell to a familiar
social network of relationships. The ethnic community plays a central role in a person’s
life. First, it offers opportunities for intimacy with others who are more likely to affirm the
life-long values. Second, the community fosters continuity with a system of shared symbols
and ideas which would facilitate adaptation to life’s stresses and transitions. Without the
ready back up of a life-long community, to whom can the caregivers turn for emotional
support and concrete assistance in the face of an illness which is little known among the
Chinese community? The loss of community also deprives caregivers of the ease of
communicating their needs in their own language. There is considerable potential for
misunderstanding as the caregivers and service providers may misinterpret each other’s
mannerisms or tone of voice. This frequently results in intense frustrations to all concerned
parties (Saldov & Chow, 1984, 1994).

In my conceptual scheme, in addition to a disadvantaged immigrant status,
caregiving response is affected by three other social forces: the cultural context; the family
system and kinship network, and the social support resources. These are discussed in the
following separate sections.
The Cultural Context of Caregiving

Cultural beliefs and normative practices affect several aspects of caregiving activities: the selection of caregivers; motives for care provision; appraisal of stress and caregiving outcomes; and performance of caregiving roles (Canton, 1979; Gelford & Kutzik, 1979; & Gordon, 1964).

Selection of caregivers - same or different formula?

Horowitz (1982c) observed that there was almost universal consensus about the identity of the primary caregiver, with selection following a hierarchial pattern. These carers were predominately female with wives and adult daughters comprising the majority of the caregivers. But Maeda (1981) cast serious doubt on the relevance of this assumption in his examination of the historical context of caregiving outside the western culture. Both in Japan and Korea (Maeda, 1981; Sung, 1992), until the 1940s, it was legally stipulated that the eldest son should care for his aging parents. In turn, he was entitled to inherit all the parent’s fortune. Though the legal stipulation was later abolished, the burden of cultural expectation regarding parental caregiving is still on the eldest son. If the eldest son does not play his role, another son is expected to assume the caregiving responsibility. A married daughter is not expected to take care of her aged parents, since she is regarded as having become a member of her husband’s family.

In the People’s Republic of China, family support is well defined by legislation. Children who have come of age have the duty to support and assist their parents. When adult children fail to perform the duty of supporting their parents, parents who have lost the
ability to work or have difficulties in providing for themselves have the right to demand that their children pay for their support. Zhu and Xu (1992) reported that regulations were made in 23 provinces, cities and autonomous regions to protect the legitimate rights of the aged. As an example, in the city of Tianjin, it is clearly stipulated in the Provisions on the Protection of Legitimate Rights of the Elderly that grown-up sons and daughters are duty bound to ensure the living standards of their parents with an income not inferior to their own average. Adult children who fail to meet their obligations may be punished under the criminal code. The incentives on adult children to support their elderly parents, then, lie not only in the tangible benefits they received and continue to receive from the parents, but also in the avoidance of the legal consequences associated with neglect of care of the elderly.

In selecting informal carers, the “principle of substitution” has long been documented in research reports (Johnson & Catalano, 1983; Shanas, 1979a, 1979b; Silverman & Huelsman, 1990; Stone et al., 1987). This principle declares that selection is based on kinship priority and operates according to formal familial distance from the member concerned. For example, when a married husband with adult children is stricken by illness, chances are that the primary caregiver will be his wife. If the wife is unavailable, then children (mainly middle-age daughters, whether married or unmarried) will step in next.

The purpose of the new conceptual scheme proposed here is to consider cultural expectations with regard to selection of carers, and understand how dilemmas, if any, can be resolved in affected families. In the new land of Canada, such families are freed from legal obligations, but can they turn a blind eye and a deaf ear to the social sanctions against non-
compliance? Can they ignore the ethical norms about parental care which have long been internalised? How might the new situation affect the eldest sons and their wives? In practice, are the married daughters entirely exempt from the caring responsibilities in circumstances where male offspring are not available?

Motivations for assuming care

A multitude of institutional, social and psychological factors come into play to determine the decision for assuming care (Finch, 1990; Globerman, 1995, 1996; Guberman et al., 1992; Hirschfeld, 1983; Walker, & Pratt, 1991; Walker, Pratt, Shin, and Jones, 1990). In Guberman et al.’s in-depth qualitative interviews (1992), 40 female francophone Quebecois family caregivers of frail elderly reported their material, social and psychological conditions as the first and most important factors inducing involvement. These conditions included feelings of warmth and emotional affection and interconnectedness with family, gender-role conditioning and life situation. The unavailability of other family members and the inadequacy of community and institutional alternatives were other reasons given by the caregivers. However, based on the 49 life history case studies/biographical research among former caregivers in Vienna, Austria, Horl (1989) asserted that his respondents were motivated more by such variables as gratitude from those cared for, material compensation and mutuality in the relationships. A sense of obligation, based on reciprocity, and a distinct feeling of a lack of alternatives were secondary incentives for assuming care.

However, contrary findings were reported by Sung (1992) who conducted a study in
South Korea. Sung identified other types of motivation for parental care. In Sung's sample, 130 Koreans who were awarded the Filial Piety Prize between 1970 and 1985 identified the following as significant motives: respect for parents; filial responsibility; maintenance of family harmony; repayment of debts; and filial sacrifice (Sung, 1992, p.109).

By contrast, Finley, Roberts and Banahan (1988) who examined attitudes of filial obligation by parent type (father, mother, mother-in-law, and father-in-law) and by gender of the adult child, revealed that caregiving obligation was also explained by such structural and demographic factors as distance and role conflict. The varied associations with filial obligation by parental type could be explained by varying costs, rewards and levels of reciprocity. Research data for this study were collected from a telephone survey of 1,760 subjects, who lived in the metropolitan area of Alabama.

To conclude, the reasons promoting sustained caregiving involvement do differ among different ethnic groups and thus the social context of caregiving must be addressed.

Appraisal of stress

Ethnicity and culture can also influence the experience of caregiving vis-a-vis the culturally specific appraisals of the caregiving situations. While there is little data on caregiver burden among Chinese, there exists a growing empirical literature that compares how different cultural groups experience the strain or positive outcomes of caring for the demented relatives (Cox & Monk, 1993; Haley et al., 1995; Hinrichsen & Ramirez, 1992; Lawton et al., 1992; Morycz, Malloy, Bozich, & Martz, 1992; Wood & Parham, 1990; Wykle & Segall, 1991). The differential caregiving impact is often correlated with
caregiving attitudes, appraisal of the demands as well as assessment of one’s sense of mastery and control. Morycz and his associates (1987), working with a sample of Black and White American caregivers from an urban geriatric assessment centre, reported that Black families were less burdened than were Whites, though the amount of care provided was similar. Only 12% of Blacks Americans compared to 82% of Whites institutionalized their demented family member. In addition, Black American caregivers were more burdened by the provision of assistance related to physical activities of daily living while the White Americans experienced an increased burden from the provision of instrumental care. Similarly, in the work of Lawton et al. (1992), initial descriptive comparisons of means indicated that Black American caregivers reported more caregiving satisfaction and less caregiving intrusion than their White counterparts. The noticeable difference identified among the two groups can be attributed to the different appraisal effect. Black American caregivers reported more traditional caregiving ideology (Lawton et al., 1992) and more strongly held attitudes of filial support than White caregivers (Cox, 1993). In a similar way, Miller et al. (1995) offer several cultural interpretations of the finding that Black carers reported less pressure and distress than White caregivers. The authors contend, for instance, that the distress of caregiving might be viewed as relatively minor in light of the continual struggles that Blacks in American society face or that Black caregivers might be more likely to view the symptoms of dementing illnesses as part of the normal aging process.

This line of interpretation was also reflected by Shaw and his associates (1997) in a cross-cultural study in the late 1980's. The comparison study took place in two different sites, Shanghai, China (n=110) and San Diego, California (n=139). The researchers found
that, though coping strategies were similar, cultural ideals promoting family interdependence, veneration of elderly family members, and acceptance of traditional family roles might have reduced the psychological impact of caregiving in the Shanghai sample. Caregiving responsibility was experienced as less onerous because family caregiving was regarded as more normative in the Shanghai sample than in the San Diego sample.

**Performance of caregiving role**

Cultural expectations not only govern the choice of caregivers or foster certain motives of care, they also prescribe specific roles and commitment. For example, many aged Chinese parents expect their adult children to take them into their households in the face of declining health or financial hardship (Ngan, 1990). Similarly, the amount of financial support given to aging parents, in particular by sons, is interpreted as a measurement of devotion. The manner whereby actual caregiving duties are fulfilled among this target group is worthy of closer consideration. Questions that remain unanswered in Chinese immigrant families include: Would a cognitively impaired parent be maintained in the family and at what cost? In whose home, the son’s or the married daughter’s, would this parent stay if independent living is no longer a viable option? How would family members apportion the personal and financial responsibility for providing care and in what way is this related to gender differences or birth order? What kind of outside assistance is necessary and appropriate and at what point would institutional placement be considered?
The Family System and Kinship Network

Informal caregiving for most Alzheimer's adults takes place at home at the early stage and thus characteristics of the family and its kinship network are critical determinants of the caregiving arrangement (Fisher & Lieberman, 1994; Garwick, Detzner, & Boss, 1994). Immigrant families are often confronted with multiple difficult tasks. First, the family system which shoulders the major caregiving responsibilities is affected negatively by its immigrant status. The size of the kinship network may have shrunk, affecting the availability of informal network support. In Wood and Parham's study (1990), household size was negatively correlated with stress. Black respondents reported that they relied upon extended kin, friends and neighbors to perform functions that only close relatives were likely to perform in White families. Hence, household size and extended kinship network were significant in mediating the caregiving burden. In addition, immigration for the Chinese offspring families frequently entails lower social status, and reduced income as educational credentials and work experience might not be recognized.

Further, these families might need to redefine their boundaries. Close kin such as siblings may still be residing in the country of origin but another relative, for instance, a niece may now become part of the family because she has already settled down in Canada and her assistance is invaluable. Similarly, family roles, previously assigned on the basis of traditional gender distinctions, might have to be reassigned to meet the demands of the new circumstances.

Immigrant families are placed under further stress by a third factor. Adjusting to a new environment often requires effective negotiation with different societal systems in the
host country: economic, educational, health care, housing, and social. Chappell (1991) identified four types of caregiving resources. These included income resources, health resources, education resources and social network resources. It is generally recognized that immigrant families suffer from reduced income and weakening of social network support in the host country. Hence, how do immigrant Chinese families manage to pool their shrinking resources or develop new resources when facing care demands? Which family rituals are helpful in keeping the family identity in the new land? These are some of the issues to be included in the conceptual framework.

The Assimilation Continuum And Use of Social Support

There are different degrees of assimilation in the acculturation process and ethnic caregivers might be at different points on the assimilation continuum (Lustbader & Hooyman, 1994; Valle, 1989). Three distinct positions are identified: the traditional, the bicultural and the assimilated. The traditional position is characterized by a strong orientation toward cultural origins and ethnic identity. Immigrants adopting this position are uncomfortable with outsiders and find it hard to negotiate with service providers of a different ethnic background. Bicultural people, however, have a foot in both worlds. They are marked by partial allegiance to their homeland culture and partial affinity to the current mainstream culture. Brownlie (1991) held the view that to be bicultural is to become an instrument of cultural change both within the mainstream and the culture of origin. When it comes to seeking help, bicultural people might make shifts as they carefully assess the consequences. Those holding an assimilated position are closely integrated with the
mainstream culture. As an illustration, a fully assimilated daughter carer may have no trouble relying on professionals from other cultural or racial backgrounds as long as she gets to meet them and assess their capability at firsthand.

Henderson (1994) later further expanded on this notion of acculturation process and brought in the “personal culture” dimension. Henderson, in discussing the ethical and racial issues in aging research pointed out that ethnic minorities adapt to life in multicultural society by revealing their ethnic culture in certain situations and concealing it in others. The decision to conceal one’s ethnic identity is affected by the penalizing experience of being perceived as different. In applying this to the caregiving situation, whether to disclose or to conceal one’s ethnic orientation depends on the calculated benefits to be gained.

Research data have consistently confirmed that social support has a mediating effect on caregiving strain (Cox, 1993; Folkman & Lazarus, 1980; McCubbin & Patterson, 1983a; Wood & Parham, 1990). For example, Zarit et al (1980) using an interview schedule found that high morale in caregivers of demented elderly persons (n=29) was associated with frequent visits from other family members. Their study has confirmed the buffering effect of social support. However, the utilization of social support is closely related to family caregivers’ acculturation processes. Acculturation patterns and recency of immigration are likely to affect the utilization of social support.

Aranda and Knight (1997) define acculturation as “the process of cultural change resulting from continuous intergroup contact” (p.348). In this change process, individuals whose primary cultural learning has been in one culture modify their beliefs, values, and behaviours and absorb the cultural behaviours and characteristic patterns of living from
another host or mainstream culture. In his study on the attitudes of Mexican Americans in the San Diego area towards support of the elderly, Zuniga de Martinez (1980) found that as acculturation increased, traditional attitudes regarding familial support of the aged decreased. Weakened reliance on the family was correlated with departure from identification with Mexican cultural heritage, loss of contact with relatives in Mexico, longer U.S. residency and English language ability. Zuniga de Martinez further found that the number of local social ties increased with the length of stay in the States. Native born individuals or immigrants living in the U.S. for an extended length of time can count on more primary and secondary kinship ties. However, recent immigrants may be more vulnerable to stress given the geographical remoteness of their natural support networks in their country of origin. Yet, these immigrants may be held accountable by distant family members who have cultural expectations about how the older adult with a dementing condition should be cared for in the foreign land. Would the Chinese carers in my study reveal similar experiences? This question warrants further exploration.

Another important consideration is that, family members and close kin may condemn caregivers’ help-seeking behaviour that violates family or community norms. When this occurs, care providers may feel torn between the need for acceptance by their subgroup and a more imminent need to obtain formal support services. Certain services, for instance, in-home health care and centred-based respite, might be approved of by the kinship network whereas others, such as residential placement, may be disapproved of because the latter may expose the family’s “failure” to outsiders. What sociocultural disincentives are at work in discouraging service take-up? Would formal social supports be
perceived as a resource by these immigrant families and under what circumstances? What type of social supports - emotional, concrete assistance or information would be most welcome? What constitutes a good support system from the viewpoint of the carers? What decision would the adult children carers be likely to make when they are caught in a conflict of dual loyalties: fulfilling the moral obligation of caring for a demented parent at home or admitting him or her to an institution? To what extent would compromise be tolerated in the use of formal services when informal care has been weakened in the foreign land? These will be some of the questions awaiting further exploration.

The preference for social support services by caregivers also varies, depending on the individual’s circumstances, the strength of the kinship network and the organization of social services in a specific context. Researchers in elderly care (Brody, 1981; Chappell & Havens, 1985; Cox & Monk, 1990; Green, 1983) have been engaging in a debate over the applicability of the “substitution model” in support utilization. The substitution model contends that formal services substitute for or replace the help given by family members. Thus, family carers would turn to outside help only when help afforded by the kinship network is lacking or inadequate. A lot remains to be explored to discover if these Chinese families follow this pattern.

Summary

This chapter discussed the various aspects of the ethno specific model of family caregiving. It began by portraying the changing nature of Canadian society and then examined the immigrant status of the ethnic Chinese seniors and their carers. Canada’s
population has become increasingly racially diverse. It is projected that by 2001, half of the population of Toronto will consist of visible minorities. Almost half of all immigrants who arrived at Toronto during the last decade were Asian born (Statistics Canada, 1996 Census). Of the Asian population, Chinese people are the most numerous (1.3 million). With a growing elderly population deriving naturally from the aging process and through family unification programs, the proportion of Chinese elderly is likely to continue to expand.

Immigrant families with cognitively impaired relatives are confronted with various unique challenges in fulfilling their caregiving commitments. The immigrant status is associated with multiple losses, for example, the loss of culture and the loss of community. Often the losses incur a deep sense of isolation, uprootedness and powerlessness. In delineating the cultural context of family care, I identified four components: selection of caregivers; motivations for assuming care; appraisal of stress; and performance of caregiving roles. In caregiving literature, the “principle of substitution” has been identified as a guide in the selection of family carers. In my new conceptual scheme, I propose the examination of this normative expectation. The second component discussed was the motivating force for assuming care. Gender-role socialization, family tradition, emotional affection and filial responsibility are frequently cited as the primary motives of care. My study proposes to come to a deeper understanding of these motivational factors.

The next component studied pertains to the family and cultural appraisal of stress and demands. With the help of the conceptual framework, I wish to assess the impact of differential appraisal on the caregiving outcome. The last component discussed is the kinship network and family system. Immigrant family caregivers may suffer from the
shrinkage of the social network of relationships in the host country. There may be fewer family members or close kin available to provide concrete assistance and psychological support. The loss of community also deprives these caregivers of the ease of communicating their needs in their mother tongue.

This chapter concluded with a discussion of the acculturation process of the immigrant caregivers. It was found that there are different degrees of assimilation in the acculturation process and my study will seek to explore the impact of this on the caregivers’ utilization of formal support resources.
Overview

In Chapter Two, I reviewed the most significant studies that followed a quantitative tradition in assessing the burden of care and level of stress in Alzheimer’s Disease caregivers (George & Gwyer, 1986; Niederehe & Fruge, 1984; Quayhagen & Quayhagen, 1988; Rabin, Mace & Lucas, 1982; Schulz, Visintainer & Williamson, 1990). Recent research has described variations in caregiver stress by gender, ethnicity, competing familial and occupational demands and the effectiveness of various interventions (see for example: Miller & Cafasso, 1992; Segall & Wykle, 1988; Skaff & Pearlin, 1992; Todd & Zarit, 1986; Ujimoto, 1987). However, in the 1990s, a number of leading investigators raised a challenging question: Do we need more studies of caregiver strain? (George, 1990; Gubrium, 1992; Lyman, 1989 & 1994; Zarit, 1989b; Yu et al., 1993) In other words, are there unanswered questions yet to be investigated? Are there unexplored caregiving behaviours that may require procedures that were not employed by earlier investigators of caregivers stress? To confront this challenge, advocates of qualitative methodologies assert that we need a new paradigm to conceptualize caregiving in terms of how people construct meaning in their lives as caregivers rather than the singular view of caregivers coping with burden and strain.
(Chaves & Cypess, 1992; Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991; Rowles & Reinharz, 1988). In discovering and describing the meaning of care, the focus of qualitative methods is not on hypothesis testing and prediction nor on quantifying the effect of care. Rather, the role of naturalistic inquiry is to unearth the “concepts, definition, characteristics, and metaphors …” emerging from the informants’ subjective experiences and their interpretations of the world. (Berg, 1995, p.2).

In the following section, I shall present my arguments for selecting a qualitative approach for my study. This will be followed by the justifications for the selection of the long interview method as the mode of data collection (McCracken, 1988; Minichiello, Aroni, Timewell & Alexander, 1990). The strategies of sampling, gathering information and analyzing results will be discussed in greater length. This chapter concludes with a scrutiny of the criteria for judging the credibility of my study (Creswell, 1998; Denzin & Lincoln, 1995; Drisko, 1998; Lincoln & Guba, 1985; Miles & Huberman, 1994).

**Qualitative Methods: Merits Explored**

The qualitative method is uniquely appropriate for aging research in natural social settings because it enables researchers to examine the daily process of caregiving as it takes place in reconstructed family networks. In my study, I explored how Chinese carers respond to care demands; particularly if they experience the care requirements differently. For these reasons, new conceptual categories were developed to more accurately reflect their unique realities.
Qualitative methods are powerful tools for discovering new understandings of how people develop their thinking, beliefs and behaviours (George, 1990; Jarret, 1992; Lyman, 1989 & 1994; Morse, 1992). In 1987, Yu and her associates (1993) conducted a study on dementia caregivers in Shanghai, China. The care recipients were either physically or cognitively impaired. They concluded that dependency was accepted as an "expected" behaviour of the aging population among the carers and thus the memory and behavioral changes associated with cognitive impairment were not perceived as deviant. As a result, family carers displayed a much higher level of tolerance towards the confused as compared with the physically disabled family members. A new conceptual apparatus must be created. The continuum of "dependence and independence" is not appropriate for these respondents. As my goal is to access the evolving themes and belief patterns as these caregivers move through periods of distress, frustration, competency and joy, the naturalistic mode offers a valuable alternative (Rowles & Reinharz, 1988; Tutty, Rothery, & Grinnell, 1996).

Qualitative data are useful in a third sense. This research approach is inherently more flexible and attuned to uncover the intricacies of the respondents' realities than a quantitative approach. This is made possible by the long interview method, which I employed in the study. With this method the conceptual and substantive topics are recast into open-ended questions and planned follow-up prompts are designed to enhance intensive probing with the aid of an interview guide. The interviewer can adjust the exact wording of specific questions, reorder the sequence and probe for greater detail as well.
The interviewees were encouraged to elaborate further on a subject and they went on to discuss their personal interpretations of the burdens of caregiving. Kaufman (1994) argues that unlike the quantitative studies, “there are no pre-worded questionnaires which force study participants to structure their responses according to the researcher’s priorities...” (1994, p.125).

Furthermore, in studying social behaviour of minority ethnic groups, we must be aware that culture reflected in behaviour is often implicit (Henderson, 1990; Henderson & Gutierrez, 1992; Wood & Parkam, 1990). To the observer, beliefs and values are not always conscious. More frequently, subtle elements can only be detected or inferred from conversations and behaviour. In interacting with the interviewees in my study, the inductive approach allowed me to stay close to their real world and cultural milieu in which they were deeply embedded (Geertz, 1973; Rowles & Reinharz, 1988).

**The Long Interview Method: A Powerful Research Instrument?**

Narrative texts generated through open-ended interviews provide useful insights into primary care issues (Crabtree & Miller, 1991). Among the various qualitative modes of information collection, the long interview has been selected for my present study, because if used skilfully, it can generate accounts that are fairly specific, richly textured and person-centred (Gubrium & Sankar, 1994; Rubinstein, 1988). Crabtree and Miller (1992) further contend that “as such, the long interview is the “holistic” ethnographic approach often used by anthropologists as a useful technique when time and money are
frequent constraints and the topic can be fairly narrowly defined." (p. 145). Although I have sustained enthusiasm in developing a deep understanding of dementia care, my time commitment is not without constraints. I cannot suspend all my obligations to my occupational and family roles and devote myself entirely to undertake a qualitative inquiry which might be typical of the anthropological tradition.

A further justification for choosing the long interview rather than other instruments such as participant observation is that this research strategy gives us access to individuals without violating their privacy or testing their patience (Globerman, 1994; McCracken, 1988). Data needed for penetrating qualitative analysis are efficiently captured without prolonged contact or obtrusive observation. According to Crabtree & Miller (1991), the long interview gives us the opportunity to step into the mind of another person, to see and experience the world as they do themselves. Rendering care to cognitively impaired family members is a highly emotionally charged endeavour. The duration of incapacity can last for years and even decades. It would be difficult for carers to cooperate in a research methodology in which their private time and space are adversely affected.

**Sampling**

I used purposive and non-probability sampling in my study because the overriding theme of my investigation relates to the lived experience of the family members’ management of Alzheimer’s Disease and its effect. McCracken explicitly states that the
respondents are not "samples and the selection should not be governed by sampling rules" (1981, p. 148). Purposive sampling relies on a smaller number of informants chosen deliberately to inform in detail about personal meaning and perception (Gubrium & Sankar, 1994; Hinds, Chaves & Cypess, 1992; Morse, 1992; Rowles & Reinharz, 1988; Taylor & Bogdan, 1984). McCracken (1988) asserts that qualitative research following the long interview method can stop when patterns become repetitive and materials are thematically saturated. This can be justified because "qualitative research does not survey the terrain, it mines it". (McCracken, 1988, p.17). To elaborate further, McCracken upholds that while the emphasis in quantitative research is on generalizability, the focus in qualitative research is on access - access to the "complicated character, logic and organization of a particular group or culture" (p.17). Clearly a sample was used in my research, but it was not the random or probability sample. Rather, it was a purposive sample directed by my research question. The total sample size is eighteen. Heterogeneity in the respondents’ pool, in terms of gender, age, marital status and relational status were selected as relevant. In order to qualify for inclusion in the study, the following criteria were established:

1) both the impaired older adult and the caregiver must live in Toronto;

2) the caregiver must identify himself or herself as belonging to the Chinese ethnic group and use one of the Chinese two dialects (either Mandarin or Cantonese) as their medium of communication;
3) either the caregiver or the impaired family person must meet the criteria for immigrant status (i.e. arriving in Canada as a permanent resident or citizen within the last ten years);

4) the caregiver must be related to the older person either by kinship or through marriage (spouse, adult children, children-in-law; grandchildren or siblings) because this study focuses on the adaptation of family members to the caregiving role. Friends and neighbours have been excluded;

5) the care recipient must reside in the community at the time of the interview or have been recently placed in an institution from the family’s home within the last three years;

6) only those caregivers who provide care to impaired older persons who are alive at the time of interview are included;

7) the caregiver must give written permission for the interviews (see Appendix 3 for the Consent Form).

A formal diagnosis of Alzheimer’s Disease was not necessary for inclusion in this study. However, all care recipients in my study demonstrated several of the following changes as reported by referrers and caregivers:

a) cognitive aspects -
   - short term memory loss, with particular difficulty in registration and recall of new information;
thinking becoming less abstract and in the more advanced stage, fragmented;
- speech becoming repetitive, disordered, and finally language impairment (dysphasia) occurs; inability to comprehend speech (receptive dysphasia); and for finding the right word (expressive dysphasia).

b) behavioral aspects -
- disorientation for time, place and person, wandering; evening and nocturnal restlessness; taking night into day; failure to recognize significant others;
- difficulty in carrying out self care tasks (e.g. dressing, & bathing);
- social withdrawal, aggression and violence.

c) emotional aspects
- shallowness of mood, lack of emotional responsiveness and consideration of others;
- irritability, hostility and aggression.

Sample Recruitment Strategies

A combination of recruitment strategies was used. A full list of organizations contacted was included in Appendix I.

i) an advertisement was placed in the three leading Chinese newspapers in Metropolitan Toronto, namely Ming Pao (明報) Sing Tao Daily (星島日報) and World Journal Daily News (世界日報) to invite participation in the research study;
ii) information letters were sent to family physicians whose clinics are located in
neighbourhoods with a high concentration of Chinese residents. These medical
doctors were asked to contact appropriate clients;

iii) information letters were sent to physicians at Regional Geriatric Assessment
Centres requesting that they identify and contact Chinese families meeting the
criteria;

iv) social workers at adult day care centres and home care agencies were requested to
identify appropriate participants;

v) social workers at Homes of the Aged and Nursing Homes which have ethnic
Chinese residents were contacted to identify participants;

vi) social workers at out-patient departments of regional hospitals serving
neighbourhoods with ethnic Chinese groups were contacted;

vii) the researcher made two appearances on radio and television stations (see
Appendix 7 on p. 299 to publicize the research and to recruit volunteer
participants.)

**Issues in Sampling Chinese Elders with Dementia**

Although the final chapter of this study gives a more detailed analysis of the
shortcomings and strengths of this study, it is important to report a few of the special
issues I encountered in sampling participants. Firstly, with the exception of three
organizations which have an explicit strategy of reaching out to ethnic minorities, most
agencies do not have data on the ethnic backgrounds of their client group. The only clue was to approach those who seemingly have Chinese family names. Several families I called up were in fact Korean and Vietnamese families and therefore they did not meet the criteria to be included.

Secondly, while some nursing homes kept detailed medical records on their residents, some had only rather imprecise labels to describe their mental status. The common ones were "mental confusion" and "senility". Upon further probing during the telephone screening stage, I confirmed that those elders were survivors of vascular conditions. Again, they did not meet the sampling criteria.

A further difficulty I encountered was the reluctance of potential respondents to engage in in-depth interviews and to have their accounts tape recorded. Two family carers declined after they learnt that my study was not a questionnaire survey. All participants confided to me at the end of the interview that this was their very first experience of talking to a researcher in great length about their caring commitment.

**Sampling Procedure**

Potential participants were informed of the objective of the study by the referral sources as described in the above section. If they expressed an interest in participating or in obtaining further information, their names were forwarded to me for contact. I then made telephone calls to the potential family carers to give them a short briefing on the purposes of the study and to invite participation. They were free to consent or not to
consent to participate. If consent was given by the respondent, an interview was then arranged at a location of his/her choice, for example, in the respondent’s home, day care centre or family visiting room of the nursing homes. At the start of the interview, I reviewed again the research protocol with the respondent and solicited a written consent. Then the interview would proceed. Twenty-three referrals were received. While seven referrals were from long term care settings primarily serving Chinese residents, two came from institutions of mixed ethnicity. The remaining fourteen referrals were from community support and counselling agencies. However, two family caregivers declined on the grounds of time constraint and two did not want their interviews to be recorded. One elderly woman passed away in the morning of the day on which I called the son caregiver. Finally, eighteen respondents agreed to participate. A full description of the sample characteristics is presented in Chapter Five.

Data Collection Method

Review of analytic categories - exhaustive review of literature.

The first step in data collection following the long interview method begins with an exhaustive review of the literature (McCracken, 1988). The review exercise has an overall objective of requiring the researcher to establish familiarity with the topic under study. In specific terms, the review serves two vital functions. First, it enables the investigator to define problems and assess data. The investigator who is well versed in the literature review now has a set of expectations which the data can defy. Counter
exceptional data are conspicuous, readable and highly provocative data. McCracken (1988) argued that these data "signal the existence of unfulfilled theoretical assumptions and these are the very origins of intellectual innovations" (1988, p.31). In other words, an exhaustive literature review searches out the conscious and unconscious assumptions of scholarly enterprises. It further helps the researcher to determine how these assumptions shape the definitions of problems and findings. This process makes the investigator the master, not the captive, of previous scholarship (Gubrium, 1992; Lyman, 1994; Rowles & Reinhartz, 1988; Sherman & Reid, 1994; Tutty, Rothery & Grinnell, 1996).

Another important function of the literature review is to aid in the construction of the interview guide. The review helped me to establish the domains that the interview would explore. I could hardly specify categories and relationships that would subsequently facilitate the organization of data without a thorough review of the existing literature. In sum, the first step of the four-step method of inquiry offers both a review and a "deconstruction" of the scholarly literature (McCracken, 1988, p. 31). In my study, the exhaustive literature review on family caregiving was presented in Chapter Two.

**Review of cultural categories.**

The second step recommended by McCracken (1988) in the qualitative circle consists of the review of cultural categories. In reflecting on one's cultural categories, the researcher embarks on the process of using the self as an instrument of inquiry. This step is so important that many pioneers committed to the qualitative tradition caution that the
deep and long-lived familiarity with the culture under study has, potentially, the grave effect of dulling the investigator's powers of observation and analysis. Hence, the object of conducting a review of cultural categories is to give the investigator a systemic appreciation of his or her personal experience with the topic of interest. This process demands a careful and honest examination of one's related experience. On a similar theme, Drisko (1997) also urged qualitative researchers to explicitly identify sources of potential bias (p.193). They should seek to limit bias through self-awareness and to report any potential biases and note content areas that might be influenced.

In recalling mentally and then sharing my set of notes on my personal experience of caregiving with my thesis supervisor, I began to make an inventory of past incidents. This exercise was most useful in enabling me to survey the unconscious cognitive domain as well as the emotional feelings and attitudes that were normally concealed from myself.

My interest in dementia care is rooted in several important career and life experiences. These aspects of my social situation, and others of which I am less aware, have formed a filter through which I might view Alzheimer's caregiving relationships.

My first social work position as a direct practitioner brought me face to face with the sad story of "unwilling or forced" family abandonment of a demented older man. At the request of a middle aged vehicle mechanic, I sought to place permanently his 86 year old father in a nursing home. When the probation period was about to expire, the superintendent of the home asked me to return the old man to his family because he was judged to be too confused to be accommodated in the facility. The older adult was said to
be incontinent, terribly aggressive and disoriented, particularly in the evening time.

Despite great efforts by the Home staff, they could not communicate with him. When I saw the son in the office, he broke down telling me that he was at his wit's end. He asked me to discharge his father to any infirmary or public hospital because he would not take him home. No contact with the son was possible afterwards because he moved out secretly from his home the next day and never left an address. In the next few months, I asked myself painstakingly: What motivated the son to become involved initially and why did he give up his responsibility later? What kind of a relationship existed between the father and son? What did caregiving mean to the son? Why was I so disappointed and angry at his action of giving up the responsibility? How could our society respond to needs of caregivers in similar deplorable situations? What was the social worker's role in holistic care planning and effective empowerment? There was not a better time to glimpse into my own expectations and assumptions than when they were violated. When I completed my review of cultural categories, I was able to acquire a clearer understanding of my vision of the caregiving world. This in turn has permitted me to establish the "distance" from my own deeply embedded cultural assumptions (Crabtree & Miller, 1992; Greetz, 1973; Lyman, 1989).

**Discovery of cultural categories.**

The third step of the long qualitative interview consists of three related procedures:

i) constructing the interview guide; ii) instituting a pre-test; and iii) interviewing the
Construction of the Long Interview Guide - The previous step in reviewing the cultural categories prepared me for the interview guide construction. I was able to identify the cultural categories and relationships that were not considered by the scholarly literature. The Interview Guide in my study (see Appendix 4) is divided into two sections. Section A is designed to collect the socio-demographic details of the care recipients and the care providers. Data on gender, age, family composition, educational background, living arrangement, immigration status, income level and occupational types were systematically collected so that I was informed of the biographical realities. Section B consists of open-ended questions, clustered under various categories, such as immigrant history and level of acculturation, disease development, caregiving response, coping and management, family networks and the use of social support. As the objective of the qualitative interview is to facilitate respondents telling their own stories in their own terms, I tried to keep as low and unobtrusive a profile as possible. Hence, I included several grand-tour questions to cover the broad categories of the research question (Spradley, 1979). Grand tour questions were supplemented by some “floating prompts” and “planned prompts” (Minichielle, Aroni, Timewell & Alexander, 1990; Taylor & Bogdan, 1994). These were to encourage elaboration and expansion. “Floating prompts” enabled the researcher to use such features of everyday speech as raising one's eyebrow at the end of the respondent's account.
or to repeat the key term of the last remark with an interrogative tone (McCracken, 1988). The purpose was to prompt the respondent to return to the utterance and expand upon it (Respondent: “I'm not sure I can have my own life as long as she [Mom] lives.” Interviewer: “Have your own life?” Respondent: “Yeh, I dare not plan for any trip at all now. My brother called as soon as I was at the door step of my son’s house in Ottawa. My mother wandered away again.”)

Planned prompts in the form of “contrast” and “special incidents” questions were highly recommended by McCracken (1988) to elicit detailed response. Therefore, I raised the following questions with my respondents: Could you describe to me a typical day now? How does it differ from your usual routine before the illness? Does your husband feel differently about the marital relationship since your Mom’s moving in to stay with you? Can you recall an exceptional incident in which you felt let down by your siblings? What was most striking about the incident? Why, precisely, was it surprising?

ii) Pre-testing - After the Interview Guide was produced, I conducted a pre-test on the Guide. In my study, pretesting involved two steps. First, the Guide was critically examined by my thesis supervisor and she helped me to identify poorly worded questions or complex questions which asked a respondent to respond simultaneously to multiple issues in a single question. Based on the feedback, I revised the Guide by separating the issues and asking brief separate questions. The second step in pretesting involved two practice interviews to assess how
effectively the interview would work and whether the type of information being sought would actually be obtained (Berg, 1986, p.26). The interview guide was further improved afterwards. The sequencing of questions was modified so that the interview began with questions on the biographic data of the elders. Questions on the carers' own demographic details and caregiving activities were asked later. This allowed me to develop gradually rapport with caregivers who felt more at ease to disclose their stories when more sensitive questions were introduced. In addition, a few planned prompts were added to invite elaboration from participants.

iii) The interview process - In depth interviews of two to three hours duration with the family carers were conducted by myself as the sole interviewer. Individuals were interviewed in locations of their choice. These included their natural homes, family room of the nursing homes, and recreational room in the day care centres. Of the eighteen cases selected, seven participated in a second interview. Two elders died between the two interviews and their caregivers gently declined revisiting and two families moved out of Toronto. Persistent observation of the respondents proved to be of utmost value. Firstly, the respondents were more open in the second interviews, confiding in me some of their intimate concerns, such as the arguments arising from unequal division of care responsibilities. Secondly, these second visits provided me with the opportunity to check the accuracy of the information solicited in the first round of contacts and my
interpretations as well. Thirdly, respondents took the initiatives to fill in the information gaps when they had more time to reflect on their experience. Memories of good as well as bad events came back on second interviews after respondents had the opportunity to reflect after the first interviews.

In order to obtain informed consent from the participants and to maintain confidentiality, the following ethical guidelines were closely observed. Firstly, I explained to the prospective participant the purpose and procedures of the study. I also asked for their informed consent for me to tape and analyze the data by completing a written consent form (see Appendix IV). I also assured them that the tapes would be kept very safely in locked cabinets in my office and except me, others would not have access to them. In addition, I promised that all information that I used would be coded in such a manner that neither the carer or his/her older relative could be identified. Pseudonyms were consistently used in the research report to protect names and keep confidences. Details in description of respondents, such as occupations, and work places were altered.

I further emphasized that their participation in my study was entirely voluntary. And if a respondent had any question about the research, he/she should feel free to ask. Furthermore, a respondent was free to withdraw from the study at any time if discomfort was experienced in recalling the event.
Data transcription

Data transcription and the interviewing process took place concurrently in my study. In other words, I started transcribing the materials as soon as the earlier interviews were concluded. A verbatim transcript was created for each interview. Translating the interview narrative from the colloquial Chinese language into the English written language was a most challenging task and the time consumed was at least double that normally required for transcription. At times, there was no English word that could accurately and vividly convey the rich meaning in the respondents' original language. Good translation work in qualitative research demands much more than language proficiency in the translator, but an insightful appreciation of the two cultures against the background of which care responsibilities were grounded. In order to overcome the difficulties, the first seven cases were transcribed by myself, with the help of a transcribing-tape recorder. These were later checked by two independent reviewers who were competent in both languages. As for the remaining eleven cases, assistants were used to transcribe the texts from colloquial Cantonese into the written Chinese language and I translated them into the English language. All transcripts were stored in the computer and appear in printed format for the thesis committee's inspection.

Genograms.

In addition to verbatim scripts, I also used family genograms to display family information graphically (McGoldrick & Gerson, 1985). The family genograms I created
provided a quick gestalt of complex family patterns which could be revised at the second visit as more was learnt about the families. This instrument was of particular value to me in grasping quickly the wide geographical dispersion of offspring carers who might be living in various continents around the world. For instance, Grace was a daughter caring for her 82 year old mother, Madam Ho. (Genogram 1). Grace had five brothers and four immigrated to various places: Texas, Washington DC, Seattle and Winnipeg. The younger brother was still working in Hong Kong. The graphic presentation helped me to understand Grace’s agony in coordinating the caregiving efforts. Most of Madam Ho’s memory was gone but she repeatedly asked on a daily basis to see her eldest son who could visit her at most once a year from Texas. In addition, Grace’s siblings left home at a young age to settle in different geographical regions.

Further, the graphic representation assists me in posing my questions systematically. I could see the larger family contexts both concurrently and historically. The structural, relational and functional information about a family on a genogram can be viewed both horizontally across the family context and vertically through the generations (McGoldrick and Gerson, 1985, p.3). More than once, scanning the breadth of the current family context allowed me to assess the connectedness of the immediate players in the family drama and the broader system. Genogram 11 gave an example of a three generation family in which Lynn, the granddaughter ended up becoming the primary caregiver. Lynn’s devotion to her grandmother was motivated by a strong attachment formed in the 1950s when the family fled Communist rule in Mainland China.
Field notes

Field notes of each encounter were carefully kept to enhance the audit trail. These included description of the setting, deliberate distortions, minor misunderstandings, topic avoidance, and my own feelings. These notes were used later in the analysis to provide a conversational context for interpreting the narrative. One of the most touching scenes concerned a man who talked about his gratitude towards his bed-ridden mother in the nursing home. In my note book, I recorded that he was feeding her prune juice. He used a wet face towel to gently wipe her forehead and cheeks. I also recorded the exact words he said: “That’s how she took care of me when I fell sick as a child. My father died when she was five months pregnant and I had bad asthma all along. Sometimes she stayed up all night when the asthmatic attacks came.”

My field notes describing this incident reinforced what he told me later on in his interview about his earnest desire to return past love.

Discovery of Analytic Categories And Theory Generation

Researchers utilizing qualitative approaches generally concur that the analysis of qualitative data is perhaps the most demanding and least examined aspect of the research process (Creswell, 1998; Denzin & Lincoln, 1995; Drisko, 1997; Lincoln & Guba, 1985; Miles, & Huberman, 1994; Riessman, 1994). The discovery of analytic categories occurs in five analytic steps that become progressively more abstract and interpretive (McCracken, 1988, p.42). These steps are:
Identifying utterances and making observations from the text.

McCracken (1988) suggested a researcher should read each interview narrative intensely and mark those phrases which were seen as significant, including key terms, interpretations and statements (p.42). At this stage, I tried to treat each utterance in the interview transcript in its own terms, ignoring its relationship to other aspects of the text. Utterances were words or phrases that stood out in each sentence or set of sentences spoken. For instance, one participant stated, “I feel very sad, I cry. We have more fresh air, more relatives to visit her in Toronto. Her dementing condition might not be that bad if I had brought her here three years ago.” These were statements which appeared to have potential in understanding the carer’s emotional reaction on detecting the onset of illness. Here I made a deliberate attempt to separate myself from my preconceptions prior to reading the data by revisiting my cultural review. In the margins, after highlighting these words and phrases, I wrote down “sadness, crying”.

The second step I made was to seek the meanings of these observations from the language used by participants. The goal was to extend the observation beyond the form in which it originally appeared. This called for identifying the descriptive properties and implications of the emerging concept described in the text. In the above instance, the participant revealed that to her, “feeling sad” was about guilt and self blame: “the dementing condition might not be that bad”, “not bringing her to Toronto three years ago”.

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Expanding observations.

In the next stage of data analysis, each observation was expanded to tease out the implications. I also strove to search for meaningful units or segments of texts. For example, when respondents spoke about caregiving strain, my margin observation was “caregiver strain”. I then collected all the quotes that were labelled as “strain” and began grouping them into themes and sub-themes. One example was a theme related to intergenerational stress. By using this analysis strategy, I was employing Crabtree & Miller’s (1992) “editing analysis style” (see Figure 5 on p.89). This style is termed “editing” because the interpreter entered the text much like an editor searching for meaningful segments, cutting, pasting and rearranging until the reduced summary revealed the interpretive truth in the text.
Figure 5  Diagrammatic Representation of Different Analysis Style
(Adapted from Crabtree, B. & Miller, W. (1992) Doing Qualitative Research, p. 18)

**Editing Analysis Style**

Interpretation
(Editor)

- Report

- TEXT

- Identify Units

- Develop Categories

- Interpretively Determine Connections

- Verify

89
Comparing different themes.

The third stage in the analysis process further took the observations generated at previous levels and subjected them to collective scrutiny. The object of analysis “was to determine patterns with inter-theme consistency and contradiction” (McCracken, 1988, p. 42). The process of transformation took place in the third stage because the very goal here was to transform the cultural categories that had been unearthed in the interview into analytic categories. Some leading qualitative researchers advise that it is absolutely essential for the analyst to look for contradicting themes and patterns which seem to deviate from the norm (Creswell, 1998; Drisko, 1997; Lincoln, 1995). These opposite cases are used to illustrate episodes of emerging contradictory themes and are called “negative case analysis”. The notion of caregiving strain stood out very clearly in my study, but while noticing the thickness of the data in some transcriptions, I noticed its absence. I began to see that although “caregiving strain” permeated some participants’ realities, it was absent in others. Rather, I could identify the notion of “satisfying experiences” in providing care. I returned to the texts again and again to tease out those satisfying experience and tried to understand why.

Establishing Trustworthiness Of The Study

It is not uncommon to hear criticisms that qualitative research is “subjective”, “impressionistic”, and “undisciplined”. Rigor in research methodology is often not associated with the naturalistic inquirer. Is the naturalist inevitably defenceless against
such charges? In which ways could I establish trustworthiness in my study so that I could persuade my audience that my findings are worth paying attention to, indeed worth taking account of?

In judging the trustworthiness of quantitative data, normally we use such criteria as “validity”, “reliability”, “objectivity”, and “neutrality” (Cook & Campbell, 1979; Denzin & Lincoln, 1994; Schwandt, 1997). Nevertheless, Lincoln & Cuba (1985, p.300) proposed an alternate framework because criteria adopted by the conventional positivist tradition are not appropriate yardsticks for qualitative data. The four terms, “credibility”, “transferability”, “dependability” and “confirmability” are the naturalist’s equivalents for the conventional terms of “internal validity”, “external validity”, “reliability” and “subjectivity”. In the following paragraphs, I shall explore the different techniques which I employed to enhance the trustworthiness of my study. Trustworthiness is here defined as that quality of an investigation and its findings that make it noteworthy and credible to audiences.

Credibility

Credibility or truth value is the interpretive equivalent of internal validity of design in the positivist research paradigm. To establish credibility, a researcher must carry out the inquiry in such a way that first, “the probability of the findings found to be credible is enhanced and second, the findings must be approved by the constructors of the multiple realities being studied” (Lincoln & Guba, 1985, p.296). In other words,
credibility addresses the issue of the inquirer providing assurances of the fit between respondents’ views of their life ways and the inquirer’s reconstruction and representation of same (Schwandt, 1997). Among the major techniques suggested by Lincoln and Guba (1985) to increase the probability of high credibility, persistent observation, negative case analysis, triangulation, peer debriefing, member checks and referential adequacy were utilized in my study.

**Persistent observation**

The technique of persistent observation was intentionally used in my study to identify those “characteristics and elements in the situation that were most relevant to the problem or issue being pursued and focusing on them in detail” (Lincoln & Guba, 1985, p. 304). This was achieved through in-depth interviews, each lasting two to three hours and revisits of eight family caregivers. These focused long interviews and second round visits enabled me to identify those characteristics and elements in the situation that were most relevant to the problem or issue being pursued. Persistent observation demanded me to engage in tentative labelling of what were perceived as salient factors and then to explore them in detail, so that those factors were understood in a non superficial way. For example, in unfolding the caregivers' struggle to care, I have tentatively identified three salient features: the struggle as an endless war; the struggle as a lonely journey; and the struggle as a battle on many fronts. Detailed exploration was then made to analyze the properties pertaining to the “endlessness” of the struggle. The experience of “endlessness” to the caregivers started with the lengthy process of obtaining an accurate
diagnosis. Endlessness also implied a prolonged burden of care which might last as long as ten years. The final purpose of persistent observation was to confirm the data from the first interviews. Participants expanded their stories, altered their narratives and even corrected my interpretations when they were given the opportunity to reflect on their first interviews.

**Negative case analysis.**

The next technique that I employed to enhance credibility was negative case analysis (Lincoln and Guba, 1988; Minichiello, Aroni, Timewell & Alexander, 1990). A negative case that did not confirm the theme of “caregiving stress” was selected. I then returned to the texts to understand more about this exceptional caregiver. What descriptions did he use exactly in labelling the experience if such words as “burden”, “stress”, and “pain” were not identified? How could I explain the benefits of caregiving? How did this information affect my understanding of the factors that determined the continuation or discontinuation of caregiving commitment? I then read other transcripts and continued the same process until the categories reached saturation (Minichiello, Aroni, Timewell and Alexander, 1990, p. 288). The end product of this review of negative case analysis was rather fruitful. A pattern showing the positive aspect of caregiving finally emerged from the data. This is discussed in greater length in chapter six.
**Triangulation.**

Triangulation is a useful technique recommended by Lincoln & Guba (1985) for improving the probability that findings and interpretations are credible. The notion of “triangulation” has its origin in the metaphor of radio triangulation, that is, determining the point of origin of a radio broadcast by using directional antenna set up at the two ends of a known baseline. By measuring the angle at which each of the antenna receives the most powerful signal, a triangle can be erected and solved, using simple geometry, to pinpoint the source at the vertex of the triangle opposite the baseline.

Four different modes of triangulation exist in qualitative research: the use of multiple and different sources, methods, investigators, and theories (Berg, 1995; Denzin & Lincoln, 1995; Sherman & Reid, 1994). In my study, I have employed multiple methods to understand the caregivers. These included the long-interview, genograms, eco-maps, reflections on family photos and videos and follow-up interviews.

**Peer debriefing.**

Peer debriefing refers to a process of “exposing oneself to a disinterested peer in a manner parallel to an analytic session for the purpose of exploring aspects of the inquiry that might otherwise remain only implicit within the inquirer’s mind” (Lincoln & Guba, 1985, p. 308). This exposure serves multiple purposes. First, the process helps to keep the inquirer “honest” exposing him or her to searching questions by an experienced protagonist who will play the devil’s advocate role. In this way, the inquirer’s biases are
probed, meanings explored, and the bases of interpretations clarified. Second, the
debriefing provides opportunities to test patterns that may be emerging in the inquirer’s
mind. Third, debriefing sessions provide the inquirer with an opportunity for catharsis,
thereby clearing the mind of emotions and feelings that may cloud good judgement.

Lincoln and Guba (1985) suggested that debriefing should be done by someone
who knows a great deal of the substantive area of the inquiry and the methodological
issues. In my study, I used my thesis supervisor and one thesis committee member to
play the roles of the peer debriefers. I reviewed honestly with my supervisor the cultural
categories that might have shaped my posture and thus influenced the research process.
The hard questions raised during the debriefing were on substantive, methodological and
conceptual aspects. Furthermore, the debriefers listened sympathetically to my feelings
and assisted me to devise coping strategies when I felt desperate. There were occasions
when I unintentionally used closure prematurely in my interviews and I was directed to
return to the participants for a second visit for an in-depth exploration. Themes were also
reviewed by peer debriefers to enhance credibility. My debriefers took the role seriously
to play the devil’s advocate even though pain was sometimes evident in the process. Both
myself and my debriefers took written records of these debriefing sessions. I learned
invaluable lessons from the process.
Referential adequacy.

Raw data, such as audio tapes, journals, transcriptions and audit trails were kept as the recorded materials provided a kind of benchmark against which later data analyses and interpretations could be tested for adequacy (Tutty, Rothery and Grinnell, 1996). The practice of storing data is intended to enhance credibility in qualitative research because such data could be retrieved when tentative findings were reached. Such materials could then be subject to review by another researcher who could demonstrate that different analysts could reach similar conclusions. They could also be used to test the validity of the conclusions. In my study where I was the sole investigator, accessing referential adequacy was of particular value. Much sensitivity and skills were required to help the respondents overcome the initial reluctance. There were two potential participants who declined my interviewing them when they learned that the interview content would be tape-recorded. Another respondent (daughter-in-law) asked me not to tape record the last part of her interview because she was about to confide in me her bitter struggle with her in-laws over the nursing home placement. Even after the tape recorder was turned off, the interviewee whispered her feelings.

Members checks.

Lincoln and Guba (1985 p.315) assert that the investigator is only able to purport that his or her construction is recognisable to audience members as adequate representation of their own realities through the use of member checks. In utilizing this
technique of member checks, data, analytic categories, interpretations and conclusions are tested with members of the stake holding groups from which the data were originally collected. In my study, members of the stakeholding groups involved the caregivers themselves and sometimes the professionals who referred them to me: members of staff in day care centres, nursing homes and geriatric assessment teams. They helped me tremendously in assessing intentionality, correct errors of facts and challenge wrong interpretations (Lincoln & Guba, 1985 p.314).

In actual practice, member checks were implemented at five different stages. The first stage was at the field study period. I asked for comments and feedback on my initial observations and constructs when I went back for a second visit. The respondents demonstrated no hesitation in correcting me or recalling additional things that were not mentioned in the first time around. The genograms and the eco-maps on support activities were powerful instruments to help them amend my preliminary understanding.

Another informal method of checking was used when I met with the staff members of the two nursing homes and a day care centre. Summaries on the most significant findings were given to them. They provided me with verbal feedback or sent me brief written comments. I was not able to honour all criticisms that were mounted, but I listened carefully to what they had to say. Member checks are such a valid way to establish trustworthiness. Lincoln & Guba (1985) strongly persuaded that "the investigator who has received the agreement of the respondent groups on the credibility of his/her work has established a strong beachhead toward convincing readers and critics of
the authenticity of the work” (p.315).

Transferability.

Transferability is the second criteria used by the naturalistic investigator to establish the trustworthiness of his/her data (Schwandt, 1997). The question asked here is: To what extent has the researcher to provide enough information so that consumers of the research can determine transferability to other situations or samples? Lincoln and Guba (1985) argue that in qualitative methodology, naturalists can only set working hypotheses together with a description of the time and context in which they are found to hold (p.316). In other words, the naturalist cannot specify the external validity of an inquiry. He or she can provide only the “thick description” necessary to enable someone interested in transferring the findings to their situations to reach a conclusion about whether transfer is appropriate. In sum, it is not the inquirer’s mission to provide an index of transferability, it is his or her responsibility to provide the data base that makes transferability judgements possible on the part of potential consumers. If there is transferability, the burden of proof lies less with the original investigator than with the person seeking to make an application elsewhere, because the original investigator inquirer cannot know the sites to which transferability might be sought.

“Thick description” refers to the detailed information given by the researcher about the context and the respondents under study (Geertz, 1973; Sherman & Reid, 1994). In my study, this has included socio-demographic profiles of the care recipients and that
of the care providers, and extensive quotes of the participants. Tables, figures and
genograms were also developed to provide sufficient descriptive data to enhance
transferability.

**Dependability**

Dependability in naturalistic inquiry is the equivalent of reliability in the positivist
paradigm. Reliability is usually attested by replication. If two or more repetitions of
essentially similar inquiry processes under essentially similar conditions yield essentially
similar findings, the reliability of the inquiry is indisputably established. However,
Lincoln and Guba (1985) rejected that there was a single, tangible reality that could be
replicated as replaceability depended on the existence of such a constantly unchanging and
tangible reality or context. Hence, instead of making claims for reliability, the
naturalistic inquirer proposes alternatives for enhancing dependability. Establishing an
“inquiry audit” is an effective technique to adopt in achieving dependability. An inquiry
audit fulfils a similar function as fiscal audit in the business world. The auditor is called
in to examine the process by which the accounts are kept to satisfy that proper procedures
are indeed followed. In addition, the auditor also comes in to examine the product and
the records to determine their accuracy. When this metaphor is applied to qualitative
work, the inquiring auditor performs similar functions. In my research, I kept detailed
note of the sampling and data collection and analysis procedures. I also kept a reflexive
journal of my experiences.
In addition, my thesis supervisor undertook to carefully monitor the research process. Throughout the last three years, very intensive meetings were held in Toronto and in Hong Kong during which my supervisor listened to my audio tapes, read the transcriptions, reviewed the audit trails, and prepared progress reports on me. The thesis committee approved my proposal, suggested amendments to improve the sampling frame and scrutinized the data and my findings. These efforts were rigorously applied to help the research outcomes to achieve a high standard of dependability.

**Confirmability.**

The last criterion developed by Lincoln and Guba (1985) to establish trustworthiness is confirmability. In examining the nature of the data, we ask rhetorically: Are they or are they not confirmable? Confirmability in naturalistic studies denotes the careful assessment of findings to ensure that findings can be substantiated. Two major techniques for establishing confirmability were utilized in my study. The first was the compilation of the “confirmability audit” or the audit trails (Lofland & Lofland, 1984; Halpern, 1983). Records collected through the research process were systematically organized and stored. These records included: raw data (for example, audio tapes); data reduction and analysis products (for example, summaries such as condensed notes); data reconstruction and synthesis products (for example, categories showing themes, definitions and relationships, findings and conclusions); process notes; materials relating to intentions (for example, research proposal); and finally instrument
development information (for example, interview schedule).

The second mechanism to increase confirmability is concerned with the use of a "reflexive journal" (Lincoln & Guba, 1985). The journal is a kind of diary in which the investigator records information of "self", such as thoughts, ideas and interpretations (hence the term "reflexive"). In my study, this included essentially, the following: the daily schedule and logistics of the study; a personal diary that provided me the opportunity for self reflection and for speculation about growing insights and a methodological log in which methodological decisions and accompanying rationale were recorded (Reinharz, 1979; Spradley, 1979). Finally, direct quotes from respondents' transcripts were used throughout to illustrate the themes and patterns.

Summary

In this chapter on methodological design, I presented my arguments for the selection of the qualitative inquiry approach. Then I proceeded to identify the specific justifications for using the long-interview method (McCracken, 1988) as a data collection strategy. McCracken's model involves four structured steps. Following his guideline, I discussed the detailed procedures of firstly reviewing analytic categories (a literature review); secondly, reviewing cultural categories (making inventory of my own implicit categories and preconceptions); thirdly, discovering cultural categories (data collection) and finally, discovering analytic categories (data analysis).
The chapter concluded with a critical review of the criteria naturalistic researchers adopt in assessing trustworthiness of the research product. It is argued that conventional terms such as “validity”, “reliability”, and “objectivity” found in the positivist model should better be replaced by “credibility”, “transferability”, “dependability” and lastly “confirmability” (Creswell, 1998; Drisko, 1997; Lincoln & Guba, 1985; Schwandt, 1997; Stiles, 1993). As Morgan (1983a) so powerfully upholds, “different research perspectives make different kinds of knowledge claims, and the criteria as to what counts as significant knowledge vary from one to another” (pp. 14-15). I reviewed these criteria for establishing trustworthiness, and identified how they were evident in my study.
CHAPTER FIVE
FINDINGS AND DISCUSSION: PART ONE

DEMOGRAPHIC DATA OF CARE RECIPIENTS AND CAREGIVERS

Descriptive Profile of the Care Recipients

In theoretical terms, this research study is based on a model designed to explore the interrelationships between caregivers and their social environments of family system, kinship network, cultural context and support resources. As the demented relative is the central component of the caregiver’s context and impacts heavily on the caregiving experience, it is important to describe the characteristics of the care recipients.

A summary of the characteristics of the care recipients is displayed in Tables 5.1, 5.2 & 5.3.

Gender, age and marital status

Among the cognitively impaired elderly sample members, women out numbered men. There were three men and fifteen women. The sample ranged in age from 65 to 89 years with a mean of 81.8. Close to three-quarters (n=13) were 80 years or older while the remaining were between 65 and 79 years of age (n=5). Again, close to three-quarters of the care recipients were widowed while two were married and another two were either divorced or separated. Only one elderly family member was single and had never married.
Table 5.1: Socio-Demographic Characteristics of Care Recipients (n = 18)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>GENDER</td>
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<tr>
<td>Male</td>
<td>3</td>
</tr>
<tr>
<td>Female</td>
<td>15</td>
</tr>
<tr>
<td>AGE</td>
<td></td>
</tr>
<tr>
<td>65 – 69</td>
<td>1</td>
</tr>
<tr>
<td>70 – 74</td>
<td>0</td>
</tr>
<tr>
<td>75 – 79</td>
<td>4</td>
</tr>
<tr>
<td>80 – 84</td>
<td>9</td>
</tr>
<tr>
<td>85 – 89</td>
<td>4</td>
</tr>
<tr>
<td>(Mean = 81.8  Median = 83  Mode = 83)</td>
<td></td>
</tr>
<tr>
<td>MARITAL STATUS</td>
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</tr>
<tr>
<td>Married</td>
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</tr>
<tr>
<td>Widowed</td>
<td>13</td>
</tr>
<tr>
<td>Separated / Divorced</td>
<td>2</td>
</tr>
<tr>
<td>Single, Never Married</td>
<td>1</td>
</tr>
<tr>
<td>RESIDENTIAL STATUS</td>
<td></td>
</tr>
<tr>
<td>Nursing Home</td>
<td>10</td>
</tr>
<tr>
<td>Live with Son</td>
<td>3</td>
</tr>
<tr>
<td>Live with Daughter</td>
<td>3</td>
</tr>
<tr>
<td>Live with Spouse</td>
<td>1</td>
</tr>
<tr>
<td>Live Alone</td>
<td>1</td>
</tr>
<tr>
<td>EDUCATIONAL LEVEL</td>
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</tr>
<tr>
<td>No Formal Education</td>
<td>6</td>
</tr>
<tr>
<td>Elementary</td>
<td>8</td>
</tr>
<tr>
<td>High School</td>
<td>3</td>
</tr>
<tr>
<td>College</td>
<td>1</td>
</tr>
<tr>
<td>EMPLOYMENT HISTORY</td>
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<td>Never Worked</td>
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<tr>
<td>Unskilled</td>
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<tr>
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<td>PERSONAL ANNUAL INCOME LEVEL</td>
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<tr>
<td>$9,999 and Under</td>
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<td>$10,000 - $19,999</td>
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<tr>
<td>SOURCE OF INCOME</td>
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<td>Personal Savings</td>
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</tr>
<tr>
<td>Support from Children</td>
<td>12</td>
</tr>
<tr>
<td>OAS / GIS / CPP</td>
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</tr>
<tr>
<td>COUNTRY OF ORIGIN</td>
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</tr>
<tr>
<td>Mainland China</td>
<td>3</td>
</tr>
<tr>
<td>Hong Kong</td>
<td>13</td>
</tr>
<tr>
<td>Taiwan</td>
<td>1</td>
</tr>
<tr>
<td>Malaysia</td>
<td>1</td>
</tr>
<tr>
<td>PRIMARY CHINESE DIALECT SPOKEN AT HOME</td>
<td></td>
</tr>
<tr>
<td>Cantonese</td>
<td>12</td>
</tr>
<tr>
<td>Toi Shanese</td>
<td>1</td>
</tr>
<tr>
<td>Chiuchow</td>
<td>2</td>
</tr>
<tr>
<td>Mandarin</td>
<td>1</td>
</tr>
<tr>
<td>Taiwanese</td>
<td>2</td>
</tr>
<tr>
<td>Code</td>
<td>Sex/ Age/ Marital Status</td>
</tr>
<tr>
<td>------</td>
<td>--------------------------</td>
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<td>F/78/S</td>
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<td>2</td>
<td>F/83/W</td>
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<td>3</td>
<td>F/79/S</td>
</tr>
<tr>
<td>4</td>
<td>F/83/W</td>
</tr>
<tr>
<td>5</td>
<td>F/78/W</td>
</tr>
<tr>
<td>6</td>
<td>F/87/W</td>
</tr>
<tr>
<td>7</td>
<td>F/83/W</td>
</tr>
<tr>
<td>8</td>
<td>M/80/W</td>
</tr>
<tr>
<td>9</td>
<td>F/87/S</td>
</tr>
<tr>
<td>10</td>
<td>F/85/W</td>
</tr>
</tbody>
</table>

Marital Status

M - Married
W - Widowed
Sep - Separated
S - Single

105
### Table 5.3: Descriptive Data of Individual Care Recipients (Continued)

Community Sample (N=8)

<table>
<thead>
<tr>
<th>Code</th>
<th>Sex/ Age/ Marital Status</th>
<th>Relation-ship between Care Recipient and Caregiver</th>
<th>Education</th>
<th>Occupation</th>
<th>Annual Income in $10,000</th>
<th>Source of Income</th>
<th>Years Diag-nosed Disease</th>
<th>Additional Illness or Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>F/69/W</td>
<td>mother-daughter</td>
<td>elementary</td>
<td>unskilled</td>
<td>below 1</td>
<td>savings, children support</td>
<td>2 - 3 yrs</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>F/79/W</td>
<td>mother-daughter</td>
<td>no formal education</td>
<td>unskilled</td>
<td>below 1</td>
<td>GWA</td>
<td>2 - 3 yrs</td>
<td>cancer</td>
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<tr>
<td>3</td>
<td>F/82/W</td>
<td>mother-daughter</td>
<td>elementary</td>
<td>none</td>
<td>below 1</td>
<td>savings</td>
<td>less than 1 yr</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>F/89/W</td>
<td>mother-son</td>
<td>elementary</td>
<td>unskilled</td>
<td>below 1</td>
<td>savings, children support</td>
<td>less than 1 yr</td>
<td>hearing defect</td>
</tr>
<tr>
<td>5</td>
<td>F/83/W</td>
<td>mother-son</td>
<td>elementary</td>
<td>unskilled</td>
<td>1 - 2</td>
<td>savings</td>
<td>less than 1 yr</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>F/80/W</td>
<td>mother-son</td>
<td>high school</td>
<td>none</td>
<td>below 1</td>
<td>OAS</td>
<td>less than 1 yr</td>
<td></td>
</tr>
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<td>7</td>
<td>M/84/M</td>
<td>father-in-law</td>
<td>elementary</td>
<td>semi-skilled</td>
<td>below 1</td>
<td>savings, children support</td>
<td>2 - 3 yrs</td>
<td></td>
</tr>
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<td>8</td>
<td>M/84/M</td>
<td>husband-wife</td>
<td>high</td>
<td>semi-skilled</td>
<td>1 - 2</td>
<td>savings, children support</td>
<td>less than 1 yr</td>
<td></td>
</tr>
</tbody>
</table>

**Marital Status**

M - Married  
W - Widowed  
Sep - Separated

**Residential status**

As Table 5.1 shows, ten of the elderly sample lived in a nursing home while seven shared the same household as their caregivers. Only one elderly woman from the community sample still managed to live on her own in an elderly person's apartment.
Educational level, employment history, annual income and source of income

Six care recipients received no formal education at all. The remaining twelve care recipients had received either elementary or high school instruction. Only one male elderly person graduated from university and thus he was the only one who was employed as a professional prior to his retirement. A clear majority of the sample (n=14) were unskilled or semi-skilled laborers.

Fifteen out of the eighteen care recipients received $9,999 or less annually, and only three had an income of $10,000 - $19,999. Over half of the care recipients (n=12) named support from adult children as their principal source of income while another fifth (n=4) depended on personal savings. Only two elderly care recipients had pensions in their retirement years.

Country of origin and primary Chinese dialect spoken at home

Close to three-quarters of the seniors (n=13) were from Hong Kong while the remaining five identified Mainland China, Taiwan and Malaysia as their country of origin.

The three most frequently used dialects were Cantonese, Toi Shanese and Mandarin and this distribution pattern reflected closely their countries of origin.
**Years since diagnosed with Alzheimer’s Disease or other forms of dementia**

According to the verbal report of the caregivers, approximately one-half (n=8) were diagnosed with Alzheimer’s Disease or other dementing illness within the last two years. (see Table 5.4) A slightly higher proportion (n=10) were diagnosed during the last two to four years. The caregivers recalled that diagnostic tests such as the CAT SCAN and the EEG had been performed in most cases.

**Table 5.4: Disease Process – Years since Diagnosed with AD / Dementia**

(n = 18)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Frequency</th>
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<tbody>
<tr>
<td>years since diagnosed with AD / dementia</td>
<td></td>
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<tr>
<td>Less than 1 Year</td>
<td>5</td>
</tr>
<tr>
<td>1 – less than 2 year</td>
<td>3</td>
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<tr>
<td>2 – less than 3 year</td>
<td>6</td>
</tr>
<tr>
<td>3 – less than 4 year</td>
<td>4</td>
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</table>

**Severity of Impairment**

Information on the severity of cognitive impairment among the study sample is shown in Tables 5.5 & 5.6. Fifteen dependent elderly people were quite impaired and they needed constant attention from the carers. The severity was greater in the institutional sample. Caregivers also reported more physical disabilities and additional illnesses in this group, as compared with the community sample.
Table 5.5: Disease Process – Extent of Mental Impairment
(n = 18)

<table>
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<td>Mildly impaired</td>
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<td>Moderately impaired</td>
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<td>Severely impaired</td>
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Table 5.6: Disease Process – Additional Illness and Disability
(n = 18)

<table>
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<th>Characteristic</th>
<th>Frequency</th>
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<td>Arthritis</td>
<td>1</td>
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<tr>
<td>Hypertension</td>
<td>1</td>
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<tr>
<td>Hip Fracture</td>
<td>1</td>
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<td>Cancer</td>
<td>1</td>
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<td>Parkinson Disease</td>
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<tr>
<td>Cataracts</td>
<td>2</td>
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<tr>
<td>Hearing impairment</td>
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</table>

The level of dependence of the elderly care recipients may also be specified on the basis of their performance of essential tasks (see tables 5.7 – 5.10). As shown in Tables 5.7 & 5.8, a significant proportion of demented elderly people needed substantial assistance from family carers to perform these tasks. The caregivers reported on their relative’s level of dependence in two functional domains: (1) Activities of daily living (ADL) which include bathing, dressing, feeding, toileting and transferring; and (2)
instrumental activities of daily living (IADL) such as meal preparation, laundry, getting about outside the house, handling finances and engaging in heavy chores. A majority of the institutional sample were severely dependent on ADL tasks and even more so in IADL tasks. The community sample had more self care abilities than their institutional counterparts. However, all subjects in the community sample (n=8) needed help everyday with meal preparation and two or three additional instrumental tasks.

Table 5.7: Level of Dependence of Care Recipients
(Institution Sample  N = 10)

<table>
<thead>
<tr>
<th>Number of ADL Tasks Performed Requiring Assistance</th>
<th>Frequency</th>
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<tbody>
<tr>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>3</td>
<td>2</td>
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<tr>
<td>6</td>
<td>1</td>
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<tr>
<td>7</td>
<td>1</td>
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</table>

<table>
<thead>
<tr>
<th>Number of IADL Tasks Performed Requiring Assistance</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>10</td>
<td>5</td>
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Table 5.8: Level of Dependence of Care Recipients  
(Community Sample  N = 8)

<table>
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<th>Number of ADL Tasks Performed Requiring Assistance</th>
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<td>3</td>
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<td>4</td>
<td>2</td>
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</table>

<table>
<thead>
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<th>Number of IADL Tasks Performed Requiring Assistance</th>
<th>Frequency</th>
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</thead>
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<td>2</td>
</tr>
<tr>
<td>10</td>
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Tables 5.9 & 5.10 show the level of dependence of each care recipient.
Table 5.9: Level of Dependence of Individual Care Recipients
(Institution Sample)
N = 10

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Table 5.10: Level of Dependence of Individual Care Recipients (Continued)
(Community Sample)
N = 8

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<th>Task</th>
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<th>Mdm. Wong</th>
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<th>Mdm. Au</th>
<th>Mr. Yeung</th>
<th>Mr. So</th>
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</tr>
</tbody>
</table>
Descriptive Profile of the Family Caregivers

Caregiving status

Of the eighteen caregivers in the study, twelve were adult offspring caring for their parents. This adult children group included six sons and six daughters (see Table 5.11). The remaining carers comprised two daughters-in-law, two granddaughters, one spouse (wife) and one sister-in-law. Fifteen respondents identified themselves as the principal carers while the other three were 'other involved carers' (see Table 5.12).

Table 5.13 displays a summary of the caregivers’ demographic characteristics and Tables 5.14 & 5.15 present the demographic details of each caregiver.

Table 5.11: Caregiver’s Relationship to Person with Cognitive Impairment
(n = 18)

<table>
<thead>
<tr>
<th>Relationship to Care Recipient</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse (Wife)</td>
<td>1</td>
</tr>
<tr>
<td>Daughter</td>
<td>6</td>
</tr>
<tr>
<td>Son</td>
<td>6</td>
</tr>
<tr>
<td>Daughter-in-law</td>
<td>2</td>
</tr>
<tr>
<td>Granddaughter</td>
<td>2</td>
</tr>
<tr>
<td>Sister-in-law</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 5.12: Caregiving Status
(n = 18)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary caregiver</td>
<td>15</td>
</tr>
<tr>
<td>Other involved caregiver</td>
<td>3</td>
</tr>
</tbody>
</table>

114
Table 5.13: Socio-Demographic Characteristics of Caregivers (n = 18)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>GENDER</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>6</td>
</tr>
<tr>
<td>Female</td>
<td>12</td>
</tr>
<tr>
<td>AGE</td>
<td></td>
</tr>
<tr>
<td>30 - 39</td>
<td>5</td>
</tr>
<tr>
<td>40 - 49</td>
<td>7</td>
</tr>
<tr>
<td>50 - 59</td>
<td>2</td>
</tr>
<tr>
<td>60 - 69</td>
<td>4</td>
</tr>
<tr>
<td>(Mean = 48.8  Median = 47.5  Mode = 47 and 36)</td>
<td></td>
</tr>
<tr>
<td>MARITAL STATUS</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>16</td>
</tr>
<tr>
<td>Divorced</td>
<td>1</td>
</tr>
<tr>
<td>Single, Never Married</td>
<td>1</td>
</tr>
<tr>
<td>RELIGIOUS AFFILIATION</td>
<td></td>
</tr>
<tr>
<td>Buddhist</td>
<td>5</td>
</tr>
<tr>
<td>Catholic</td>
<td>3</td>
</tr>
<tr>
<td>Protestant</td>
<td>5</td>
</tr>
<tr>
<td>None</td>
<td>5</td>
</tr>
<tr>
<td>EDUCATIONAL LEVEL</td>
<td></td>
</tr>
<tr>
<td>Elementary</td>
<td>1</td>
</tr>
<tr>
<td>High School</td>
<td>11</td>
</tr>
<tr>
<td>University</td>
<td>6</td>
</tr>
<tr>
<td>EMPLOYMENT STATUS</td>
<td></td>
</tr>
<tr>
<td>Outside, Full Time</td>
<td>11</td>
</tr>
<tr>
<td>Retired</td>
<td>2</td>
</tr>
<tr>
<td>Unemployed</td>
<td>5</td>
</tr>
<tr>
<td>OCCUPATIONAL CATEGORY</td>
<td></td>
</tr>
<tr>
<td>Homemaker</td>
<td>7</td>
</tr>
<tr>
<td>Unskilled</td>
<td>1</td>
</tr>
<tr>
<td>Semi-skilled</td>
<td>3</td>
</tr>
<tr>
<td>Managerial</td>
<td>1</td>
</tr>
<tr>
<td>Professional</td>
<td>6</td>
</tr>
<tr>
<td>PERSONAL ANNUAL INCOME LEVEL</td>
<td></td>
</tr>
<tr>
<td>$9,999 and less</td>
<td>3</td>
</tr>
<tr>
<td>$10,000 - $19,999</td>
<td>5</td>
</tr>
<tr>
<td>$20,000 - $29,999</td>
<td>2</td>
</tr>
<tr>
<td>$30,000 - $39,999</td>
<td>1</td>
</tr>
<tr>
<td>$40,000 - $49,999</td>
<td>4</td>
</tr>
<tr>
<td>$50,000 and above</td>
<td>3</td>
</tr>
<tr>
<td>COUNTRY OF ORIGIN</td>
<td></td>
</tr>
<tr>
<td>Hong Kong</td>
<td>16</td>
</tr>
<tr>
<td>Taiwan</td>
<td>1</td>
</tr>
<tr>
<td>Malaysia</td>
<td>1</td>
</tr>
<tr>
<td>RESIDENTIAL ARRANGEMENT</td>
<td></td>
</tr>
<tr>
<td>Institution Sample (10)</td>
<td></td>
</tr>
<tr>
<td>Share residence with care recipient prior to nursing home placement</td>
<td>7</td>
</tr>
<tr>
<td>Keep separate residence prior to nursing home placement</td>
<td>3</td>
</tr>
<tr>
<td>Community Sample (8)</td>
<td></td>
</tr>
<tr>
<td>Share residence with care recipient</td>
<td>6</td>
</tr>
<tr>
<td>Keep separate residence</td>
<td>2</td>
</tr>
</tbody>
</table>
Table 5.14: Descriptive Data of Family Caregivers  
(Institution Sample N=10)

<table>
<thead>
<tr>
<th>Caregiver Serial No.</th>
<th>Relationship to Care Recipient</th>
<th>Age/ Sex/ Marital Status</th>
<th>Religious Affiliation</th>
<th>Education Attainment</th>
<th>Employment Status</th>
<th>Occupation Status</th>
<th>Annual Income Level in $10,000</th>
<th>Caregiving Status</th>
<th>Country of Origin</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>DA</td>
<td>47/M</td>
<td>NIL</td>
<td>U</td>
<td>O,FT</td>
<td>PROF</td>
<td>above 5</td>
<td>P</td>
<td>HK</td>
</tr>
<tr>
<td>2</td>
<td>DA</td>
<td>47/M</td>
<td>NIL</td>
<td>H</td>
<td>O,FT</td>
<td>UN</td>
<td>below 1</td>
<td>P</td>
<td>HK</td>
</tr>
<tr>
<td>3</td>
<td>DA</td>
<td>36/M</td>
<td>NIL</td>
<td>H</td>
<td>UNEM</td>
<td>-</td>
<td>1-2</td>
<td>O</td>
<td>HK</td>
</tr>
<tr>
<td>4</td>
<td>SON</td>
<td>54/M</td>
<td>P</td>
<td>U</td>
<td>O,FT</td>
<td>PROF</td>
<td>4-5</td>
<td>P</td>
<td>Malaysia</td>
</tr>
<tr>
<td>5</td>
<td>SON</td>
<td>46/M</td>
<td>B</td>
<td>H</td>
<td>O,FT</td>
<td>MAN</td>
<td>above 5</td>
<td>P</td>
<td>HK</td>
</tr>
<tr>
<td>6</td>
<td>SON</td>
<td>63/M</td>
<td>B</td>
<td>H</td>
<td>RET</td>
<td>-</td>
<td>1-2</td>
<td>P</td>
<td>HK</td>
</tr>
<tr>
<td>7</td>
<td>D-I-L</td>
<td>35/M</td>
<td>P</td>
<td>H</td>
<td>UNEM</td>
<td>-</td>
<td>2-3</td>
<td>P</td>
<td>HK</td>
</tr>
<tr>
<td>8</td>
<td>GR-DA</td>
<td>36/M</td>
<td>B</td>
<td>H</td>
<td>O,FT</td>
<td>TECH</td>
<td>2-3</td>
<td>P</td>
<td>HK</td>
</tr>
<tr>
<td>9</td>
<td>GR-DA</td>
<td>36/S</td>
<td>P</td>
<td>U</td>
<td>O,FT</td>
<td>PROF</td>
<td>3-4</td>
<td>O</td>
<td>HK</td>
</tr>
<tr>
<td>10</td>
<td>SIS-I-L</td>
<td>58/M</td>
<td>C</td>
<td>H</td>
<td>O,FT</td>
<td>PROF</td>
<td>4-5</td>
<td>P</td>
<td>HK</td>
</tr>
</tbody>
</table>

Table 5.15: Descriptive Data of Family Caregivers  
(Community Sample N=8)

<table>
<thead>
<tr>
<th>Caregiver Serial No.</th>
<th>Relationship to Care Recipient</th>
<th>Age/ Sex/ Marital Status</th>
<th>Religious Affiliation</th>
<th>Education Attainment</th>
<th>Employment Status</th>
<th>Occupation Status</th>
<th>Annual Income Level in $10,000</th>
<th>Caregiving Status</th>
<th>Country of Origin</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>DA</td>
<td>37/M</td>
<td>C</td>
<td>H</td>
<td>UNEM</td>
<td>-</td>
<td>below 1</td>
<td>P</td>
<td>HK</td>
</tr>
<tr>
<td>2</td>
<td>DA</td>
<td>49/M</td>
<td>C</td>
<td>H</td>
<td>UNEM</td>
<td>-</td>
<td>below 1</td>
<td>P</td>
<td>HK</td>
</tr>
<tr>
<td>3</td>
<td>DA</td>
<td>48/M</td>
<td>NIL</td>
<td>U</td>
<td>O,FT</td>
<td>PROF</td>
<td>above 5</td>
<td>P</td>
<td>HK</td>
</tr>
<tr>
<td>4</td>
<td>SON</td>
<td>66/M</td>
<td>NIL</td>
<td>H</td>
<td>RET</td>
<td>-</td>
<td>1-2</td>
<td>P</td>
<td>HK</td>
</tr>
<tr>
<td>5</td>
<td>SON</td>
<td>49/M</td>
<td>P</td>
<td>U</td>
<td>O,FT</td>
<td>TECH</td>
<td>4-5</td>
<td>P</td>
<td>Taiwan</td>
</tr>
<tr>
<td>6</td>
<td>SON</td>
<td>60/D</td>
<td>B</td>
<td>H</td>
<td>O,FT</td>
<td>TECH</td>
<td>1-2</td>
<td>P</td>
<td>HK</td>
</tr>
<tr>
<td>7</td>
<td>D-I-L</td>
<td>47/M</td>
<td>P</td>
<td>U</td>
<td>O,FT</td>
<td>PROF</td>
<td>4-5</td>
<td>O</td>
<td>HK</td>
</tr>
<tr>
<td>8</td>
<td>SP</td>
<td>65/M</td>
<td>B</td>
<td>E</td>
<td>UNEM</td>
<td>-</td>
<td>1-2</td>
<td>P</td>
<td>HK</td>
</tr>
</tbody>
</table>

LEGEND:

- Relationship to Care Recipient:
  - DA: Daughter
  - D-I-L: Daughter-in-law
  - GR-DA: Grand-daughter
  - SIS-I-L: Sister-in-law
  - SP: Spouse

- Marital Status:
  - M: Married
  - S: Single, Never married
  - D: Divorced

- Religious Affiliation:
  - P: Protestant
  - C: Catholic
  - B: Buddhist

- Education Attainment:
  - E: Elementary
  - H: High School
  - U: University

- Employment Status:
  - O, FT: Outside, full time
  - UNEM: Unemployed
  - RET: Retired

- Caregiver Status:
  - P: Primary
  - O: Other involved caregiver

- Occupation:
  - PROF: Professional
  - TECH: Technical
  - UN: Unskilled
  - MAN: Managerial

- Country of Origin:
  - HK: Hong Kong

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Age & Marital Status

The ages of the caregivers in this study ranged from 35 to 66 years with a mean of 48.8.

Religious Affiliation

Five were affiliated with the Buddhist faith; three were Catholic and five were Protestant. Another five carers reported that they were not affiliated to any religion at the time of the study.

Education, employment status and personal annual income

In comparison with the care recipients, the caregivers were much better educated: eleven had high school education while six had university training. As for employment status, eleven were employed outside full time while the remaining were either unemployed or retired. Close to one-third of the sample occupied managerial or professional positions. Approximately one-half of the caregivers had a personal annual income of $30,000 and above.

Caregiving commitment

Among the community sample, six caregivers shared the same residence with their demented relatives in order to provide the necessary daily assistance. And for the institutional group, seven care recipients were accommodated in the carers’
households prior to their placement in the nursing home. Only five subjects were capable of self care and kept separate residences among the combined group. This situation is not surprising as the elderly relatives were fairly impaired both cognitively and functionally.

Caregivers in the sample had been providing home care from under one year to as long as 7 years with a mean of 3.1 years (see table 5.16). Seven caregivers had been involved for more than 4 years. As for the hours of care per week, there were wide variations in the amount of time spent on caregiving tasks. One family carer spent less than 5 hours per week, but the average carer invested 14 hours and 3 carers as much as 21 to 24 hours (see Table 5.17). In addition, a majority of the caregivers helped their dependents with six or more IDAL tasks while one-third were responsible for the daily essential caring tasks of bathing, transferring and cleaning up after incontinence (see Tables 5.7 – 5.10).

<table>
<thead>
<tr>
<th>Table 5.16: Length of Caregiving</th>
</tr>
</thead>
<tbody>
<tr>
<td>Factor</td>
</tr>
<tr>
<td>----------------------------------</td>
</tr>
<tr>
<td>Years of Caregiving (mean = 3.1)</td>
</tr>
<tr>
<td>1 or less</td>
</tr>
<tr>
<td>2</td>
</tr>
<tr>
<td>3</td>
</tr>
<tr>
<td>4</td>
</tr>
<tr>
<td>5 or above</td>
</tr>
</tbody>
</table>
Table 5.17: Provision of Care by Family Caregivers  
(By Hours Per Week)

<table>
<thead>
<tr>
<th>Factor</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hours of Care Per Week (mean = 14.1)</td>
<td></td>
</tr>
<tr>
<td>1 - 5</td>
<td>1</td>
</tr>
<tr>
<td>6 - 10</td>
<td>4</td>
</tr>
<tr>
<td>11 - 14</td>
<td>5</td>
</tr>
<tr>
<td>15 - 20</td>
<td>5</td>
</tr>
<tr>
<td>21 - 24</td>
<td>3</td>
</tr>
</tbody>
</table>

Informal network of care support

The majority of caregivers (n=15) were the principal care providers. Only three caregivers were other involved carers. Seven carers had the privilege of at least one more caregiver to whom they could turn for sharing the tasks. Another seven carers were part of an extended system of two or three more informal family carers. As can be seen in chapter eight of the thesis, the availability of other informal carers was a significant back-up support to these families although their members were widely dispersed geographically in different countries and provinces in Canada.

Table 5.18: Availability of Alternate Informal Caregivers

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>4</td>
</tr>
<tr>
<td>One additional caregiver</td>
<td>7</td>
</tr>
<tr>
<td>Two additional caregivers</td>
<td>4</td>
</tr>
<tr>
<td>Three additional caregivers</td>
<td>3</td>
</tr>
</tbody>
</table>

*Footnote  Other caregivers include husband, wife, daughter, son, daughter-in-law, mother-in-law and sister-in-law, siblings and spouse of siblings.
Length of Immigration of the Care Recipients

Thirteen elderly relations arrived at Toronto within the last three years while five stayed for more than four years. The main reason for immigration was for family reunion.

Table 5.19: Length of Immigration of the Care Recipients

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than two years</td>
<td>2</td>
</tr>
<tr>
<td>Two to three years</td>
<td>11</td>
</tr>
<tr>
<td>Four to five years</td>
<td>5</td>
</tr>
</tbody>
</table>

Length of Immigration of the Caregivers

Half of the caregivers have stayed in Toronto for more than six years. Most came because of their preference for political stability, better living environment and a more balanced educational system for their children.

Table 5.20: Length of Immigration of the Caregivers

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than three years</td>
<td>3</td>
</tr>
<tr>
<td>Three to five years</td>
<td>6</td>
</tr>
<tr>
<td>Six to eight years</td>
<td>8</td>
</tr>
<tr>
<td>Above nine years</td>
<td>1</td>
</tr>
</tbody>
</table>
Summary

This chapter outlined the demographic characteristics of the family caregivers and their demented relatives. Among the cognitively impaired elderly sample, women outnumbered men. There were three men and fifteen women. The sample ranged in age from 65 to 89 years with a mean of 81.8. Close to three-quarters of the care recipients were widowed. Ten of the elderly sample lived in a nursing home while eight still resided in the community at the time of the study. On the whole, the elderly sample had received little education, and if they were employed before becoming ill, they were unskilled or semi-skilled laborors. With respect to economic status, fifteen care recipients earned $9,999 or less annually and over half of the care recipients named support from adult children as their principal source of income. The great majority (n=13) were from Hong Kong originally while the remaining identified Mainland China, Taiwan and Malaysia as their country of origin.

Approximately one-half of the care recipients were diagnosed with Alzheimer’s Disease or related disorders within the last two years. The severity of impairment was greater in the institutional sample. On the whole, the elders were quite dependent on their caregivers for providing them assistance in all activities of daily living.

The caregivers who participated in the study were: 6 sons, 6 daughters, two daughters-in-law, two granddaughters, one sister-in-law and a wife. The ages of the caregivers ranged from 35 to 66 years with a mean of 48.8. With regards to religious affiliation, five carers were Buddhist, three were Catholic and five were Protestant. In
comparison with the care recipients, the caregivers were much better educated having university training. Occupationa...
CHAPTER SIX
FINDINGS AND DISCUSSION: PART TWO
STRUGGLING TO CARE

The Caregiving Struggle: Salient Features

Families involved in dementia care do not address problems or needs that can be quickly handled or easily dismissed. On the contrary, care commitment often lasts for a long time and caregivers, once they have assumed the role, embark on a lonely journey and a battle on many fronts. The 18 caregivers whom I have interviewed converged on a similar point when they described their unique experience as being caught up in the “caregiving struggle”. The purpose of this chapter is to discuss this overriding theme of “struggle” and to understand its various dimensions from the perspective of the respondents.

The Caregiving Struggle As An Endless War

The process by which caregivers come to define their family members as having Alzheimer’s Disease or a related disorder is a long and complicated one (Fisher & Lieberman, 1994; Moritz, Kasl & Berkman, 1989). The definition process tends to begin with a vague recognition of the trouble by caregivers. When bizarre behaviours are exhibited over a long period of time, with increasing frequency and severity, caregivers come to see the accumulation of events in an integrated manner. Incidents of forgetfulness, accusations of theft, disorientation of time and place, and other behavioural deficits finally convince caregivers that they must seek experts’ advice to identify the root of the trouble.
The second phase of the long struggle is marked by a more definite diagnosis by medical personnel. Often the diagnosis is obtained after a series of diagnostic tests, brain scans (CTScans-Computerised Tomography), repeated consultations and probably referrals to specialists to exclude reversible conditions. For those families who might contest the diagnosis due to reactions such as disbelief or denial, an even lengthier process takes place. Caregivers in this study confirmed findings previously established by Blum (1992), Chenoweth and Spencer (1986), Rabins, Mace andLucus (1982). In the following retrospective accounts, carers highlight the lengthy character of this struggle at the diagnostic stage. A daughter-in-law described her experience:

About 3 years ago we noticed that he (father-in-law) made incorrect tender when he went shopping. He always gave a $20 note, no matter what was the actual cost of the item and accepted whatever change the shopkeeper cared to give him. Or alternatively, he took out a pack of bank notes, $20, $10 or $5, asking the shopkeeper to help himself. We were puzzled but we didn’t know what was it...

Then I noticed he could not prepare his usual simple breakfast, that is boil some water, fix a cup of coffee, and enjoy his slice of bread. He just sat in front of the kitchen table and expected to be served.

... since last Christmas, he refused to take baths, put on heavy clothing in June and asked repetitive questions. We took him to see Dr. Tse twice but he was not particularly alarmed, telling us he was just being forgetful. We were told that his errors in money changes might be a result of worsening vision. So, we consulted an optometrist. He had a pair of new glasses. It was after 6 months of our persistent persuasion that Dr. Tse finally agreed to make a referral to the neurologist who said it was probably dementia of the Alzheimer’s type. My sister-in-law was a nurse. She wanted her father to see a consultant for a second opinion. So we waited for another couple of weeks for an appointment. So, in short, it took the family at least 2 years altogether to obtain a diagnosis.

(CGC-7)
A similar struggle was noted by a son caregiver:

It took me 18 months to find out the truth. I didn’t stay with my mother. So when my sister... told me that Mom’s apartment was rather dirty, I just took it as her way of grieving over the death of her brother. ... Gradually, she didn’t cook much, not having proper meals. I still didn’t pay much attention to it until all of a sudden a hard blow hit me in the face. The super [superintendent] of her senior apartment called me to say Mom lost her way in the neighborhood and was taken home by another resident. It was not possible because that had been her home for a long time...

She was seen by several doctors in the next nine months. But nobody could deliver a conclusive diagnosis. The endless uncertainty held me in terrible suspense. Eventually, a doctor at the teaching hospital downtown gave a diagnosis of Alzheimer’s Disease. In a way, it came as a relief to me after this long period of endless waiting.

(CG-6)

A number of scholars of family care of the dependent elderly contend that caregiving could take up a substantial portion of a carer’s life and, hence, the struggle could be as long as fifteen years (Archold, 1983; Dhooper, 1992; Finley, Roberts, & Banahan, 1988; Pratt, Schmall, Wright & Cleland, 1985). Findings from my study concur in particular with the experience made by respondents in Chenoweth and Spencer’s (1986) study who perceived the agony of care as a “funeral stretched out in one week bits over four years”. A daughter in my sample described it thus:

It’s like a weight on my shoulder which I cannot relinquish easily. Dr. Wong said Alzheimer’s patients could live from 2-10 years, depending on the pace of deterioration and other complications. I said “Well, it’s just 2 years. She has diabetes. If I don’t take her into my home, nobody will.” But now, I have been with her for 4 years. I wish somebody could tell me, when will this struggle come to an end?

(CG-2)
Providing care to a dementing relative over the years is demanding by nature, but the "endlessness" of the struggle tends not to stop there. The routine caregiving task can totally engulf a carer’s daily life, making the struggle an "endless" chore. A son caregiver once described his daily caregiving duty as stretching from "dawn till dusk":

...I work in the afternoon shift. So starting from 6 a.m. I have to get ready for my parents’ house. I visit them twice a day, prepare their breakfast and lunch, finish the laundry before 9 a.m. and take Mom out for a walk if the weather allows. She can still get excitement at hearing the birds singing. Dad used to take her out but now he is almost totally blind. After an early lunch, I have to run fast to make sure I won’t be late for work at 11 a.m. I call to check on them at 5 p.m. ... I do the grocery shopping and marketing on my way home and then set the dinner, ...I go to China town almost everyday because they insist on having fresh meat and Chinese vegetables. By 9 p.m. I am so exhausted but I'll wait to give Mom the medicine and remind her to use the bathroom. I do it five days a week, literally from sunrise till sunset. ...my sister delivers the meals to them on weekends.

(CG-4)

The Caregiving Struggle As A Lonely Journey

Previous research data often testify to the availability of emotional support from secondary caregivers within the kinship network (Matthews and Rosner, 1988; Stoller, 1983; Stoller, Forster, Duniho, 1992; Zarit, Orr & Zarit, 1985), but the caregiving journey is nevertheless a "lonely" path. Several caregivers in my study captured this aspect of the struggle and gave their explanations. A daughter-in-law expressed this sentiment very directly, as reflected in her comment:

Nobody seems to fully appreciate the difficulties, none from my family recognises the full impact of the burden. This has never happened to anyone before in my own family or in my husband's.

(CGC-7)
Another caregiver who was caring for her sister-in-law attributed her sense of loneliness to the lack of knowledge of Alzheimer’s Disease among the Chinese community:

Outsiders don’t understand. I don’t blame them. Who knows what’s Alzheimer’s Disease? This disease is little known among Chinese families.

(CGI-10)

A daughter caregiver, while appreciating the back-up sporadic and intermittent relief, spoke of her sense of loneliness:

My sister and her husband drop by when work is over to help out. They shop for her, sometimes take her to the tea house on Saturday morning. They also try to calm her down whenever she becomes too agitated for no good reasons. ..., but I am the one who always stands by, other people come and go, whenever it fits their time-table. Well, they came in once in the mid-night as I phoned them to say mother slipped out from a chair in the bathroom. She had minor bruises on her arms and legs. She screamed for help. I didn’t know what to do ... and I hated to wake up the neighbours at such late hour. Of course I am not entirely on my own when it comes to caring for her, but I myself bear the full brunt of the work. I alone feel the heaviness of the stress.

(CGCI-1)

Unlike other physical disabilities such as stroke and Parkinson Disease, cognitive impairment at the early stage of its development does not necessarily entail visible impediment. Hence, caregivers are often robbed of the normal sympathy which they might obtain from kin and friends. This characteristic of the disease also explains the “emotional loneliness or isolation” found by some caregivers. A daughter-in-law recalled vividly an episode:

On the surface, he [father-in-law] was perfectly normal. Physically, he was robust, ... he ate well, he walked faster than me. His bone and flesh were intact. Once I ran into my manager, Mr. Poon in the Mall when we were in the supermarket. I gently introduced him to Mr. Poon. He put up a
broad and lovely smile, greeting and shaking hands warmly with Mr. Poon. Then, he asked me who this gentleman was as soon as my boss was just out of our sight. In the following week, he had a medical appointment. I had to take half day off to escort him. I still remember Mr. Poon's facial expression as he asked me suspiciously before letting me go, "A Memory Clinic for your father-in-law? What's that? What went wrong with him?" (CGC-7)

In addition, a carer's deep sense of loneliness does not come to an automatic and abrupt end at the point of institutionalization of the dementia relative. On the contrary, literature on social aspects of burden over time indicates that social isolation experienced by caregivers continues for an extended period (Zarit et al., 1986). In Lewis and Meredith's (1988) study, caregiving daughters remained unsupported when their mothers died because of the prolonged involvement in care provision. Thus, although the burden of round-the-clock care may have been relieved, they would still face emotional emptiness. Similarly, relatives of institutionalised and deceased Alzheimer's Disease persons frequently report their difficulties in reconnecting and resuming their lives (Globerman, 1994, p.221). This was best illustrated by a son in my study:

Definitely, it was a great relief when they [staff of the nursing home] took her [mother] in. But, I was very restless and apprehensive in the next few weeks. I wanted to see my friends but I didn't know how to start socializing all over again after this extended period of providing care to her.

(CGI-5)
Caregiving Struggle As A Battle On Many Fronts

To define accurately the role of a family caregiver of a dementing relative is never an easy task. Previous literature indicates that family carers could be variously identified as “victims” or “clients” (Bonder, 1986; Clarke & Watson, 1990; Mace & Rabins, 1981; Morycz, 1985, 1990; Pratt, Schmall, Wright, & Hare, 1987); “change agents” in the resource system (Gruetzner, 1992); or “allies” of the helping profession (Powell & Courtice, 1993; Williams & Kay, 1995). However, as I talked to the caregivers in my study, the image of an active “fighter” gradually unfolded. These fighters were not commonplace soldiers normally found in the real battlefield of bombs and tanks. They did not face real life threats as such, for example, impending death, fatal injury, or devastating hunger. But they were aware that they must fight a vigilant battle, a battle on many fronts, otherwise the well-being of their relatives would be threatened. The following descriptions explain the multiple “fronts” that carers encountered in the struggle.

Difficult Behaviour

Alzheimer’s Disease and its related disorders give rise to a variety of troubles that often call for management on the part of the caregiver and this constitutes the very first “front” of the battle. A wife taking care of her husband commented:

I must be on guard 24 hours a day, he [the husband] may engage in actions that endanger himself or the property. He can just walk out and leave the door open, wander away and get lost, start fires while preparing snacks. I dare not doze off.

(CGC-8)
Another son caregiver who shared the residence with his mother related this story:

She [mother] resented my authority and didn’t comply when I stopped her from switching the thermostat program. We set the thermostat program in order to save energy and cut down the electricity bill, but whenever we left her for an hour or so, she messed up the program. ... It was freezing cold when we were home. Her finger nails also turned blue and purple. Now I have put a wooden case over the thermostat and lock it up so that she will not be exposed to such extreme coldness.

(CGC-4)

Environmental Hazards

While the caregiver often tries to manage and exercise control to combat difficult behaviour, he or she also takes quite creative steps in removing the environmental hazards to guarantee a safer place for the affected relative to live. The specific choice of aids depends on the problem at hand. A daughter-in-law suggested to other family members:

We should put more lights around at night. ... When she [mother-in-law] sees a little bit better, she might not be that frightened. Instead of her wandering in every room until she finds the bathroom, we should just close all those doors to see if it helps. Also, take away the pills in the medicine cabinet. She cannot follow the medication regiment any more.

(CGC-7)

A son found the following ways to cope with the potential danger in his mother’s immediate environment:

I removed the knobs on the stove; took away the kitchen knives, not even small knives for fruits or any sharp item, because she hid them in her drawers, saying she must protect herself against the “invader”.

(CGC-4)
Formal Support Systems

When signs of impairment become obvious and the level of dependence increases, many family carers turn to service systems for assistance. This trend has been well documented by Caserta, Dale, Lund, Wright & Redburn (1987), Litwak (1985) and Ory et al. (1985). The role for the family may be variably called linkage, mediation, or management (Horowitz, 1985). Shanas and Sussman (1977) in elaborating on the specifics of the role argued that the family could "... be a buffer for elderly persons; examine the service options provided by organizations; effect entry of the elderly person... and facilitate the continuity of the relationship of the aged member with the bureaucracy" (p. 216). Among my interviewees, the most commonly used support systems were the health care delivery and social service systems. One of the essential tasks in this help seeking process was to negotiate with these systems, for instance, institutions, in-home and day care programs in soliciting the most appropriate help. As Brody (1977) noted, this phase might represent the first time any member of the family had reason to need or use formal service. Archbold (1983) identified a distinctive caregiving role performed by her sample and she described this as the "care managers", in contrast to the "care providers" who were engaged in direct assistance. In Archbold's (1983) study, the major involvement of family members who performed the "care manager's" role was to negotiate with different service systems in obtaining appropriate services for their relatives. In contrast, "care providers" in Archbold's research gave "hands-on" care to the demented relatives. The distinction of these two roles was discussed in greater details in chapter seven (pp. 166-174). When asked of their difficulties, respondents in my study revealed considerable hardship in performing the "manager" role. As stated by a daughter carer in my sample:
We [the family members] were at our wits end. Mother was so confused that we called up the nursing home for help. "No vacancy," the head nurse replied. What a disappointing answer to us! But the social worker was sympathetic, ...and eventually offered a temporary placement of two weeks. Mother calmed down a bit, I guess, with the help of the medication and we had a real break. Then the time came when we had to take her home. We fought with the Home senior management..., we spoke to a Board member, but we had signed a consent form to take her home at the end of the relief period. Absolutely no other option for us. Yet, after much back and forth talking, they bent and extended the period. She could stay for another week.

(CGI-1)

Family carers are also involved in continuing negotiation after institutionalisation. In my study, a son carer reflected a similar need as articulated by respondents who were interviewed by Duncan and Morgan (1991) in their study on sharing the care with home nursing staff. My informant stated:

I was very determined to explain to them [the home nursing staff] my mother's daily routine, what she liked and didn't like. I believe they would give good nursing care, but that was not all. She was not just another crazy old woman. Yeah, they should listen to me.

(CGI-4)

Unraveling The Paradox of The Struggle

Alzheimer's Disease and its related disorder has a profound impact on the victim's personality. Caregivers struggle along to adjust and readjust constantly to ever-changing situations. Often, they find the struggle embedded in an ironical and complex "paradox". The following sections unravel the paradox and examine the coping practices adopted by family caregivers in addressing this unique aspect of the caregiving phenomenon.
1. **Valuing Who The Relative Was In The Past and Accepting Who The Person Is In The Present**

The struggle to keep a dual perspective: to focus on the “past” while accepting the “present” condition of the demented relative is the very first hard reality confronting caregivers. This is quite evident in my data and a pattern emerged as I read the transcripts. It showed that cognitive impairment did threaten the caregivers’ view of who their family members were. The mourning of the loss of their relatives’ personality or identity is consistently confirmed in previous work on dementia care (Boss, 1993, 1989, Boss et al., 1990; Cohen & Eisdorfer, 1987; Gubrium, 1987). In looking back into the past and reflecting on the present, the following four caregivers in different families spoke about their experience:

I had lots of respect for her [mother]. She was a very sensible woman even though she did not have much formal schooling. But now she talked nonsense. I found it quite annoying. She is not my Mom any more. In the past, she was a reasonable person by nature. She never expected too much from her children. Her current demanding behaviour makes me realize that my Mom is dead. It’s a terrible feeling.

(CG-3)

... We had a most difficult time in the 1950s. But mother was always optimistic, cheerful and well contented. She was on top of every trouble. She has changed a lot now, tearful, complaining and the smallest inconvenience upsets her.

(CG-5)

Now he [husband] loses interest in the outside world. He just withdraws into his own small, small world. He is not keen at all to view the news program on TV. He stills reads the newspapers occasionally. ...in the past, he read almost all the leading newspapers before bed time.

(CG-8)
We used to have pot-lucks once in awhile and all my cousins and their families came. Mother was never short of words or humour. She entertained the guests, played with young children and above all, fed us with her delicious dishes. Her cooking skills are now gone...

(CGI-3)

Having recognized the insidious and progressive changes of personality, family caregivers in my study gradually came to terms with the disease and its devastating impacts. Then the initial grief and despair evolved into acceptance. Several caregivers gave accounts which portrayed their adjustment process.

From a granddaughter-in-law:

Yes, grandmother’s judgement and memory are lost forever. But I fix my eyes on her remaining strengths - a kind heart and a nice character.

(CGI-9)

From a son carer:

I remind myself and my wife that we must do everything to support Mom’s dignity, to keep her active, to make her feel useful, and not to ignore the memory of who she was. She was the one who sat up for the whole night to care for me. ...My father died when Mom was five months pregnant and I had bad asthma all along.

(CGI-5)

From a daughter caregiver:

It was hard on my sister. No, she couldn’t bear it. She wanted to get away from mother, at least for a short respite. ... my sister came home late deliberately and I knew she cared as much as I do. As for myself, I said, “everyone has his/her good days and bad days. I can’t get rid of the bad days, so face them squarely.” I still let her do a bit of household work, just to keep her occupied. But I don’t expect much from her now.

(CGI-3)
2. **Cherishing The Past Relationship While Maximising The Current Relationship**

A dementing illness such as Alzheimer’s Disease erodes personality and it ultimately affects the affective relationship which has been gradually built up between the caregiver and the dependent relative over a long period of time (Archbold, 1983; Cantor, 1983; Johnson & Catalano, 1983). In fact, Noelker and Poulshock (1982), in studying caregiving within shared households, reported that the caregiver-older person relationship was the second most affected area after personal time restrictions. Researchers attributed this caregiving outcome to the loss of reciprocity of care, support and affection in the relationship and the decline of communicative skills of the family member (George & Gwyther, 1986; Gruetzner, 1992; Rabins et al, 1982).

Loss of a cherished relationship is mostly felt by spousal carers (Lustbader & Hooyman, 1994; Rankin, 1990). Several explanations have been suggested by previous researchers to account for their experience. In Rankin’s study, 41 elderly spousal carers identified deficits in self care and instrumental ability of their life partners as constituting the greatest burden because their own personal resources, such as physical and financial status, were also declining. On the other hand, deteriorating communication skills tend to affect the kinds of issues that can be shared by the marital couple. In addition, an explicit shift in the relationship might take place, with the family member becoming one who must be looked after and managed while the caregiver makes an increasing number of decisions about the relative’s life (Pearlin et al., 1990).

Among dependent adult children carers, resentment can occur too at the decline of the dominant parent’s capabilities. However, Horowitz’s (1984) data provide a contrary view. Horowitz urged us to make a distinction between permanent effects on the caregiving
relations and the more transient relationships in daily interactions. While a substantial minority in her study sample reported a definite deterioration on a daily basis, very few reported change in their overall affective relationships. In other words, the experience of disruption and consequences is not universal and controversy exists as to its prevalence and severity. This view was supported by Adams et al. (1979) whose longitudinal study examined caregiving dyads. These researchers maintained that there was an equal likelihood of both improved and deteriorated relations. Certain characteristics which are external to the dyad dynamics are in operation to influence the direction of the effect and this will be examined in the next chapter when I discuss family processes of communication, decision making and conflict resolution in caregiving families.

However, in my study, the experience of the caregivers revealed a consistent pattern of “letting go” of the past relationship while “holding on” to the altered relationship. And this integrated approach of letting go and holding on has helped them to survive the struggle of caregiving.

From a daughter-in-law:

My husband and I tried not to leave him [father-in-law] out of any important family event. We made it possible to include him in our lives. Sometimes it worked, sometimes it didn’t. We wouldn’t take him to fancy Chinese restaurants, but he loved to get to places where he could sit and watch people. We brought him to the parks in the summer so that he could watch the children playing and hear the birds singing. We took him on short trips too. He was delighted to see the changing colour of the Autumn leaves. On Father’s Day, I took him along to visit my father’s grave yard. I said, “My father was buried here”. He nodded his head gently and said it would be nice to see him. His response showed us he didn’t quite understand but I must allow him to live on his own terms. He had been the father of my husband. ...We recognize we don’t have the same relationship we used to have...

(CG-3)
From a son carer whose mother was at the terminal stage of dementia:

I was fortunate to get a job in the second month after landing [in Canada]. But the company closed down 3 months later. Mother had been my support in those dark days. She said, “life has its up-hills and down-hills. Never give up!”. But now this caring part of her was gone. She is mute, bed-ridden, hardly says a word. Only the picture reminds me of our mutual concern for each other. It’s important that I must live in the present... indulging in the past is useless.

(CG-C-5)

A daughter carer illustrated the reciprocal relationship she had with her mother prior to the onset of illness:

It still hurts when I remember those heart-warming moments of mutual support in the past. Mother gave me numerous concrete assistance around the house, she baby sat my 3 kids so that I could work full time. In return for her help, I brought her to Toronto. We were close to each other... But things have changed now. Her mind has gone, she is very dependent on me, ... I couldn’t depend on her at all now... I’m learning to accept her. Sometimes it works, sometimes I succeed, sometimes I fail.

(CG-C-3)

3. Managing Own Emotional Response To The Loss While Handling Reactions of Other Family Members

Family caregivers of persons with cognitive impairment experience a great deal of stress throughout their relatives’ illness, but the emotional reactions to the stress take on different forms (Schulz, 1990; Scott, Roberto, & Hutton, 1986). The most common reactions observed by previous studies are feelings of guilt, depression, embarrassment and powerlessness (Chu, 1991; Farran et al., 1991; Haley et al., 1987; Mace & Rabins, 1991; Ngan, & Cheng, 1992; Zarit, Reever & Bach-Peterson, 1980).
When I examined the transcripts of the interviews, it was evident that these reactions were present. However, what was equally obvious was that, the caregivers had to cope with the reactions of other family members. They experienced it as a “dual mission” in their caregiving career. Hence, the third paradox of the caregiving struggle is concerned with a double requirement - dealing with their own reactions while addressing the emotional needs of other family members. At times, these reactions were congruent, but frequently, they were incongruent and the primary family caregivers were consumed by these internal conflicts. As for my respondents, their emotional reactions were often exacerbated by the cultural shock of the family members or the caregivers themselves. Feelings of extreme remorse and guilt were expressed. The exact circumstances of each caregiver was different. Nevertheless, the common denominator - the feeling of guilt, was perceived to be linked closely with the immigration decision or process. A daughter whose mother landed in a remote small town with virtually no other Chinese population described her perceptions of her mother’s troubles:

I felt that the whole immigrant experience has made my mother neurotic. I felt living in a small town where there were no other Chinese women for a long time, being ripped away from her daughter like that, her helplessness, her poverty, all those things made her a neurotic woman. I don’t think it was one specific experience, it was the whole package... I felt her suspicion, her various accusations of theft were just part of it [neurosis]. I never made any connection between dementia and all those odd behaviours. I was mad at myself for ignoring it until the situation turned real bad...

(CG1-1)

A son caregiver put the blame on himself for persuading his mother to immigrate because he felt that the immigration experience triggered off the illness:

People from the neighborhood brought my mother home twice last winter. I said to myself at the beginning, “I must not allow her to go out on her
own. This is not Taipei...It's easy to get lost in a new city such as Toronto. By the way, she hasn't the language to get by. My wife said, "You should not take the risk of bringing her over [to Canada]. She might fare better in her native land. The adjustment process is particularly hard on older people..." Am I to be blamed? I couldn't reverse the decision now.

(CG1-5)

A grand-daughter felt that if her grandmother could be united with her family in Canada earlier, the chance of getting the disease would be reduced:

If grandma were to come earlier, her deterioration would not be that bad. Here [in Canada], we have more fresh air, more relatives to cheer her up. She had a hard life - raising four children single-handedly, spending long hours to earn a very meagre income. I should have insisted that she must come to Canada in 1992, not 3 years later.

(CG1-9)

From a son carer while showing me a photo of himself and his mother in front of the Great Wall of China:

... This was her last visit to her homeland. She wanted to visit her folks once more, but I rejected it because it was too far away. The air ticket was expensive... I didn't make much money here. Now, she is too frail and confused to travel. I feel sad, I can't forgive myself.

(CG1-6)

It would be easier for the caregiver to understand and to cope with similar reactions felt by other family members. However, prior family relations influence caregiving attitude and it is not uncommon that within the same family, members react quite differently. The struggle of these caregivers was best illustrated by the following three examples. In the first case, while a primary caregiver was patient with the odd behaviour of the older relative, her children were intolerant. In the second situation, a granddaughter could survive the sleep disturbance caused by the sick grandmother, but her sister was consumed by anger and
resentment. In the third case, while the primary caregiver had started to mourn quietly over the loss of the "good mother", her brother was still hiding behind a wall of denial.

From a daughter-in-law:

I was much more tolerant than others in the family. I knew it was his [father-in-law] illness. He can't help it. But my two teenage children felt very disgusted at seeing granddad fiddling with his dentures while having dinner at the restaurant. They felt embarrassed. We tried to stop them from showing their displeasure openly though I knew at heart they were right. It was hard for me to take sides.

(CGC-3)

From a granddaughter who is in conflict with the other granddaughter:

My sister's family stayed in our basement. She was angry with her [grandmother] ...losing, hiding and hoarding things, pacing the floor, ransacking drawers and closets. She was disturbed that grandma disrupted the family, kept everyone up at night, upset the boy and left her exhausted. My nephew was born with a birth defect and thus the parents were already very stressed. My sister screamed at grandma, blaming me for spoiling her. She said, "Isn't it enough that you visit her every weekend at the nursing home? Why take her home for an overnight stay?" ... I was attached to grandma but not my sister. Well, I think it's mean for her to be like this toward grandma.

(CGI-9)

A daughter caregiver expressed her utter frustration in dealing with her younger brother's denial:

Before I took Mom into my home, I knew nothing about dementia. The family doctor said that it was a disease with no known origin, no effective treatment, it would ultimately shorten her life span. ... But my brother kept on cheating himself, saying that her mood changes, being forgetful, so on and so forth did not mean anything. It was just her bad day. How can I make him understand? He was not involved in the day-to-day care. Of course, he could stay aloof and dismiss the changes easily. But I can't.

(CGI-2)
4. **Maintaining A Balance Between Meeting Needs of the Family Member While Fulfilling Own Life Tasks**

A further aspect of the caregiving struggle pertains to addressing the paradox of fulfilling competing task demands. On one hand, caregivers are profoundly committed to taking care of their family members. On the other, they are required to perform other roles in their lives and often, these demands are incompatible. Struggle of this kind is not a new concept in caregiver literature. A number of studies have suggested a significant correlation between the presence of competing demands and the experience of burden (Canton, 1979; Morycz, 1985; Noelker & Poulshock, 1982; Zarit, Orr, & Zarit, 1985). For example, based on a sample size of 41 caregivers, Rankin's (1990) study established that both spouse and daughter carers were extremely involved in providing care. They participated intensely in approximately five of the ten identified areas: personal care, supervision, meal preparation, dispensing medication and housekeeping (pp.64-65).

Similarly, in my present study of the Chinese families, it was shown that caregivers of all categories reported a high level of involvement. Six carers in the community sample shared their households with family members in order to provide the necessary daily assistance. Another six in the institutional sample had offered accommodation prior to the nursing home placement. In addition, close to forty percent of the caregivers have been involved for more than four years. While the average carer invested 14 hours a week in the caregiving role, 3 carers spent as much as 21 to 24 hours (refer to Tables in Chapter Eight).

When asked to identify the biggest difficulty in carrying out the caregiving role, respondents in my study mentioned the following: combative behaviour of the family members, mental stress and social restriction. However, among the employed caregivers,
competing task demands was on the top of the list. Several explanations were evident and they concurred with existing findings. Rankin (1990) attributed the hardship to the confluence of tasks outside the caregiving relationships, for instance, career aspirations, marriage or remarriage, child-rearing and extra-familial commitments. Similarly, Rosenthal (1997) argued that the role configuration combining “an adult child providing care to a disabled parent, a parent of a dependent child, and a paid worker, held the greatest structural potential for competing demands” (p. 19).

One theme to emerge from the analysis of competing demands in my qualitative data was ambivalence. And again, the feeling of ambivalence was further compounded by the unique situation of these immigrant caregivers:

I needed to find a job desperately at that time to support a family of four. My husband had been a technician in our homeland. But he didn’t possess any credentials recognizable by Canadian employers. But my mother was already quite confused. Part-time position in any garment factory was hard to get in those days. After a lengthy job hunt, I finally got a temporary job. However, half a month later, my mother fell and broke her leg. She has become incontinent since then... I really didn’t know what to do, to stay home to look after her or to continue to work.

(CGI-2)

From a son caregiver who retired the year before I interviewed him:

I am the eldest child in the family and relatives expected me to look after her [mother]. But I couldn’t make up my mind at the beginning. Finally I decided to take an early retirement. If it was not for my mother, I would have worked until 62. My wife was not too happy about my decision because in the first two years after coming over to Canada, I was unable to get a stable job as I couldn’t speak the language [English]. My wife worked long hours at her relative’s restaurant to earn a living while I stayed home to raise the kids from time to time.

(CGI-6)
From a daughter-in-law who has combined the roles of a primary caregiver, a mother of two teenagers, a wife of a busy professional and an employed professional herself gave the following accounts:

Normally by five o'clock I am free to go, but because of the traffic congestion in the highways, I might not be able to get home early enough to get the food ready by 6:30 p.m., the time when my parents-in-law used to have their dinner. When I brought the food to them after that hour, they announced their dinner was over. My mother-in-law would keep the food in the refrigerator for the next day. ... of course, they wouldn't throw it away, but I felt very stupid and cheated for dashing to their house immediately after work to bring them food. Isn't it a waste of effort?

I became dead tired after taking him [father-in-law] out for walks. Remember, I did it after a long day of work. What's more, I had to finish other household chores: the dirty plates were sitting on the counter, and loads of clothing were in the laundry room. I could only take up my school work late in the evening in order to upgrade my professional qualifications...

(CGC-3)

From another daughter-in-law who was caught between attending to her father-in-law's needs and her own health needs:

My mother-in-law was the primary caregiver but she was far too weak to look after him during her own terminal stage [of cancer]. Hence, I took over the entire responsibility from her since last year. I helped him with weekly shopping, laundry, heavy household cleaning, medical appointments and even occasional personal care.

I hurt my spine when I tried to transfer him from the wheelchair to the bed. The pain was so severe that I must lie down on the hard wood floor to sleep at night. The doctor did not recommend surgery to fix it because the injury was so close to the spiral cord and it could be a dangerous operation. However, despite the worry over my poor health, I continued to look after him...

(CGI-7)
Another daughter-in-law described her tension:

Our family had not been away at all for vacation in the last few years. Last Easter, I felt I must get away, just to relax. We took our van and travelled to the northern part of the province to visit my uncle. But upon arriving, we got a phone call from my sister-in-law, saying he [father-in-law] had got lost again. Though she had already notified the police, she still wanted us to return home... She was a night shift nurse and must leave home before 7:00 p.m. We left my uncle's house immediately without even opening our bags.

(CG-3)

5. Acknowledging The Distress Associated With Caregiving While Appreciating Its Positive Aspects

In the last two decades, the primary thrust of caregiving research has centred on the negative and detrimental aspects of the caregiving process (Cantor, 1983; Chenoweth & Spencer, 1986; Haley et al., 1987, 1996; Matthews, 1988; Montgomery, Gonyea, & Hooyman, 1985; Oxlad, 1996; Pearlin, Mullan, Semple & Skaff, 1990; Semple, 1992; Zarit, Todd & Zarit, 1986). This trend can be explained by a dominant theme underpinning most studies. Kramer (1997) suggested that “investigations in stress and burden have been driven by the desire to understand variations in caregiver adaptation so that interventions and policies may be designed to enhance well-being” (p.218). While this line of inquiry has enhanced understanding of the challenges facing family caregivers and has led to a proliferation of intervention studies designed to reduce caregiver stress, the striking omission of positive aspects of family care has been denounced with increasing concern (Cohen, Gold, Shulman, Wortley, McDonald, & Wargon, 1993; Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991). Hence, in recent years, there have been numerous calls to take a more holistic view of caregiving by considering its positive aspects. Why is
it important to study positive aspects of caregiving? Do we have emerging theoretical constructs to describe the positive components of care provision? Can we find a distinctive contribution offered by qualitative data in capturing the positive meaning of providing care?

The following discussion focuses on the last theme of the caregiving paradox by examining the tension between acknowledging the distress while appreciating benefits in care provision.

A number of researchers have confirmed the value of understanding more about the gains and benefits accrued to caregivers in meeting the needs of their disabled family members (Kramer, 1993a, 1993b; Lawton, Moss, Klebau, Glickman & Rovine, 1991).

First, it is an aspect of care provision that is reported by many caregivers and one that caregivers wish to talk about. Second, understanding positive aspects of caregiving may help practitioners to work more effectively with the family caregiver if predictors of positive outcomes can be identified. This would be achieved by more appropriate validation of positive feelings and experiences. Third, there has been a significant association between positive aspects of caregiving and the quality of care provided to older adults. Key terms used in previous literature to identify gains include variations of the following: benefits (Talkington-Boyer & Snyder, 1994); rewards (Kramer, 1993a); satisfaction (Kramer, 1993b); gratification (Motenko, 1989); and uplifting experiences (Pruchno, Michaels & Potashnik, 1970).

In looking through the transcripts of the interviews in my study, I have identified numerous incidents where caregivers spoke about their gratification, and not just loss and frustrations. In an attempt to explore the positive dimensions of caregiving in my study, I raised several questions: How would you describe your life right now? Have roles changed?
Have relationships changed? Do you think the family has changed? How? In what ways?
What's the difficult part in looking after your relative? Did you have any positive experience at all? In what sense? How has that changed over time? What keeps you going?

Positive feelings and experiences of caregiving mentioned by my respondents include: enhanced relationships with the care receiver, satisfaction in seeing that one's efforts are helping, satisfying relationships with other family members, feelings of pleasure in preventing accelerated deterioration in the care receiver, and expressions of appreciation from the care receiver.

While commenting on the relational aspects of gratification, a son said:

Probably I am the only person whom Mom can recognize now. During those visits [to the nursing home], she smiled when I held her hands. That smile told me that our mutual bonding was still there although her mind was gone. That was a source of comfort to me.

(CG1-5)

Another son carer offered this answer:

Why do I continue to take care of my mother? It's hard to name a specific reason. But relationships are important in my family and I am pleased that I can still maintain them by taking her into our home.

(CG1-6)

A granddaughter caregiver appraised the caregiving gain as related to the caregiving aspect:

I am quite sure that she [grandmother] has received good loving care from us in the past. I was happy to know she was contented. Indeed, I have done my best and it made me feel at ease with myself.

(CG1-9)
From a daughter-in-law:

Last Spring, my father-in-law was still capable of responding to our care. He nodded his head to show his appreciation after we gave him a bath and shaved him. I felt good learning that he was appreciative of our efforts.

(CG-7)

A daughter carer further illustrated the gains perceived by her family:

His illness pulled the family together. Everyone contributed, not just in the financial sense, but more importantly, in terms of time, attention and commitment. Honestly, this rarely happened in our family in the past... because we were children from different mothers. My father had three wives...

(CG-3)

A daughter spoke of her satisfaction in perceiving the slowing down of her mother’s memory loss:

I’ll do whatever I can to help her to retain her memory. The only person she can now recognize in the photo is my eldest brother. So I spend some time each week to go through the photo albums with her... Those are the moments of warmth to me...

(CG-1)

Previous researchers on caregiving burden have identified some common predictors of stress, including severity of impairment and functional loss (Noelker & Poushock, 1982; Montgomery, Gonyea, & Hooyman, 1985; Stoller, 1983); caregiving duration and involvement (Morycz, 1985; Skaff & Pearlin, 1992); appraisal variables (Lazarus & Folkman, 1984; Poushock & Deimling, 1984; Zarit & Zarit, 1982); social support resources (Cicirelli, 1983; Scott et al, 1986); quality of prior relationships; and coping style of the caregivers (Johnson & Catalano, 1983; Pratt et al, 1985). More recently, increasing interest has been given to identify predictors of satisfaction. For example, based on a study
of 72 wife carers involved in providing care to their Alzheimer’s husbands, Kramer (1993a, 1993b) found that caregiving satisfaction was correlated with such variables as activities of daily living capacity, quality of the prior relationship, satisfaction with social involvement and problem-focused coping. But Motenko’s analysis (1989) on wife caregivers identified a different set of variables. First, wives who perceived the same degree of marital closeness after the onset of the illness had greater gratification than those who did not. Second, caregivers who continued to receive companionship, affection and continuity from the marriages derived greater gratification from caregiving than those who experienced discontinuity in social supports. Third, those who provided care to reciprocate past attention and to nurture (providing tender loving care) their husbands were more gratified than wives who gave care out of a sense of obligation.

The qualitative data in my study tended to support Monteko’s last conclusion, though the focus of my review was more on intergenerational caregivers. The respondents in my study consisted of six sons, six daughters, two daughters-in-law, two granddaughters, one sister-in-law and one spouse. The desire to reciprocate for past attention was expressed by several relatives in five different families.

A son found comfort in taking care of his mother:

That’s how she took care of me when I fell sick as a child. Because I had asthma all along, sometimes she sat up for the whole night to attend to me... My father died when Mom was five months pregnant. She needs me now... I feel better that I can return partly her affection.

(CGI-5)
A daughter whose mother has made a big sacrifice in raising five kids described her gratification:

My mother had no time for herself, no time at all to participate in any social activity during those hard years. Her sole concern was to earn more money in Canada so that she could send home [Hong Kong] more. If she was to have 8 days a week, she would work 8 days... It would be naive to believe taking care of her was easy, but I wouldn’t change it for anything... I want to do it for her, in return for her sacrifice.

(CG-2)

The following daughter carer gave care out of a sense of obligation and her gratification was low:

She is my mother. I mean, there is a responsibility there... I am close to my mother only in the viscous sense. I am not close to my mother because of the person that [who] she is... I have to look after her just because she is my mother. Anything positive about my caregiving role? Hardly any, but I guess I have no option.

(CG-1)

From a daughter-in-law whose involvement was motivated by a sense of duty to her husband. She came out of the experience with bitterness:

... I felt bitter about taking care of a suspicious and paranoid father-in-law. Yet, I did this for my husband. He felt it was his duty and as a wife, I ought to support him...

(CG-7)

The last predictor of positive caregiving outcome relates to the construct of “finding meaning” through the caregiving experience. Utilizing an existentialist perspective, Farran and her colleagues (1991) found that positive aspects of caregiving were not correlated with any of the quantitative measures. Instead, they suggested that through caregiving, carers assumed responsibility for making personal choices about life and caregiving and they also
found provisional and ultimate meaning. Making personal choices in Farran’s (1991) study refers to “developing a positive attitude toward caregiving and appreciating positive aspects of life” (p.487). It also implies “drawing upon their own sense of personal fortitude and to consciously choose to take one day at a time” (p.487). Searching for provisional meaning was established when carers reported feeling that they were growing and that something good would come out of it. Searching for ultimate meaning on the other hand, implies a sense of reassurance provided by their philosophical and spiritual beliefs.

In reviewing the experience of the caregivers in my study, I found no direct reference to the theme of finding ultimate meaning. However, positive components pertaining to finding provisional meaning were evident. Some family carers openly acknowledged that they were stronger persons or better caregivers as a result of the experience. One caregiver saw herself as role model for the younger generations. The following illustrate their perceptions:

... I’m a better caregiver now. I feel stronger. In the past, I didn’t have the requisite skills to take care of my mother. I was my own supervisor. Nobody taught me how to do it.

(CG1-2)

I’m glad that I didn’t let myself down. I have tried to live up to my own expectations. My mother’s condition has brought out the caring part in me...

(CG1-3)

Nobody can ever force me into taking up the role, I decided to stay with her [mother]... I don’t regret.

(CG1-5)

I take care of my mother to set an example for my children, so that the younger generation will look after me when I am old and frail. It’s important that they follow my example...

(CG1-1)
Summary

Three major salient features of the caregiving struggle were explored in this chapter. For many Chinese family carers, the struggle was an endless war, a lonely journey and a battle on many fronts. Their experience echoed what had been previously reported in the caregiver literature. However, much of their experience was unique because of their immigrant status and the contextual environment in which caregiving activities took place.

The second part of the chapter focused on the various facets of the caregiving paradox. Caregivers were constantly confronted with a dual mission - to concentrate on the present and yet not to forget the past; to enjoy the current relationship with the relative in spite of the cognitive impairment and yet to cherish the old intimacy; to cope with one’s sense of loss and yet to handle the emotional reactions of other significant others in the family; to meet the needs of the sick relative and yet to fulfil their own life tasks; and lastly, to acknowledge the stress impacts and to appreciate the gains of providing care.

These exploratory findings suggest several researchable hypotheses related to family care in families with cognitive impairment. In relation to the various aspects of the caregiving struggle, it is important to examine how informal and formal support systems may help to overcome difficulties. The study findings also suggest the need for research on interventions, particularly, whether selected interventions based on a culturally sensitive model are more successful than those that group together families with diverse cultural and immigration backgrounds.
CHAPTER SEVEN
FINDINGS AND DISCUSSION: PART THREE
SHARING OF CAREGIVING RESPONSIBILITIES IN FAMILIES:
FACILITATORS AND BARRIERS

Introduction

In the last chapter, I examined the "struggle" faced by the Chinese family carers and discussed the various aspects of the "caregiving paradox". However, when I reviewed the research data more closely, it became obvious that some families fare better than others in the midst of the caregiving struggle. The purpose of this chapter is to identify these distinguishing features and explore how these impact on the family's caregiving experience.

Family Identity

The first concept identified in this study is family identity. Sluzki (1979) suggested that for migrant families, the process of migration could be broken down into five distinctive phases: (1) preparatory phase; (2) act of migration; (3) period of overcompensation; (4) period of decompensation, and (5) transgenerational phenomena. The phase of decompensation is of particular relevance here because most of the families in my study were at this phase of adjustment. The family entering the decompensation phase has already survived the most difficult period of "uprooting" from their own culture. Its major tasks at hand at this phase are: first, to reshape its new reality in the country of adoption; second, to maintain the continuity of its identity; and last, to maximize its
compatibility with the environment (p. 384). The maintenance of the family identity is crucial to a family’s satisfactory functioning. In a specific sense, family identity in my study refers to the gestalt of qualities and attributes that differentiate it from other families. Family identity is comprised of “shared systems of beliefs which embody the implicit assumptions about roles, relationships and values that govern interaction in families and other groups” (Bennett, Wolin and Mcavity, 1988, p. 212). Bennett and associates further contended that family identity represented a strong force mitigating change and encouraging cultural continuity. In the face of uprooting life events such as immigration, family identity can enhance stability by tying the family to old routines and traditions. In trying situations where family members have little control over its external world, family identity can serve as a port in the storm of uncertainty in the external world. Bennett and associates (1988) argued that family identity was largely unarticulated and this is also true in my study. However, a close examination of the research data brought to the surface the various facets of family identity. These shared systems of family beliefs include: family themes, family rules, family myths and family constructs (Bennett, Wolin & MCavity, 1988).

**Family Theme**

In an immigrant family, a family theme can be found in its notion of “who we are” in the host country. And in confronting the crisis of a dementing disease, a family theme predisposes the family to decide “what we do about it”. It may have both adaptive and dysfunctional features, affecting behaviour in a variety of areas and activities (Handel, 1967). A family theme helps a family to organize its view of reality by regulating its
interaction with the external world and by influencing interpersonal involvement within the family. The Ho family demonstrates the family theme construct.

Family History 1: The Ho Family (refer to Genogram I)

Grace, aged 48 has been caring for her 82 year old mother, Madam Ho for the last five years. The diagnosis of Alzheimer’s Disease came eight months ago after Madam Ho was found wandering twice in the neighbourhood. Grace’s father, a successful entrepreneur, died in his late 40s and left behind him the widow and six children. Dave and Henry, the older two sons, immigrated to Texas and Washington DC respectively to start their own businesses and families while Bill, the third child left for Seattle in 1986. Grace later decided to settle down in Toronto while Albert moved to Winnipeg. Mike, the youngest brother, remained in Hong Kong.

Grace was very proud of the close relationships that members of her family of origin shared despite the wide dispersion of residences across oceans, states and provinces. She said that her oldest brother had been like a father to her because when her father died, she was still very young. Her father’s death was very sudden. Madam Ho was a traditional Chinese woman who had little formal education. Bringing up her six children was her entire life mission.

Though the physical distance between her siblings’ families was great, Grace felt a distinct family identity was kept. This had been a strong force binding the family together and made sharing of caregiving duties for Madam Ho feasible. Grace remembered vividly in particular how her family celebrated Lunar New Year in her childhood days and how this had been continued in the post immigration era.

The following is a digest of Grace’s description:

We always had new clothing and new shoes for the Chinese New Year. Mother used to cook special dishes for the occasion: roast pork, fried shrimps and steamed fish (footnote 1). After lunch, we paid visits to our paternal uncle and had a great time with the cousins... Relatives gave us red packets of “lucky money”. Mother usually gave each of us $5 to spend and she would save up the rest for buying new text books when the new school term began after the New Year...
As Chinese New Year (footnote 2) was not a holiday in the States or Canada, we couldn't continue the ritual celebration. But mother kept the custom of sending us and our children red packets of lucky money. We, in return, would send a family photo and a New Year greeting card to her, wishing her good health and longevity. This exchange of “gifts” had been upheld until this very day. The only difference was that I sent the red packets to my siblings instead of having Mom do it. She has been going downhill since last Christmas. My children helped her to put the family photos in the album ...

(CGC-3)

Family Rules

Family rules, the second component of family identity, are “binding directives” formulated by members, either individually or collectively, to provide clear guidance for behaviour. Ford and Herrick (1974) comment that while ‘smaller’ family rules help to regulate behaviour, ‘larger’ rules express a family’s goal or orientation. An analysis of the family rules in a caregiving family may help us understand better how membership is redefined - who is in and who is out, both now and in the past. In addition, family rules explain the intensity of life in the family - the degree of detachment versus intimacy and the breadth of family experience in terms of geographic dispersion and social interaction. When I discuss the differential patterns of formal support utilization in Chapter Eight, I shall demonstrate the importance of family rules in these Chinese families.

The tradition which had helped the Ho family to maintain unity was the annual remembrance of her father’s death. Grace continued:

My mother set up a family shrine in her household. On this special day, everybody must come home before 6:00 pm. (footnote 3). Incense was burnt. Children took turns, in descending birth order, to bow our heads in
front of father’s shrine. Mother would quietly say “a prayer” to father, telling him the outstanding performance that each of us might make in that year. For example, Dave got a promotion in his job while Albert got married... Mother would also take this special occasion to remind us that as a family, we must be united and help each other in dealing with the hostile external environment... Afterwards, we ate dinner together and only vegetarian food was served (footnote 4).

(CGC-3)

To the family, remembering father’s death was no longer a time of sadness, but rather an opportunity to revive a long cherished family theme: that of uniting together against adversity. After Grace and her siblings left Hong Kong and settled in foreign countries, the family tradition could not be held in its original manner. Yet, Madam Ho found a creative substitution to maintain this family rule. She would call all the children by long distance the week before the remembrance day, asking them to prepare their own “scripts of achievement”. She would then put these scripts together and said her usual “prayer” to her deceased husband on the day of the anniversary. Since 1993, Henry suggested to his siblings that the family could combine the remembrance of this important day with the annual family reunion. The Ho family used to have a family reunion once a year in the summer, either in the States or in Canada. As their father died on the third week of August, it was not difficult for the adult children to combine the two meaningful traditions. In this way, the usual “scripts” were made; the “prayer” was said; and the vegetarian family meal was served. And when they were all there for the meal, Grace’s siblings took turns to talk about the big events that had happened in each individual family.
Madam Ho
care recipient
moved to Toronto
in 1992

d. in 1957
d.

immigrated
to Texas,
1976

son
60
Dave

Henry
immigrated
to Washington,
DC, 1979

son
57

Bill
immigrated
to Seattle,
1986

son
50

Don

daughter
48
Grace
primary caregiver
moved to Toronto
in 1987

Albert
immigrated
to Winnipeg,
1980s

son
42

Mike

resided in
Hong Kong

22
college

15
high school

13
high school

Genogram 1: The Ho Family
Family Myths

Family myth, a third form of family identity, constitutes a well organized system of beliefs which supports pathology (Ferreira, 1966). Whereas ritual transmits family identity via behavior, myth conveys it in narrative form. In creating its myths, the family draws upon its factual history and its folklore. The myths that emerge are a blend of fact and fantasy, incorporating crucial events, important people and major themes in the family’s history. Bennett and colleagues (1988) explain that family myths and rituals were mutually reinforcing and their function was essentially the same: to inform or remind all family members who they were, what they were to believe, and how they were to behave, and to promote the continuity of family identity from one generation to another. In my data, an example of a family myth found in these Chinese families was the social stigma attached to seeking help from mental health practitioners. Family members might welcome referrals of their relatives to neurologists or geriatricians, but they displayed resistance towards securing help from psychiatrists because psychiatrists were conventionally perceived as doctors for “mad” patients.

Family Constructs

The last form of the shared belief system is the “family construct”. Reiss (1971), through a series of experimental studies, has demonstrated that each family “created its own paradigm, a system of shared assumptions to make sense of the world and to coordinate the actions of the members” (p. 131). Grace recalled how decisions on sharing caregiving responsibilities were made in her family. The decision making process was not spectacular.
Despite the geographic dispersion, members of the family felt they were emotionally well connected. Apportioning of caregiving responsibilities was decided rather informally as Grace revealed:

We didn’t have formal “family meetings” as such to discuss the caregiving issues. There was a tacit understanding among us. We gave according to our abilities and we accepted individual constraint. In a sense, every one chipped in to pay for a privately hired home helper for Mom. That would not be possible without their financial contribution because it was expensive to get a good person here... I didn’t just get anybody referred by the agency, I insisted that the helper must be a reliable person and she must be acceptable to Mom. Since Mom stayed with my family, my siblings sent me money on a quarterly basis... They also called me once in a while to check on her condition. When I felt exhausted and stressed out, I would also talk to them [long distance call] and they always listened. Before the rapid decline, Mom was still able to recognize Dave’s voice. She responded better to his advice. For example, she rejected our idea of enrolling her in the day care program initially, but after Dave talked to her, she agreed to go...

Grace elaborated further when I explored her care motives toward her mother:

It was just very natural in our family to help each other... This was part of our father’s teaching and surely, mother’s belief. We had a strong sense of belonging... We saw each other almost like every year in the summer. I didn’t feel that they [the other siblings] abandoned me to take up this caring business on my own. No, not at all, ... I was closer to Mom, but my sisters-in-law didn’t know mother well enough to really understand her. Remember, my older brothers left home young to settle in the States. Their wives and mother had never shared a common history... But my sisters-in-law respected mother and the grandchildren were fond of their grandma too... Yes, the children didn’t understand grandma’s Chinese, but they had their own way of talking to each other. We [parents] wouldn’t intervene until we were invited to serve as interpreters.
The Lam Family demonstrates a “negative case” wherein the family never had the opportunity to develop a family identity as described by Bennett and colleagues (1988).

**Family History 2: The Lam Family** (refer to Genogram 2)

June, aged 47, was a language and art teacher in a local high school. Her husband was a Caucasian. Her two teenage children did not understand Chinese at all. She had been the primary caregiver of her mother Madam Eng prior to her admission into a nursing home two years ago. June was the only child from her mother’s first marriage to Mr. Lam whose first wife died and left behind four sons, Lai, Zi, Ling and Wai in China Mainland. Mr. Lam was the first one to arrive at Canada alone to start a laundry business in a remote small town. June and her mother immigrated to Ontario later under the sponsorship of the family unification scheme. They were later joined by Ling and Wai, her half brothers from China Mainland. When Mr. Lam also died, Madam Eng got married to Mr. Yip and Helen was born to the couple.

Unlike the Ho family, the Lam family never had a chance to build up or nurture a family identity. The Lam family had gone through a lot of disruption and separation during the Communist Regime. The family was further plagued by the miserable immigration process. Mr. Lam’s four sons in Mainland China never saw their father after he left home for Canada. Mr. Lam’s original plan was to work for several years in Canada and then pack up to go home with some savings to start his business in China. But his plan was never realized. And although Madam Eng became the surrogate mother to the four sons born to her husband’s first marriage at the death of their natural mother, she was never truly accepted by her parents-in-law because she came from a poor peasant family. June could hardly recall any significant festival celebration except the following:

I had a faint memory of Chinese New Year. That my mother always prepared a special meal. It was the chicken dish, or something like that...No other rituals apart from the meal and we didn’t feel excited by the occasion. But what I remember most was that we had the same dish day after day. We would eat it for lunch, and then the next day, the next day and the next day... When I looked back on it as an adult, I thought that was a sign of mother’s depression...

(CGJ-1)
Genogram 2: The Lam Family

came to Canada under Family Reunification Program care recipient Madam Eng

during Japanese occupation had owned a laundry shop 1st family member to arrive at Canada

Son Lai 65 still resided in China

Son Zi 63 still resided in China

Son Ling 56 moved to Canada in 1951

Son Wai 54 moved to Ontario in 1950 owned a restaurant

Suzanne 15 teenager

Scott 11 teenager

Jim Caucasian supported June in looking after Madam Eng worked in computer firm

Daughter Helen 53 a professor

Harold 56

Mr. Yip d. 1960s

Mr. Lam d. 1970 m 1910 1st wife m 1946
d. during Japanese occupation

Son B. Lai still resided in China

Son E. Zi still resided in China

Son H. Ling moved to Canada in 1951

Son J. Wai moved to Ontario in 1950

Owen a restaurant

June 47 primary caregiver art teacher

63

49

47

161
As to birthday tradition, June told her family story as follows:

absolutely nothing of that order... My father worked seven days a week and honestly, I didn’t know when his birthday was. We were the only Chinese family in that area. No newspapers nor radio programs in our native language were available. My mother only spoke the Toishan dialect and she struggled hard with the few English phrases which she could possibly manage...

(CG1-1)

Compared with her mother, June’s assimilation into the Canadian culture was relatively easy. She summarized her experience as an immigrant in the following way:

I fitted in well. I went to the public school. I learnt to speak English. I played with other kids... I did all the things that small town kids did. I played hide and seek. I joined the Brownies... I rode my bicycle.

(CG1-1)

When June was asked of her primary motive in providing care, she shared with me quite honestly and openly that her commitment was prompted by a sense of duty and the lack of an alternate carer:

Why me? There wasn’t anyone else. I don’t know. First of all, my two brothers were not her natural children. So, it was natural that they remained distant. Helen, my half sister had a difficult relationship with mother. Mother left her to the care of a child minder and she did not join us until much later. Looking at the bare bone facts, logically, she should be the one taking care of my mother since she was not working... She lived in a very large comfortable house...her husband was in a secure position, she could drive and was mobile... But I think, if she took up the responsibility, emotionally it would be a bad decision... And so, there was no one else except me. And she was my mother. I mean, there was a responsibility there... I approached the task [caregiving] fairly rationally in a cut and dried way.

(CG1-1)
Family Conflicts

As can be shown in the following, family constructs explain the differential strategies these families have adopted in resolving conflicts precipitated by the cognitive impairment of their relatives.

Crises like Alzheimer's Disease and related disorders have the capacity to stimulate family conflicts (Aneshensel, Pearlin, Mullin, Zarit & Whitlatch, 1995; Mullan, 1993; Sample, 1992). Gruetzner (1992) has identified three common types of family conflicts and whether these can be resolved satisfactorily depend on a variety of factors. Continuing conflicts are those that have been present between the care receiver and other family members, for instance, an adult child or a spouse. When cognitive impairment develops, the adult child or the spouse who is expected to provide care may decline to become involved. This situation is evident in several of the Chinese families in this present study.

Continuing Conflicts.

Continuing conflicts involving a history of abuse can predict risks in dementia caregiving when the abused child is faced with caring for the abusive parent. Under those circumstances, norms pertaining to reciprocity between parent and child have been violated. To the abused child, the normal dependency needs had not been adequately met in the past and he/she felt no moral obligation towards providing care.
Family History 3: The Mak Family (refer to Genogram 3)

The following family histories gave me a glimpse into those complex family conflicts:

Carol was referred to me by the nursing home social worker as she was the primary caregiver of her grandmother Madam Chow (age 87). Madam Chow was the first wife of Mr. Siu, a very wealthy Chinese scholar. However, Mr. Siu took into his household two young concubines (footnote 5) in subsequent years. Madam Chow gave birth to a daughter two years later and who later married Mr. Mak and became Mrs. Mak, mother of Carol. Madam Chow wrongly put the anger and blame on her daughter Mrs. Mak, because she believed that if a son instead of a daughter had been delivered, she might be able to restore her husband’s lost favour. This explained why Mrs. Mak suffered from swearing and beatings in her childhood days. In order to escape from her abusive mother, Mrs. Mak married at a young age but her marriage turned out to be disappointing. Nevertheless, she gave birth to five children, Aaron, Terry, Winnie, Andy and Holly. When Mr. Mak, her first husband died, she married Mr. Wan, the natural father of Carol. From this marriage, she had two children, Carol and John.

At the persistent request of Mrs. Mak, Winnie, the half sister of Carol sponsored Mrs. Mak to come over to Canada. Mrs. Mak was accompanied by Carol and John. John settled down in Vancouver afterwards as he had more friends there. Madam Chow, the grandmother also came later as the last dependent family member. Though Winnie was the sponsor of Mrs. Mak, she made it very clear that neither she or any sibling from the Mak family would provide her with any assistance because none of the children had a real relationship with her. Thus Mrs. Mak, Carol and Madam Chow lived separately from the Maks upon their arrival in Toronto. Madam Chow was diagnosed to have been suffering from Alzheimer’s Disease since 1993. Three months after the diagnosis of Alzheimer’s in Madam Chow, Mrs. Mak suffered a minor stroke. Without having come to any concrete care plan agreeable to all the involved parties, Mrs. Mak bought a plane ticket and flew to Vancouver to stay with John. Carol, in explaining to me the dysfunctional family interactions, related to me bitterly her reactions towards the caregiving responsibility:

That’s why I got “dragged into the troubled water”. ... My husband was very upset about my mother’s irresponsible attitude, in particular that now I am four months pregnant with our second baby. I could well understand
why my mother didn’t want the responsibility because grandmother had never been a good mother to her... But it’s extremely unfair to me, what obligations do I have towards grandmother?

(CG1-8)

Genogram 3: The Mak Family

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Family History 4: The Yeung Family (refer to Genogram 4)

Continuing family conflicts not only exist between parent and children, they can also be found between married couples as well. The following vignette shows how rifts worsen the caregiving task in the Yeung family.

Mr. Yeung, the care receiver, was diagnosed with senile dementia of the Alzheimer’s type. He lived with his wife, Mrs. Yeung, aged 79 and his daughter, Florence who was a nurse. Alice, the daughter-in-law, participated in my research as the secondary caregiver. She attributed part of the caregiving strain to the continuous conflict between her parents-in-law:

I didn’t quite understand the full picture [in the Yeung family], because as a daughter-in-law, I had been an “outsider” to my husband’s family of origin. My mother-in-law was rather hostile to my father-in-law. Though she knew it was the disease which robbed him of his memory and common sense, she teased him harshly, saying that he was thoroughly useless (emphasis)... She told all her friends in his presence that he lost his way twice within a month and was brought home by the police...

When we discovered that he was not taking proper meals, we brought the concern to my mother-in-law. Her response was, “since he was so stupid and failed to remember whether he has taken food at all, why should we be bothered?”. In addition, she dominated over him all the time. She scolded him and insulted him. Therefore, in her presence, he became very withdrawn. For instance, when we were looking at the family photos the other day, my mother-in-law challenged him cruelly, demanding him to identify each person by name in the picture. When he failed to do so, she said nastily, “see, what a stupid man! You can’t even recognize your own son”...

At the assessment clinic, when the doctor asked my father-in-law a question or requested him to do a task, my mother-in-law would either answer it for him or told the doctor impatiently that it was no use testing, because he had lost all abilities...

(CGC-7)
When I asked Alice if she knew the root cause of the continuing conflict between her parents-in-law, she responded:

I didn’t have the hard facts, but it seemed that my mother-in-law felt disappointed with her husband. He had been working in a Chinese herbalist shop for over 40 years. Life was hard in those days. The family had to feed five children... In addition, their personalities were incompatible. The onset of the disease just added fuel to the fire.
**Reactivated Family Conflicts.**

Another type of family conflict that emerges from my study are reactivated conflicts. Gruetzner (1992) argued that reactivated conflicts were old conflicts that might have been buried or avoided so successfully that they were forgotten. Reactivated conflicts in the family tend to focus on “issues of independence and dependence, acceptance and rejection, and sibling rivalries that had become more obscure” (p.122). In the following family situation, old conflicts were revived and they severely interfered with the effective sharing of caregiving responsibilities between two sisters.

**Family History 5: The Lam Family (refer to Genogram 2)**

June (aged 47) took care of her 83-year-old mother Madam Eng out of a sense of obligation. She expected Helen (age 53), her half sister to share the caregiving responsibility with her because Helen also lived in Toronto and she was not working. However, the level of acceptance between the sisters had been low and in June’s opinion, Helen was jealous of her achievement. June had a university education and was a teacher in a local high school. Her husband Jim was a Caucasian, and an engineer. She had two children, Suzanne and Scott. June came to Toronto with Madam Eng while Helen was left to the care of a child minder until she was five. Helen’s son died of cancer at a young age. Though her husband was a professor in a university and the couple owned a comfortable home, Helen seldom found fulfilment in life. As June and Helen reached mid life, the relationship became less tense because June wanted to put aside the damaging family legacy. Thus for a few years, the two sisters got along much better. They visited each other and shared a common hobby of knitting. Nevertheless, the onset of dementia in Madam Eng brought to the surface old wounds and June told of her fight with Helen:

One summer, Jim was having a number of relatives arriving from England. It was a very, very stressful time. I wanted Helen to take Mom home for six weeks so that Jim’s relatives could stay at our home while they were in Toronto. I knew Mom had difficulty in getting along with my sister. When I went to see Dr. Tang, I explained to him the situation saying that my mother should have a sedative or something of that sort to
calm her down, in case she acted up in Helen’s place... It became very ugly (emphasis). Helen accused me of poisoning Mom. “That’s why she had dementia,” she insisted. Eventually, my mother stayed with Helen for about three weeks and she phoned me one afternoon asking me to pick up mother before dinner time. Our guests were still with us. I begged her on the phone to give me two more weeks but she was determined... I took Mom home. After that, I decided not to contact her any more. Since mother was in the nursing home, Helen paid her visits once in a month. But we never met... I tried to avoid her.

Reactivated conflict was also evident between June and Wai, her 54 year-old half brother and this made care planning within the family difficult. When June tried to sort out the financial part of the caregiving commitment prior to her mother’s admission to the nursing home, old resentment was revived. Old hurt feelings came to the surface. A lack of trust further marred the already weak relationship between June and Wai. June gave her story as follows:

I was concerned that at some point mother might need a fund for hiring private nursing care in the nursing home. So I thought it was important that her money be pulled together into one account so that she could draw from it... And I also went to a lawyer and had her give me power of attorney so that I could combine all her bank accounts into one. I also had her draw up a will. And in that will, I had her give a fair share to her four children who were here in Canada. Wai, with whom mother had lived in the small town, was used to running a restaurant. He was very upset when he found out what I had done, because he felt he should have the lions share because mother had lived with him longest. But what he had failed to remember was that, my mother had been working for him: peeling onions, washing dishes, filling salt and pepper shakers, mopping the floor, all sorts of dirty work that no paid worker would do long... Sometimes he paid her, sometimes he didn’t. She worked up to 14 hours a day and it was not much different from slave labour (emphasis).
New Family Conflicts

Not all families experience continuing or reactivated conflicts when they are confronted with the challenge of dementia care. However, new conflicts may develop in families confronted by cognitive impairment and reflect issues that have never required attention before. These new crises include decisions concerning the distribution of family resources and responsibilities, negotiation of new relationships, living arrangement, the type
of professional help that might be needed and nursing home placement (Chenoweth & Spencer, 1986; Finch & Mason, 1993; Gubrium, 1988; Horowitz, 1985a; and Matthews & Rosner, 1988). Conflicting views can be intense and divergent. As revealed by the respondents participating in my research, these families possess differential capabilities in resolving new conflicts associated with dementia care. While some families came out of the experience with more confidence and renewed hope, some were badly shattered. The following two families were at the opposite ends of the spectrum and they demonstrated different caregiving outcomes.

**Family History 6: The Poon Family** (refer to Genogram 5)

Mr. Poon, aged 80, has been living in the nursing home for a year when I interviewed Wai Ying, the daughter-in-law who became the primary carer of Mr. Poon upon the death of her mother-in-law. Mr. Poon had multiple health problems: senile dementia, partial hearing loss and Parkinson disease. Edwin, Wai Ying's husband was the only child in the Poon family.

Mr. Poon studied economics in an overseas university. He aspired to become a national scholar. But in the heat of the political unrest in Mainland China in 1948 (footnote 6), Mr. Poon fled the Communist rule, only to arrive at Hong Kong with very little money. While in Hong Kong, Mr. Poon had been living a humble life because his past working experience was not fully recognized by the local employer. His life was full of frustrations and insecurity. He and his wife immigrated to Toronto a few years ago under the sponsorship of Edwin who completed his university education in Canada.

The older couple lived separately until obvious signs of cognitive impairment were shown in Mr. Poon. In his last year, he became very confused and was in need of constant supervision for his dangerous behavior, verbal aggression, mild physical violence and a hallucinations. When Edwin and Wai Ying could not cope with the caregiving burden any longer, they decided to look for a nursing home placement. But this decision opened up acute conflict and led to turmoil in the already fragile
family. Wai Ying sadly reflected:

My father-in-law felt we were abandoning him... To be placed in an institution was a total loss of face to him. He saw himself as “a prisoner behind bars” and his freedom was taken away. Because he had a habit of wandering away, he was placed in the special care unit for Alzheimer’s disease patients in the nursing home... A censor alarm system was installed on that wing to help prevent patients from wandering away... He became very bitter. He even threatened Edwin that he would make a public announcement in the leading Chinese newspapers to declare the termination of the father and son relationship (footnote 7)... He might want to use this as a retaliation tactic to induce guilt and shame in us.

The new conflict arising from the nursing home placement in the Poon family was further complicated by the adverse comments of Mr. Poon’s younger brother who resided in Hong Kong. He took sides with Mr. Poon, blaming Edwin for not fulfilling his filial responsibility.

Wai Ying’s own parents showed more understanding but they also raised doubts about the timing of the nursing home placement. They suggested that the younger couple should give Mr. Poon some time to adjust to the death of his wife first, otherwise it would be perceived as a “double abandonment” to him. First, he felt he was “abandoned” by his wife through death and second, by his son through the nursing home placement. The rejection of the extended family towards the nursing home placement made the younger couple even more sensitive to critical remarks. Wai Ying, in particular, thought her sacrifices and dedication were not fully recognized and thus they were alienated further from the kinship network.
Genogram 5: The Poon Family
Conflict Resolution and Family Resources in Handling Crisis

Dementia is a disruptive and difficult experience for families. However, scholars such as Bonder (1986) and McCubbin & Patterson (1983a, 1983b) found that caregiving consequences could be mediated by certain adaptive resources in the families. Five types of resources were suggested in McCubbin and Patterson’s (1983b) work and these included: 1) personal resources of family members, for example, financial assets, 2) family system internal resources, 3) collective social support, 4) intergenerational support, and 5) family’s prior experience of coping. Findings in my study support previous research results regarding the importance of mobilizing the family’s resources. The following description demonstrates how a family’s prior adaptive experience was utilized in overcoming the caregiving strain.

Family History 7: The So Family (refer to Genogram 6)

Mr. So (aged 84) and Mrs. So married in 1931 and two children, Diana and Victor were born to them. In 1950, Mr. So met Madam Liu, a high school graduate who was twenty years younger than him, and with the consent of Mrs. So, he took Madam Liu into his household to become his concubine. Madam Liu gave birth to four children, Pat, Ann, Don and Lisa. The whole family including the father, two mothers and six children lived under the same roof. Harmony within the family was maintained as Madam Liu was a submissive woman who yielded to the authority of her husband and his first wife. Mrs. So treated the four step children as if they were her natural children (footnote 8).

Pat and her siblings immigrated to Toronto upon completion of their college education. Mr. So, and his two wives came to Canada under the family unification scheme while Diana moved to Toronto in late 70’s and Victor chose to remain in Vancouver.

Mr. So had been an investor in real estate and Madam Liu was his assistant in his business. With his wealth, Mr. So could provide the
family with a very comfortable life. When Mrs. So undertook massive surgery to treat colon cancer three years ago, Mr. So, Diana and Madam Liu took good care of her. Yet, sixteen months later, Mr. So was diagnosed to have senile dementia of the Alzheimer’s type. In view of the multiple illnesses in the family, the caregiving responsibility was shared between Madam Liu, Diana, Pat and Ann. Madam Liu who shouldered the major bulk of the responsibility perceived the care demand as a tremendous burden, but she could rely on the informal resources provided by her adult children. She spoke of the family’s prior experience in coping with illnesses and challenges:

Illnesses were frequent events in our family. Victor and Diana were premature babies and they often fell sick when they were little. Pat had severe neck pain, because of her job [a piano teacher]. Then, Tai Ma (Mrs. So) (footnote 9) got cancer ... Later on, my husband lost his memory... Yet, ours was a strong family...

...We also had several major ups and downs in our real estate business in the last ten years... Certainly the situation looked pretty bad at the beginning and I remember crying day and night over the loss... However, Pat and Ann reminded me we mustn’t give up hope and lose heart. And honestly, we were rather united in spirit (齊心)... When my husband began to behave strangely, each child contributed some money and I pulled it together to hire a home helper. The woman [home helper] came 4 days a week... Victor [in Vancouver] called every week to check on his father; Don, Lisa and their spouses helped with the transportation to medical appointments and grocery shopping...

(CG-8)

When I returned to revisit Madam Liu ten days later, she gave the following supplementary account on the family’s effort in acquiring outside help:

...Pat got in touch with the agent for a visiting nurse [for Mrs. So]; and my husband was on the waiting list for dementia day care... Don’s old friend, a lawyer, advised us on the power of attorney...
Mr. So took Madam Liu as concubine in 1950

M. 1931, wife of Mr. So

Mrs. So

84

Operated on colon CA in 1993, very frail

Madam Liu

65

Mr. So, primary caregiver, immigrated to Toronto in 1977 at age of 40

Genogram 6: The So Family
In the So Family, several vital resources may be identified. First, the family has accumulated considerable wealth over the years. With the financial assets, the family was able to engage a private home maker to provide the much needed respite for family members. Second, intergenerational support was evident. Adult children, though born to different mothers, shared the caregiving responsibilities willingly under the leadership of Madam Liu. Third, the family experienced several economic crises and multiple sickness before but its members survived the hardship and made constant adjustments and readjustments to reach a new equilibrium. Indeed, the onset of Alzheimer’s Disease in Mr. So was an added burden to the family as Mrs. So had just gone through a major surgery. Yet, with the joint effort of the family members, normal family functioning was restored quickly. The experience of this family lends support to the findings of research into aspects of family stress (Aneshensel, Pearlin, Mullan, Zarit & Whitlatch, 1995; Bonder, 1986; Lazarus, 1993; McCubbin and Patterson, 1983b; Pratt, 1996; Zarit, Pearlin, & Schaie, 1993) and confirms the significance of family resources in alleviating caregiving strain.

Performance of Key Family Roles During the Alzheimer’s Crisis

Individuals in a family may take on different roles to cope with the situation and demands associated with Alzheimer’s Disease. Generally, these roles are supportive of the impaired person and enable the family to cope more adequately. In some families, several roles may be assumed by the same family member but in others, different roles may be assumed by different family members at various times. On examining the data in my present study, two roles can be distinguished.
The Role of Care Manager

In the So family (see Genogram 6), Madam Liu moved in quickly to take charge as soon as Mr. So's dementing condition further deteriorated. She remained a stabilizing force throughout the adaptation period. As a care manager, she played a key role in organizing the family's response to what needed to be done. She undertook important liaison with professionals and performed linkage functions. However, in contrast to her daughters, Pat and Lisa, Madam Liu was not able to give emotional support to her husband, who was deeply disturbed by his own increasing loss of memory and independence. Madam Liu was used to be the "aide" to her husband in the business world and was more comfortable to assume a leadership role. Pat and Lisa had a family reputation of being "nice girls" who catered to the socio-emotional needs of other family members. By maintaining some distance emotionally, Madam Liu was less involved in the intimate aspects of care. Nevertheless, her central role as a director in the family kept the family together. Her leadership in practical problem-solving complemented the "hands-on" care largely provided by Pat, Lisa and the home maker. Madam Liu described her involvement as follows:

I asked everybody - Diana, Victor, Pat, Ann, Don and Lisa to come home for a family session. I realized that there were at least three things which we must settle: health care, financial arrangement and the legal aspect... Pat was directed to contact the visiting nurse [for Mrs. So]. Diana had a stroke last year and she got good help from a home maker. So I asked her to call the home care agency. Ken, Don's friend was a lawyer working for a big health insurance company and so I invited him to advise us on legal matters...

(CG-8)
The care manager in other families performed similarly concrete duties. A daughter caregiver took pride as she showed me how she physically redesigned a home to accommodate her mother’s decreased mobility and declining spatial orientation:

This picture was taken three years ago when we gave her a birthday party on her 75th birthday. We had a larger dining room in the past but there was no bathroom facility on the ground floor... I consulted my brother who worked in the construction industry. He suggested knocking down the partition wall and putting up a bathroom next to the dining room. I followed his advice and drew up a rough floor plan. After renovation, the dining room is smaller now but Mom can get out of the house with more ease as her bedroom is on the ground floor. You see, we converted the family room into a bedroom for Mom. My children and I moved upstairs for TV programs and sleep...

(CGC-3)

A further family carer assumed the managerial function by exercising control. In his own words Mr. Leung described his function (refer to Family Genogram 7):

I’m sort of a chief conductor (總指揮), I planned a weekly work schedule so that my sister, my wife and myself took turns to look after my mother on different nights in the week. This gave us at least five to six straight hours of undisturbed sleep. Honestly, if I was not “on call” on that evening, I would not wake up to provide care...This arrangement lasted for about nine months but unfortunately mother sustained another bad fall. Afterwards, she was transferred here [nursing home] from the hospital directly.

(CGI-4)
father, moved to Toronto
with wife and daughter Ah Fun
from Taiwan under the
sponsorship of Mr. Leung

Used to be the primary
caregiver of Madam Au
prior to death
died in May 1995 from cancer
his death had never been
disclosed to wife

Ah Fun
moved to Toronto with the old parents
under the sponsorship of Mr. Leung
never married, stayed with the Leung family
worked shifts as a health care aid
shared caregiving with Mr. Leung
and a paid home helper

Madam Au
immigrated from Taiwan in 1992
& had been living with the son’s
family ever since
Alzheimer’s Disease confirmed
in May 95,
had applied to the day care centre

care recipient,
moved to Toronto

Son
49

Mr. Leung
primary caregiver,
graduate of technical college,
immigrated to Toronto
with wife and
children in 1983
self-employed,
electronic security system,
hired a part-time home helper
to share care provision

Daughter
52

Ah Fun

Daughter

Mother
83

Madam Au

Genogram 7 : The Leung Family
A third family carer, a sister-in-law called Fay in the following case history, performed the “care manager” tasks by making short-term plans and setting concrete limited goals (see Genogram 8). She also actively sought support and information from close kin and professionals. She described her strategy in this way:

Her [sister-in-law] aggression became so severe that it led to violent verbal assaults. We understood that it was not her but it was too much to deal with. Her behaviour was like a 6 year-old child, but a 6 year-old you can control. The situation got out of hand at night. I knew I'd have to do something... So I went to see the nursing home placement officer. This would be our permanent solution for her. Meanwhile, I turned to my son for temporary relief and he agreed to stay with us during the weekends. Well, this was better than no help at all. But this was only a short term arrangement. As for her incontinence, I consulted my nephew who happened to be her family doctor. He gave us some good medical advice...Now, we can only plan ahead on every two months basis and in order not to be disappointed, our goals must be realistic and limited. 

(CGI-10)

The findings of my research concur with Archbold’s (1983) study, which also documented the roles of care manager and care provider among the adult children caregivers. In Archbold’s study, care managers tended to be employed full time, in socially valued career positions. Care managers, on account of their higher socioeconomic status, were in contact with a broad range of social support resources, such as physicians, lawyers, nurses and social workers. Their major involvement entailed obtaining and retaining appropriate systems for their relatives.

The care managers in my study emphasized such tasks as “conducting”, “directing”, “coordinating”, “planning a schedule”, “drawing up floor plans” and “setting realistic goals”. The requisite skills developed by these managers included: assessing the care recipient’s
functional and mental capacity, seeking out the strengths of each family member, pulling together family assets, and gaining access to the formal care systems.

parents of Madam Chin died in Mainland China long time go

Genogram 8: The Chin Family
My interview data also confirm earlier findings of Globerman (1996, p.39) who identified two roles among her respondents: the performer and the director. In her study, daughters-in-law were actors, initiators, always taking control and being proactive. They supervised paid caregivers and home care support staff, intervening in crises and keeping the family informed.

The Role of Care Provider

"Care providers" are those family members who give "hands-on" care to the demented relatives. Some care providers in my study assume this role because they have an innate need to nurture. However, the care provider’s need to nurture may obscure their need to care for themselves. When they respond to their relative as a helpless person, their nurturing tendencies seem to recreate a relationship with the parent or the spouse that resembles the kind of relationship they might have with a child. When this occurs, it may reinforce a rebonding process which results in the creation of an inseparable bond. The relationship would then appear to become resistant to any threat of separation and the care provider’s life can be singularly consumed by caring for a loved parent or spouse. Other family attempts to separate them from this consuming activity is resisted because it is all they can do for the loved one. In contrast to the "care managers" whose roles are examined in the previous section, care providers might obstruct other family efforts to get help for the impaired person, for example, getting second opinions or seeking treatment for the psychiatric manifestations of the disease. Several caregivers in my study were so intensely involved with their relatives that they wore themselves out to the point where they had no
desire for any other useful activities. Three caregivers from different families reported similar experiences:

My other siblings were very career-minded. They had nice jobs and could not afford to spare the energy and time to attend to Mom. In addition, my previous work schedule was more flexible, so I took up the carer role. I felt this was expected of me... I didn't have much time for myself.

I felt relieved when the family service coordinator told me that the Home could take her in. But as I walked down the road after leaving her there, there was a strange feeling inside. Do I want my own life back again?  
(From a daughter – CGC-1)

Oh, a long list of tasks: personal care, light or heavy; household chores; escort to medical appointments and comforting him (father-in-law)... Well, these responsibilities all fell on me. My husband avoids any personal contact with his father as much as possible.  
(From a daughter-in-law – CGI-7)

My mother always phoned me up for help. Small things, big things, no difference. She seldom approached my sisters, who would turn down her requests for assistance anyway. I’ll do everything for her though I wish privately that she should not be totally dependent on me... Her gross loss of self confidence was the first sign of her change...

It’ll be a matter of weeks before mother can get in [to the nursing home]. But all of a sudden, I'm now not sure whether it is the best place for her. She is so used to having me around. I feel useful in that sense...  
(From a son – CGC-5)

“Care provider”, another category of family caregivers was found by Archbold (1983) to perform a significantly different set of responsibilities. In Archbold’s study, care providers were not career oriented (p.41). Their occupational roles, for example, housewife, and non-skilled worker, tended to be less valued by society than those of the managers. The salary provided by their work was not enough to purchase needed services for the parent. Thus, providers were engaged in providing personal and emotional care to the parent. Their
lives could become rigidly scheduled around the parent’s need for care, including meals, bowel movements, bathing and exercise.

Similar functions in Globerman’s (1996) study were fulfilled by the “performers”, who were the sons-in-law of the care recipient. This role meant “being supporters, listeners, souschefs, chauffeurs, or errand boys for their wives” (p.40). They did not appraise the relative’s situation or organize their involvement.

The experience of the “care providers” in my study were consistent with Archbold’s (1983) and Globerman’s (1996) findings. These care providers were so overwhelmed with the physical tasks of caring that they had no time or energy for other activities. They identified deceased freedom, a lack of privacy, and constant daily irritations as the major costs of caregiving. The deprivation of freedom had two components: the loss of freedom on a daily basis and the loss of freedom in a larger sense, for example, to make long range plans. In the words of a respondent caring for her father-in-law:

My daily life revolved round his needs – his joys as well as his complaints. He could not be left alone. We couldn’t make any long range plans: vacations, and moves.

(CGC-7)

**Family Expectations in Role Assignment**

A close scrutiny of my data also confirms the significance of family rules and expectations in role assignment and enactment during the dementia crisis. In the So family (Genogram 6), Madam Liu was supported by her children in performing the decision-making role. Her strong character, her determination to fight against adversity and her
leadership potential were met with the ready approval of her children, Diana, Pat, Lisa and Don. The division of labour was not gender-based in this family. In addition, Madam Liu, though occupying a concubine status, enjoyed the same level of respect as Mrs. So, the first wife. In this family, a pragmatic problem-solving approach was adopted to ease the caregiving strains.

A similar pattern emerged when I studied closely the care providers in these families. Like the care managers, the role of providers was to a large extent, “designated”. These adult children care providers were often bound to their unspoken promise to their parents, either because they were the parent’s favourite, or they had a reputation of looking after the weak member in the family. In the eyes of other family members, these principal care providers were “natural helpers”, the “patient persons in the household” and carers who had “looked after so and so before and it was likely that they had the skills”.

From a daughter-in-law:

I took care of my mother-in-law during her terminal stage [of cancer]. I literally did everything for her, feeding, comforting... So when it came to my father-in-law, my husband expected me to do it again. He had no idea how to attend to his father’s needs...

(CGI – 7)

From a son:

They [his sister and close family kin] knew that I would not give up my responsibility towards Mom. I have always been a responsible person, in the workplace, as well as in the family setting.

(CGI – 4)
In these families, members did not contest with one another over issues as to who should do what and at what time. They had clear rules for responding to problems. A family hierarchy existed that determined in advance how changes in leadership should be handled. For example, when the family noticed the obvious cognitive decline of Mr. So, the members knew that someone had to replace him. The flexibility of the family in responding to a situation that requires change in leadership is critical. Flexibility in the So family enabled members to adapt and change, regroup and develop new patterns in an established hierarchy so that the family could develop new patterns to care for the impaired relative. The presence of clear family rules has been an important facilitating force in adjusting to the caregiving challenge.

Family Boundaries and Dementia Care

The boundaries are largely invisible. While the relative flexibility and rigidity of family boundaries regulate the interactions between the family and its larger environment, boundaries between sub-systems in the family context suggest how closely family members should be involved in each other's lives (Handel, 1985). In disengaged families, the boundary between the parent and child sub-systems may be quite rigid. This rigidity can inhibit communications and support between parent and their adult children. For example, the spouse of the affected elderly person may be emotionally isolated from the children and he/she would then be unlikely to request help unless the level of stress becomes quite extreme.
At the other extreme of the continuum of involvement is the enmeshed family which is characterized as being so close that its members lose their own sense of autonomy. The over involvement that characterizes the enmeshed sub-system can produce overload during Alzheimer’s caregiving. The situation of Rom (see Genogram 9) and Pancy (see Genogram 10) exemplifies the family boundary issue. As stated by Rom, during my subsequent interviews with him:

My Mom’s illness was a severe strain on my already stressed out marital relationship with my wife Rose. Mom expected me to visit her twice or thrice in a week when my work was over. I brought a take-out dinner for her, did the laundry, also, cleaned up a bit... In the past, I could do that without much trouble because Rose was not working and she stayed home to look after Anna and Betty... The girls are teenagers now and Rose wishes to bring home a second income to meet the growing needs. Rose was very upset because if I paid visit to my mother at her senior apartment, I could not get home by 7:00 p.m. to prepare the family dinner. Rose worked from 2:00 p.m. to 8:00 p.m...

Mom also called me late in the evening to talk about trivial matters. Rose thought it was a big nuisance to us. Mom also expected me to run errands for her: depositing money in the bank and taking her out on grocery shopping trips on Saturdays. I did those things for her. But Rose was angry with my excessive help to my mother. So frequently we ended up in heated arguments.

The onset of confusion in Mom was the last straw in causing the ultimate marital breakup. Mom denied that I spent time at her place when Rose called to check why I was not home yet. Even worse, she told Rose that a couple of women paged me and I left in a hurry... In addition, I gave Mom a certain amount of money to support her. I kept this secret from Rose...It wasn't too difficult on my part to hide some money because I was a sales person. You know, no fixed income. But she revealed this to my daughters. As time went by, Rose became suspicious, accusing me of having affairs with other women... At the beginning, I didn't realize this was part of Mom’s sickness. I condemned her for telling lies and creating those “stories” in her mind...
... Outcome? Rose filed for divorce and she got the sole custody of the two girls. I got the visiting rights... I am the big loser in the fight; I lost my wife, my children and my Mom. Mom lost her mind two years ago but now she loses her love for me as well... Didn’t she feel my pain? I am 60 now, the prospect of remarrying is not too promising. I’ll retire in a few years time...

(CG-6)

Genogram 9: The Ko Family
The excessive concern and involvement characteristic of Rom was indicative of the enmeshed relationship between the mother and son, to the detriment of the husband and wife sub-system. A similar pattern was found in the following family (see Genogram 10).

Pansy was the principal carer for her mother Madam Wong, who had five children. Pansy had Cathy, an elder sister and Robert, a younger brother to share the caregiving responsibilities. However, there was a special attachment between Pansy and Madam Wong because Pansy was used to being the “sick and fragile” child in the family. Yet, Pansy was the first family member to settle in Canada. Madam Wong gave Pansy the down payment for her apartment. When it became clear that Madam Wong could no longer look after herself, Pansy agreed to take her in during the day time but Robert must pick her up in the evening. Pansy was a full time housewife. Madam Wong would normally reside with Robert’s family. Kati, Robert’s wife, resented this arrangement because she had two young children to attend to and Madam Wong’s behaviour at night were especially uncontrollable. On the other hand, Rock, Pansy’s husband expressed similar resentment. As described by Pansy, her mother was:

...rather possessive and bossy. She moved the furniture around to suit her needs, asked us to give her the south-east facing bedroom and disallowed my boy to watch his cartoon program... I gave in to these demands. We had planned a short trip to New York last Christmas, just 4 days. So, I said, “Mom, you had to stay with Robert for a short while.” She cried days and nights and finally I gave up going! Rock took the two children to visit his uncle... Since then, she checked on us several times whenever we were enjoying the family time in the family room... Worse still, sometimes she would order me to do this and that when Rock was home. I tried to obey her to keep her quiet. But Rock felt she robbed us of a decent family life... This lasted for a year and Rock finally decided that he would not cope any further. Mother has been placed on the priority list for institutional care.

(CG-C-1)
died of liver CA in 1986, 3 months after the diagnosis his death was too sudden and a great shock & sorrow to family

Mother
Madam Wong
care recipient, moved to Toronto in 1987 shortly after the death of husband
dementia of the Alzheimer's disease type confirmed in June 94

Son
44
Mac
eldest son, favourite child of mother, resided in Hong Kong

Daughter
39
Lily
a housewife, looked after Madam Wong when she returned to Hong Kong for a 6-month visit

Daughter
36
Cathy
shared caregiving willingly immigrated to Toronto in Feb 95 a welfare worker in Hong Kong

Daughter
37
Rock
a mechanic graduate of a Canadian university objected to wife's involvement in giving care to Madam Wong

Daughter
37
Pansy
Primary caregiver, immigrated to Toronto in 1984 high school graduate full-time housewife felt partly responsible for mother's deterioration

Son
30
Robert
realtor broker, moved to Toronto in 1989, shared care giving

Katti

Genogram 10: The Tao Family
In the above family situations, Rom and Pansy allowed their dementing mothers to insinuate themselves into the marital relationship. The boundary between the extended family and the nuclear family was especially vulnerable during the period of dementia care. The conflicts thus generated within the family systems became the “secondary stressors” in the family stress perspective model (McCubbin et al., 1980; McCubbin & Patterson, 1983b; Mullan, 1993, & Pratt et al., 1976). This also coincides with a central theme examined by Bell (1985) who examined the extended family relations of disturbed and balanced families. Bell (1985) concluded that in disturbed families, extended kin became competing sources for and objects of support and indulgence for the nuclear family (p.167). This situation was also evident in the Chu Family (refer to Genogram 11). Madam Chu stayed with her granddaughter’s family prior to her admission to the nursing home. After Susan, her granddaughter, gave birth to a moderately handicapped baby, Mrs. Fu had to share the childcare burden and the family felt extremely stressed in providing care to a dementing member as well as a handicapped new born. Susan mentioned that her sleep was disturbed by the restlessness of Madam Chu and the family conflict further intensified.
Grandmother Madron Chu
immigrated to Toronto in 1986 to join Lynn Pi Chi.

Mrs. Fu (60) m. 1952
immigrated to Toronto in 1986 to join Lynn

Mr. Fu

Grandson Jackie
emigrated to US 20 years ago

Grandson Paul
resided in Texas, died of liver cancer in 1994

Granddaughter Lynn
primary caregiver, never married, U graduate from a Canadian University, immigrated to Toronto in 1979

Granddaughter Susan
joined Lynn under the Family Unification Program in 1991

Granddaughter Rick
shared same household with Mr. & Mrs. Fu and Lynn in Toronto

Genogram 11: The Chu Family

Mrs. Fu provided active care to John while Susan and Rick were working

John had cerebral palsy, needed heavy care

Care recipient, immigrated to Toronto with Susan as last remaining family member in 1991 had colon cancer, surgery done in HK, resided in nursing home
Summary

Based on the research data collected from the family caregivers, I have identified certain facilitators as well as barriers to care sharing within the family networks. The onset of the progressive brain disease required the family to make constant adjustment in handling continuing conflicts, appeasing reactivated conflicts and overcoming new conflicts. Continuing conflicts are those that have always been present between the care recipient and the caregiver or among the caregivers. In order to enhance participation in sharing care, those continuing conflicts representing unfinished business in the prior relationships must be addressed. Reactivated conflicts were those that may have been buried or avoided so successfully that they were forgotten. Those reactivated conflicts in the family tend to focus on issues of sibling rivalries that had become increasingly obscure over time. These were rivalries, however, reactivated by the new situation of dementia care. Furthermore, new conflicts were also identified in these families confronted by the disease and reflected issues that might never have required attention before. Typical issues included concerns about nursing home placement, living arrangements and the acquisition of professional help.

Certain features were evident in those families who coped better in the caregiving struggle. First, these families were able to maintain a distinctive collective identity despite the structural disruption and wide geographic dispersion. The continuity of group identity in these families enabled members to remain emotionally connected and to function as a unit rather than isolated individuals. This strong identity provided a sense of belonging and a common goal. In particular, siblings were motivated to render support to each other in providing parental care. Family rituals, rules and themes were found to unite these cohesive
families together in the battle against the ravages of Alzheimer's.

Dementia care also exposes the family to another crisis: the challenge of new role assignments. Roles previously assumed by the dementia victim might need to be reassigned and the family will certainly need to make decisions on the apportioning of new responsibilities. Two distinctive roles were revealed as I analyzed the interview data. First, the role of care manager was consistently found in these families. Care managers were characterized by their superior abilities in planning, organizing, coordinating, and delegating responsibilities and activities. They tended to assess the environment outside of the family, identify the internal resources and also mobilize other family members as soon as the family is stricken by the disease. New leadership patterns were seen developing gradually in these families. Although minor differences might still exist, members in these families would overcome the conflicts through enhanced communication and negotiation.

The role of care provider was found to be performed by some of the respondents in my study. These care providers gave regular hands-on care over a lengthy period of time. Their lives could be so singularly consumed by caring for a close relative that they might sacrifice their own well-being. When the older relative was admitted to a nursing home facility, the care provider became entrenched in the care provider role to the extent that he or she could suffer a tremendous void.

The last section of this chapter discussed some of the problems experienced by enmeshed families. Over-involvement of some family caregivers has produced overload and threatened the effective functioning of the family. In some more difficult situations, the adult children caregivers had to make compromises so that they could also accommodate
their own family’s needs.

Endnotes

1. Fried shrimps and steamed fish are two popular seafood dishes in the Chinese New Year traditional meal. Shrimps are lively and they symbolize energy. The pronunciation of fish resembles a Chinese word which means “surplus”. Taken together, these two dishes convey a New Year wish of liveliness and abundance for the coming year.

2. Lunar New Year often falls in the month of January or February. And since it is not a holiday in Canada or USA, most Chinese will go to work as usual on that day.

3. If a special remembrance ceremony is held to mark the anniversary of a family member’s death, participants have to go home before it gets completely dark, around six o’clock in the winter.

4. Vegetarian food is often served when family members gather together for a communal mourning feast.

5. A concubine is a socially recognized mistress who lives with a man who is already married. The couple may live separately from the wife and her children, but alternatively, the concubine can share the residence with the family under the same roof.

6. There was a civil war in China in 1949 after which the Communist Party set up the People’s Republic of China in the Mainland while the National Party fled to Taiwan to set up its own government.

7. When a tension between a father and his son becomes so acute and the difference is irreconcilable, the father can make a public announcement in the newspapers to declare the termination of the father-son relationship. From then onwards, the son will have no claim to his inheritance entitlement.

8. A concubine will treat children of her “husband” as her own natural children.

9. Tai Ma means “the senior mother” and children of the concubine will greet the wife of their father as “Tai Ma”.

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CHAPTER EIGHT

FINDINGS AND DISCUSSION: PART FOUR
THE LINKAGES BETWEEN INFORMAL AND FORMAL SUPPORT

Introduction

This chapter examines both the informal and formal sources of social support of the family caregivers in my study. In discussing the findings, I have identified the types of help they have received from these different sources, the meaning they attach to the assistance, the dilemmas they encountered in obtaining support and finally the interdependence of the informal and formal systems of social resources.

The most frequently mentioned sources of support included: spouse, sons and daughters, children-in-law and other family kin such as cousins, nephews, nieces and siblings of the older relative (see Table 8.1 below). In addition, the assistance was given mostly on a regular basis and as frequent as everyday or several times a week (see Table 8.2).

Table 8.1: Main Source of Informal Social Support Received by Caregivers
(By Order of Importance)

<table>
<thead>
<tr>
<th>Source of Support</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Son</td>
<td>Daughter-in-law</td>
</tr>
<tr>
<td>Daughter</td>
<td>Son-in-law</td>
</tr>
<tr>
<td>Sister</td>
<td>Brother-in-law</td>
</tr>
<tr>
<td>Brother</td>
<td>Sister-in-law</td>
</tr>
<tr>
<td>Grandchildren</td>
<td>Other family kin (cousin, nephew, niece, aunt, and siblings of the older relative)</td>
</tr>
</tbody>
</table>

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Table 8.2: Frequency of Assistance with Activities of Daily Living Received from Informal Source

<table>
<thead>
<tr>
<th>Frequency</th>
<th>(n = 18)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Every day</td>
<td>4</td>
</tr>
<tr>
<td>Several times a week</td>
<td>5</td>
</tr>
<tr>
<td>Once a week</td>
<td>2</td>
</tr>
<tr>
<td>Several times a month</td>
<td>6</td>
</tr>
<tr>
<td>Once a month</td>
<td>1</td>
</tr>
</tbody>
</table>

* multiple response

Categories of Support Resources

A wide variety of forms of help was received by these family carers, ranging from very tangible assistance to emotional and moral support (see Table 8.3). The most frequent type of assistance given by other members of the family were supervision of safety, shopping, errands, transportation and direct monetary help. For the functionally impaired relatives, caregivers received a great deal of assistance in such areas as physical care and domestic help (for example, cleaning, laundry, meal preparation and respite). However, the counting of concrete tasks in caregiving does not reflect the entire picture of caregiving commitment. Neysmith and Aronson (1997) argue that “the adequate performance of tasks, such as meal preparation, is not the subject matter of caring; to define it as such misses the relationship-based components of the work. Caring is unpredictable, emotional work which, ... does involve commitment to developing and sustaining a relationship” (1997, p.496).
Table 8.3: Caregivers Receiving Assistance from Informal Source (n=18)

<table>
<thead>
<tr>
<th>Nature of Help</th>
</tr>
</thead>
<tbody>
<tr>
<td>Practical Assistance</td>
</tr>
<tr>
<td>Provide physical care</td>
</tr>
<tr>
<td>Provide domestic help (i.e. cleans, cooks)</td>
</tr>
<tr>
<td>Provide respite care (i.e. stay with relative, take relative out)</td>
</tr>
<tr>
<td>Prepare meals for relative and/or caregiver</td>
</tr>
<tr>
<td>Accompany relative and/or caregiver to doctors</td>
</tr>
<tr>
<td>Arrange appointments to doctors</td>
</tr>
<tr>
<td>Run errands</td>
</tr>
<tr>
<td>Visit relative and/or caregiver</td>
</tr>
<tr>
<td>Provide transportation to relative and/or caregiver</td>
</tr>
<tr>
<td>Handle legal matters</td>
</tr>
<tr>
<td>Handle financial matters</td>
</tr>
<tr>
<td>Guidance and Advice</td>
</tr>
<tr>
<td>Provide information</td>
</tr>
<tr>
<td>Provide emotional support</td>
</tr>
<tr>
<td>Offer friendship and socialization</td>
</tr>
</tbody>
</table>

* multiple responses

The words of five carers help to illuminate the statistics presented above:

My sister residing in the U.K. comes every summer [to take care of Mom] between June and August to give me a break after my wife left...

(From a son - CGC-6)

My sister-in-law from Brampton came every weekend to take him [father-in-law] out for a ride to the Chinese tea house in the winter and the parks in the summer... In addition, my cousin worked in the social service department at the hospital and he sent me a brochure on Alzheimer’s Disease. He also gave me a phone number to call to enquire about day care.

(From a daughter-in-law - CGC-7)
My brother-in-law ran the errands while my sister took Mom to the clinic and talked to the family doctor about medicine repeats...

(From a son – CGC-4)

My wife helped me to give Mom hot bath and she also did the household chores. My nephew, a mechanic, did the minor home repairs once in a while.

(From a son – CGC-5)

My sisters visited regularly with mother... they also made a financial commitment to the care of her so all of mother’s bills did not fall on me alone...

(From a daughter – CGC-3)

Declining Support from Neighbours and Community-Based Groups

It is somewhat surprising to discover that although the family carers often turned to other close kin for support, they seldom approached neighbours or community-based groups, such as neighbourhood associations, ethnic societies and fraternal organizations. The reasons for not utilizing help from these potential sources are explained by the following three carers:

My parents-in-law maintained a separate household. They moved house three times in the last two years because my father-in-law’s condition kept deteriorating. First, they moved from a semi-detached [house] to the ground floor of a town house. My mother-in-law insisted she wanted to have a back yard to grow her plants. Then, seeing that it was unrealistic to keep even that, they moved to a condo so that my father-in-law would not need to climb the stairs... Six months ago, they moved again, to be closer to us so that we could give them support when my sister-in-law was on duty.

(From a daughter-in-law – CGC-7)

Yes, there was a fraternity society for those folks coming from Shanghai, a big Chinese city. But members only met two to three times a year, mostly for Chinese festive occasions. The social convenor phoned me once to ask if he could be of any help after learning that my father-in-law would go to the nursing home. I welcomed his visit to him. Yet, I did not expect further assistance. Given my father-in-law’s confusing mental state, he
could not always recognize this friend. I think he stopped going after the first visit...

(From a daughter-in-law – CGI-7)

Mother’s friend has asked her son to call to find out if my mother needed rides to medical appointments. Her son has been unemployed for quite a while, ... we declined gently his offer of help because I can’t return the favours. I am retired now. I gave up driving last year and have been using public transport instead.

(From a son – CGC-6)

A common reason for declining instrumental assistance from neighbours, representatives of fraternal organizations and friends is that close and durable relationships had not been established between the carer and/or the older relative and the network members. For example, in the first family, the parents-in-law had moved house so often that they could hardly have sufficient contacts with the neighbours to establish close relationships. Second, the length of time of the network’s existence was too transient to nurture a deep and continuous aid pattern. Furthermore, the caregivers felt reluctant to receive help because the relationships were seen as uni-directional. A bilateral flow of prior support between the two sides was absent and carers might not be able to reciprocate in the foreseeable future.

My findings seem to concur with Rothman’s (1994) contention that certain structural attributes of the family are related to the use of informal support (p.158). He asserts that intensity, durability and the frequency of contacts between the network members will influence the extent and the quality of available support. Aside from intensity, sensitivity to and acceptance of the carers’ needs increase with the permanence of a
relationship. A third variable affecting the use of informal help from friends and distant kin is the prior exchange pattern of mutual aid. Reciprocity entails normative behavior involving the exchange of benefits and this has been shown to be a facilitator in the utilization of informal resources (Antonucci, & Jackson, 1990).

Network Size, Helpfulness and Accessibility

The analysis of my qualitative data also reveal the significance of three network variables in shaping the use of informal resources: size, helpfulness and accessibility. Presumably, if a family immigrates to a foreign country, its kinship size will shrink naturally and this will negatively affect the availability of help (Horowitz, 1981). However, if the network size is huge and the caregiving responsibility can be distributed among many members, the carer’s burden of support for the relative might ease. As a result of immigration, close to half of the caregivers I interviewed reported that there was a real shrinkage of network size. Nevertheless, this disadvantage was compensated for by the enthusiasm of the available members. Providing assistance to siblings and close kin in the care of an impaired relative was a high priority among these families.

Geographic Dispersion And Informal Support

Geographic dispersion can be a further potential barrier to the mobilization of informal support linkages. While this factor is perceived as an impediment to co-operation and the co-ordination of aid among the families under study, its effect on mutual emotional support is less clear. The documentation of family genograms in my study has indeed
helped me to visualize the wide dispersion of families across regional jurisdictions, national boundaries, continents and oceans. And what is more, these adult child caregivers tended to emigrate to countries overseas at different stages of their developmental life cycles. For example, some left home for higher education at a young age and never returned to the home country. Others decided to leave in the late 1980’s or early 1990’s when the sovereignty of Hong Kong was scheduled to be returned to China from Britain. Yet, in spite of the disruption of family ties arising from immigration, the great majority of the families were determined to overcome the challenge posed by the physical distance. Impressive incidents of emotional support rendered to the carers were not difficult to find.

Emotional support was given in various forms, such as words of comfort, gestures of understanding, signs of encouragement and practical advice and guidance. Carers openly acknowledge this kind of support:

I didn’t feel my brothers abandon their responsibilities. They resided outside of Canada. They called me [by long distance] two or three times a month to monitor Mom’s condition. They listened patiently when I poured out my frustrations... My elder brother even suggested once that I could make collect calls if my phone bill got big!

(From a daughter – CGC-3)

My husband’s aunt [sister of my mother-in-law] has been a great help to us whenever we felt distressed. This aunt understands the hurt caused by her false accusation of theft, because my mother-in-law also blamed her for stealing her treasures. The aunt also gave me helpful insights as to how to respond better to some of her awkward behaviour.

(From a daughter-in-law – CGI-7)

I felt I could cry to relieve my pent up feelings when my other sister came to visit from the States.

(From a daughter – CGI-3)

Mother promised to be a companion to Grandma and kept an eye on her whenever I needed to slip out for one to two hours on Saturday afternoons... I dare not take Grandma home even for a weekend unless
mother agreed to share the burden.  

(From a granddaughter – CGI-9)

My husband didn’t blame me for talking to the social worker about possible nursing home placement. I just told him frankly that I couldn’t take it any further. My sister-in-law was getting worse and worse... My husband’s understanding took my initial guilt away...  

(From a sister-in-law – CGI-10)

Affective Solidarity

Families can be described on the affective dimension (Bengston & Schrader, 1982; Matthews, 1987). Affective solidarity within a family system measures the extent of emotional closeness or distance between family members. As for the families participating in my study, the strength of the emotional ties between specific sibling dyads or triads did affect the pattern of caregiving. This falls in line with the conclusions of Matthews (1987) who studied 50 pairs of sisters, one employed and the other unemployed in each dyad.

Caregivers in my study explained the importance of emotional bonds:

... in a way, my sister has rescued me from ruining my marriage. My husband said he would not tolerate mother’s control any longer. He would move out if mother moved in to stay with us... My sister came the next day following our fierce argument to persuade me to accept the offer of temporary placement at that nursing home.

She offered to share the expenses because the benefit entitlement was just enough for basic costs. There were extras, and we need to make ends meet. She would also talk to my younger brother to see if he could make a small monthly contribution...

This sister was close to me. We grew up together and went to the same high school.  

(From a daughter – CGC-1)

My sister came over from June to August to give me a break. Age wise, we were close to each other. She felt my dilemma after my wife left...
Prior to her current marriage, she had a broken romance. When I look back, mother might also have played a part in causing the separation.

(From a son – CGC-6)

Dad died in his mid forties. We kids cling to each other for security and support. School mates knew we were from the same family, not so much because we looked alike. Rather, they knew we were brothers and sisters because we stood by each other’s side against the bullies.

(From a daughter – CGC-3)

Appraisal of Informal Support: Personal Meaning

Social networks do not equate with social support since the social support system only refers to that subset of persons in the individual’s social network “upon whom he and she relies for socioemotional aid, instrumental aid, or both (Thoits, 1982, p.18). In addition, social system members may not be supportive all the time. Scholars such as Burda & Stewart (1986), and Vaux (1988) argue that the subjective appraisal of social support by the recipient is more important than the mere existence of supportive relationships. The perception that others are willing to help will provide comfort. On the other hand, the perception that no one is willing to help will increase the stress level. To researchers pursuing the subjective appraisal approach to informal help, social support is the “individual’s cognitive appraisal of his or her social environment and the level of confidence he or she has that when support is needed it will be available, sufficient to meet the need, and offered in a way that is perceived as beneficial (Tracy, 1990, p. 252).

Positive support appraisals may lead to beliefs of being cared for, esteemed and a sense of belonging, or a feeling of dependable reliance (Cobb, 1976). A careful examination of my research data unfold the personal meaning of these support resources to
the family carers. Some examples are given below:

Unlike my husband’s uncle who resided in Hong Kong, this aunt didn’t raise any objection against our plan to look for a nursing home. Her gentle nod of understanding spoke more than a thousand words of love.

(From a daughter-in-law — CGI-7)

The fact that my son agreed to spend the weekend here to share the care is a great relief to me...

(From a sister-in-law — CGI-10)

The absence of understanding, emotional support and tangible assistance from close kin, however aroused a deep sense of alienation in the family carers. Several caregivers described their feelings thus:

Outsiders don’t understand. I don’t blame them, who knows what Alzheimer’s Disease is? This disease is little known among Chinese families.

(From a daughter — CGI-2)

I hated to wake up the neighbours at such a late hour... I myself bear the full brunt of the care demands. I alone feel the heaviness of the stress.

(From a daughter — CGI-3)

...my mother stayed with my sister for about three weeks and my sister phoned me one afternoon asking me to pick Mom up before dinner time. I begged her to give me two more weeks as our [overseas] guests were still with us. She refused...I took Mom home. I was engulfed by bitterness. Why couldn’t she give me some help when I needed it most?

(From a daughter — CGI-1)

A third theoretical orientation that examines informal care follows the “whole network” approach. Wellman and Wortley (1990) argued that support should be examined within the context of broad social network ties. They proposed that “whole networks”
rather than "personal networks" should be studied, since this would produce a more integrated view of both the social system as a whole and the parts that make up the system.

In their study (1990) on the social networks of the Canadian East Yorkers, Wellman and Wortley found that most support relationships provided specialized support. For example, strong ties provided emotional aid, small services and companionship. Physically proximate ties generated tangible support. In addition, parents and adult children were involved in a variety of exchanges, such as financial help, emotional support and tangible service. Female kin specialized in providing personal and emotional care.

An analysis of the receipt of informal care among my respondents supports Wellman and Wortley's findings. In my study, siblings and their spouses made up half of all supportive relationships. Other family members, such as spouse and adult children made up most of the other half of the relationships. Extended family kin only played a marginal role in the care provision scene. Consistent with Wellman and Wortley's findings, most support relationships in my research study provided specialized care, with spouse and siblings giving the most intense and regular support. Adult children often performed the duties of a secondary caregiver if their parents were caring for the grandparents.

Use of Formal Services: The Structural and Cognitive Approaches

Research interest on the use of formal services by family caregivers has been stimulated by both practical and theoretical concerns. On the practical side, research has attempted to understand whether the intended clients of a program are actually being served, as well as to evaluate the effectiveness of these programs in achieving their stated goals. On
the theoretical side, service utilization has been conceptualized along two dominant frameworks: the structural approach (Bass & Noelker, 1987; Noelker & Bass, 1989; Stoller, 1983, 1989; Stoller & Pugliesi, 1989) and the cognitive approach (George, 1987; McCaslin, 1989; Mullan, 1993; Pearlin, Mullan, Semple & Skaff, 1990; Soldo, Agree & Wolf, 1989).

The structural approach assumes that differential use of services by caregivers is a function of interwoven structural variables: a) personal and social resources of the caregiver; b) enabling factors such as low socio-economic status, lack of benefit coverage and other barriers to informal care; and c) need-for-support factors such as functional impairment, cognitive difficulties and problematic behaviours of the older relative. These structural variables have been discussed in Chapter Two when I analyzed the individual and family stress paradigms.

The cognitive decision-making approach to understanding caregivers' use of formal services, on the other hand, views the art of seeking help from a formal service organization as a "culmination of a process of gathering, organizing and evaluating information about the self, significant others and the formal service environment" (Stephens, 1993, p.270). The cognitive approach further suggests that by examining the caregivers' decision making processes, researchers can identify the critical conditions that either promote or impede formal help-seeking.

Table 8.4 highlights the formal services that have been used by the caregivers in my study. Contrary to my expectation, the majority of the caregivers (n=10) did not use formal services at all. This is consistent with earlier findings reported in other caregiving literature.
(George, 1987; Noelker & Bass, 1989; Office of Technology Assessment, 1990; Swan & Estes, 1990). Only a few reported having used in-home care services such as home help and visiting nursing. Psycho-educational programs such as support groups and family counselling were seldom mentioned by the respondents. Even the respite program, which has an aim of providing instrumental support to family carers, was little used by the respondents.

Table 8.4: Six most Frequently used Formal Services by Family Caregivers (n=18)

<table>
<thead>
<tr>
<th>Type of Formal Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Homemaker Service</td>
</tr>
<tr>
<td>Visiting Nurse</td>
</tr>
<tr>
<td>Meals Delivered</td>
</tr>
<tr>
<td>Day Care</td>
</tr>
<tr>
<td>Transportation</td>
</tr>
<tr>
<td>Temporary Residential Respite</td>
</tr>
</tbody>
</table>

* multiple responses

Respondents were asked to discuss the formal services they ever used in the last year and answers were later coded. Columns do not add up to 100% because respondents could give more than one response.

In analyzing the barriers to formal service utilization, the best fitting model for the data in my study is the help-seeking approach proposed originally by Stephens (1993). Five components were identified by Stephens in her model. They are the caregiver's role
experience with dementia; the caregiver's other role experiences (for example, the "women in the middle"); the socio-cultural and family context; the service system context and the judgement on need for use of formal care. These five components interact to determine the help seeking behaviour.

In Chapters Six and Seven, much was discussed about the caregiver's role experiences with dementia and other role commitments. Thus, in the following section, I shall concentrate on the influence of the contextual variables and the judgement variables in acquiring formal help. Fig. 6 provides an overview of the connections between these variables.

Figure 6: Caregivers' Decision Making Process for Utilizing Formal Services

(Adapted from P. Stephens, Understanding Barriers to Caregivers' Use of formal Services: The Caregivers' Perspective, p. 268.)

**Socio-Cultural And Family Context**

The sociocultural and family milieu of the caregiver is the first contextual component to be discussed. Several caregivers in my study cited discomfort or
embarrassment over their relative's behaviour as an impeding factor to service use because they wanted to hide from service providers. Fear that their relative would be upset if an outsider were to help with care was perceived as another reason for declining formal help.

Fear and embarrassment are clearly in evidence from this daughter caregiver:

When I first took my Mom to see the doctor, I didn’t tell the doctor about her disturbing behaviour... I was still embarrassed by her accusing people of stealing. It wasn’t until I had actually applied to the nursing home and had been in contact with the social worker that I dared to face my own emotions. I didn’t even tell the social worker immediately some of the difficulties that I was going through with my mother because I was embarrassed. Embarrassment was the first emotion that I had. Fear was the next one. I asked myself silently, “What if she goes into the nursing home and starts accusing people of stealing?” They wouldn’t want her. She’ll just be a trouble maker.

... and then, when I think about it, this is ridiculous. Now here I am, a well educated and literate person having this kind of thought, what would it be like for someone who does not have my background and skills?

When Mom was discharged from the hospital after the cancer treatment, she had a home helper come in for a couple of mornings a week, to make her lunch and whatever. But she didn’t like her after the first week, so we dropped her. Mom was more restless when this home helper was around. She said the home maker made her only packaged chicken soup. She made it too salty and Mom didn’t like it.

(CG1-1)

Another daughter commented:

I doubt if my mother can adjust to the new environment: the institutional setting of the nursing home, the large number of staff at different levels... She is more or less like a young child now, clinging to me all the time.

(CG1-1)

Another son carer told me his embarrassment when he found that his mother's social judgement was impaired:

She [the mother] could drive me crazy. Once she asked an old man in his
seventies if the young child whom he was carrying was his son. Of course not, probably the kid was his grandchild. She lost her mind... she lost her sense of social judgement as well... I am not ready to let other people know about her poor condition.  

(CG-4)

Another son expressed his concern:

The social worker intended to arrange a volunteer to visit Mom, to keep her company... However, Mom was so confused, she might open the door to the volunteer today, and ignore her the next day. With anxiety and fear of this kind, I finally said no to the social worker.  

(CG-5)

Concerns about criticisms from other family members regarding relinquishing some caregiving responsibilities to an outsider constitute the next significant barrier to the utilization of formal help. This is exemplified below by a daughter-in-law:

It was most unfortunate that my father-in-law spread the word to his friends that we [the only son’s family] have been mistreating him. Several of his friends called and blamed us for placing him in the institution. Their criticism deterred us from making a definite plan on institutional placement until much later. The social pressure outside of the family circle was really difficult to cope with. We wish there was a small group of people who could appreciate our situation. Friends of my father-in-law were all in their seventies and eighties by age. They inclined to sympathize with him because they belonged to the older Chinese generation who tend to see institutional care as an equivalent of family abandonment.

... Thus, I feel the brother of my father-in-law was not the only one who was against us. The whole cohort of seniors was after us. The standard of care at this nursing home is quite good. To me, placing your loved ones in a care home does not imply an act of cruelty.  

(CG-7)
The availability of intimate relationships for sharing feelings and for discussing ways to cope with these feelings can reduce the need for outside help. However, some caregivers were not keen to avail themselves of counselling sessions, and they explained.

From a wife carer:

Given the busy schedule that I already had in arranging those caring tasks for my husband and his first wife, I didn’t have much time and energy to talk to other people about my own adjustments... I’ll turn to Pat for this sort of family talk.

(CG-8)

A daughter-in-law gave the following explanation for not seeking outside help:

I can confide this to my husband..., maybe my sister-in-law from Brampton is another one whom I can approach. My need for sharing with someone outside my immediate family is not very strong...

(CG-3)

Service Systems Context

The context of service systems refers to characteristics pertaining to the service providers including the availability, quality and cost of services that are in the caregiver’s local community. Obtaining formal services often involves out-of-pocket expenditure and some caregivers are reluctant to spend money for formal services at present for fear of future dementia-related costs (Mullan, 1993; Stephens, 1993). A few of my respondents did identify costs as obstacles to service use.

A daughter explained this problem concisely:

We didn’t have many funds set aside for meeting Mom’s needs... her personal savings were shrinking. I prefer to cook for her, rather than having meals delivered by the agency. We just could not afford the charges.

(CG-1)
A daughter-in-law carer quoted an actual example to illustrate how high cost could deter service use:

We learnt about the adult day care just last month. My mother-in-law was concerned about the charges. I said, “Well, don’t worry, we (adult children) will foot the bill for Dad. Since the day care centre provides hot meals, physical exercise, and group activities and so forth, it will expect families to bear part of the cost.” ... the next morning, my mother-in-law persuaded my father-in-law to cancel his visit to the centre, because she felt the charge would be an additional burden to us.

(CGC-3)

A son caregiver who retired the year before the study shared his concern:

Two of my older daughters are now working. The youngest one is still in college, but she has a stipend. With their partial support, the family’s financial condition has been improved and thus we can afford to pay for the extras towards my mother’s expenses at the nursing home. We didn’t approach the placement officer earlier on, our budget was tight.

(CGI-6)

The lack of effective marketing strategies on the part of the service providers in promoting service programs also explains insufficient participation of prospective clients. A daughter carer’s complaints are expressed below:

I didn’t even realize that there were day care centres. I haven’t heard of them. I have heard that my Mom could attend some kind of recreational programs for senior citizens, but the problems with those programs are that they start at about 10:00 a.m. How was she to get to them? The whole situation was just very problematic...

I guess I had done my investigation about a friendly visitor that they had, some kind of program about people coming in to visit. But I couldn’t find someone who was Chinese. And this was about the best I was offered. I sort of turned off because I was given such a run-around. I remember I spent about two days on the phone before I found out that I couldn’t even get someone.

(CGI-1)
In order to deal with the bureaucratic procedures more effectively, the family caregivers must assume an assertive stance, but this may add one more layer to the complexity of the caregivers’ lives. Zarit and Pearlin (1993) argue that this is a psychological dimension to the issue of service access (p.307). The caregivers cited above did not feel they were in control of decisions about services. They did not know what help they could expect or even what the rules of the game were. For example, families receiving in-home services were given little say over who would come out to their home though they could suggest when that person should come. In addition, carers also tended to decline formal assistance when trust was essentially lacking. This concern is confirmed by Zarit and Pearlin (1993) when they point out that family carers “do not take good advice unless they have implicit trust in the advice giver” (p.307). And as can be seen among my respondents, development of a helping relationship with service providers was necessary before they could make adequate use of services. A son caregiver identified the following as a priority for service improvement when I asked how satisfied he was with the nursing home facility:

... they must understand my mother’s circumstances. They must look out for my mother’s best interests, ... they must listen, not just aim at meeting the basic needs of lodging and care.

(CGI - 5)

In addition, concern about service quality was explicitly expressed by two carers.

A son explained thus:

I dropped the idea about nursing home placement after a visit to two of those homes. They were terrible, I mean, the residents were so severely impaired...; two of the nursing aid vacancies had not been filled...

(CG-4)
A daughter voiced criticism openly:

We would rather wait until a vacancy becomes available at that particular nursing home. The others which we have visited aren’t suitable. I mean... we are not impressed by the quality of care at some sites.

(CGJ-2)

Judgement on The Need for Formal Services

Before a caregiver decides whether to seek some form of assistance from the formal service system, he/she has to make a judgement on whether he/she is experiencing stress and whether the values, norms and expectations of the caregivers’ demographic and reference groups support the help seeking efforts. Sometimes barriers created by family, service systems and society are too formidable to permit the use of needed services. Caregiving research conducted among the ethnic minority groups consistently testifies to the vital importance of culturally defined caregiving attitudes and appraisal of stress in shaping coping mechanisms (Cox & Monk, 1993; Haley et al., 1995; Lawton et al., 1992; Morycz, Malloy, Bozich & Martz, 1992; Wood & Parham, 1990; Wykle & Segall, 1991). Shaws and his associates (1997) carried out a comparative study on Chinese in two different sites, one in Shanghai, China (n=110) and the other in San Diego, California (n=139). The researchers found that caregiving responsibilities were considered less of a burden among the Shanghai sample. My data render partial support to Shaws et al.’s (1997) findings.

Looking back at the early stage of the disease process, these caregivers felt no need for formal service assistance because they did not regard the relative with dementia as having a disease. In their mind, their relative’s occasional challenges was just part and parcel of old age. They were rather tolerant towards the cognitive decline until the behavioral deficits
sent a dangerous signal. Sometimes, the caregivers interpreted the change in their loved ones as a result of cultural shock and poor adaptation to the immigration requirements. Access to formal expert advice was sought only after they decided that either their relative was at risk or they themselves reached their limits. A daughter shared with me her decision making process:

Finally I got to a point that I told the social worker some of the things that were happening because what was beginning to occur was that my mother’s safety would be compromised.... she would be putting something on and forgetting it and leaving the kitchen. Also, she was getting lost... It was when she finally got lost that it clicked that it was Alzheimer’s. We always hear from the newspapers that people with Alzheimer’s wander and they get lost. At that point, I told the social worker... I expressed some serious concerns about her being here alone when I went back to school after the Fall...

(CGI-1)

Another daughter carer made a thorough evaluation of her own psychological state and concluded:

I was convinced that I must take the offer of the temporary residential respite. My mother was doing much harm to my marital relationship... I had to do something to prevent my breaking down... her stay at the nursing home, though temporary, gave me some time away from caregiving responsibilities... to permit my energies to be replenished...

(CGC-2)

The Linkages Between Informal and Formal Systems of Care

Using a national sample of Canadians aged 65 who have functional disabilities, Denton (1997) examined the validity of five competing explanations of the relationship between informal and formal care of the elderly. The five models are: the task specificity model (Litwak, 1985; Penning & Chappell, 1990); the substitution model (Edleman &
Hughes, 1990); the compensatory model (Cantor, 1979, 1991); the supplementary model (Stoller & Pugliesi, 1988); and the complementary model, which combines both the compensatory and the supplementary functions of formal care (Chappell, 1985; Chappell & Blandford, 1991; George, 1989). While there is some evidence to support the task specificity and substitution models, little consistent empirical data are available to confirm their validity (Denton, 1997). More recent research findings tend to support the supplementary and the complementary models of care. In the supplementary model, formal care supplements informal care with declines in health status. On the other hand, formal care is accessed when crucial elements of the informal network are lacking or when there is great need and the informal care system is unable to provide the assistance required. Chappell and Blandford (1991), based on their study in Winnipeg, Manitoba indicate that the formal systems can aid the informal network when health deteriorates sufficiently and when elements of the informal care network are not available. The informal care networks provide the necessary care when the formal system cannot do it all.

The Interdependence of Formal & Informal Systems of Support

A close examination of the caregivers’ experience in my study did confirm the presence of patterns established by the complementary model. Firstly, receipt of informal care relates positively to living in a multiple-person household, the availability of spouse and other family members. Conversely, receipt of formal assistance for these family carers is linked to the lack of availability of spouse or adult children. Utilization of home based health care services relates to age and the extent of cognitive and functional limitations of
the older relative.

Second, these family carers would firstly turn to other family members for assistance. Nevertheless, they did not necessarily follow a definite pattern in selecting helpers. Rather, physical proximity and the strength of the emotional ties were more important determinants in explaining their preference. Adult child caregivers involved in parental care would most likely approach their spouse (if available) and siblings. They would also seek help from their grown-up children. When significant elements of the informal network are lacking or when the need exceeds the coping ability of the informal care system, these carers would look for external resources. But external resources could be either privately paid or publicly funded. Several families engaged privately paid home helpers or home-based respite service. In general, they were highly satisfied with the quality of care provided to their relative. This is attested by the following caregivers:

The home helper came from 10:00 a.m. to 3:00 p.m. to prepare meals, to do the heavy housework. She also helped me to give Mom a bath twice a week. Mom was heavy and I could not manage it on my own. My family was happy with her service.

(a daughter carer - CGC3)

The home helper used to come for two hours on Monday and Friday afternoons, just to give us relief and she would do the grocery shopping as well.

(a son carer - CGC5)

Since my father-in-law refused to consider day care, we have hired a home-based helper to look after him on Saturday mornings... to give my mother-in-law temporary relief.

(a daughter-in-law - CGC7)
Apart from unavailability of informal help, caregivers would also turn to formal resources when the psychological cost of obtaining help from kin increases. Respondents explained this behavior thus:

Initially I hoped someone, maybe my husband’s uncle (brother of her father-in-law) could talk to him about the nursing home placement. But this uncle rejected the idea of residential care as much as my father-in-law. He gave us a real hard time and relatives in Hong Kong either called us or wrote to us... My husband was so hurt that he couldn’t face this uncle any more.

(daughter-in-law – CGI-7)

My mother wanted my two elder sisters to visit her. They said they were busy, could not spare the time... Once a month was just what they could possibly do. Finally, I gave up trying to persuade them. And in front of Mom, I just picked up the phone to pretend I was calling [my sisters]. Later on, I arranged for the home-delivered lunch. Mother could see somebody other than me...

(daughter carer – CGI-3)

I was mad with my sister... she wouldn’t even share part of the care... Finally, I decided that institutional placement was the only answer to mother’s need.

(a daughter carer – CGI-1)

The two eco-maps in the next two pages show the interdependence of the formal and informal systems of support in the Ho and Yeung families:

Grace, the daughter caregiver has been looking after her mother Madam Ho and sharing the residence with her (see Eco-Map 1). Informal support from her extended family members, including five brothers and their wives was alive and well. In addition, she would seek help from her husband and teenage children. The assistance from the extended family network came in the form of financial contribution, and psychological support. The next layer of informal sources were the privately hired home helper, her friends, the church and the cleaning lady and colleagues at work. But Grace obtained specialist support when it came to health care. The family consulted the family physician and the geriatrician on a regular basis while the visiting nurse came twice weekly. She was also in touch with the Alzheimer’s Society and a dementia care specialist day care centre for referral and information services. Grace felt she could
Eco Map I: The Ho Family

Finance
- Grace’s 5 brothers all contributed to caregiving expenses

Home Help
- paid by family
- 3 days a week
- great relief to family
- prepared meals & shared personal care

Extended Family
- 5 brothers and their families
- shared caregiving expenses
- all residents outside Ontario
- provided emotional support e.g. long distance calls
- annual family gathering

Health Care
- visiting nurse twice weekly
- visited family doctor every 2 months
- visited geriatrician every 3 months

Information Service
- provided by day care centre
- community resources

Day Care Centre
- on waiting list for priority consideration

Alzheimer’s Association
- enquiry only

Church
- Grace attended Sunday service
- pastoral team visits

Social/Recreation
- homemaker took Madam Ho out for walks once daily

Friends
- large circle of friends for Grace
- provided friendship and socialization

Cleaning Lady
- came in every 2 weeks

Transportation
- outreach service of day care centre arranged transportation to medical appointments

Work
- Madam Ho never worked outside the home
- Grace and husband had good jobs & stable income

Neighbourhood
- quiet, clean semidetached homes
- infrequent interaction

Key:
- Strong support
- Moderate support
- Irregular and little support
- Signify flow of energy and resources
- Formal care
- Informal care
Eco Map II: The Yeung Family

Extended Family
- husband's 3 brothers and their spouses
- all resided outside Toronto
- husband's sister was the primary caregiver
- shared caregiving expenses
- provided practical help and respite during weekends and long vacation

Health Care
- geriatrician gave medical monitoring

Privately Paid Home Helper
- paid by family
- a sitter service
- family satisfied with the sitter's service
- prepared meals & shared personal care

Friends
- George and Alice well integrated into the Canadian community
- friends were of diverse ethnic groups

Work
- Alice and husband were professionals
- stable income

Finances
- George's 3 brothers all contributed to caregiving expenses

Church
- Alice belonged to a Christian community
- Spiritual comfort

Neighbours
- infrequent interaction and distant
- care recipient moved house too frequent

Fraternal Association
- potential support for Mr. Yeung

Key:
- Strong support
- Moderate support
- Irregular and little support
- Signify flow of energy and resources
still manage the caregiving task marginally. However, she anticipated that institutional placement would be the ultimate answer in view of her mother's quick pace of deterioration. In other words, the needs of her mother would soon exceed the capacity of the informal network of care.

The eco-map of the Yeung family shows another caregiving scenario:

The family was largely dependent on its own informal system of assistance. Alice, whom I interviewed, was the daughter-in-law of Mr. Yeung. With the stable support of her husband and his kin members, she seldom acquired external help except for regular medical monitoring carried out by the family doctor. But Alice was also worried that there might come the time when her father-in-law would need personal care. “That would be our limit,” Alice firmly maintained. Therefore, the family would not exclude the possibility of nursing home placement in the future.

**Summary**

In this Chapter, I examined the linkages between informal and formal networks of care as experienced by the family caregivers. A great variety of forms of assistance were provided by immediate family members and close kin. The most frequently mentioned forms of help were direct monetary contribution, shopping and errands, supervision of safety and, for the more impaired relatives, light house-keeping chores, meal preparation and respite care. They also provided emotional support by listening to caregiving experiences, offering empathy and understanding for the difficult times, offering helpful insights and possible solutions to frustrating situations and accepting the caregiver as he/she expressed joy or anger about the caregiving experiences. Spouses, children and sibling carers made significant contributions to sharing parental care.

The research data further confirmed that geographic dispersion across regional jurisdictions, national boundaries, continents and oceans was indeed an impediment to
caregiving involvement but this was partially compensated by the helpfulness of the network members. This was most impressive in psychological caring activities. The carers in my study attached important personal meaning to the help rendered by their kin. This finding is consistent with current caregiving literature, which suggests that positive support appraisals would lead to beliefs of being cared for and feelings of dependable reliance.

The family caregivers would turn to formal help as well when informal assistance was lacking or when the caring demands exceeded their own limits. However, it was demonstrated that the help seeking behaviour was shaped by certain contextual factors. These included the socio-cultural and family context, the formal system context and the caregivers' own judgement on the need for formal support. Social and family factors included concerns about criticisms from others regarding relinquishing caregiving responsibilities to an outsider, or concerns about upsetting the relative if such help were sought. Additionally, the values, norms and expectations of the caregivers' reference groups could affect the carer's decision on service use. In addition, caregivers showed a preference for outside help when the psychological cost in obtaining the help of kin was excessive.

This chapter concluded with an exploration of the different models which delineate the relationship between formal and informal support. My findings support the complementary model because a high level of interdependence between the two systems was witnessed among the family carers in my study.
CHAPTER NINE

CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

An Overview

The findings of this exploratory study substantiate the extent and complexity of caregiving in Chinese immigrant families. As confirmed by the eighteen family caregivers participating in my research, there was close involvement in the provision of care to their older relatives when the latter were affected by cognitive impairment. However, their involvement and support was not without risk to their own well being. Typically, they felt confused about their relative's unexplained changes; often got angry at the situation; and found the diagnostic process long and frustrating. When signs of increasing disorientation, social withdrawal and definite loss of autonomy became explicit, the caregivers tended to assume more responsibility for decision making. On looking back to the difficult days which were full of despair and frustration, the dementia carers came to perceive the caregiving struggle as an endless war, a lonely journey and a fierce battle on many fronts.

Furthermore, the carers' experience revealed a unique paradox consisting of five recurrent themes. First and foremost, they were summoned to value who their relative had been in the past and to accept who the person had become. Second, in confronting an altered relationship, they learned to value the current relationship while cherishing the past intimacy. The third challenge to my study participants was to manage their own emotional response to the progressive decline of their loved one while dealing effectively
with the varied reactions of other family members. Keeping a delicate balance between providing adequate care to the relative and performing their own essential life tasks was the fourth care demand. The last lesson learned by the family caregivers was to sustain the stress of care while appreciating the gains and benefits arising from the labour of giving.

Caregiving of the demented relative occurs in the context of the immediate family and its close kin. My study clearly demonstrates that often the dementia process generates stress which in turn can bring families into a dysfunctional state. In providing care there are many decisions which have to be made by families. Most of the problems encountered are complex, multifaceted and involve a variety of possible options from which to choose. During this period of extreme distress, unresolved family conflicts from the past can reappear and may influence the decision making process. In addition, new difficulties may emerge requiring the family to tackle challenges outside their existing comfort zone.

In trying to work out satisfactory solutions to issues of conflict, changing roles and relationships, symptoms of stress, behaviour problems and prolonged dysfunctioning, a family can obtain resources from its own internal system as well as from its external environment. For the Chinese immigrants, the ability to maintain a solid family identity in the host country of Canada is a source of strength. Family rituals and certain positive family themes have assisted these families in transmitting the identity which has been put under considerable strain because of the wide geographic dispersion of its members.

Though small in number, the family case histories described in my study suggest
the variety of situations faced by carers. These inherent varieties include differences in living circumstances, gender of the care recipients and caregivers, duration of care provision, extent of acculturation to the host country and the specific kinship relationships that connect them. In the Ho and Lam families (see Genograms 1 and 2), Grace and June were caring for their mothers with whom they resided, whereas Rom (see Genogram 9) and Alice (see genogram 4) had to travel back and forth between their own apartments and that of their relative. Twelve of the eighteen carers were female and the remaining were male. The relationships between primary carers and their kin included six daughters (and their mothers); six sons (and their mothers); two daughters-in-law; two granddaughters, a wife and a sister-in-law. At the time of the research, eight carers were continuing to provide care at home, while ten had placed their relatives in nursing home facilities.

An additional point worthy of emphasis is that, these carers bore the burden of responsibility with different motives. While some caregivers had consciously or willingly chosen to take on the role, others simply felt that they had no viable alternative or that a commitment of care was implicit in the nature of family ties. In addition, in virtually all the situations studied, the major burden of work seemed to fall mainly on one person, although other family members also played a supportive function in the caregiving scenario. All the caregivers in the study were looking forward to some kind of outside assistance, for example, day care service. Nevertheless, many of them would not or could not fully utilize this help because of personal disinclination, family ethos, cultural beliefs, organizational barriers, and service constraints.
Implications for Social Work Intervention

In view of the findings described in the last three chapters, certain strategies should be developed at the micro, mezzo and macro levels to enhance the family’s caregiving capabilities. Yeatts, Crow and Folts (1992) have identified three types of knowledge barriers to service utilization; all of which are of special relevance to carers from ethnic minority backgrounds.

Intervention at the Micro Level of Direct Practice

The first type of knowledge barrier is related to the knowledge of or perceived need for a service. Potential clients who lack knowledge of the early signs of cognitive impairment will not recognize the need to obtain help. The majority of the respondents in my study were not well informed about the nature of dementia or the benefits and supports available. For example, June, a daughter carer (see Genogram 2), reflecting on a more general lack of awareness, bemoaned the fact that none of her early professional contacts had advised her about the course that her mother’s dementia was likely to take. Her mother’s decline would have been easier to handle, June felt, had she been able to anticipate the dementia process. Similarly, Rom, a son carer (see Genogram 9), might have been able to save his marriage had he understood better the “fabricated stories” told by his mother to alienate his wife.

Additionally, two nursing staff I met expressed the hope that families would seek help in the early stages of senile dementia, but many caregivers deferred such requests until late in the disease’s progress because of their lack of understanding and an
unrealistic belief in self-sufficiency. The family service coordinator of a nursing home facility who has handled a couple of such cases once explained that she hoped for early referrals because “I need to know the elderly person before the dementia sets in deeply, and then I've got something to that person’s history and identity to hold on to... But if I only get to meet the individual after he is far gone, then there is little to build on. You know, relationship building with the client is crucial to effective direct practice.”

There is, then, an urgent need to bring the clients who are not cognizant of their need for a service to a conscious awareness of that need. The use of outreach programs and public media, such as television and radio, should be introduced to breach this knowledge gap. Minority-oriented television and radio shows appear to be particularly effective. In an attempt to recruit family carers to participate in my study, I approached the program director who was in charge of a health care series at a Chinese television channel (refer to appendix 7). After I spoke on the social aspects of dementia care in the panel discussion, five families audience members phoned in to share their difficulties in looking after their demented relatives. One was also keen to find out how the disease would affect her relative’s self care ability in the future.

Insufficient knowledge of dementia services and their associated enrolment procedures constitute the next barrier to proper care. Studies consistently highlight the importance of making services known to those for whom they are intended (Brownlie, 1991; Cantor, 1979; Cox, 1993; Henderson, 1993). Over half of the caregivers in my research reported that the family doctor was the first person to whom they turned for expert assistance. However, virtually none of the caregivers received any substantial
guidance other than a brief statement pertaining to the medical diagnosis. Besides, the
diagnosis was often delivered to the family carers in a hurried manner by the physicians.
The following are examples of the carers’ painfully recalled experiences. Their physicians
announced:

This is a terrible disease with no effective medical treatment.  
(CGI - 2)

Hardly any cure, it’s irreversible...  
(CGI - 6)

I’m afraid nothing can be done... the family should be prepared to
provide total care.  
(CGI - 9)

You might need to start looking for a nursing home for your mother.
Bring her back in three months time for on-going monitoring... there is
little I can offer now as your family doctor.  
(CGC - 3)

Among those older residents who were still capable of staying in the community,information occasionally came from managers of the housing projects or senior
apartments. Again, these focal persons had failed to give the families any counsel except
reminding them to consider institutional placement as care in the community was no
longer a feasible alternative.

It seems that several strategies could be initiated to overcome this type of barrier.
First, health care personnel including doctors, and visiting nurses should be provided with
informational materials that could be readily passed on to the elderly and their families as
soon as a diagnosis was reached. In Toronto, I came across many useful printed
materials which were freely distributed to families, but unfortunately, all of those booklets and pamphlets are written in English. This may mean that Chinese families who are only proficient in their indigenous language will be denied the vital information and the subsequent care provision. Therefore, efforts must be strengthened to develop indigenous informational materials. Additionally, those at the focal point of initial contacts must be assisted in passing on the materials.

Many caregivers expressed frustration that their doctors did not have time for them to discuss their various concerns. Wai Ying (see Genogram 5), a daughter-in-law caregiver explained, “The doctor at the hospital just told us that it was either Alzheimer’s or something related to that. That was the only answer I got... He did not have time to elaborate, you know.” Continuing in the same vein, Mr. Leung, (see Genogram 7) reported that the doctor told him, “There is nothing I can do for your mother. There is nothing known medically at this point that would help her. If your family takes care of her, she will last longer, if not, she will lose ground soon.” Mr. Leung added later, “But the doctor didn’t tell the family how to take care of her. I had no idea where and how I could find help.”

Several caregivers also expressed the desire that they preferred the doctor to deliver the diagnosis without their relative present. Speaking privately with the doctor, a wife caregiver maintained, would give her “the necessary space to deal with her own initial response of shock, disbelief and sadness.” In view of the very concrete requests suggested by the caregivers, it is imperative that sufficient time and patience be allowed for the family carers to digest the information, to clarify perceptions and to discuss in
sufficient detail the course of the disease and its potential impact whenever a diagnosis is delivered.

While the family caregivers would appreciate an early diagnosis, they also indicated an earnest desire for a comprehensive needs assessment. The lack of a comprehensive assessment approach creates certain negative consequences. Firstly, each professional discipline might conduct its own evaluation on the older relative. But their separate reports are not necessarily put together to create a holistic picture of the older adult. Secondly, family carers are directed to different locations for different assessment purposes. Thirdly, the report so compiled rarely covers the carers’ abilities, needs and preferences. Carol, a granddaughter (see Genogram 3: the Mak Family) who did not voluntarily offer care to her grandmother described:

That was how I was dragged into the troubled water... My mother left grandmother to live on her own. I was never consulted on a personal basis... and the social service coordinator assumed I would take up the caring job willingly and naturally. I was desperate... I was seven months pregnant with our second baby. I didn’t want to avoid my responsibility, but it was not right that the entire burden was on me alone... Could somebody open his eyes and look into the situation and spare his ears to listen?

(CGI - 8)

Similarly, Breadshaw and Towell (1990) have urged social workers to move towards a more genuinely holistic model of assessment where client and carer wishes are central and aim at identifying a range of appropriate supports for clients, rather than standard service packages. Breadshaw and Towell further argue that the challenge for social work in the new era of community care is to arrive at “needs led” assessments and
deemphasize assessment for services. This is not an easy task for a social worker because he/she is bound to look at any situation in relation to services which already exist. It will need a change of organization, access to budget and some space in workload to enable the development of such an approach.

In order to provide a comprehensive assessment, a single entry point is recommended. This can be accomplished through establishing a number of single access centres which would combine information, referral, service coordination and service provision on a case management basis. Service prescription should then flow from the outcome of this assessment. The purpose of proper assessment of needs, as advocated by McWalter and associates is that, “it is a cornerstone for high quality care” (McWalter, Toner, Eastwood, Corser, Marshall, Turvey & Howie, 1996, p.1). At an individual level, needs assessment should focus on identifying the needs of those assessed with a view to determining how needs might be met, not on the suitability of clients for particular services. To follow from this, the essence of needs assessment is firstly to identify needs of care and secondly, to specify what type of care is needed. For example, the assessment should not just indicate the need for day care, but specify that day care is required for “social stimulation” for the withdrawn; counselling the person with dementia for “fearfulness and anxiety” or carer training for “management of challenging behaviour”.

As important as the assessment of the person with cognitive impairment was the statement of needs of the carer. In the carer’s assessment report, the professional worker should specify the health status and perceived needs of the carer. The carer should feel
free to describe his or her daily difficulties; the expectation for and actual availability of support. Also, the exploration ought to cover the affective as well as the attitudinal components because these factors tend to shape the appraisal of the caregiving situation and influence the outcome and the carer's response toward obtaining help. Such information would also help the staff member understand the strengths, potential and intentions of the carer. For example, a primary carer might say that she would stop giving care if no secondary supports are anticipated from other informal or formal caregivers.

Another advantage of a comprehensive study is to place the principal carer in relation to his other network resources and enable the person to achieve an overview of the circumstances. Alternate strategies for conflict resolution, handling of ambiguous boundaries between family subsystems and improvement of communication can be quickly identified by using tools such as "genograms", "eco-maps", "circular questioning" and "homework". Genograms and eco-maps have been widely used in my study and thus they need no further comment. Circular questioning, the third technique suggested here is designed to gather information about the behaviour that occurs around dementia. Circular questioning has been likened to asking family members to "gossip" about one another in order to identify differences between family members in their response to care. "Homework" is an assessment as well as therapeutic process through which the family members can highlight issues that they wish to resolve. When a staff member shares with several carers in the family his/her assessment, the latter will gain understanding as to how they have contributed to the maintenance of the problem.
Homework also encourages families to practice new ways of interacting. For example, if the primary carer is feeling unsupported, and would like some help from her sister in bathing her mother, she should tell the sister and practice working out a plan of action which is agreeable to them. Often, family members want to help, but are unsure how to provide the assistance.

**Intervention at the Mezzo Level of Program Design and Delivery**

The findings of this study also reveal some of the inherent problems encountered by the caregivers at the mezzo level. Yeatts and associates (1990) contend that access barriers exist when factors external to the potential client prevent the person from using a service. The major access problem reported by the caregivers was non availability. Support groups for dementia carers, counselling programs, short-term respite, day care and volunteer services have been provided in the Toronto community since the early 80’s but very few of the existing service centres are equipped to serve the Chinese minorities. Literature on caregiving in minority groups testifies that a potential client may have the knowledge of a particular service but lack the interest or desire to use them because the service is not culturally sensitive or specific (Maclean & Bonar, 1983, 1986; Morycz, 1993; Valle, 1981, 1989). For example, several carers in my study gently declined a nursing home placement which had no staff who could communicate meaningfully with the elderly in their own language. They pointed to the health care practice differences between their relative and the service provider. On the one hand, the reluctance might stem from a general suspicion of unknown cultures. But on the other, the tension could be
a result of past negative experience with persons from other ethnic backgrounds.

In an effort to overcome the access barrier I just described, the following strategies should be considered. These include ensuring minority group representation on advisory boards, hiring indigenous workers, engaging staff members who can speak the minority group language, sensitizing non-minority group participants and staff members to the discomfort felt by minority participants, developing an appreciation of minority cultures and vice versa. Making special arrangement for each minority participant to be accompanied by members of the same minority group when participating in centre activities could also be an effective intervention. Colen (1983) proposed that alternative methods to attract and engage minority clients should be implemented and evaluated. Appointing members of a minority group to serve as greeters in a day care centre with the express responsibility of making newcomers of the same minority group feel comfortable is worth trying.

Another approach to facilitate access is to arrange for caregivers to attend activities in ethnic groups, for example, educational seminars on Alzheimer’s Disease, and the service options organized in different localities. Forming car pools and other ride-sharing arrangements are also effective mechanisms. Resistance to service use can be overcome when the elderly persons and their carers are motivated to pay a visit to the centres to have an opportunity to be shown what the centres have to offer. If separating the delivery of services for a minority group from the delivery of services for other groups is not appropriate or economically viable, other alternatives could be introduced. Some organizations try to overcome this access problem by using the same facilities, such
as a dementia day care centres, but having separate services scheduled for different times of the day or different days of the week for different minority groups.

However, I am not advocating a care system based on systematic separation along ethnic lines. But the shared cultural knowledge and values of members of particular ethnic groupings may help to make the already disoriented elderly persons feel a degree of comfort and relaxation which, if experienced positively, may be beneficial to them and their family carers. Since the Chinese community is not a homogeneous group with uniform needs, individual differences and preferences must be respected. While some carers feel perfectly at ease in a multi-ethnic group, others would benefit more if they are enabled to become connected to their own group. Therefore, service providers should provide a diversified approach to service planning and delivery.

Additionally, the broadcast format of promoting the availability of services should be further enhanced. This type of publicity frequently affords the agency representative an opportunity for discussion on the program content, eligibility criteria and other important aspects of the service prior to actual program contact. Similarly, minority newspapers, natural community centres such as social clubs and fraternal societies have proved to be beneficial sources in informing caregivers of the availability of services. In recommending the use of outreach activities in engaging minority clients with service programs, Valle and Mendoza' (cited in Colen, 1983) have identified a critical path showing the process of integrating a formal and informal system. This path starts with a local link person (a work mate, or another family member) who is not necessarily more knowledgeable about services than the primary family carer, but who might know the
second contact, the community service broker (for example, the housing project superintendent or a public health nurse). These brokers were found to be more aware of potential assistance and were in touch with the third level of helper, the agency link person (for example, the social service worker).

Influential ethnic leaders in the local community can also be approached. Due to the important position these leaders occupy within the network of support services and the trust placed in them by minority clients, they constitute a critical link between clients and programs. Apart from advocating service use, these leaders can assist in collecting acceptable preferences for program features. Colen (1983, pp. 255) further suggested that “while the community service broker aided agency staff in understanding the client and his family and served as a buffer, the agency link person generally had established contacts in other agencies who could provide the services through culturally syntonic modes” (pp. 255).

The next type of access barrier emphasized by the interviewees in my study is affordability. Potential clients are less unlikely to use a service if the costs are high relative to their individual income. As most of the care recipients (n=16; 89 %) were not entitled to any pension benefits or retirement insurance, the major sources of their income were personal savings or contributions from their adult children. This placed them in considerable economic need. Without the protection of a reliable source of income, it is not uncommon for them to defer access to fee-charging services. Hence, provision of affordable community-based services must be a priority consideration in program design and delivery.
The last type of access barrier to service utilization concerns the relationship between the service provider and the prospective user. We usually consider access to services and the interface of formal and informal helpers solely from an organizational or management perspective, but often there are also important psychological dimensions of this process. Three issues: assertiveness, control, and trust can affect the worker-client-bureaucracy relationship. As there is more pressure to control costs, families may be faced with the task of becoming advocates for their relative or for themselves in order to obtain necessary services. The need to take on this assertive stance adds one more layer to the complexity of caregivers’ lives. For Chinese immigrants, knowing when and how to push a provider to do more is a skill not commonly found because they may not be able to articulate their needs. Therefore, special efforts must be made to assist them to understand their basic rights through advocacy programs. In addition, family caregivers and their relatives should be empowered to engage in more open discourse of their needs. As Aronson (1992a, p. 84) asserts, “in a culture that favours youth, physical vigour and self sufficiency, translating private experiences of physical and mental frailty and neediness into open and public issues is not an easy transition”.

A related issue is the extent to which families feel in control of decisions about services. Many families feel confused when they are confronted with a patchwork system of programs and eligibilities, or when they do not know what help they can get, or even what the rules of the game are. Additionally, services are sometimes provided in a way that further undermines control. A caregiver in my study objected fiercely to having a different person sent for each home care visit as her relative adjusted poorly to frequent
changes. Thus, for families to accept services, every care must be taken to enhance self-reliance and control. In addition, service providers should allow room for flexibility and openness when new administrative arrangements and service practices are introduced, so that expression of needs that “do not conform to the official discourse can be heard and met with innovative responses” (Aronson, 1990, p. 239). Flexibility and openness are of particular importance when increasing emphasis has been placed on the value of a single gatekeeper to service and efficient case management as ways of facilitating access, assessment, planning and monitoring.

However, the carers did not raise the issue of institutional or individual racism. Further studies are needed to inquire into any racist practice which might constitute an experienced barrier to access.

**Intervention at the Macro Level of Policy Initiatives**

Family caregiving for dementing illness presents a unique challenge to policymakers because often the interests of the family member and that of the caregiver do not converge and societal policies have to reconcile the divergent needs. Aneshensel et al. (1995, p.329) argue that “there are few precedents for policies that must consider both the disabled elder and his or her family”. For example, a major point of divergence may involve the decision to place a dementia relative in a nursing home or to continue care at home. This issue entails balancing costs and benefits for the relative, the caregiver and society.
From the family’s perspective, there are obvious risks associated with continuing in-home care. As experienced by many carers in my study, such risks include: financial expenditure; foregone earnings; social repercussions such as disruption of work and conflict with other family members; and damage to health and emotional well-being. However, from the viewpoint of the person suffering from the degenerative disease, the positive aspects of continued home care might outweigh the negative effects. In general, the care recipient tends to function better in familiar settings than in an institutional environment where he/she needs to learn new spatial information and routines (Hooyman, Gonyea & Montgomery, 1985).

There are considerable risks to institutional placements. Mortality rate during the first few months of admission are especially high and in some facilities, elderly residents also face the possibility of overmedication and excessive restraints (Greene, 1993). A further risk is the lack of stimulating physical and mental activity, which might hasten decline in remaining functional abilities (Duncan & Morgan, 1991). Of course, care in the home without proper support from relatives raises another set of problems, for instance, frequent falls, malnutrition and even self harm and abuse in the more extreme situations (Aneshensel et al., 1995).

Given the background of the likely divergent interests of the older relative and his/her family carer, policy makers must carefully deliberate on the controversies (Kane & Penrod, 1995). Kane and Penrod strongly recommend that as a guideline for a good long term family caregiving policy, intervention should aim at achieving several closely related goals. First, it should provide “a minimum floor of adequate care for each person
needing long-term care” (Kane & Penrod, 1995, p.167). As part of the minimum floor, Kane and Penrod specifically stipulate the ability to receive that care without compromising the ability to live in normal surroundings characterized by privacy, choice and control over day-to-day life. Second, it should maintain any self-selected mutually agreeable caregiving relationships between adults and elderly family members needing care. It follows that family carers should not be forced to provide care to elderly relatives in the absence of such agreement. Similarly, no adult parent should be “coerced to receive care from a particular child or grandchild, nor should anyone be conscripted into family care” (Kane & Penrod, 1995, p.167).

In advocating the rights of the family caregivers with demented relatives, Gwyther (1990) has helped a support group of family carers to formulate a Caregivers’ Bill of Rights. The Bill affirms the spirit of the policy proposed by Kane and Penrod (1995). The following clauses are particularly noteworthy:

The right to seek options that reasonably accommodate our needs and the needs of our loved ones;
The right to love ourselves and accept that we have done what was humanly possible;

The right to be free from feelings and thoughts that are negative, destructive, unfounded, and to work through feelings that are hard to understand.

(Gwyther, 1990, p.699)

Therefore, policy initiatives should be grounded in a comprehensive review of the multiple parties involved. It is not sufficient to address the older relative’s needs in isolation from the primary caregivers, nor those of the primary carers in isolation from the elderly or the rest of the family. Given the heterogeneity of needs, resources and
structural compositions of families, a variety of services should be flexibly and selectively available. This orientation to policy formulation calls for an integrated approach that seeks to build a partnership between caregiving families and support services. This further implies that adequate supports must be developed to assist caregivers throughout their careers as carers. The needs of the suffering relative change as impairment increases and caregivers' concerns would also alter. The mix of services, therefore, must be able to evolve over time in response to changes in the relative's condition and the family's ability to provide appropriate care. Informal care "should be viewed as a resource to be maintained, not subverted or displaced by formal support" (Anshensel et al., 1995, p. 338).

The second policy dilemma is to determine the uniqueness or distinctiveness of 'dementia' and whether a specific system should be developed to help families affected by this particular illness. Alzheimer's and related disabilities are often thought to be the cruellest of diseases. Family caregivers often attest to its long course and tragic end, its ability to rob its victims of their memories, histories, personalities and the very sense of self. Besides, family caregivers often suffer the additional anguish of doing difficult caring tasks without being rewarded by the appreciation and companionship of the person receiving care. However, some researchers have found that the caregiving experience of family members dealing with Alzheimer's are no different from other groups whose relatives are cognitively intact (Birke, 1987; Montgomery, Kosloski, Borgatta, 1988). For example, Montgomery, Kosloski, and Borgatta (1990), after controlling for the disability levels of the older person, found that people with Alzheimer's had similar needs.
for care. No differences were found among the caregivers of the three groups (Alzheimer’s Probable, Other cognitive impairment, and No Cognitive Impairment) in the levels of subjective or objective burden. The only significant variance was reported in the amount of duty/obligation expressed. Findings of this nature raise serious issues for the policy makers and service providers who advocate dementia specific programs of care.

Other literature on dementia care, however, portrays a different picture. Statistically, it has been shown that Alzheimer’s sufferers were almost twice as likely to go into nursing homes as the cognitively impaired non-Alzheimer’s group, and more than three times as likely to do so as those with no cognitive impairment. In addition, Alzheimer’s patients were described as being the most dependent upon others and therefore made greater use of formal services (Johnson & Catlano, 1983). Birkel (1987) also reported evidence that caregivers of dementia care expressed significantly greater negative feelings toward the recipients of their care. To sum up, at the end of the day, policy makers must come out of the debate to decide which is a more effective, efficient and equitable way of addressing the needs of dementia caregivers: to target services using the disease category as a classification, or look at other related variables such as the caregiving context.

Of the eighteen carers whom I interviewed, most preferred dementia specific placement or day care centres because they felt the staff have the required knowledge and professional skill to offer appropriate help. The environmental design and programme initiatives are also geared to promote maximum independence and autonomy. They also objected to excessive restraint which could be used to handle occasional challenging
behaviour and severe emotional outbursts in their relatives. Others mentioned that the “we feeling” — being in the same boat, could only be generated when group members in the carer support groups share similar struggles.

Implications for Research

Issues of public policy direction, program planning and delivery, and intervention effectiveness are constantly under scrutiny among those whose work is to enhance family caregiving. However, before suggesting concrete proposals and action plans for these matters, more basic questions need to be examined and this analysis calls for a new research agenda and methodological approach. What is the prevalence of family care? What exactly are the carers doing for their demented relatives? What subsets of the populations are engaged and what particular characteristics, such as household configurations and care sharing patterns among family members, are important? What effects does giving this care have on those who do so? What role can public policy play in accentuating the positive and eliminating the negative in this regard? What mix of in-home care and institutional service would be appropriate? And what would be the future demographic trends and economic changes that impact on the family’s ability to care?

The Need For Qualitative Analyses

In the past, we have benefited much from the findings generated by cross-sectional studies (e.g. Canadian Study of Health and Aging Working Groups, 1994a, 1994b; Cantor, 1979, 1983; Caserta, Lund, Wright & Radburn, 1987; Gonzaley, 1997;
Rosenthal, 1997; Smith, 1989; Stone, Cafferata & Sangle, 1987). But there is comparatively little information from qualitative analysis (e.g. Bar-David, 1992; Farran et al., 1991; Globerman, 1996; Hinrichsen, Hernandez, & Pollock, 1992) and longitudinal designs (e.g. Johnson, Catalano, 1983; Montgomery, Kosloski, & Borgatta, 1990; Yu et al., 1993). Therefore, more naturalistic inquiries and longitudinal studies are clearly needed to help us fill in knowledge gaps. Qualitative designs that seek to capture the dynamics of caregiving would certainly add depth and colour to the existing knowledge.

In the area of family caregiving, Gubrium (1988) and Matthews and Rosner (1988) have provided two examples of the fruitfulness of the qualitative approach. Their studies present a more complete picture on the strengths and strains experienced by families. Also, qualitative data may illuminate the interface between individuals, families and bureaucracies. In-depth data portraying the linkages between impaired relatives, their family and formal care systems might reveal that some barriers are more inhibiting than others, and the barriers to service use may be different according to service type.

However, to emphasize the importance of qualitative studies on dementia care in families does not negate the contribution of quantitative research. I am advocating more mixed method studies. For example, a quantitative study that would logically follow my qualitative research is to assess the prevalence and the significance of care sharing in the ethnic Chinese families. In my study, three network variables: shrinking informal network; feeling of helpfulness; and accessibility, were identified as associated with informal help. How valid and reliable are these indicators among other Chinese groups residing in other Canadian cities? A larger study conducted in different sites with a finer
conceptualization will likely lead to fruitful findings.

The Need For Continued Use of Longitudinal Designs

Longitudinal designs which are used to explore caregiving experience over time should also be utilised more frequently in research. In particular, good longitudinal studies can be powerful instruments in identifying the caregiving trajectory and the differential needs and patterns of service use at various points on the caregiving continuum. With such information at hand, we may learn why some carers persist despite hardship, while others, relinquish their caring tasks later. Additionally, some intervention programs are shown to be more effective at a specific phase of caregiving, for example, educational intervention in the earlier days of the diagnosis. Longitudinal data inject a temporal perspective which would help practitioners to address needs within a specified time frame. A further reason why longitudinal studies should be considered is the changing status of immigrant families. My study has only sampled care receivers and carers who are recent arrivals (10 years being the limit), but cultural attributes may be eroded gradually as immigrants become acculturated to the host country, and new ones are acquired. Thus, it would be interesting to determine if the caregiving experience of first generation immigrants is different from subsequent generations.

Research on Caregiving Gains

The primary thrust of caregiving research over the last two decades has centred on the negative aspects of the caring process (George & Gwyther, 1986; Haley, Levine,
Brown, Berry & Hughes, 1987; Wright, Lund, Caserta & Pratt, 1991). But in an experience that is generally regarded as burdensome, it is interesting to chronicle the satisfaction or the “uplifts” of care-giving (Kramer, 1997). In my study, many caregivers agreed that the positive experiences included a sense of achievement, closer bonds between caregiving family members, pleasure in seeing the family member improve and the satisfaction of fulfilling one’s duty. Thus, further research focusing on examining carers’ gratifications is warranted. If we can better understand the predictors of caregiving gains and distinguish them from the strain variables, then intervention strategies can be better targeted at alleviating the difficult circumstances of a particular subgroup, or controlling the negative factors that create undue stress.

Limitations of the Study

Every research study has its limitations and the first criticism of the present study is the retrospective nature of the research data. The concern may be that respondents are more likely to remember events and symptoms when the degree of discomfort and/or disruption to the routine is greatest. Some may point out that this is an inherent flaw in the design because it biases the issues that are most painfully remembered and related in detail to the interviewer. In response to this criticism, it must be reiterated that the purpose of my study is not to confirm or reject hypotheses or existing theories. Caregivers were invited to recall from memory and did speak from the “top of their head” as well as from the “bottom of their heart”, and so the resultant stories are well grounded in experience and reflect their views at the time. The findings gathered in my
study should expand our current understanding on the complexity of a life task which will be increasingly assumed by the average family.

A second limitation of my research is the source of referrals. Though a deliberate attempt was made to recruit openly family carers from the community using mechanisms such as the media, it was not very successful. The respondents who participated in the interviews were either referred by the nursing homes or were placed on the waiting list for day care or home placement service. This raises the concern that the sample represents those in the greatest need of assistance, those most willing to come forward for help or those already connected to some form of formal care system. It is possible that the sample presents the more extreme view of the situation. My research did not include families who might be coping with the caregiving demands most competently and do not perceive the need for outside help. Thus, in interpreting the data, this should be borne in mind. In order to better understand the latter group of family carers, similar studies should be replicated. It must be noted, however, that the sample in my study is described in detail to enhance transferability and that the goal of sampling was not representativeness for the purpose of generalising to the population.

A closely related issue to one described above is that my study does not identify carers by subtypes. It has been consistently documented in literature that the perceptions of care requirement and indeed commitment are different for son and daughter carers (Finley, Roberts, Banahan, 1988; Hooyman, 1990; Horowitz, 1985a; Walker, & Allen, 1991). Similarly, the motives prompting care provision for daughters might not be the same for daughters-in-law (Globerman, 1996; Kivett, 1989; Walker, Pratt, Shin & Jones,
1990). Furthermore, the type of assistance mostly needed by the care managers may not be the same as that required by the care providers (Archbold, 1983). To fully address such concerns, more research is needed in the future.

**Toward a New Conceptualization of Dementia Care**

Demographic changes and medical advances will bring more people into the eighth and ninth decades of life. And among all the changes that have occurred in dementia care, a gradual reconstruction of dementia has been initiated. Nowadays, men and women who have dementia have emerged “from the places where they were hidden away and walked onto the stage of history” (Kitwood, 1977, p.133). In the new era of understanding, dementias are no longer perceived as devastating diseases in which personality and identity are progressively destroyed. Instead, dementing illnesses are seen as forms of disability and how a person is affected depends crucially on the quality of care. While providing a safe environment, meeting basic needs and good care are all essential, the highest quality care comes with the maintenance and enhancement of personhood. The priority areas of understanding a demented individual should focus on the person’s abilities, values, interests and preferences rather than on the pathology and associated deficits.

This new conception also sets new parameters for assessing excellence in research. In promoting the new ethos of dementia care, the investigative skills required are not those of a dispassionate researcher (Kitwood, 1997; Marshall, 1997), but those that are energised by vision, commitment and engagement. The positive transformation
of care practice also brings a new paradigm to the care of the caregivers. Rather than expecting carers to set aside their own concerns, feelings and vulnerabilities and get on the caring tasks in an efficient way, the process of helping should sensitise them to their own spontaneity, possible negligence and indeed faults while they continue to gain confidence in giving, knowing and loving.

The strategic mission of the social work professional in this specialised field of practice, therefore, must go beyond piecemeal improvements in practice interventions; better staff development; more efficient running of organisations and careful co-ordination of programme design and policy initiatives. The greatest challenge confronting us is to transform the way dementia care is conceived, so that both caregivers and recipients maintain their distinctive individuality in the face of a cruel and exhausting affliction.
REFERENCES


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LIST OF ORGANIZATIONS CONTACTED FOR RECRUITING RESPONDENTS

Name of Organization & Address

(I) Community-Based Agencies

1. Yee Hong Centre for Geriatric Care, 2319 McNicoll Avenue, Scarborough, Ont. M1V 5L3.

2. Division of Family Service Association of Metropolitan Toronto, 55 Eglinton Avenue East, Ste. 701, Toronto, Ont. M4P 1G8.

3. Woodgreen Community Centre, Senior Service Unit, 835 Queen Street East. Toronto, Ont. M4M 1H9


5. Chinese Senior Support Services Association, 201, Tempo Avenue, Scarborough.

6. Hong Fok Mental Health Service, 260 Spadina Avenue, Ont. M5T 2E4.


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8. Family Caregiver's Support Network,  
    Self Help Clearinghouse Metro Toronto,  
    40 Orchard View Blvd.,  
    Ste 219, Toronto,  
    Ont. M4R 1B9.

9. St. Elizabeth Visiting Nursing Association,  
    10 Gateway Blvd.,  
    650 Don Mills,  
    Ont. M3C 3A1.

10. Victoria Order of Nurses,  
    50 Hallcrown Place,  
    Ont. M2J 1P7.

11. Community Occupational Therapist Associates,  
    3101 Bathurst Street,  

12. Visiting Home Makers Association,  
    1700 Merton Road,  
    Ont. M4S 1A1.

13. Home Care Program,  
    45 Sheppard Avenue,  
    7th Floor, Willowdale,  

(II) Institutions (Homes for the Aged & Nursing Homes)

1. The Chinese Community Nursing Home for Greater Toronto,  
    2319 McNicoll Avenue,  
    Scarborough, Ont, M1V 5L3.

2. Mon Sheong Home for the Aged,  
    36 Darcy Street,  
    Toronto, Ontario,  
    M5T 1J7.

3. Providence Centre (Alzheimer's Day Program),  
    3276 St. Claire Avenue East,  
    Ont. M1L 1W1.
4. Kennedy Lodge,
   1400 Kennedy Road,

5. Baycrest Centre for Geriatric Care,
   (Special Day Care Program)
   3560 Bathurst Street,
   Ont. M6A 2E1.

6. Fudger House – Home for the Aged,
   439 Sherbourne Street,
   Toronto, Ont. M4X 1K6.

7. Extendicare Bayview and North York,
   1925 Steels Avenue East.

8. Barton Place,
   914 Bathurst Street,
   Ont, M5R 3G5.

(III) Hospitals

1. The Queen Elizabeth Hospital,
   Medical Social Service,
   (Geriatric Psychiatry)
   550 University Avenue,
   Ont. M5G 2A2.

2. The Salvation Army Scarborough Grace Hospital,
   Social Work Department,
   3030 Birchmount Road,
   Scarborough, Ontario,
   M1W 3W3.

3. Mt. Sinai Hospital,
   Social Work Department,
   600 University Avenue,
   Toronto, Ont. M5G 1X5.
(IV) **Regional Geriatric Program**

1. Regional Geriatric Program (Central),
The Queen Elizabeth Hospital,
550 University Avenue,
Ont. M5G 2A2.

(V) **Psychiatrist in Private Practice**

Dr. Tat LO

Dr. Peter CHANG
Dear

I am Ms. Carrie Lee’s Ph.D. supervisor and I am writing in support of her research study on "Caregiving in Chinese Families with Cognitively Impaired Older Relatives". Ms. Lee has been a student in our graduate program for 3 years and has proven to be an extremely responsible and respecting colleague. She has held the Connaught Fellowship for two years and has been a fine student.

I am very familiar with the research in family care of relatives with mental impairment and Ms. Lee’s research will be a much needed contribution to the field. There is little research about the ethnic or immigrant experience of caregiving, particularly with Asian families. Ms. Lee’s research will help both policy makers and practitioners make decisions about programs and directions in family care.

In keeping with the University of Toronto requirements for ethical research practices, Ms. Lee’s research will be reviewed by a university ethics committee. She has already satisfied her doctoral committee that she will respect the confidentially of the study participants and manage the data responsibly. None of the identities of the participants will be revealed and all reports of the findings will respect their privacy and none will be identifiable. Her research protocol includes a letter of consent and information letter and any participants will be informed that they will be free to withdraw from the study at any time. The research approach will be very respectful of them and they will not be required to fill out any questionnaires or undergo any tests. I will carefully supervise Ms. Lee’s research and am fully confident that she is very capable and will respect all of the research ethics principles.

I am very enthusiastic about this research project. I strongly support it and believe that it will make a significant contribution to our knowledge about Chinese families’ experiences with impaired relatives, and in future, our programmes for them. I encourage you to also support this project. If you have any concerns about it, please contact Ms. Lee or myself (978-5900) and we would be happy to discuss this further.

Sincerely,

Judith Goberman, Ph.D.
Associate Professor
INFORMATION LETTER TO AGENCY
(Sample)

Name of the Executive,
Name of the Agency,
Address.

Date

Dear ,

I am a doctoral candidate at the Faculty of Social Work of the University of Toronto. I am conducting a study to explore the caregiving experience of Chinese families whose elderly relatives are cognitively impaired. The focus of the research is to discover how the immigrant status, family network characteristics, use of social support and cultural beliefs influence the ways the families manage and cope with their relatives.

To my knowledge, there have been no systematic attempts to understand the Chinese family’s experience in accommodating to the needs of their impaired relatives. It is anticipated that data collected from this unique group will shed light on the coping and adjustment strategies of these caregivers and subsequently inform us about how social programs should be organized to provide effective services.

In order to locate potential participants who might meet my research criteria, I need your assistance in identifying the family caregivers from your agency/clinic case files. Once you have identified them, please contact and ask them if I may call them. Appended is a brief synopsis of the study for you to give or read to prospective participants. After they have indicated their interest in participating, I will contact them directly within the next few days to arrange an interview.

The participation of the caregivers in the research will involve one to two private interviews of approximately two to three hours each. Participants will be asked to respond verbally to an interview schedule. Please rest assured that the responses given
by the caregivers will be kept in strictest confidence and none of the participants will be identified by name, or in any other way in the published reports on the study.

It is my sincere hope that valuable information gathered from this study can enable us to serve the impaired elderly Chinese persons and their families better. I will send you a summary of the major findings that will result from this research. I hope that you will be able to assist me in this important project. If you have any questions or concerns, please do not hesitate to contact me at (416) 490-0494 for further information.

Thank you for your assistance in advance.

Sincerely Yours,

Carrie LEE
B.Soc.Sc, MSW
CONSENT FORM FROM PARTICIPANTS

CONSENT FORM

Family-based Caregiving of Cognitively Impaired Members:
The Case of Chinese Immigrants in Toronto

I acknowledge that I have been provided with information which explained that Carrie Lee, a doctoral candidate in social work, is conducting a study to investigate the experience of caregivers in Chinese families with older relatives suffering from cognitive impairment. The research procedures have been explained to me and any questions that I have asked have been answered to my satisfaction. I understand that the information I give will be used to help benefit caregivers of elderly Chinese people in the future though I may not personally benefit from the study at that time. Findings from the study will be shared with social service agencies which strive to provide appropriate social programs to cognitively impaired Chinese senior citizens and their relatives.

My participation in the study will involve one to two interviews of approximately 2 to 3 hours each. The interviews will be taped and analyzed. The tapes will be kept very safely in locked cabinets and only the researcher will have access to them. In the interview, I will be asked about the tasks I perform in providing care to my relative and how I feel about them. I understand that all information that I share will be coded in such a manner that neither I nor my relative can be identified. I also understand that the data will be kept completely confidential. All data will be used solely for research purposes and no information will be released or printed that would disclose my personal identity or that of my relative without my permission.

I understand further that my participation in this study is entirely voluntary and if I have any questions about the research procedures, I can ask now or in the future. I know also that I am free to withdraw my participation from the study at any time. My decision to participate or not to participate will not affect any services that I may receive from the agency.

I hereby give consent to participate.

Participant’s Name (print)  Witness’s Name (print)

Participant’s Signature

Date
接受訪問同意書

我承認就讀多倫多大學社會工作系博士課程之研究員，李賀元女士，曾向我解釋她將要進行的研究。該項研究是探討老年癡呆症患者家庭，在照顧方面的經驗。李女士已經解釋清楚該研究之步驟。本人所提出的問題亦獲得滿意的答覆。我明白研究之成果，在此刻而言，對本人沒有直接益處，但將來會令其他的護老者受惠。研究的結論將會提交予社會服務機構，其最終的目標是為華裔家庭提供適切社會服務。

我將會接受一或兩次的訪問。每次大概需要兩至三個小時。為了方便進行分析，訪問之內容將會被錄音。錄音帶會存放在鎖好的文件櫃中。訪問時，我會被問及有關我如何照顧患有老年癡呆症之家人。我明白我的資料會絕對保密，未得我同意之前，決不會被披露。

我接受訪問是純粹出於自願。甚至在訪問期間，我可以隨時提出終止該訪問。最後，接受或不接受該項訪問，都不會影響我將來所接受的任何服務。

本人現在以書面簽署（同意書），以表示本人的贊同。

接受訪問者姓名

接受訪問者簽署

見證人

日期

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INTERVIEW GUIDE

Part A

(I) Demographic Particulars (The Care Recipient)

Now, I would like to ask you some background questions on your elderly relative (Y).

When was Y born?

What is Y’s gender?

What is the marital status of Y?

Does Y have a religious preference?

Has Y received any formal education?

What language did Y first learn and still understand?

What language or dialects does Y often use at home?

Has Y ever worked outside the Home?

If yes, what was the nature of Y’s job?

Is Y working currently?

What is Y’s work status?

What is Y’s total annual income from all sources?

What is the main source of Y’s income?
(II) Immigration History & Level of Acculturation (The Care Recipient)

Now I would like to learn something about your relative’s immigration history.

Where was Y born?

If foreign born, when did Y come to Canada, to Toronto in particular, as a landed immigrant or citizen?

How old was Y then?
What was the most important factor in making Y decide to come to Canada, and to Toronto in particular?

Tell me about the experience of Y as a new immigrant in Canada.

In your immediate family, who was the first one to come to Canada?

Now I would like to learn about the daily experience of Y in a foreign culture.

Did Y belong to club(s)s and/or organizations or participate in activities organized by these organizations?
(prompt: What is the nature of the group and what does it do? Are most of the members of that clubs from the same ethnic group as Y?)

How did Y celebrate special occasions such as birthdays, and festivals? How did Y feel about them?

Who are Y’s close friends?
(prompt: Do they have the same nationality by birth as Y? Do they share the same mother tongue?)

(III) Demographic Particulars (The Care Provider)

Now, I would like to ask you some general background questions about yourself.

In what year were you born?

The gender of the respondent (checked by the interviewer)

What is your marital status?

Do you have a religious preference?

Have you received any formal education?
What is the highest level of education you achieved?

What ethnic group do you feel you belong to?

What language did you first learn and still understand?

What language and dialect do you often use at home?

Have you ever worked outside the home?

(IV) Immigration History & Level of Acculturation (The Care Provider)

Now I would like to learn something about your own immigration history.

Where was Y born?

If foreign born, when did you come to Canada, to Toronto in particular, as a landed immigrant or citizen?

How old were you at that time?

What was the most important factor in making you decide to come to Canada, and to Toronto in particular?

Tell me about your initial experience as an immigrant in Canada.
  (prompt: Did you have difficulties in adjusting to the new environment? What efforts have you made to overcome them?)

Now I would like to learn about your daily experience in a foreign culture.

Could you tell me what clubs and/or organizations you belong to or take part in?
  (prompt: What is the nature of the group and what does it do? Are most of the members of that club(s)/organization(s) from the same ethnic group as yourself?)

How do you celebrate special occasions such as birthdays, weddings and festivals? How do you feel about them?

Who are your close friends?
  (prompt: Do they have the same nationality by birth as you? Do they share the same mother tongue?)
Part B

(1) Disease Development

Now I am going to review the history of Y's disease with you.

Recognition of Symptoms

Looking back, when would you say you first began to notice difficulties with Y?

What did you think it was?

What kind of problems did you encounter?
   (prompt: memory; disorientation, confusion, communication, losing and hiding things, difficulties with driving, wandering, hygiene; sleeping, handling of money, violence, social embarrassment, logical reasoning, repetition etc.)

Under what circumstances did these occur?

How often did they take place?

Response & Coping

What did you think about the disease in the beginning?

Did you feel that you understood it?

What did other family member(s) think about it?

How did you and other family members try to handle the situation when you noticed it?
   (prompts: What was the outcome? What led you to do so?)

Did you talk to other people / how did you go about his / her behaviour?

What was their response?

Did it help or not, why?
(2) Seeking Professional Help

Now let's talk about seeking help from professionals when you first noticed the problem.

Did you turn to any professional person, such as your family physician for help when you first noticed the trouble?

Can you tell me about the experience?
   (prompt: What happened, diagnostic tests conducted? Diagnosis? What you feel about the diagnosis? Did it affect your relationship with Y after learning the diagnosis?)

Did you seek help from sources other than the family doctor?

What did you want when you sought this help?

What was their response? How did it work out?

(3) Physical and Mental Health Status of the Family Member?

Now, I would like to ask you a few questions related to Y's general health situation.

What is Y's physical health status now?

How would you see Y's degree of independence in doing the following?
   (prompt: e.g. shopping for personal items, managing money, using the toilet, preparing meals, getting around in the house, getting around outside the house, taking medication, dressing, bathing.)

What characterises Y's mental functioning now?
   (prompt: Has sudden changes of mood, is unaware of limitations imposed by illness, shouts or yells, threatens to harm others, destructive of materials around him/her, e.g. tears up newspapers, breaks furniture.)

(4) Prior Knowledge of Alzheimer's Disease

Have you ever heard of senile dementia? Alzheimer's disease?

What is the source of your information?

What does it mean to you?

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(5) Caregiving Involvement of the Family Member

How long have you been providing care to Y?

How many hours per week do you spend in caring for Y?

Describe to me a typical day in providing care to Y.
(Prompt: Kind of assistance provided, frequency of help.)

Do you have other people to help you out in taking care of Y?
(Prompt: Who are they? Why is so and so involved? Why is so and so exempted? What do other caregivers do? How often? Does it work out well? What sort of problems are created, if any, by sharing the caregiving responsibilities?)

What impact do these caring tasks have on your life?
(Prompt: Family relationships with others, employment, social entertainment, financial constraints, sense of privacy, vacation plans, relationship with Y?)

How do you handle the problems created by the caring responsibilities?

Tell me about how it feels to provide care to Y?

You have been caring for Y so far, why do you do so?

(6) Social Support from Family and Kinship System

I shall now ask you a few questions related to your family and kin.

Do you have members of the immediate family living in Canada, in Toronto? Who are they? How far away do they live?

Can you tell me about your relationships with them?

Which of the above do you feel close to?

Compare and contrast the family relationships and size of your kinship network here and that in the country of origin, what are the major differences? What changes have taken place in Toronto?
(7) Use of Social Support

If you were to list the names of the relatives who are available to you for support in your caregiving responsibilities, how many people could you count on for support?

How easy is it for you to contact these people?

As a group, how often do they help you?

How satisfied are you with their support?

Is there one specific person that you can rely on to share your caregiving burden?

Other than your family members and kin, do you seek help from community service agencies in providing care to Y? Why or why not?

What services have these agencies provided? How satisfied are you with them?

What changes would you prefer to see in these service agencies?

What single type of community services would you most like to have available?
ADVERTISEMENTS IN CHINESE NEWSPAPERS

世界日報 (World Journal Daily News), June 17, 1995

華裔耆老調查研究

明報 (Ming Pao), June 17, 1995

華裔耆老調查研究

星島日報 (Sing Tao Daily), June 18, 1995

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INVITATION LETTER TO SPEAK AT THE
PANEL FAIRCHILD TELEVISION

FAIRCHILD TELEVISION 香港電台

Fairchild Television Ltd.
35 East Beaver Creek Road, Richmond Hill Ontario L4B 1Z3
Phone: (905) 682-7120 Fax: Executive Office - (905) 682-7120 News & Production - (905) 682-7110

Sept. 2, 1995

Ms. Carrie Lee
Ph.D. Candidate
University of Toronto

Dear Ms. C. Lee,

On behalf of the Television and the audience, I would like to extend the greatest gratitude to your appearance at our program named "The Healthy Way Out".

Your expert opinions contributing to the following topic(s) are very much appreciated:

Dementia & Care-Giving

Without your professional contribution, our program can not achieve any success.

Thank you very much again!

Yours faithfully,

[Signature]

OTTO LEE
Production Controller
Ms. Carrie Lee
Ph.D. Candidate
University of Toronto

Dear Ms. C. Lee,

Thank you very much for accepting our invitation to be interviewed at our program named "The Healthy Way Out".

This is to confirm the date and time for videotaping, unless specified, all the taping work will be held at our studio at the above-stated address.

Topics: Dementia & Care-Giving
Date: September 2, (Sat.) 1995
Time: 10:30 a.m.
Remarks: Free make-up & service will be available during 10:00 - 10:30 a.m.

This is an informational and educational program with aim at increasing audience's awareness to psychological well-being, to promote mental health, also to provide alternative ways to cope with problems and life in more healthier ways. In view of this and in line with our Television's policy, without prior mutual consent, content facilitate commercial benefits of any specific individuals and/or institutions is not allowed. The speaker's contribution to our program will be acknowledged in the form of roller credits by end of the concerned session(s).

To get an overview about the content/questions being discussed/asked during the session, please refer to the appendix for details.
Should you have any questions, please feel free to contact our program's hostess Ms. Zion Ping Law at Phone/Fax: (416)462-0977 or pager (416)501-1531.

Thank you very much again for your expert contribution and we are looking forward to seeing you.

Yours sincerely,

[Signature]

OTTO LEE
Production Controller
STANDARD SYMBOLS FOR GENOGRAMS

The following standard symbols have been used in describing the genograms of the families in Chapter 7.

(A) Family memberships and structure

- male
- female
- Identified Patient
- died in 1948
- d.1948
- died at 78 yr old
- d.78
- marriage
- marital separation
- divorce in 1972
- children listed in birth order, beginning with oldest on left

48 45 41
(B) Family interaction patterns

- **Close relationship**
  - and arrow signifies flow of support and resources

- **Very close relationship**
  - and strong support
  - signified by double line arrow

- **Conflictual relationship**

- **Estrangement or cut off relationship**

- **Fused and conflictual relationship**