The Caregiving Experience: A Comparison of Adult Daughters of Community Dwelling Parents With and Without Dementia

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ABSTRACT

This case-control study compared the caregiving experience of adult daughters of parents with and without dementia who resided in the community. A synthesis of diverse theoretical perspectives, developed by the researcher, provided direction for this study. The data used in the analysis were drawn from the 1991-92 Canadian Study of Health and Aging.

A representative sample of one hundred and six daughters of parents with dementia and forty five daughters of parents without dementia provided information regarding the context, stressors, and the level and correlates of depressive symptomatology associated with provision of care to parents. Analysis revealed both similarities and differences between the two groups of caregivers.

With respect to the context of care, findings indicated that in large measure, daughters of parents with dementia tended to be slightly older, single or widowed, co-resided with their parent and used more formal care services when compared to daughters of parents without dementia. Differences between groups were also found regarding the stressors they experienced while providing care. More specifically, daughters of parents with dementia assisted with more personal and instrumental care. Their parent's functional status was more impaired and they contended with more behavioural disturbances and experienced greater burden than daughters of parents without dementia.

There were no statistical differences between groups with respect to mean scores on the CES-D scale. However, fully one quarter of daughters of parents with dementia and one fifth of daughters of parents without dementia achieved scores indicative of at least a mild level of depressive symptomatology.

Finally, self reported health, health interferences, the need for additional formal care services and feelings of caregiver burden were associated with depressive symptoms for both groups of daughters. In addition, for daughters of parents with dementia, depressive symptoms were associated with the provision of personal care tasks, behavioural disturbances and the functional status of parents.

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The press of green over
and the ritual of leaves
the wood has settled
into its prime dimensions
the lines etched in the light
pouring in from all sides.
Walking through
I can now see where the main path ends
and the others
branching off like veins on a leaf.
The palm of a hand
with a well-marked lifeline.
A wood thickened with possibilities.

The sky, bluest in the north
and visible only in snatches before,
has opened up all around me,
as if the clouds have lifted at last.

(adapted from Late Autumn Woods written by Rina Ferrarelli)

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DEDICATED TO

Samuel and Herbena Ellenor

To laugh often and love much;
to win the respect of intelligent persons
and the affection of children,
to earn the approbation of honest citizens,
to appreciate beauty;
to find the best in others;
to give of oneself;
to leave the world a little better,
whether by a healthy child,
a garden patch or a redeemed social condition;
to have played and laughed with enthusiasm
and sung with exultation;
to know even one life has breathed easier
because you have lived -
This is to have succeeded.
(written by R.W. Emerson)

CHAPTER 1

INTRODUCTION

One of the most devastating and debilitating health conditions that may develop with advancing age is a dementing illness. The Canadian Study of Health and Aging Working Group (1994) estimates that approximately 123,900 Canadians aged 65 and over living in the community are experiencing dementia. The care of such individuals rests in large measure with members of their families, in particular, adult daughters. Indeed, a large proportion of adult daughters feel a sense of responsibility for the well-being of their parents, in particular, those with declining cognitive capacity (Abel, 1990; Birkel & Jones, 1989; Brody, Kleban, Hoffman & Schoonover, 1988; Cicirelli, 1992; Rubinstein, 1990). This sense of responsibility is evident in the care that they provide, which may ultimately have consequences for their own health and well-being. One such consequence is depressive symptomatology.

While much research has focused on depression and caregiving, methodological limitations preclude generalizing to the experience of Canadian women at large. Studies that were conducted in the United States do not necessarily reflect the situation of adult daughters in Canada. Canadian studies, in large measure, employ small samples that derive from clinical settings and therefore may not reflect the situation of Canadian daughters in general. Consequently, the overall purpose of this study is to compare the caregiving experience of adult daughters of parents with and without dementia who reside in the community.

REVIEW OF LITERATURE

The following literature review begins by describing cognitive impairment and the concomitant challenges of care. It then reviews research pertaining to the context within which informal care to older adults is provided, continues with stressors associated with care and the prevalence of depressive symptomatology among caregiving women. The concluding section identifies gaps in research and offers a critique of previous studies which the present study begins to redress. Wherever possible, the literature reviewed deals specifically with the experience of adult daughters.

Cognitive Impairment

This section focuses on the natural course of dementing illness and the challenges to care resulting from such illness.

The Natural Course

According to the American Psychiatric Association's Diagnostic and Statistical Manual (DSM-111-R, 1987), dementia refers to a multifaceted syndrome characterized by "impairment in short and long term memory, associated with impairment in abstract thinking, impaired judgment, other disturbances of higher cortical function, or personality change" (p. 103). Recent Canadian statistics suggest that Alzheimer's disease accounts for 64% of dementia cases; vascular dementia accounts for 19% of cases; and other non-specified diagnosed dementia accounts for the remaining cases (Hill, 1994). Progressive dementias such as Alzheimer's disease may have a clinical course ranging from 2 to 20 years, however cognitive decline generally occurs over a 7 year period (Abrams, Beers & Berkow, 1995).

Although the course of dementing illness is unpredictable, it usually begins insidiously and may include mild memory loss, personality changes, decreased ability to perform complex tasks (Abraham et al., 1994), emotional changes (Biegel, Sales & Schulz, 1991), altered attention span (Davies, 1991; Katzman, 1986; Mace, 1990) and repetitive actions (Kane, Ouslander & Abrass, 1994). Informal caregivers at this stage may attribute these symptoms to temporary changes in the environment or the individual (Biegel et al., 1991). As the dementia progresses, behavioral problems such as wandering, uncooperativeness, physical aggressiveness and severe agitation (Abrams et al., 1995) may occur. Eventually, paranoid delusions, hallucinations (Filley, 1995) as well as profound short and long term memory deficits, and increased difficulty performing activities of daily living become apparent (Collins, Given & Given, 1994). During the final stages of a dementing illness, all language abilities are lost and the individual is unable to perform any of the activities associated with daily living (Filley, 1995; Reisberg, Ferris & De Leon, 1982).

Throughout the progression of the disease, there is an increasing dependence on caregivers. Finally as a consequence of the disease process, individuals become bedridden, mute and incontinent (Filley, 1995) and complete dependence on the caregiver occurs (Collins et al., 1994).

Challenges of Care

When family members engage in the provision of care to a relative with dementia, they frequently find themselves in intense and interpersonally demanding situations (Cohen & Eisdorfer, 1988). In addition to assisting with daily maintenance activities such as cooking, cleaning, dressing and personal hygiene (Green, 1991), caregivers may be required to spend sleepless nights trying to ensure the safety of their relatives. Often times, older adults with a dementing illness wander aimlessly in the middle of the night, rummaging through dressers and urinating in inappropriate places (Gwyther, 1990; Mace, 1990). These older adults become increasingly at risk for falls and other accidents (Abrams et al., 1995) such as injuries from using the stove and driving the car (Lach, Reed, Smith & Carr, 1995). The necessity for round-the-clock vigilance culminates in a "36-hour day" because of the seemingly endless responsibilities involved (Mace & Rabins, 1981).

Attempting to deal with the behavioral disturbances of a cognitively impaired parent is yet another challenge that family caregivers confront

(Hinrichsen & Niederehe, 1994; Schulz & Williamson, 1991; Woods & Ashley, 1995). Stress may be intensified as caregivers attempt to deal with behavioral disturbances in counterproductive and ineffective ways (Hinrichsen & Niederehe, 1994; Neundorfer, 1991). During the early stages of the dementing illness, they may view the older adult's behaviour as purposeful because of the periods of lucid moments (Noelker & Somple, 1993). This can lead to feelings of guilt (Gwyther, 1990) and denial of the disease process (Noelker & Somple, 1993). Behavioral disturbances are rated by caregivers as the most stressful aspect of caregiving (Haley, Brown & Levine, 1987). Embarrassing behaviours such as inappropriate sexual advances, making accusations, incontinence, wandering and combativeness may result in social isolation of caregivers (Brody, 1990; Mace, 1990) and possible institutionalization of parents (Jackson, 1995). Witnessing the gradual deterioration of a loved one has been described by caregivers as a "living death" (Haley, Levine, Brown, Berry & Hughes, 1987).

Context of Care

This section explores the experience of women as caregivers and includes socio-demographic characteristics and information about their physical health status and use of formal services.

Women As Caregivers

It is estimated that 123,900 Canadians over the age of 65 with dementia are living in the community and that 98% of these older adults have an informal caregiver (Canadian Study of Health and Aging, 1994). For the majority of these individuals, their caregiver is a woman, either a spouse or a daughter. Research demonstrates that women assume primary responsibility for the provision of care to a family member with dementia in an effort to maintain their relative in the community for as long as possible (Horowitz, 1985; Ory et al., 1985; Shanas, 1979; Springer & Brubaker, 1984). In many situations, adult daughters are expected to assume the role of primary caregiver when a parent is unavailable or unable to provide the required assistance (Atkinson, Kivett & Campbell, 1986; Birkel & Jones, 1989; Chappell, 1992; Neysmith & Nichols, 1994; Noelker & Townsend, 1987).

Daughters are more likely than sons to provide informal care to a parent with dementia. In a study examining patterns of parent care on the basis of sibling network, Coward and Dwyer (1990) reported that a greater proportion

(77%) of daughters than sons (23%) provide care to an impaired elderly parent. Daughters also provide more hours of assistance than sons (Coward & Dwyer, 1990). In one study, daughters spent an average of 30 hours/month providing assistance when compared with sons who provided 15.1 hours/month of care (Stoller, 1983).

With respect to the type of care provided, daughters are more likely to provide assistance with indoor household chores, meal preparation, transportation and personal care tasks; whereas sons are more apt to assist with financial management and tasks associated with household maintenance (Abel, 1990; Horowitz, 1981; Stephens & Christianson, 1986; Stoller, 1983).

Some researchers have reported that caregivers who reside with a person with dementia experience higher levels of stress (Eagles, Craig, Rawlinson, Restall, Beattie & Besson, 1987; Grafstrom, Fratiglioni, Sandman & Winblad, 1992; Hooker, Monahan, Shifren & Hutchinson, 1992), poorer physical (Brodaty & Hadzi-Pavlovic, 1990) and mental health than non-resident caregivers (Grafstrom et al., 1992). It may be that caregivers who reside with a parent who has dementia become more involved in the provision of care and thus are more apt to experience negative outcomes of such care (Schulz, 1990).

Physical Health of Caregivers

The provision of care to a family member with a dementing illness has been linked to the development of physical health problems among women caregivers (Chenoweth & Spencer 1986; George & Gwyther, 1986; Moritz, Kasl & Ostfeld, 1992; Neundorfer, 1991; Pratt, Schmall, Wright & Cleland, 1985).

Physical health problems may exacerbate the stresses of caregiving. These include interrupted sleep, chronic fatigue, muscle aches and irregular eating (Pratt et al., 1985). Other caregivers of demented relatives experience heart attacks, ulcers, fractures from falls or prolonged illnesses as a consequence of the demands of caregiving (Chenoweth & Spencer, 1986). Although statistical analyses were not conducted specifically on the experience of adult daughters, Haley et al. (1987) report that 14% of family caregivers were hospitalized for health problems such as low back pain, back surgery, and cardiac symptoms. These results must be viewed with caution due to the lack of a representative sample. Participants were drawn from an Alzheimer Society, were recruited by physicians, or through newspaper and radio advertisements.

Baumgarten, Battista, Infante-Rivard, Hanley, and Becker (1992) report that caregivers of older adults with dementia experience a higher frequency of physical health problems including persistent coughs, fatigue, chest pain and headaches when compared to noncaregivers. Caregiving wives experience more physical health problems than daughters. Their study used a convenience sample of caregivers of demented family members drawn from a geriatric assessment unit. Less is known of the experience of adult daughters due to the small number of daughters interviewed (N=21).

Use of Formal Services

The literature suggests that formal services such as support groups and respite care may be helpful in mediating feelings of stress and may lead to less depressive symptoms among caregivers (Cairl & Kosberg, 1993; Pallett, 1990). Generally speaking, however, utilization rates of formal care services are low (Kuhlman, Wilson, Hutchinson & Wallhagen, 1991; Shantz, 1995). Some reasons cited include a lack of knowledge of existing services (Caserta, Lund, Wright, & Redburn, 1987), perceived or actual financial cost (Graham, 1989; Hay & Ernst, 1987), negative attitudes towards the receipt of assistance (Scott & Roberto, 1985) and a lack of trained people for services such as homemaking (Ontario Ministry of Health and Ministry of Community and Social Services, 1987).

There appears to be a relationship between the level of depression among women caregivers and their perception of the adequacy of social support received from others (George & Gwyther, 1986; Mohide et al., 1990; Robinson, 1989; Schulz & Williamson, 1991). The frequency of support received from others is less important than the caregiver's perception of the adequacy of support received (Given, Collins, & Given, 1988; Lawton, Body

& Saperstein, 1989) and may have an impact on the stresses associated with caregiving. Caregivers who indicate a need for more social support often have lower levels of affect (George & Gwyther, 1986) and significant levels of depression (Noelker & Townsend, 1987; Robinson, 1989; Schulz & Williamson, 1991).

Mohide and colleagues (1990) conducted a randomized trial of the effectiveness of supportive interventions for family caregivers of a community dwelling older adult with moderate to severe dementia. Sixty caregivers were stratified according to their gender and whether the family member with dementia attended a day program. Prior to the trial, both groups reported above average levels of depression. After six months the levels of depression were unchanged. However, the experimental group when compared to the controls, reported that their caregiving role was less problematic. They also reported an improvement in their quality of life, increased satisfaction with nursing care and a delay in institutionalizing their relative with dementia.

Noelker and Townsend (1987) investigated depression among intergenerational caregivers (N=109) of a cognitively impaired parent by comparing them to a group of noncaregivers (N=44). There were no differences in the level of depression between the caregiving and noncaregiving groups. However, higher depression scores were found among caregiving daughters and sons, who felt their parent's needs were not met by formal and informal sources of assistance. Those who were satisfied with the use of community resources had lower depression scores.

Stressors Associated With Caregiving

This section focuses on some of the stressors associated with the provision of care including functional decline and behavioral disturbances of parents and feelings of caregiver burden experienced by adult daughters.

Functional Decline

The literature reports conflicting findings regarding the relationship between the functional abilities of an older adult with dementia and the prevalence of caregiver depression. Measures of functional ability have commonly included indicators of common activities of daily living (ADL) such as dressing, ambulating, eating, bathing, toileting, and instrumental activities of daily living (IADL) such as shopping, handling finances, and preparing meals. Deimling and Bass (1986) report that limitations in an older adult's ability to engage in activities of daily living are positively associated with the level of depression among spousal and daughter caregivers ($r=0.11$, $p<0.05$). Furthermore, parent's ADL limitations restrict the caregiver's social and recreational activities.

Williamson and Shulz (1993) also report a positive correlation ($r=0.19$, $p<0.01$) between assistance with activities of daily living and depressive symptomatology.

In contrast, Stoller and Pugliesi (1989) found that the functional limitations of the older adult are not associated with depressive symptomatology among caregivers. Although analyses were not conducted on the basis of kinship ties, 60% of their sample were daughters and sons.

Lawton, Moss, Kleban, Glicksman, and Rovine (1991) also report similar findings. In their study, assistance with activities of daily living was inversely related ($r=-18.0$, $p<.05$) to the level of depression among parental caregivers ($N=244$). Although the provision of a high level of assistance was associated with greater caregiver satisfaction, it was offset by feelings of greater burden. These authors suggest that parental caregivers who engage in greater assistance with personal care activities may affirm their sense of duty which in turn, increases their sense of satisfaction. They also suggest that the degree of burden may be a reflection of the competitive energy demands required by multiple roles. There was sampling bias in this study as caregivers were recruited through support groups, service providing agencies and media announcements targeting caregivers. Another aspect of dementia is behavioral disturbances and the association between these disturbances and depression as a response to providing care to a dementing parent.

Behavioral Disturbances

Behavioral disturbances may contribute to caregiver depression (Deimling & Bass, 1986; Neundorfer, 1991; Pruchno & Resch, 1989a; Semple, 1992; Wallhagen, 1992). In recent years, studies have attempted to identify the specific aspects of dementia impairment that may contribute to caregiver depression. Baumgarten and colleagues (1992) report significantly higher depressive symptoms among caregivers of family members who exhibit intermediate levels of cognitive impairment, increased behavioral disturbances and greater functional impairment when compared to caregivers of relatives who are not cognitively impaired.

Deimling and Bass (1986) interviewed 614 family members providing care to an elderly relative who exhibited signs of mental impairment including cognitive incapacity, disruptive behaviour and impaired social functioning. Disruptive behaviours such as striking family members, swearing, and disrupting meals, were positively related ($r=0.36$, $p<0.01$) to the level of caregiver depression. Similarly, Pruchno & Resch (1989b) found an association between wives depression scores ($r=0.24$, $p<0.05$) and the behaviours exhibited by a demented husband such as verbal abuse, disrupting meals, or losing their temper.

Additional insight into the aspects of dementia that may contribute to depression draws on the work of Dura, Stukenberg and Kiecolt-Glaser (1991). These researchers conducted a case-control study of the prevalence of depression among 78 siblings caring for a parent with a progressive dementia. The majority (81%) of parents were severely impaired and in need of assistance with self-care and instrumental activities of daily living, and had frequent behaviour problems. They found that 26% of these caregivers reported depression whereas it was reported by only 4% of the comparison group. There were no differences in the proportion of siblings experiencing depression on the basis of gender. However sampling bias precludes generalizing their results to all adult daughters. Participants in the caregiving group were recruited from support groups, respite programs, or self-selected by responding to advertisements in an Alzheimer's newsletter.

Burden of Care

Numerous researchers have conceptualized the psychological impact of caring for a family member as feelings of caregiver burden (Burdz, Eaton & Bond, 1988; Draper, Poulos, Cole, Poulos & Ehrlich, 1992; Motenko, 1989; Pratt, Wright & Schmall, 1987; Vitaliano, Russo, Young, Teri & Maiuro, 1991; Zarit, Todd & Zarit, 1986). The term caregiver burden often refers to the extent to which caregiving affects the caregiver's physical or emotional health, social life and financial resources (Scott, Roberto & Hutton, 1986; Zarit, Reever & Bach-Peterson, 1980; Zarit et al., 1986). Factors that contribute to feelings of caregiver burden include restriction of time for oneself, number of visits by other family members (Zarit et al., 1980), and feelings of guilt or uncertainty about the future (Chiriboga, Weiler, & Nielsen, 1988-89).

Zarit et al. (1980) investigated correlates of burden among relatives who provide care to a family member. Adult daughters' subjective appraisal of caregiver burden was negatively related to the frequency of visits by family members to the demented relative. Zarit concluded that there was no association between feelings of burden among daughters and parent's behaviour problems, level of cognitive impairment, nor ADL and IADL limitations. However, the researchers drew their sample from among caregivers attending a training centre that offered counselling and memory training. Thus, the caregivers were self-selected out of the broader caregiver population on the basis of seeking assistance.

In contrast, Barber (1988) reports that daughters' overall involvement in caregiving tasks such as transportation, financial management and meal preparation are positively associated with feelings of burden. Also, daughters experience significantly greater feelings of subjective burden when compared to sons.

Prevalence of Depression among Caregivers

The literature reveals several approaches to determining the prevalence of depression among caregivers of cognitively impaired older adults.

One approach is to compare caregivers of cognitively impaired individuals to caregivers of noncognitively impaired individuals (Cattanach & Tebes, 1991; Draper et al., 1992). Gallagher, Wrabetz, Lovett, Del Maestro & Rose (1990) compared 112 family caregivers of a relative with a dementing illness to 78 caregivers of a relative with other health problems such as heart disease or severe mobility problems. They report that 23% of those caring for a relative with a dementing disorder experienced moderate to severe depression; whereas only 17% of caregivers of the noncognitively impaired group report moderate to severe depression. Although statistical analyses were not conducted on the basis of kinship, 83% of those caring for a demented relative were women, of whom slightly more than half (46%) were adult daughters. Sampling bias was introduced because caregivers of demented family members were recruited from those who participated in a psychoeducational program for distress.

A second approach has been to compare depression rates among caregivers to a control group (Dura et al., 1991; Russo, Vitaliano, Brewer, Katon & Becker, 1995). In one study, women's depressive symptomatology scores were almost twice as high as non-caregivers (Baumgarten et al., 1992).

However, the explicit assumption was that both groups from a convenience sample were comparable on factors linked to the participant's choice to use the services provided by the same teaching hospital.

Haley, Levine, Brown, Berry, and Hughes (1987) compared 44 family caregivers of a relative who had senile dementia with 44 control subjects matched according to age, gender, race and marital status. Caregivers of family members with dementia reported significantly higher levels of depression than the control group ($t=4.07$, $p<0.01$). It is unknown whether daughter caregivers experienced higher levels of depression than the control group due the small number of daughters interviewed ($n = 22$).

A third approach has been to compare caregiver depression rates with population norms. In their review of health effects of caregiving, Shultz, Visintainer and Williamson (1990) report that studies that used the Beck Depression Inventory questionnaire tend to have elevated depression rates among caregivers of demented persons, regardless of gender or kinship ties (Dura et al., 1991; Gallagher-Thompson, Brooks, Bliwise, Leader & Yesavage, 1992; Vitaliano et al., 1991). Similarly, the majority of studies that use the Centre for Epidemiologic Studies Depression (CES-D) scale report substantially elevated rates of depressive symptomatology among caregivers (Biegal et al., 1991; Cattanach & Tebes, 1991; Moritz et al., 1992).

Acknowledging the methodological shortcomings of some prior research, women caregivers experience higher rates of depression when compared to caregivers of nondemented, control groups or general population norms. However, less is known about the experience of depressive symptomatology among adult daughters who engage in the provision of care to a parent with a dementing illness. Given the multifaceted nature of dementia, perhaps there are aspects of dementia that are more strongly associated with caregiver depression than others.

Summary

The literature provides evidence that the provision of care to an older adult with a dementing illness is, in large measure, carried out by family members, particularly adult daughters. Literature focusing on the natural course of a dementing illness including behavioral disturbances and functional incapacities identifies a variety of responses from caregivers to the provision of care. Depression may be one of these responses. However little is known of the experience of depression among Canadian adult daughters who provide care to persons with dementia or about the correlates of that depression. Knowledge of the caregiving experience of adult daughters derives in large measure from biased or convenience samples that precludes generalizing to the population as a whole.

Although a large body of literature reveals the contribution of women to the care of older adults, less is known of the experience of adult daughters due to substantive gaps and methodological limitations. Studies have shown that among intergenerational caregivers, daughters are much more likely than sons, to provide care to a parent with a dementing illness. No studies examined only the experience of daughters caring for a parent with dementia. Furthermore, no research focused exclusively on identifying the aspects of a dementing illness that may contribute to depression among daughters. A review of the social support literature revealed that the adequacy and quality of social support are related to depression among women, but again, the experience of adult caregiving daughters remains unknown.

In addition to gaps, methodological limitations preclude generalizing the findings to Canadian women. The majority of caregivers who participated in the studies had been recruited from clinics or agencies. Thus, data were collected from caregivers who sought help and were more likely to be distressed than caregivers who had not sought help. These caregivers were more likely to report higher depression rates when compared to representative samples of caregivers (Shultz et al., 1990). Most data concerning caregiving are American and thus the generalizability of the research findings to Canadians may be limited given the differences in our health care systems (Degner, 1989). Difficulties also arise in drawing conclusions about the prevalence and correlates of depressive symptomatology among caregiving daughters due to inconsistent conceptualizations of variables and the variety of instruments used to measure depression.

Consequently, this research builds on previous knowledge by using a representative sample of Canadian daughters to address the caregiving experience of adult daughters who provide care to a parent with and without dementia who reside in the community.

CONCEPTUAL FRAMEWORK

Although a conceptual framework was not explicit in the parent study from which this secondary analysis was derived, the researchers used variables salient to existing conceptual frameworks in the field of aging were used. Hence, the conceptual framework providing direction for this study derives from the diverse theoretical perspectives found within an abundant literature on the provision of care to older adults and the outcomes of such care. Caregiving research has developed along two major streams (Biegal et al., 1991; Schulz, 1990). The first has focused on the caregiving process itself, with major emphasis on the effects of caregiving on the caregiver. The second has focused on interventions to address caregiver and patient needs. Much of the literature on the effects of caregiving attempts to link some antecedent variables such as behavioural disturbances of the care-recipient to outcomes assessing the well-being of individuals who provide care to elderly relatives. There exists considerable consensus regarding the central variables to understanding caregiving outcomes. The differences that do exist are primarily related to emphasis, reflecting the disciplinary orientation of the investigator rather than fundamental disagreement about the nature of the phenomenon being studied. Regardless of the discipline, the theoretical underpinnings of much of the research conceptualize variables situated within the caregiving experience as stressors (Deimling & Bass, 1986; Haley, Levine, Brown & Bartolucci, 1987; Pearlin, Mullan, Semple & Skaff, 1990; Schulz, Beigel, Morcyz & Vistainer, 1989; Zarit et al., 1980). A typical independent variable in this conceptualization might be functional or behavioural status of the patient and a representative outcome variable, any one of a number of measures assessing the psychosocial status or physical and mental health of the caregiver such as morale, life-satisfaction, depression or perceived strain. Located in between the independent and dependent variables are a large number of individual and situational variables characteristic of stress and coping models such as age, gender, socio-economic status, type and quality of the caregiving relationship, social support and others. This basic model has been elaborated by a number of researchers (Cohler, Groves, Borden, & Lazarus, 1990; Given, King, Collins, & Given, 1988; Haley, Levine, Brown, & Bartolucci, 1987; Montgomery, Stull, & Borgatta, 1985). It is reported by Schultz (1990) that on the whole, these models provide a convenient framework for organizing the large number of variables relevant to understanding the provision of care to frail and elderly family members.

Consequently, the conceptual framework developed for the purposes of the present study is based upon the assumption that as a function of a dementing illness, the afflicted person becomes increasingly reliant on others to meet their needs, thus creating a dependency relationship between the recipient of care and the care provider. Moreover, stressors arise as a function of providing informal care to a person with a dementing illness. Appendix A contains the definition of terms used in the conceptual framework. In the present study, the variables selected include those related to context, stress and outcome as depicted in Figure 1.

Figure 1

CONCEPTUAL FRAMEWORK

CONTEXTUAL VARIABLES	STRESSOR VARIABLES	OUTCOME VARIABLE
Age Marital status Living arrangements Education Self-reported health Use of formal services	Parent's Functional status Parent's Behavioural disturbances Type and extent of care provided Burden	Depressive symptomatology

Context

All models of caregiving recognize that contextual variables contribute to caregiving outcomes. In this study, this category of variable is defined to include the characteristics of the caregiver, including age, marital status, living arrangements, education, self-reported health and use of formal services.

Stressors

Interest in and concern about caregiving is based on the underlying assumption that the provision of care to ill and disabled relatives represents significant stressors for families (Bunting, 1989; Deimling & Bass, 1986; Given, Collins, & Given, 1988; Haley, Levine, Brown & Bartolucci, 1987; Pearlin et al., 1990; Schulz, Beigel, Morcyz & Vistainer, 1989; Zarit et al., 1980). Illness or disability is typically characterized on a number of dimensions including the need for assistance with activities of daily living, behavioral problems and emotional responses. Caregiving is typically characterized according to the nature and extent of care and emotional responses to that care. In this study the stressors investigated include the functional status and behavioral disturbances of the elderly parent, type and extent of care provided by adult daughters and their feelings of burden associated with such care.

Depressive Symptoms

Although some studies base outcomes on clinical assessments of caregivers aimed at identifying the prevalence of actual clinical cases (Cohen & Eisdorfer, 1988), the majority of studies use standardized self-report inventories to measure the outcomes of caregiving (Schultz, 1990). The evidence is strong for increased symptom reports for depression among caregivers (Chiriboga, Weiler, & Nielsen, 1988-89; Gallagher et al., 1990; Noelker & Townsend, 1987; Robinson, 1989; Schulz, O'Brien, Bookwala & Fleissner, 1995). These data are supported by anecdotal reports of increased health care utilization and higher rates of psychotropic drug use among caregivers than non caregivers (George & Gwyther, 1986). In this study the CES-Depression scale is used to measure depressive symptomatology.

Given the conceptual approach described in the above section, and concern with associations among factors identified in the literature and in clinical practice as salient to the experience of adult daughters who provide care to parents with dementia, a representative sample of Canadian adult daughters of parents with and without diagnosed dementia was used to address the research objectives and related questions.

RESEARCH OBJECTIVES AND QUESTIONS

The objectives of this study were to: (1) investigate the context within which adult daughters provide care; (2) explore the stress that they experience while providing care and; (3) determine the level and correlates of depressive symptomatology among adult daughters who provide care to their elderly and community dwelling parents. This study is designed to answer the following questions:

1. What is the context (socio-demographic and care-related characteristics) within which adult daughters provide care to elderly and community dwelling parents?
2. What are the stressors (task performance, parent's functional status and behavioural disturbances, burden) they experience while providing care?
3. What is the prevalence of depressive symptomatology among adult daughter caregivers?
4. What is the relationship between the caregiving experience (context and stress) and level of depressive symptomatology?

Overview of the Remaining Chapters

The following chapter outlines the methodology used in this study, including an overview of the larger study from which the present study was derived, the design, setting and sample, measures used, ethical considerations and approach to data analyses.

Chapter three presents the study findings organized according to the conceptual framework. It begins with the socio-demographic, support and health characteristics of respondents, continues with the stressors associated with caregiving and the proportion of daughters experiencing depressive symptoms and concludes with a correlational analysis among variables.

Chapter four discusses the study findings, continues with the strengths and limitations of the study and concludes with the study implications for the practice of Clinical Nurse Specialists and directions for research.

CHAPTER 2

METHODS

The data used in this study were drawn from the Canadian Study of Health and Aging. This chapter includes a brief overview of the Canadian Study of Health and Aging (CSHA), a description of the sub-sample used in the present study, an outline of the measures used and the approach to data analysis employed.

The Canadian Study of Health and Aging

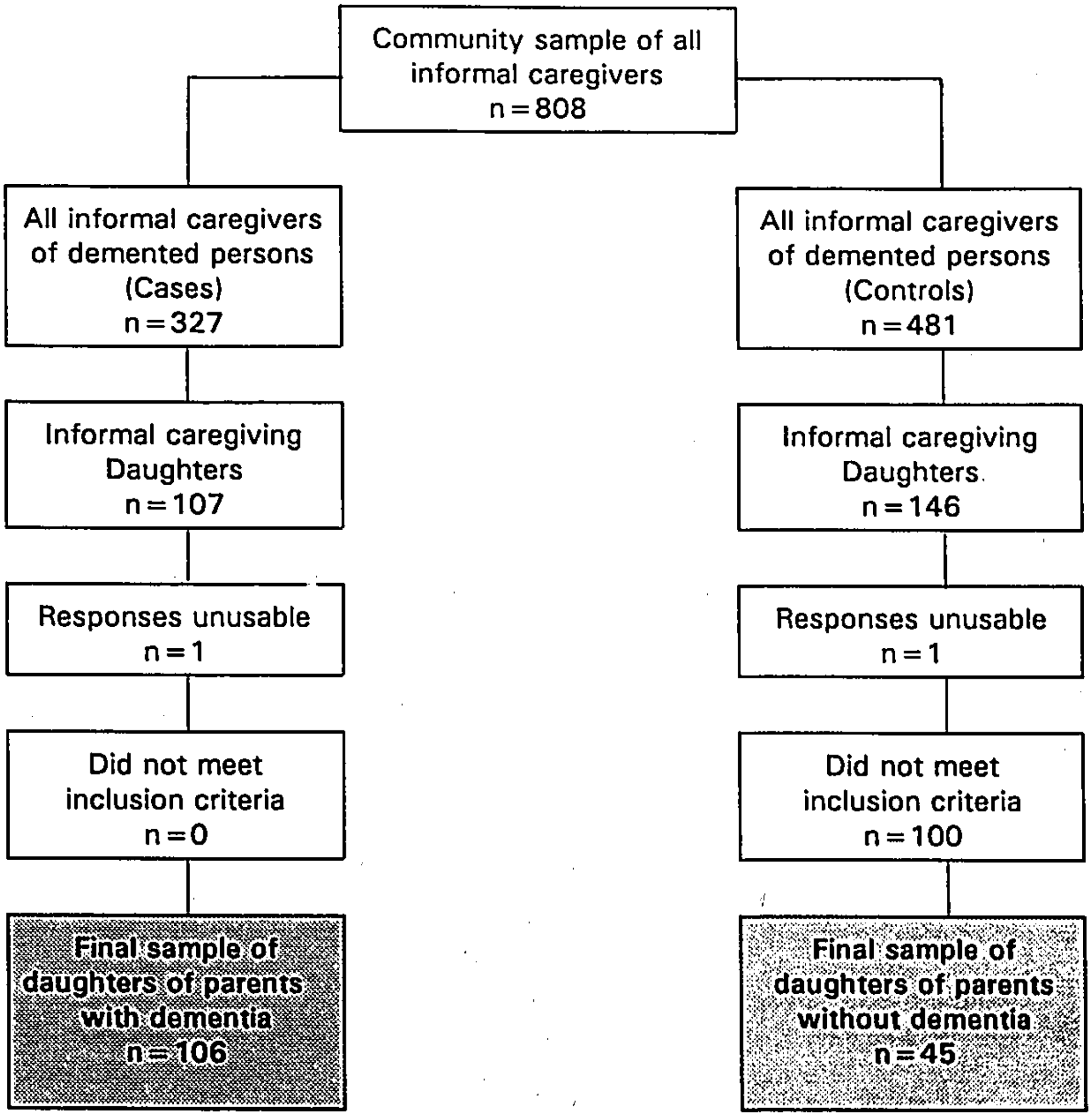
The CSHA was a nation-wide Canadian study that collected information from community and institutional settings regarding the prevalence and risk factors for persons with dementia. Data were gathered from people engaged in the provision of care to individuals with dementia and individuals without dementia to assess patterns of caregiving, their use of formal services and the health status of the caregiver.

Design

The 1991-1992 CSHA was a nation-wide epidemiological study of dementia that included a case-control study of the health and formal service use of people who were providing care to a person with dementia (Canadian Study of Health and Aging Working Group, 1994). A random sample of 10,263 people aged 65 and over were allocated into one of two groups based on whether they lived in the community (N = 9,008) or in an institution (N = 1,250). Subjects were then allocated into one of two groups based on the presence or absence of dementia. All subjects who were diagnosed as having dementia formed the case group whereas those subjects who were cognitively normal formed the control group. The caregiver component of the CSHA was composed of people who provided care to a person diagnosed with dementia (cases) and a random sample of people who provided care to a person who was cognitively normal (controls). Figure 2 shows the evolution of the case and control groups of adult daughter caregivers for the present study.

Figure 2

Evolution of the Case and Control Groups of Caregivers



Setting and Sample

The setting for the CSHA included all Canadian provinces, excluding the Yukon, Northwest Territories, military units, and Indian reservations. Thirty-six cities and surrounding rural areas were selected considering both accessibility to one of 18 study centres and feasibility of arranging for clinical assessments.

For the community sample (except Ontario), the sampling frame consisted of computerized provincial health insurance records. In Ontario, the Enumeration Composite Record was used because the Ontario health insurance database was unsuitable for sampling. A population based, stratified sample of persons aged 65 and over was randomly selected from among three age groups: 65 to 74 years, 75 to 84 years, and those aged 85 or older.

Formal and informal caregivers in the community sample were identified by either the subject over the age of 65 or by their families. Formal caregivers were paid professionals whereas informal caregivers were unpaid family members or friends. Interviews with 327 informal caregivers of older adults with dementia residing in the community and a comparison group of 481 informal caregivers of cognitively normal older adults were conducted. Interviews were in large measure conducted at the home of the caregiver or care-recipient and lasted approximately 30-45 minutes.

Data Management

To ensure uniformity, all data collected were entered centrally by the Ottawa Coordinating Centre using SPSS software for microcomputers.

The Present Study

Design

This descriptive comparative study involved a secondary analysis of data drawn from the 1991-1992 CSHA.

Sample

This study used a subsample of 151 daughters identified from the CSHA who met the following criteria: (a) responsible for the day-to-day decision making and provision of unpaid care to a parent; (b) contact with their community dwelling parent at least on a weekly basis; and (c) responded to Zarit's Burden Inventory. Respondents were divided into two groups based on the cognitive status of their parents. The first group consisted of 106 daughters of parents diagnosed with dementia. The second group was composed of 45 daughters of parents without dementia.

Sample Size

Determination of whether or not the sample was sufficiently large to detect meaningful differences between the two groups was done using the statistical program Epi-info (Fleiss, 1981), which calculated sample sizes for unmatched cross-sectional studies. The procedure is based upon sample size determination described by Fleiss (1981). Fifteen percent of the population demonstrates depressive symptoms when tested by the CES-D (Devins & Orme, 1985; Hsu & Marshall, 1987). Given this, an alpha of 0.05 (two-tailed), beta of 0.20 and a power of 80%, the sample size required to detect a difference between groups was estimated to be 154 respondents. The subsample of 106 daughters of parents with dementia and 45 daughters of parents without dementia is sufficient to detect a difference.

MEASURES

Measures selected for the study reflect the conceptual framework. The interview schedule (Appendix B) consisted of 12 questions regarding contextual, stressor and outcome variables.

Contextual Variables

Data related to the sociodemographic profile, self-reported health and support network of adult daughters were collected.

Age

Respondents were asked to indicate the year of their birth (see Appendix B, question 1). Ages were calculated by subtracting their year of birth from the year the respondent was interviewed (1991/1992).

Marital Status

Respondents were asked to indicate their marital status (0=never married, 1=married, 2=common law marriage, 3=divorced, 4=separated, 5=widowed, 6=other). (see Appendix B, question 2).

Living Arrangements

A single item question asked respondents whether they were currently living in the same house as their parent (see Appendix B, question 3).

Responses were dichotomous (1 =yes, 2=no).

Education

Respondents were asked to identify the number of years of education and the level of schooling they had completed. Responses were coded as the number of years of education and the level of education (see Appendix B, question 4).

Self-reported health

Health status of respondents (see Appendix B, questions 5, 6) was measured using two questions. The first question was "How would you say your health is these days?". Responses were made on a 5-point scale (1 = very good, 2= pretty good, 3= not too good, 4= poor, 5= very poor). This self-report measure has been used in several caregiving studies (Haley, Levine, Brown & Bartolucci, 1987; Stephens, Ogrocki & Kinney, 1991). It is reported to have convergent validity with physician's ratings of the health of older adults (LaRue, Bank, Jarvik & Hetland, 1979; Stahl, 1984) and correlates with three objective measures of health among people (N=937) residing in the community including the number of: health-related problems (F=162.77, df=3,929, p<0.01), medicines taken (F=85.75, df=3,927, p<0.01), and illnesses or disabilities present (F=130.07, df=3,924, p<0.01) (Fillenbaum, 1979). Predictive validity of survival for those people between 77 to 84 years has been previously demonstrated by Mossey & Shapiro (1982).

The second question asked respondents "How much do your health troubles stand in the way of doing things you want to do?". Responses were made on a 3 point scale ranging from 1 = not at all, to 3 = a great deal. This question also correlates with three objective measures of health among people (N = 937) residing in the community including the number of: health-related problems (F = 205.77, df = 2,931, p < 0.01), medicines taken (F = 94.82, df = 2,929, p < 0.01), and illnesses or disabilities present (F = 168.60, df = 2,926, p < 0.01) (Fillenbaum, 1979).

Use of formal services

Two questions elicited information about respondents' formal service use and additional services required (see Appendix B, question 7, 8). Formal service use was ascertained by asking respondents to identify the services used in the past which included: homemaking, home delivered meals, home help for personal tasks, in-home nursing care, physiotherapy, occupational therapy, podiatry or chiropractic treatments, attended a day centre or day hospital, respite care, counselling and self-help or support groups. Responses to each formal service were coded as 1 = yes, 2 = no. Total use of formal services was calculated by summing the number of "yes" responses.

The second question elicited information pertaining to a need for additional services. Daughters were asked "Are there any services, that you are not already receiving, that would help you in caring for (___)?" For the purposes of this study, the underlying assumption of this proxy indicator was that daughters were likely to identify other formal services if a parent's needs were not met. Responses were categorized according to the type of service identified. The total number of services required was calculated by summing the types of services daughter's identified.

Stressor Variables

Fillenbaum's (1988) Older Americans Resources and Services Multidimensional Functional Assessment Questionnaire (MFAQ) was used to measure the functional status, type of care and extent of task performance.

Functional status

The functional status of parents was measured by Fillenbaum's (1988) MFAQ, (see Appendix B, question 9). Daughters were asked to rate their parent's ability to accomplish a total of 14 personal care and instrumental activities of daily living. According to Fillenbaum (1988) a single summary ADL rating score classifies the level of functional ability on a six point scale:

1. Excellent ADL capacity: Can perform all of the ADL without assistance and with ease.
2. Good ADL capacity: Can perform all of the ADL without assistance.

3. Mildly impaired ADL capacity. Can perform all but one to three of the ADL. Some help is required with one to three, but not necessarily every day. Can get through any single day without help. Is able to prepare his/her own meals.

4. Moderately impaired ADL capacity: Regularly requires assistance with at least four ADL but is able to get through any single day without help or regularly requires help with meal preparation.

5. Severely impaired ADL capacity: Needs help each day but not necessarily throughout the day or night with many of the ADL.

6. Completely impaired ADL capacity: Needs help throughout the day and/or night to carry out the ADL.

A multidisciplinary team at Duke University developed this instrument using items derived from other published instruments with established content and consensual validity (Fillenbaum, 1988; Fillenbaum & Smyer, 1981). Criterion validity for self-care capacity was established by comparing ratings made by clients (N=30) from a family medicine clinic with those made by physical therapists. The comparison criterion was a 12 point scale developed by physical therapists that measured the participants capacity to perform activities associated with daily living. Spearman correlation coefficient between the clients and physical therapists was 0.89, $p<0.01$ for self-care capacity (Fillenbaum & Smyer, 1981, p. 432).

This instrument was extensively tested for reliability at the various stages of development (Fillenbaum, 1988; Cairl, Pfeiffer, Keller, Burke, & Samis, 1993). Fillenbaum and Smyer (1981) reported an inter-rater reliability correlation coefficient of 0.87, ($p<0.01$, N=30) for self-care capacity (p. 432).

The raters were in complete agreement on 74% of the ratings and differed by 1 point on 24% of the ratings (Fillenbaum & Smyer, 1981; p. 432). Test-retest reliability over a three to eight week interval using a subsample of 30 older adults over the age of 65 years, resulted in correlation coefficients of 0.71 ($p<0.01$) for activities of daily living and 0.82 ($p<0.01$) for instrumental activities of daily living (Ernst & Ernst, 1984, p. 25). This instrument was recommended by McDowell and Newell (1987) in their review of fifty health measurement methods. In the present study, Chronbach's alpha for all 14 items was 0.90.

Type of care

The type of care provided by respondents was identified using Fillenbaum's (1988) MFAQ (see Appendix B, question 9). Respondents were asked to identify the person in the previous month, who had provided assistance to their parent with personal care (eating, dressing, grooming, walking, getting in and out of bed, bathing and toileting) and instrumental (telephoning, transportation, shopping, preparing meals, housework, medication administration and managing finances) activities of daily living. Responses to each of the 14 tasks were coded according to the relationship of the helper to the parent. Only responses that indicated that the respondent had provided assistance were selected for this study. The total number of activities performed by daughters was calculated by summing their responses.

Extent of care

The extent of care provided by respondents was also ascertained from two questions from the MFAQ scale (see Appendix B, question 9). The first question asked how frequently daughters provided assistance to a parent in each of the 14 tasks. Responses were coded as daily, weekly or monthly. This was subsequently recoded into the number of times per month. The second question asked daughters to identify the amount of time they spent providing assistance with each of the 14 tasks. Responses were coded in minutes. An index of the overall time daughters spent providing assistance was created by multiplying the frequency of helping by the time spent for each task and summing these values.

Behavioral disturbances

The number and type of behavioral disturbances manifested by a parent were measured using the Dementia Behaviour Disturbance (DBD) scale developed by Baumgarten, Becker and Gauthier (1990) (see Appendix B, question 10). This scale consists of 28 specific, observable behaviours such as dressing inappropriately, wandering, throwing food, etc. The frequency of occurrence of each behaviour in the previous week was rated using a 5 point Likert scale (0= never, 1= rarely, 2= sometimes, 3= frequently, 4= all of the time). For the purposes of this study, which was to quantify the number of behaviours manifested by parents, responses were collapsed on the basis of whether each of the 28 behaviours had occurred (1 =yes, 2=no).

Baumgarten et al. (1990) report that construct validity, internal consistency and test-retest reliability of their recently developed scale have been tested in two samples (n = 50 and n = 46) of older adults with dementia. The extent to which the DBD scale relates to other measures of the same construct was measured using two different approaches. First, correlation coefficients between the DBD scale and Greene's Behaviour and Mood Disturbance (BMD) scale were calculated. The correlation coefficients for the subscales were; 0.46, $p<0.05$ for apathetic/withdrawn subscale, 0.59, $p<0.05$ for the mood disturbance subscale and 0.72, $p<0.05$ for the active/disturbed subscale. The correlation coefficient between the total DBD score and BMD score was 0.73, $p<0.05$. Overall, these correlation coefficients indicate that the DBD scale measures a similar construct. The second approach to construct validity was conducted by examining relationships between the mean DBD score and several clinical variables thought to be associated with behaviour disturbances such as functional status and the clinical severity of dementia. The relationship between the mean DBD scores with functional status and the clinical severity of dementia were all significant at $p<0.01$.

In the same study, the stability of the DBD scale was measured by administering the instrument to the two samples (n=96), over a two week interval. The Pearson correlation coefficient between their DBD scores at the two interviews was 0.71, indicating acceptable test-retest reliability for a recently developed tool (Burns & Grove, 1993).

Chronbach's alpha of internal consistency for the instrument tested on both samples was 0.83, suggesting that the 28 items of the instrument measure the same attribute. Correlation coefficients between each of the 28 items and the total DBD score for both samples ranged from 0.07 for throws food to 0.66 for dresses inappropriately. Although the item-total correlation coefficients were quite low for 3 of the behaviours, the authors state that until further testing is done, they have chosen to retain these items (Baumgarten et al., 1990).

In the CSHA study Chronbach's alpha was 0.88. In the present study, the reliability for all 28 items was 0.88.

Burden

Respondents' feelings of burden was measured using Zarit's Burden Interview (Zarit, Reever, & Bach-Peterson, 1980). This instrument has been widely used in caregiving studies (Barber, 1988; Milne, Sacco, Cetinski, Browne & Roberts, 1994; Pratt, Schmall & Wright, 1986; Reese, Gross, Smalley & Messer, 1994; Zarit, Anthony & Boutselis, 1987). Twenty two items assess caregivers' perceptions regarding the impact of responsibilities associated with caring for a family member who is mentally and/or physically impaired, on the caregivers' health, finances, social life and interpersonal relations. In this study, daughters were asked the extent to which each of the

22 items described how they felt, with responses ranging from "0= not at all" to "4= all of the time" (see Appendix B, question 11). The sum of all responses may range from 0 to 88, with higher scores indicating greater feelings of burden. Although norms have not yet been established to categorize the degree of burden, consistent with previous research (Price & Levy, 1990; Smith, 1989), scores of 20 or less indicate little or no burden, 21-40 indicate mild to moderate burden, 41-60 indicate moderate to severe burden and scores of 61 or more indicate severe burden.

Items for inclusion were selected from areas of concern that previous research and clinical experience identified as being most frequently affected by the caregiving experience. Construct validity was examined by Pratt, Schmall, and Wright (1986) whereby burden was inversely related to morale and health status, and positively related with hours spent in giving care. Internal consistency using Chronbach's alpha has been reported at 0.79 (Anthony-Bergstone, Zarit, & Gatz, 1988; Zarit & Zarit, 1982).

In the Canadian Study of Health and Aging, Chronbach's alpha was 0.89. In the present study, the reliability for all 22 items resulted in a Chronbach's alpha of 0.87.

Depressive Symptoms

Depressive symptoms among respondents were measured using the Centre for Epidemiologic Studies Depression (CES-D) scale (Radloff, 1977) (see Appendix B, question 12). Daughters were asked how frequently they had experienced each of the 20 items during the past week using a 4 point Likert scale (1 = less than one day, 2 = one to two days, 3 = three to four days, 4 = five to seven days). Potential scores range from 0 to 60, with higher scores reflecting greater depressive symptomatology. Consistent with previous research (Blazer, 1989; Canadian Study of Health and Aging, 1994; Cohen, Luchins, Eisdorfer, Paveza et al., 1990; Mohide et al., 1990), a score of 16 or greater was used as indicative of a case of possible depression. For one daughter, there was a missing value for one of the 20 questions asked on the CES-D. Therefore, to calculate her total CES-D score, the mean CES-D score of this daughter's responses to the remaining 19 questions was calculated, and substituted for the 1 missing value.

The CES-D was designed for epidemiologic research as a screening tool to detect depressive symptoms among the general population (Radloff, 1977; Radloff & Teri, 1986). Items for inclusion in the CES-D are representative of major symptoms of clinical depression identified from clinical literature and factor analytic studies. The twenty items were subsequently selected from previously validated depression scales (Radloff, 1977; Weissman, Sholomskas, Pottenger, Prusoff & Locke, 1977). Establishing the validity of the CES-D scale has been the focus of study by several researchers (Husaini, Neff, Harrington, Hughes & Stone, 1980; Weissman et al., 1977).

Concurrent and discriminant validity of the CES-D scale was investigated by Weissman and colleagues (1977) using five psychiatric samples (n = 406) and 3845 randomly selected adults in the community. Concurrent validity was assessed in two ways. First, CES-D scores were compared within the five different psychiatric samples and the community population. The psychiatric sample consisted of acutely depressed clients, previously depressed clients, drug addicts, alcoholics, and clients with schizophrenia. The psychiatric sample scored higher on the CES-D than the community population. For example, the mean CES-D score for the acutely depressed subgroup was 38.10 whereas the mean CES-D score for the community sample was 9.10. Furthermore, the CES-D discriminated between depressed and non-depressed clients within the five psychiatric subgroups.

Second, correlation coefficients were examined between clinician's ratings of clinical symptoms of depression and scores obtained on various self-report scales completed by the psychiatric subgroups. There were significant associations between clinician ratings on the Hamilton and Raskin Depression scales and two self-report scales. For example the correlation coefficient between the Hamilton Depression Scale and the CES-D scale completed by clients (N=148) who were acutely depressed was 0.49, $p < 0.01$.

Discriminant validity was investigated using two different approaches. The first approach consisted of examining the extent to which differences existed between the CES-D scales and variables thought not to influence CES-D scores. They found no correlation between CES-D scores and client's age, social class and gender with the exception of upper class schizophrenics and drug-addicted women.

Second, the utility of the CES-D questionnaire to screen depressive symptoms, was assessed by comparing the cut-off score of the CES-D with the cut-off score of the Raskin Depression scale as criterion. They reported that of 148 clients medically diagnosed as acutely depressed, 147 clients scored above the cut-off points for depression on both scales (sensitivity=99%), thus differentiating between depressed and non-depressed groups.

Radloff (1977) reports significant test-retest correlation coefficients obtained 2 - 8 weeks apart averaged 0.57 (N=419) indicating a change in CES-D scores. Reliability was also assessed by determining the internal consistency of the scale among psychiatric and community populations. The coefficient alpha in the community population (N=2,514) was 0.85 whereas in the psychiatric population (N=70) the coefficient alpha was 0.90. (Radloff, 1977; Radloff & Teri, 1986).

In the larger CSHA study, Chronbach's alpha was 0.88. In the present study, Chronbach's alpha is 0.88.

Approach to data Analysis

The Ottawa Coordinating Centre for the CSHA provided the data set on a computer diskette. The data were suitable for analyses using SPSS for Windows (Version 6). Univariate analyses included frequencies, percentages, ranges; measures of central tendency included means, medians, modes and standard deviations. Bivariate analyses were conducted using Spearman's rho, Pearson correlation, independent samples t-tests and Chi-squares (Burns & Grove, 1993; Hulley & Cummings, 1988).

Ethical Considerations

The researcher used a public access data file to conduct a secondary analysis. All identifying information about the daughters and their parents had been previously removed.

Feasibility

Permission was granted by Dr Ian McDowell, Dr. Neena Chappell and Dr. Mona Baumgarten to conduct a secondary analysis on a subsample of data from the Canadian Study on Health and Aging (1994). For the purposes of the present study, a sample of 151 daughters provided a sufficient number of cases to analyze.

CHAPTER 3

FINDINGS

This chapter presents the findings of the study beginning with the socio-demographic, support and health characteristics of respondents, their caregiving situation and depressive symptomatology. The chapter concludes with the relationships among contextual, stressor and outcome variables.

The Context of Care

Socio-Demographic Characteristics

Data were gathered about the age of respondents, their marital status, living arrangements and education. These data are presented in Table 1.

Table 1
Socio-Demographic Characteristics

	Daughters of Parents with Dementia		Daughters of Parents without Dementia	
	n 106	% 100	n 45	% 100
Age				
Less than 39	6	5.7	6	13.3
Between 40 and 49	29	27.3	20	44.5
Between 50 and 59	45	42.5	11	24.4
60 plus	26	24.5	8	17.8
Marital Status				
Single	36	34.0	11	24.5
Married	56	52.8	31	68.9
Widowed	13	12.3	2	4.4
Common Law	1	0.9	1	2.2
Living Arrangements				
With parent	50	47.2	5	11.1
Separate from parent	56	52.8	40	88.9
Education				
Grade 8 or less	11	10.4	4	8.8
Some high school	23	21.7	11	24.4
Finished high school	22	20.8	10	22.2
Some college/university	20	18.8	10	22.2
Finished college/university	26	24.4	9	19.9
Other	4	3.8	1	2.2

Daughters of parents with dementia tended to be somewhat older, ranging in age from 35 to 71 with an average age of 53.5 years (SD=8.3). Conversely, daughters of parents without dementia were somewhat younger, ranging in age from 27 to 73 with an average age of 48.5 years (SD=9.0). A comparison of means indicated a significant difference between the groups on daughter's age ($t=3.29$, $df=149$, $p<0.01$). The majority of respondents were either married or living common law. Among daughters of parents with dementia, slightly over one-half (53.7%) were either married or living common law, whereas among daughters of parents without dementia, almost two-thirds (71.1%) were either married or living common law. A chi-square analysis revealed a significant difference in the proportion of daughters based on their marital status (chi-square=3.92, $df=1$, $p<0.05$). There was also a significant difference in the proportion of respondents who resided with their parents (Chi-square=17.73, $df=1$, $p<0.03$). Indeed, a substantial proportion (47.2%) of daughters of parents with dementia resided with their parent, whereas only a very small proportion (11.1%) of daughters of parents without dementia reported doing so. The vast majority of respondents had achieved at least a high school level of education. Daughters of parents with dementia averaged 12.6 years of education with 64.4% having achieved a minimum level of high school. Similarly, daughters of parents without dementia averaged 12.2 years of education with 64.1% having also completed high school. There were no significant differences between the groups based on their average number of years of education (t=0.37, df=149, p=0.71) or their level of education (chi-square 1.8, df=3, p=0.60).

Support Characteristics

Data were gathered about respondents' use of formal care services and about additional services that would be helpful to them.

Formal Care Services

Respondents were asked to identify the services they employed in the care of their parent. These data are presented in Table 2.

Table 2
Formal Care Services

	Daughters of Parents with Dementia		Daughters of Parents without Dementia	
	n 106	% 100	n 45	% 100
Homemaking	38	35.8	15	33.3
Assistance with tasks	28	26.4	6	13.3
Nursing services	25	23.6	4	8.9
Rehabilitative services	19	17.9	16	35.6
Home delivered meals	11	10.4	1	4.4
Counselling services	10	9.4	0	0.0
Daycare services	9	8.5	1	4.4
Respite care services	6	5.7	0	0.0
Support groups	3	2.8	0	0.0

The table reveals that on the whole, a minority of caregivers used formal services. The service most frequently used was homemaking services. However, only one-third of both groups actually used the service. Assistance with tasks (26.4%) and nursing services (23.6%) were used by fully one-quarter of daughters of parents with dementia, whereas rehabilitative services were used by fully one-third (35.6%) of daughters of parents without dementia. Chi-square analysis revealed a significant difference in the proportion of daughters who used one or more formal services (chi-square = 6.65, df = 1, $p < 0.01$).

Additional Services Required

Respondents were asked to identify additional formal care services that would be helpful in the provision of care to their parents. The majority of respondents (daughters of parents with dementia: 52%; and daughters of parents without dementia: 75%) stated that they did not require additional services. Those reporting that they required additional services are presented in Table 3.

Table 3
Additional Services Required.

Services	Daughters of Parents with Dementia*		Daughters of Parents without Dementia**	
	n 96	% 100	n 43	% 100
Daycare services	15	15.6	4	9.3
Respite care services	12	12.5	3	7.0
Medical services	8	8.3	1	2.3
Counselling services	5	5.2	2	4.7

* missing data for 10 respondents, **missing data for 2 respondents.

Although Chi-square analysis revealed a significant difference between groups regarding the proportion of daughters who identified additional formal care services required (chi-square=6.37, df=1, $p<0.01$), there were no significant differences found on individual services. A small proportion of daughters of parents with dementia required day care or respite services. Only a very small proportion required other types of support such as medical and counselling services. Similarly, very few daughters of parents without dementia required additional services. Only a small proportion required day care, medical, and counselling services.

Health Characteristics

Data were gathered about respondents' self reported health and the degree to which their health interfered with activities of daily living.

Self Reported Health.

Respondents rated their present health as very good, pretty good, not too good or very poor (see Table 4).

Table 4
Self Reported Health

Health Status	Daughters of Parents with Dementia*		Daughters of Parents without Dementia**	
	n 105	% 100	n 39	% 100
Very good	44	41.9	17	43.6
Pretty good	50	47.6	19	48.7
Not too good/very poor	11	10.5	3	6.7

* Missing data for 1 respondent.
**Missing data for 6 respondents.

There were no significant differences in self-reported health status between both groups of daughters (chi-square=0.79, df=3, p=0.85). Indeed, the vast majority of daughters of parents with dementia (89.5%) reported their health as either very good or pretty good. Similarly, the vast majority of daughters of parents without dementia (92.3%) reported their health as very good or pretty good.

Interferences with Activities of Daily Living

Respondents were also asked whether their health interfered with their activities of daily living (see Table 5).

Table 5
Interferences with Activities of Daily Living

Level	Daughters of Parents with Dementia*		Daughters of Parents without Dementia**	
	n 105	% 100	n 39	% 100
Not at all	78	74.3	29	74.4
A little	20	19.0	7	17.9
A great deal	7	6.7	3	7.7

*Missing data for 1 respondent.
**Missing data for 6 respondents.

Respondents did not significantly differ in the extent to which their health interfered with their activities of daily living (chi-square=0.06, df=2, p=0.96). Regardless of parents' cognitive status, the majority of daughters in both groups reported that their health did not interfere with their activities. However it is notable that one-quarter of daughters in both groups reported that their health did indeed interfere with their activities. Close to one fifth reported that their health interfered a little and a small proportion (6.7%) reported that their health interfered a great deal with their activities of daily living.

Stressor Variables

The stress of caregiving included the type and extent of care enacted for parents. In addition, parents' functional status, their behavioural disturbances and daughters' feelings of burden contributed to the stress of caregiving.

Type of Care

Daughters carried out a wide variety of personal care and instrumental tasks related to the provision of care (see Table 6).

Table 6
Type of Care

Tasks	Daughters of Parents with Dementia		Daughters of Parents without Dementia	
	n 106	% 100	n 45	% 100
Activities of Daily Living				
Bathing	30	28.3	2	4.4
Dressing	27	25.5	1	2.2
Grooming	27	25.5	1	2.2
Toileting	15	14.2	0	0.0
Walking	13	12.3	0	0.0
Eating	12	11.3	0	0.0
Transfers	11	10.4	0	0.0
Instrumental Activities of Daily Living				
Shopping	77	72.6	12	26.7
Managing finances	66	62.1	3	6.7
Getting to places	62	58.5	7	15.6
Housework	55	51.9	5	11.1
Preparing meals	53	50.0	3	6.7
Taking medications	38	35.8	2	4.4
Using the telephone	15	14.2	0	0.0

Chi-squares was done to determine differences in the proportion of daughters who assisted with personal and instrumental care. Yate's correction for continuity was applied where there were small cell sizes. Typically, the type of care provided by daughters involved instrumental activities of daily living.

However, a greater proportion of daughters of parents with dementia provided assistance with instrumental tasks, in particular, shopping, managing finances, getting to places housework and meal preparation when compared to daughters of parents without dementia (Chi-square=68.26, df=1, p<0.01). Furthermore, assistance with medications was also provided by fully one-third of daughters of parents with dementia whereas only a very small proportion (4.4%) of daughters of parents without dementia did the same. Although only a small proportion of daughters of parents with dementia assisted their relative with the telephone, virtually none of the daughters of parents without dementia assisted in this activity.

There was also a significant difference between groups with respect to the proportion of daughters who assisted with personal care (Chi-square =0.35, df=1, p<0.01). Approximately one-quarter of daughters of parents with dementia assisted with bathing, dressing and grooming. In contrast, only a very small proportion of daughters of parents without dementia assisted with these tasks. Furthermore, a small proportion daughters of parents with dementia also assisted with toileting, walking, eating and transfers, however none of these activities were carried out by daughters of parents without dementia.

Extent of Task Performance

Extent of task performance was calculated by multiplying the frequency with which daughters enacted each task by the amount of time spent carrying out each task during the previous month and summing these values. The average number of hours spent in the performance of activities of daily living (ADL) and instrumental activities of daily living (IADL) is presented in Table 7.

Table 7
Mean Hours per Month

Task	Daughters of Parents with Dementia		Daughters of Parents without Dementia			
	Mean	SD	Mean	SD	t	df
ADL	15.1	33.7	0.2	1.1	-2.95*	149
IADL	47.5	49.9	4.6	11.1	-5.68*	149

*p<0.01

Significant differences were found between groups of daughters on their extent of task performance. Overall, daughters of parents with dementia spent an average of 62.6 hours in the previous month assisting their parent with activities associated with daily and instrumental living. In contrast, daughters of parents without dementia spent significantly less time (4.8 hours) assisting their parent. Although both groups of daughters spent a considerable number of hours with instrumental activities of daily living, daughters of parents with dementia spent a significantly greater amount of time carrying out instrumental activities associated with daily living when compared to daughters of parents without dementia. Daughters of parents with dementia also spent a significantly greater amount of time providing assistance of a personal care nature. The difference between groups was statistically significant.

Parent's Functional Status

Using the typology developed by Fillenbaum (1988), the functional status of parents is presented in Table 8.

Table 8
Parents' Functional Status

Rating	Daughters of Parents with Dementia		Daughters of Parents without Dementia	
	n 106	% 100	n 45	% 100
Excellent	4	3.8	26	57.8
Mildly impaired	14	13.2	13	28.9
Moderately impaired	32	30.2	4	8.9
Severely impaired	21	19.8	2	4.4
Totally impaired	35	33.0	0	0.0

For the purposes of chi-square analysis, the functional status of parents was collapsed into two groups that seemed clinically reasonable. The first group consisted of those with excellent functional status and those who were only mildly impaired. The second group consisted of those who were moderately/severely/totally impaired. Chi-square analysis revealed a significant difference between daughters with respect to the functional status of their parents (Chi-square=65.27, df=1, $p<0.01$). The majority of parents with dementia were functionally impaired with respect to their ability to perform personal care and instrumental activities of daily living when compared to parents without dementia. Indeed, the majority (83%) were at least moderately impaired with fully one-third (33%) totally impaired. In contrast, the majority of parents without dementia were able to perform personal care and instrumental activities of daily living. Only 13.3% were moderately or severely impaired. None of which were totally impaired.

Behavioural Disturbances

The Dementia Behavioural Disturbances Scale (DBD) was used to identify the specific behaviours with which respondents had to contend. Among daughters of parents with dementia, only two reported that their parent manifested no problem behaviours. Close to half (48.9%) of daughters of parents without dementia also reported no problem behaviours. Daughters of parents with dementia reporting behavioural problems reported an average of 8.5 (SD=5.7) such problems whereas daughters of parents without dementia reported an average of 1.8 (SD=2.5) behavioural disturbances. A comparison of means revealed that daughters of parents with dementia had to contend with a significantly greater number of behavioural disturbances when compared with their counterparts (t=-7.45, df=149, $p<0.01$). The number and proportion of respondents who reported various types of behavioural disturbances are presented in Table 9.

Table 9

Behavioural Disturbances

	Daughters of Parents with Dementia		Daughters of Parents without Dementia	
	n 106	% 100	n 45	% 100
Repetitive questions	84	79.2	7	18.9
Lack of interest	75	70.8	9	24.3
Loses or hides things	66	62.3	10	27.0
Sleeps excessively	61	57.5	10	27.0
Unwarranted accusations	59	55.7	3	8.1
Wakes at night	51	48.0	12	32.4
Incontinent of urine	45*	41.9	3	8.1
Refuses assistance	36	44.0	4	10.8
Dresses inappropriately	31	29.2	1	2.7
Hoards for no reason	30	28.3	2	5.4
Refuses to eat	30	28.3	0	0.0
Becomes lost outdoors	30	28.3	1	2.7
Repetitive actions	29	27.4	1	2.7
Empties drawers/closets	27	25.5	1	2.7
Paces up and down	26	24.5	0	0.0
Restless	26	24.5	2	5.4
Wanders at night	25	23.6	12	32.4
Verbally abusive	25	23.6	2	5.4
Incontinent of stool	25	21.7	1	2.7
Cry/laugh inappropriately	23	17.9	1	2.7
Wanders during the day	19	16.2	0	0.0
Overeats	17*	10.4	7	18.9
Screams for no reason	13	12.3	0	0.0
Attacks physically	11	10.4	1	2.7
Destroys property	9	8.5	0	0.0
Exposes self indecently	8	7.5	0	0.0
Advances sexually	6	5.7	0	0.0
Throws food	5	4.7	0	0.0

* missing value for 1 parent

The majority of daughters of parents with dementia had to contend with repetitive questions, a lack of interest, losing or hiding things, excessive sleeping and unwarranted accusations on the part of their parent. Close to half had to deal with wakefulness at night, incontinence and parents who refused assistance. Approximately one quarter had to deal with other disturbances such as becoming lost outdoors, pacing and restlessness, wandering at night, verbal abuse and other behaviours of a disruptive nature. There were also reports by a minority of daughters of parents with dementia of more violent behaviours such as screaming for no apparent reason, physical attacks, and others. It is interesting to note that approximately one third of daughters of a parent without dementia also had to contend with wakefulness and wandering at night. In addition, fully one quarter had to deal with a lack of interest in daily life, excessive sleeping and losing things. Unlike daughters of parents with dementia, none of the comparison group of daughters had to contend with more violent behaviours with the exception of one daughter who had been physically attacked.

Burden

The Burden Interview (Zarit, Reever, & Bach-Peterson, 1980) was used to measure feelings of burden. Scores for daughters of parents with dementia ranged from a low of 0 to a high of 67 with the higher scores indicating a greater level of burden. Scores for daughters of parents without dementia ranged from 0 to 53. Table 10 reveals daughter's mean burden scores.

Table 10

Mean Burden Scores

	Mean	S.D.	t	df	p
Daughters of Parents with Dementia (n=104*)	27.1	16.9	-5.4	147	<0.01
Daughters of Parents without Dementia (n=45)	12.0	12.1			

*missing value for 2 respondents

A comparison of mean scores indicated a significant difference between the groups on feelings of burden (see Table 10). Daughters of parents with dementia scored significantly higher on the Burden Interview than daughters of parents without dementia.

Burden scores were collapsed according to a typology developed by Price and Levy (1990) to estimate level of burden (see Table 11).

Table 11
Level of Burden

Level	Value	Daughters of Parents with Dementia		Daughters of Parents without Dementia	
		N 104*	% 100	N 45	% 100
Little/none	(0-20)	46	44.2	37	82.2
Mild	(21-40)	30	28.8	7	15.6
Moderate	(41-60)	25	24.0	1	2.2
Severe	(61-88)	3	3.0	0	0.0

*missing data for 2 respondents

When scores were collapsed, the majority (55.8%) of daughters of parents with dementia fell into categories suggesting some degree of burden. Indeed, over one-quarter had burden scores indicating moderate to severe levels of burden. Unlike daughters of parent with dementia, the vast majority of daughters of parents without dementia experienced ittle or no feelings of burden. Only one daughter achieved a score that suggested a moderate degree of burden. No daughters of parents without dementia were categorized as experiencing a severe level of burden.

Outcome Variable

Depressive Symptomatology

The CES-D scale was used to measure depressive symptomatology among respondents. Mean scores were calculated for both daughters of parents with dementia and daughters of those without dementia. These data are presented in Table 12.

Table 12
Mean CES-D Scores

	Mean	S.D.	t	df	p
Daughters of Parents with Dementia (n=106)	9.7	9.8	-1.2	148	0.2
Daughters of Parents without Dementia (n=44*)	7.5	9.5			

*missing value for 1 respondent.

In large measure, respondents scores indicated little problem with feelings of depression. Scores for daughters of parents with dementia ranged from a low of 0 to a high of 39. Those of daughters of parents without dementia ranged from 0 to 41. A t-test revealed no statistically significant difference in mean scores between the two groups of respondents. Level of depressive symptomatology was investigated further by collapsing scores according to a typology developed by Barnes and Prosen (1984) and is presented in Table 13.

Table 13

Levels of Depressive Symptomatology

Levels	Values	Daughters of Parents with Dementia		Daughters of Parents without Dementia	
		N 106	% 100	N 44*	% 100
None	(0-15)	78	73.6	36	81.8
Mild	(16-20)	10	9.4	5	11.4
Moderate	(21-30)	15	14.2	0	0.0
Severe	(31+)	3	2.8	3	6.8

*missing value for 1 respondent

When scores were collapsed, although the majority of respondents were categorized as experiencing no depressive symptomatology, fully one quarter of those whose parent had dementia fell into categories suggesting the presence of at least a mild level of depressive symptomatology. These results compare with amost one-fifth of respondents of parents without dementia who reported some level of depressive symptomatology.

Relationships among Contextual, Stressor and Outcome Variables

Data analysis proceeded with an investigation of the relationships among contextual, stressor and outcome variables. Relationships were investigated using Spearman Rank Order for categorical data (indicated in *italics*) and Pearson correlations for continuous data. These data are presented in Table 14.

Table 14

Relationships Among Contextual, Stressor Variables and Daughters Depressive Symptoms (CES-D Scores)

	CES-D Scores	
Variables	Daughters of Parents with Dementia	Daughters of Parents without Dementia
Contextual		
Marital status	*-0.01*	*0.26*
Living arrangements	*-0.11*	*0.04*
Self reported health	*0.45***	*0.48***
Health interferences	*0.33***	*0.45***
Daughter's age	0.06	0.03
Years of education	-0.14	-0.01
# of formal services	0.17	0.16
# of additional formal services	0.25*	0.41**
Stressor		
Type of care provided		
ADL	*0.19**	*0.05*
IADL	*0.18*	*0.14*
Parents functional status	*0.30***	*0.15*
Extent of task performance	0.07	0.19
# of behavioural disturbances	0.37**	-0.04
Burden	0.62**	0.59**

* p=0.05, ** p=0.01

Significant associations were found between several of the contextual and stressor variables with depressive symptomatology for both groups of daughters, i.e., those of parents with and without dementia. There were statistically significant and positive correlation coefficients between self reported health, health interferences and the number of additional services required with depressive symptomatology. Daughters who rated their health as not too good or very poor had CES-D scores that were higher than those rating their health as pretty good or very good. In addition, daughters who reported that their health interfered with their activities of daily living achieved higher scores on the CES-D scale. A significant association was also found between the number of additional services required and depressive symptomatology. This association was particularly strong for daughters of parents without dementia. Daughters who required additional formal services had higher CES-D scores than daughters who did not require additional formal services. Finally, burden was also associated with depressive symptomatology. Daughters with higher levels of burden achieved scores on the CES-D that were higher than daughters with lower levels of burden.

Significant associations were found between several stressor variables with depressive symptomatology for daughters of parents with dementia but not for daughters of parents without dementia. Among daughters of parents with dementia, significant associations were found between behavioural disturbances, functional status of parents, the provision of personal care and depressive symptomatology. More specifically, behavioural disturbances were significantly associated with the CES-D scores for daughters of parents with dementia. Those reporting behavioural disturbances achieved higher levels of depressive symptomatology. A modest correlation coefficient was observed between parent's functional status and depressive symptoms for daughters of parents with dementia. Those reporting a parent with poor functional status achieved higher CES-D scores than those with parents with good functional status. Finally, the provision of assistance with personal care activities of daily living also correlated with depressive symptoms for daughters of parents with dementia. This last association, while statistically significant, was the weakest among the stressor variables. These associations were not found among daughters of parents without dementia.

CHAPTER 4

DISCUSSION

This chapter begins with a discussion of the study findings, continues with the strengths and limitations of this study and concludes with implications for the practice of Clinical Nurse Specialists and directions for future research.

Discussion of Study Findings

This study compared the caregiving experience of adult daughters of parents with and without dementia who reside in the community. The objectives were to provide information about the context of care, the stress of care, the prevalence of depressive symptomatology and the relationships among these variables. Analysis revealed both similarities and differences between the two groups of caregivers.

Daughters who were providing care to parents with dementia were on average 53.5 years old. Approximately half were married or living common law and more than two thirds were living with their parent. Those providing care to parents without dementia were on average 48.5 years old. Two thirds were married or living common law and just over ten percent were residing with their parent. The majority of all daughters reported that their health was good or very good and that their health did not interfere with their daily activities.

Typically, daughters used few formal services to assist them in the provision of care to their parent. Approximately one-third of daughters in both groups used formal care services. These findings regarding the use of formal services are congruent with previous research that has demonstrated a reluctance to use formal services to assist in the care of older adults (Kuhlman et al., 1991). It is suggested that families are too embarrassed and ashamed to ask for assistance (Wilson, 1989) and reluctant to leave them with strangers (Caserta et al., 1987). Although a similar proportion of daughters in both groups used formal care services, daughters of parents with dementia used a significantly greater number of formal services averaging 3.4 formal services, when compared with daughters of parents without dementia, who used an average of 1.5 of formal services. This difference was particularly so with nursing and counselling services. It seems that parent with dementia have more needs for care that daughters require assistance with than parents without dementia.

The majority of daughters of parents with dementia provided care of an instrumental nature involving shopping, managing finances, getting to places, housework and meal preparation. Close to one third also provided care of a personal nature such as bathing, dressing and grooming. Between ten and fifteen percent provided care related to toileting, mobility and eating. The task most often carried out by daughters of parents without dementia was shopping. This was followed by helping parents get places. Although no research was found that explored differences in the type of care provided by adult daughters of parents with and without dementia, it is worthy of note that several researchers have reported that attending to a parent's essential aspects of self-care may be particularly distressing (Cohler et al., 1990; Quayhagen & Quayhagen, 1988). There were also differences in the functional status of parents that influenced the caregiving experience of their daughters. More than half of parents with dementia were severely or totally impaired with respect to their ability to perform personal care and instrumental activities of daily living. Conversely, only four percent of parents without dementia were severely or totally impaired. Daughters of parents with dementia also had to contend with a greater number of behavioral disturbances when compared with daughters of parents without dementia who had to contend with very few. These disturbances included wakefulness at night, incontinence and repetitive questions, to name a few. These daughters also experienced a greater degree of burden than daughters of parents without dementia. These findings may be due in part to the fact that almost one-half of daughters resided with their parent with dementia. Hence, these daughters may witness more behavioural disturbances and feel the impact of responsibilities associated with caring for a parent more so than daughters who do not reside with their parent. Nevertheless, this study's findings regarding behavioral disturbances (Boss, Caron, Horbal & Mortimer, 1990; Hinrichsen & Niederehe, 1994; Semple, 1992; Schulz, 1990) and burden (Cairl & Kosberg, 1993; Draper et al., 1992) are congruent with the broader caregiving literature.

Although the mean CES-D score of daughters of parents with dementia (mean=9.7) was slightly greater than that of daughters of parents without dementia (mean=7.5), the difference was not statistically significant. This finding is in contrast to that of researchers who note that caregivers of those with dementia are more likely to experience depressive symptoms when compared with caregivers of those who are not demented (Gallagher et al., 1990). Nevertheless, when scores in this study were collapsed, approximately twice as many daughters with dementia experienced a moderate or severe level of depressive symptomatology when compared with daughters of parents without dementia. In trying to interpret these findings, it is important to note that the trend was in the direction expected, i.e. daughters of parents with dementia scored higher on the CES-D scale than did daughters of parents without dementia. Daughters of parents with dementia are noted in the literature (Haley et al., 1987) to witness the unrelenting deterioration of their parent and to experience in some ways, the premature loss of their parent. This can be seen to be stressful and reflected in the presence of depressive symptoms. Indeed, a sensitive indicator of stressful conditions is depression, particularly when there is a loss of relationships (Brown, Bifulco, Harris & Bridge, 1986) as may be experienced by daughters of a parent with dementia. It is also notable that daughters in this study reported a higher proportion of depressive symptoms, regardless of the cognitive status of their parents, than would normally be found in the general population. Hsu and Marshall (1987) in a review of studies of depressive symptomatology among a community dwelling population, reported that the average proportion of individuals scoring 16 or greater on the CES-D scale was 15%. Similar findings were reported by Devins and Orme (1985). The proportion of daughters in this study scoring 16 or greater on the CES-D was 22.3%. Daughters who are engaged in the provision of care to an elderly or demented parent, are faced with assuming the additional responsibilities which may serve to heighten their awareness of the fact that their parent is getting older and frailer and also results in less time for themselves and their families. They may also become increasingly aware of the fact that their parent is reaching the end of their life, an awareness that may be difficult to come to terms with. Findings from this study also provide support for the findings of Montgomery, Kosloski, & Borgatta (1990), that regardless of the type of impairment, the provision of care to older adults is demanding.

Finally, self-reported health, health interferences and the need for additional services were positively related to depressive symptomatology for both daughters of parents with dementia and daughters of parents without dementia, as was the level of burden. Daughters who reported their health as poor reported greater symptoms of depression. This was also the case of daughters who reported that their health interfered with their daily activities. These findings parallel other studies reporting a correlation between poor health and high levels of depression among caregivers (Mittelman et al., 1995;

Moritz et al., 1992; Pruchno & Resch, 1989b; Robinson, 1989). There was no relationship found between the use of formal services and depressive symptoms among both groups of daughters. Rather than the actual use of formal services, it has been suggested that it is a daughter's perception of the adequacy of support that is closely related to depressive symptoms (Brodaty & Hadzi-Pavlovic, 1990; Fink, 1995; Krause, Liang, & Yatomi, 1989; Robinson, 1989; Schulz & Williamson, 1991). Indeed, among both groups of daughters, there was a relationship between the need for additional services and depressive symptoms, particularly so among daughters of parents without dementia. It may be that services for those who are demented are more plentiful or available than services for elderly and community dwelling older adults without dementia. Although daughters of parents with dementia reported a significantly greater level of burden than those of parents without dementia, there was a significant correlation between these feelings and depressive symptomatology for both groups. These findings concur those of other studies that show an association between feelings of burden and level of depressive symptoms (Brown, Williams, Mitchell, & Brown, 1992; Lawton et al., 1991; Pruchno, Kleban, Michaels & Dempsey, 1990; Vitaliano et al., 1991). It is possible that the relationship between a parent and caregiving daughter changes from one of reciprocity to that of extraordinary and unequally distributed burden.

The type of care provided, behavioural disturbances and the functional status of parents were also associated with CES-D scores for daughters of parents with dementia. The relationship between type of care and depressive symptoms, while weak, parallels other studies (Deimling & Bass, 1986; Williamson & Schultz, 1993) showing that it is personal care activities of daily living, rather than instrumental activities that are associated with depressive symptoms. As with other studies, it may be that attending to a parent's personal and intimate needs may be particularly distressing for daughters (Cohler et al., 1990; Quayhagen & Quayhagen, 1988). The relationship between functional status and level of depressive symptoms in this study mirrors that found in a study by Bass, McClendon, Deimling and Mukherjee (1994), who also found that higher levels of functional disability among elderly parents were associated with higher levels of depressive symptoms among caregiving daughters. The finding in this study of a relationship between behavioural disturbances manifested by a parent and depressive symptoms experienced by caregiving daughters is also congruent with the caregiving and gerontological literature (Baumgarten et al., 1992, Deimling & Bass, 1986, Pruchno & Resch, 1989b; Rabins, Mace & Lucas, 1982; Rankin, Haut, & Keefover, 1992). Behavioural disturbances are one of the most frequently reported stressors by caregivers of older adults with dementia. It is suggested that regardless of the filial relationship, behavioural disturbances represent a major source of depressive symptoms (Brodaty & Hadzi-Pavlovic, 1990; Draper et al., 1992; Hinrichsen & Niederehe, 1994; Semple, 1992) for caregivers.

In conclusion, the conceptual framework provided the necessary direction for the present study. The findings of the present study suggest that regardless of the cognitive status of parents, the context within which daughters provide care are quite similiar with the exception of the use of formal services. However, a number of differences were found between groups of daughters regarding the stresses associated with depressive symptoms. These differences included parent's functional status, behavioral disturbances, type of care provided and the extent to which daughters experienced feelings of burden. Finally, it is interesting to note that daughters of parents with and without dementia experienced a greater level of depressive symptoms than would be expected in community dwelling populations. The results of the present study suggest that regardless of the cognitive status of parents, adult daughters who engage in the provision of care to elderly parents may do so at the risk of their own health and wellbeing.

Strengths and Limitations

Implications of this study are influenced by the study's strengths and limitations. Strengths of this study are related to the representativeness of the sample and the use of a comparison group. Limitations of this study are related to the cross-sectional design, exclusion of some older adults and the disadvantages associated with the secondary analysis of data.

This study of the caregiving experience of adult daughters of elderly community dwelling parents is important for several reasons. The majority of previous caregiving studies have used convience samples or otherwise biased samples (Dura et al., 1991; Scharlach, 1989) which provide a skewed view of the caregiving experience. This study, however, employed a nationally representative sample of adult daughters, which provided a much broader portrait of the experience of providing informal care to older adults. In addition, this study compared the experience of two groups of caregivers, i.e., daughters of parents with and without dementia. The results of this study revealed that regardless of the cognitive status of parents, daughters engaged in the provision of care are at risk of developing depressive symptoms. Finally, this was a timely study given the current climate of health care reform which is characterized by a realignment of health care resources. It appears as if women will be increasingly called upon to provide care to older adults in the home. It is important that health care providers and policy makers are well versed in the realities and outcomes of the provision of such care.

This study is also limited in several ways. First, the cross-sectional design of the study precluded the researcher's ability to establish the causal determinants of depressive symptomatology among adult daughter caregivers. Second, the exclusion of older adults who spoke neither English nor French, or those who did not have access to clinical centers, limited the researchers' ability to fully generalize the results of the study to all Canadian daughters who provide care to community dwelling parents with and without dementia on an informal basis.

There were also some disadvantages associated with conducting a secondary analysis of data. The choice of variables was confined to those that were used as part of the larger study.

The variables used as part of the larger study influenced the development of the conceptual framework. Definitions of concepts were bound by the instruments. Nevertheless, a conceptual framework was developed that incorporated the variables considered salient to existing conceptual frameworks. Lastly, the gathering of data of a qualitative nature might have helped to explain some of the quantitative findings.

Scholarly Implications

The significance of this study for nursing is framed within the context of the practice role of the Clinical Nurse Specialist and the need for further research.

The Role of the Clinical Nurse Specialist

In large measure, the practice role of the Clinical Nurse Specialist is grounded in research based imperatives. The implications of this study for the role of the Clinical Nurse Specialist lie within the context in which adult daughters provided care to their parent, the stress of that care and the level of depressive symptomatology they experienced and its correlates.

Typically, daughters provided care without a great deal of assistance from the formal care system. They reported the use of few formal services to assist them in the care of their parents. Nevertheless, they perceived the need for additional services. This was particularly so for daughters of parents with dementia. Perhaps daughters are not aware of the services available or have difficulty accessing services due to the demands of caregiving. These findings suggest that Clinical Nurse Specialists need to explore formal service use with daughters, provide them with information regarding the services available and facilitate the identification and use of appropriate additional services that would assist daughters in the care of their parent.

Daughters of parents with dementia provided care of an instrumental and personal care nature for parents who were in large measure, at least moderately if not severely impaired. They had to contend with behavioural disturbances related to night wakening and incontinence among other problems. Their burden scores, while not excessively high, were greater than those of daughters of parents without dementia. These findings suggest a level of distress which, if unabated, may ultimately interfere with their being able to continue to care for their parents. Furthermore, continued feelings of burden may result in the deterioration of their own health. These findings point to the need for case finding by Clinical Nurse Specialists, so that early referral of daughters to the appropriate interdisciplinary team members can be inititated. For example, a social worker may be required to provide extended counselling or an occupational therapist may be necessary to assess safety issues in the home. Clinical Nurse Specialists could develop educational programming such as sleep and incontinence programs to help daughters manage the behavioral disturbances of cognitively impaired parents.

In general, respondents' level of depressive symptomatology was greater than would normally be found in the general population. It was particularly notable that approximately twice as many daughters of parents with dementia scored above 16 on the CES-D scale when compared with daughters of parents without dementia. These findings suggest that regardless of the cognitive status of parents, daughters providing care to a parent with or without dementia are at risk of developing symptoms of depression. Clinical Nurse Specialists need to be aware of this risk and observe closely for depressive symptoms when they interact with daughters.

The relationships between poor health, the need for additional services, the provision of personal care and parents functional status and levels of depressive symptoms point to the need for Clinical Nurse Specialists to be sensitive to the needs not only of the recipient of care i.e. parents, but also adult daughters. The provision of care to an elderly parent can be both physically and emotionally demanding. Clinical Nurse Specialists must be vigilant during interactions with informal providers of care and observe for indicators of poor health. Should such indicators be noted, steps should be taken such as exploring the perceived barriers for daughters in maintaining their health, encouraging daughters to have their health assessed by their family physician or nurse practitioner and identifing strategies daughters can use to minimize the physical and mental health consequences of caregiving. Strategies should include linking daughters with the appropriate formal services. This study also found that the provision of personal care was related to depressive symptoms of daughters. Perhaps the provision of intimate personal care to a parent elicits feelings of role reversal or reinforces a sense of loss in daughters. Clinical Nurse Specialists need to explore daughters' feelings related to the provision of personal care. Where indicated, Clinical Nurse Specialists can teach daughters alternate techniques for bathing which may ensure greater privacy for their parent while at the same time altering daughters' feelings towards the provision of such care.

In summary, Clinical Nurse Specialists need to be aware of the risks to the health and well-being of daughters that are associated with the provision of care to elderly parents. In addition they need to incorporate this knowledge into assessment and intervention strategies supporting the continued involvement of adult daughters in the care of their parent in whatever ways are mutually beneficial.

Directions for Further Research

The findings of this study provide direction for future research. There is a need to continue to employ samples that are generalizable to the larger population. Too many studies derive from convenience and biased samples.

There is a need for further research related to service utilization among informal caregivers. Despite the availability of a variety of formal services, caregivers in this study used few services yet expressed a need for additional services. It may be that the criteria by which services are granted require examination or daughters are not aware of all the services available to them. Future studies that explore these issues are required.

There is also a need for further research related to the provision of particular types of care. The provision of personal care which is intimate in nature may be more problematic than care of a less personal nature. Such care may take on a different meaning. It may be the meaning that is important rather than the actual provision of care. Hence, studies that examine the meaning of care for informal caregivers seem important.

There are few studies that have investigated change over time among informal caregivers, both with respect to the provision of care and the outcomes of such care. Such studies require longitudinal approaches. Do caregivers begin with a period of watchfulness, then gradually assume the provision of instrumental care and then engage in the provision of personal activities of daily living? Are there differences in providing care to parents who are physically disabled when compared with parents who are cognitively disabled? Are there different patterns of caregiving and do these patterns have different characteristics which lead to different mental health outcomes for caregivers?

Finally, studies that investigate the interventions that reduce problematic behaviours and assist caregivers to deal with these problems are needed. For example, what are the interventions that are effective in reducing the night wakening among community dwelling older adults with dementia? Are there methods that caregivers can employ to promote continence? What strategies can caregivers use to deal with incontinence in the home?

In conclusion, this study shows that the provision of informal care to parents is challenging and characterized by multiple stressors that place daughters at risk for adverse health outcomes. This study shows that the provision of care by adult daughters to elderly parents, whether cognitively able or cognitively impaired, is challenging. More research is needed to guide the practice of Clinical Nurse Specialists as they strive to provide care, not only to elderly parents, but also to those caregiving daughters.

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APPENDIX A

Definition of Terms in Conceptual Framework

Informal Caregiver

A person who assumes responsibility for the provision of care to a family member, that is situationally derived as a function of caring for a person with a dementing illness. In this study, the focus was on adult daughters with responsibility for the provision of care, at least on a weekly basis, to a parent with or without dementa.

Caregiving

The provision of assistance with personal care activities and instrumental activities of daily living (Green, 1991; Mathews & Rosenthal, 1993), and/or actions taken on behalf of the family member (Davis, 1992; Lang & Brody, 1983) who cannot perform these activities themselves as measured by the OARS Multidimensional Functional Assessment Questionnaire (MFAQ) (Fillenbaum, 1988).

Self-reported Health

Health is a personal construct, temporally located and unique to the individual. In this study, the focus was the adult daughter's subjective appraisal of her health as measured by two self-rated health status questions.

Use of Formal Services

Formal services were defined as services used in the past year by adult daughter caregivers to assist them in the provision of care to an elderly parent. These services may have been provided by the government, hospitals, private or volunteer agencies.

Parent's Functional Status

This construct was conceptualilzed as the extent to which a parent is able to perform; (1) activities of daily living including eating, dressing/undressing, grooming, walking, getting in/out of bed, bathing and toileting; and (2) instrumental activities which are associated with independent living including using the telephone, public transportation, and going shopping, preparing meals, doing housework, taking medications and handling finances (Fillenbaum, 1988). The empirical indicator was the OARS Multidimensional Functional Assessment Questionnaire (MFAQ) (Fillenbaum, 1988).

Parent's Behavioural Disturbances

Consistent with the definition of Baumgarten, Becker, and Gauthier (1990), behavioural disturbances were defined as " the outward manifestation of some underlying cognitive, psychological, or physiological deficit - regardless of etiology - likely to cause stress to those caring for the patient" (p.221). The empirical indicator was the Dementia Behaviour DIsturbance Scale developed by Baumgarten and colleagues (1990).

Type of care

Type of care refers to: (1) activities of daily living which included assistance with eating, dressing, grooming, ambulation, transfers, bathing, toileting; and (2) instrumental activities associated with independent living including using the telephone, transportation, shopping, preparing meals, housework, taking medication and managing finances, that adult daughters perform in an attempt to meet the dependency needs of their parent. The empirical indicator was the OARS Multidimensional Functional Assessment Questionnaire (MFAQ) (Fillenbaum, 1988).

Extent of Care

Extent of care provided was conceptualized as the number of hours per month daughters spent in the performance of tasks associated with activities of daily living and instrumental activities of daily living to meet the dependency needs of their parent. The empirical indicator was the OARS Multidimensional Functional Assessment Questionnaire (MFAQ) (Fillenbaum, 1988).

Burden.

The level of discomfort experienced by daughters as a function of their perception that their health, social life and financial status suffer as a function of providing care to a family member with dementia (Zarit, Reever & Bach-Peterson, 1980). The empirical indicator was the Burden Interview developed by Zarit, Reever and Bach-Peterson (1980).

Depressive Symptoms.

For the purposes of the present study, depressive symptoms were defined as feelings of guilt, worthlessness, helplessness, hopelessness, accompanied by loss of energy and sleep disturbances (Radloff, 1977; Radloff & Teri, 1986). This definition is consistent with the Center for Epidemiological Study Depression Scale (CES-D) which was used in this study to screen for possible depression among adult daughter caregivers.

APPENDIX B

THE CANADIAN STUDY OF HEALTH AND AGING

CAREGIVER INTERVIEW

(Version 2: Informal Caregiver,
Subject in Community)

Identifying Information
(complete in the office before the interview)

Sex of Caregiver M F

Relationship to Study Subject:

W	Wife	H	Husband	D	Daughter
So	Son	Si	Sister	B	Brother
F	Friend	PC	Paid Caregiver	O	Other______

(If paid caregiver, switch to version 1 of questionnaire)

Date of Interview ____/____/____
D M Y

Place: 1. Cg's home 2. Subject's home 3. Other ______

1. **When were you born?** _____/_____/_____
D M Y

2. **Are you single, married, divorced, or separated?**

0	Never married	4	Separated
1	Married	5	Widowed
2	Common law marriage	6	Other ____________
3	Divorced	7	DK

3. **Are you currently living in the same house as (___________)?**

1 Yes 2 No

4. **How many years of education did you complete?** _________ Years 88 DK

So that means that you have . . . . (select suitable category) **(completed primary school, completed part of high school, all of high school, some university)?**

1	No formal schooling	8	Some university
2	Some primary/elementary school	9	Bachelor's degree
3	Finished primary/elementary school	10	Master's degree
4	Some secondary or high school	11	PhD
5	Completed secondary or high school	12	Other ___________
6	Some community or technical college, CEGEP, (e.g. nursing program)	88	DK
7	Completed community college, technical college, CEGEP, (e.g. nursing program)	99	Not asked

5. How would you say your health is these days? Would you say your health is very good, pretty good, not too good, or poor, or very poor?

1 = very good   2 = pretty good   3 = not too good   4 = poor
5 = very poor

6. How much do your health troubles stand in the way of doing things you want to do?

1 = not at all   2 = a little (some things)   3 = a great deal

7. "Many services are available to help elderly people and those who care for them. Services may be provided by the government, hospitals, private agencies or volunteer agencies. You have probably heard of some of these: for example, Homemaker Services, In-Home Nursing, or Self- Help Groups."

Has a homemaker service of cleaning lady been used in (_______)'s household in the past year (e.g. to help with cleaning, laundry, meal preparation)?
1 yes   2 no

Has (_______) received home delivered meals (e.g. Meals on Wheels) in the past year?   1 yes   2 no

Has (_______) received home help for personal tasks (e.g., bathing, dressing, grooming, toileting, etc) in the past year?   1 yes   2 no

Has (_______) received in-home nursing care (e.g. for changing dressings, checking blood pressure, medications, etc.) in the past year?
1 yes   2 no

Has (_______) had physiotherapy, occupational therapy, podiatry or chiropractic treatments in the past year?   1 yes   2 no

Has (_______) attended a day centre or a day hospital in the past year?
1 yes   2 no

Has (_______) used a hospital or nursing home for respite care in the past year? (i.e. he/she was admitted temporarily to hospital or a nursing home to give relief to the family. Do not include admissions for assessment of treatment, etc.)   1 yes   2 no

Have you received counselling (e.g. from a social worker or psychologist) during the past year to support you in caring for (_______) ?
1 yes   2 no

Have you used health-related self-help or support groups (e.g. Alzheimer's Society) to assist you in the past year?   1 yes   2 no

8. Are there any services that you are not already receiving, that would help you in caring for (________)? ________________________________

9. OLDER AMERICANS RESOURCES and SERVICES MULTIDIMENSIONAL FUNCTIONAL ASSESSMENT QUESTIONNAIRE (Fillenbaum, 1988)

"Now, I want to ask you about how (____) manages (her/his) daily life. I will mention a number of common, daily activities, and for each, I want you to say if (_____) can manage this without help, or with some help, or whether he/she cannot do it at all, that is, someone has to do this for them."

** Hand Respondent Cue Card **

If the respondent has difficulty in selecting the appropriate response category, read the example in parentheses below each option. Only use these if help is required, or if you feel that the respondent has not understood the response options. For all responses, even if the person can do something, ask:

"Has anyone helped (her/him) with (the task) during the last month? Include yourself and any family members, friends and neighbours, paid workers, visiting nurses, etc. What is the relationship of this person to (_____)? How often do you/they help? About how long does this take?

(Code relationship to (__) as: W=Wife; H=Husband; D=Daughter; So=Son; Si=Sister; B=Brother; F=Friend; PC=Paid Caregiver; V=Volunteer; FS=Formal service; O=Other. See Interviewer manual for explanation of coding frequency and time). Add more names, if necessary.

Task	Who helped?	Rel'n	Frequency	Time
a. Can (_______) eat... 1 without any help? 2 with some help (cutting food, identifying food for people with vision problems, etc)? 3 or is he/she completely unable to feed himself/herself?	1.		_____ D W M	
	2.		_____ D W M	
	3.		_____ D W M	
b. Can (_______) dress and undress... 1 without any help (pick out clothes, dress and undress self)? 2 with some help (dressing or undressing)? 3 or is he/she completely unable to dress and undress?	1.		_____ D W M	
	2.		_____ D W M	
	3.		_____ D W M	
c. Can (_______) take care of his/her own appearance, for example combing his/her hair and (for men) shaving... 1 without help? 2 with some help? 3 or is he/she completely unable to do this?	1.		_____ D W M	
	2.		_____ D W M	
	3.		_____ D W M	
d. Can (_______) walk... 1 without help (except from a cane)? 2 with some help (from a person or with the use of a walker, crutches, etc)? 3 or is he/she completely unable to walk?	1.		_____ D W M	
	2.		_____ D W M	
	3.		_____ D W M	
e. Can (_______) get in and out of bed... 1 without help? 2 with some help (from a person or device)? 3 or is he/she unable to get in and out of bed unless someone lifts him/her?	1.		_____ D W M	
	2.		_____ D W M	
	3.		_____ D W M	

Task (In the last month)	Who helped?	Rel'n	Frequency	Time
f. Can (______) take a bath or shower... 1 without help? 2 with some help (from a person or device)? 3 or is he/she completely unable to bathe?	1.		______ D W M	
	2.		______ D W M	
	3.		______ D W M	
g. Can (________) use the bathroom or toilet... 1 without help? 2 with some help? 3 or is he/she unable to use the bathroom or commode unless someone moves him/her?	1.		______ D W M	
	2.		______ D W M	
	3.		______ D W M	
h. Can (________) use the telephone... 1 without help (including looking up numbers and dialling)? 2 with some help (can answer phone, dial operator in an emergency, but has a special phone or needs help in getting numbers or dialling)? 3 or is he/she completely unable to use the phone?	1.		______ D W M	
	2.		______ D W M	
	3.		______ D W M	
i. Can (______) get to places out of walking distance... 1 without help (can travel alone on buses or drive own car)? 2 with some help (needs someone to go with him/her or help)? 3 or is he/she completely unable to travel unless special arrangements are made?	1.		______ D W M	
	2.		______ D W M	
	3.		______ D W M	
j. Can (______) go shopping for groceries or clothes... 1 without help (can take care of all shopping himself/herself, assuming he/she has transport)? 2 with some help (needs someone to go with him/her on all shopping trips)? 3 or is he/she completely unable to do any shopping?	1.		______ D W M	
	2.		______ D W M	
	3.		______ D W M	
k. Can (______) prepare his/her own meals... 1 without help (can plan and cook full meals)? 2 with some help (can do some things but unable to cook full meals)? 3 or is he/she completely unable to prepare any meals?	1.		______ D W M	
	2.		______ D W M	
	3.		______ D W M	
l. Can (______) do his/her housework (including laundry)... 1 without help (can do heavy housework) 2 with some help (can do light work but needs help with heavy work)? 3 or is he/she completely unable to do housework?	1.		______ D W M	
	2.		______ D W M	
	3.		______ D W M	
m. Can (______) take his/her own medicine... 1 without help (in the right doses at the right time)? 2 with some help (can take medicine if someone prepares it for him/her and or reminds him/her to take it)? 3 or is he/she completely unable to take his/her own medicines?	1.		______ D W M	
	2.		______ D W M	
	3.		______ D W M	
n. Can (______) manage his/her own money... 1 without help (write checks, pay bills, etc.)? 2 with some help (can manage day-to-day buying but has help with her/his check book and paying bills)? 3 or is he/she completely unable to do day-to-day buying?	1.		______ D W M	
	2.		______ D W M	
	3.		______ D W M	

10. DEMENTIA BEHAVIOUR DISTURBANCE (Baumgarten, Becker & Gauthier, 1990)

"I am going to read you a list of common problems. Please tell me if (___) has had any of these problems generally these days (e.g. in the past week). If so, how often have they occurred?"

Hand the subject Cue Card

FREQUENCY RATINGS

0 = Never 1 = Rarely 2 = Sometimes 3 = Frequently 4 = All of the time

BEHAVIOURS			FREQ
1.	(_)	shows lack of interest in daily activities.	0 1 2 3 4
2.	(_)	makes unwarranted accusations.	0 1 2 3 4
3.	(_)	is verbally abusive, curses.	0 1 2 3 4
4.	(_)	empties drawers or closets.	0 1 2 3 4
5.	(_)	dresses inappropriately.	0 1 2 3 4
6.	(_)	exposes himself/herself indecently.	0 1 2 3 4
7.	(_)	screams for no reason.	0 1 2 3 4
8.	(_)	makes physical attacks (hits, bites, scratches, kicks, spits).	0 1 2 3 4
9.	(_)	makes inappropriate sexual advances.	0 1 2 3 4
10.	(_)	paces up and down.	0 1 2 3 4
11.	(_)	moves arms and legs in a restless or agitated way.	0 1 2 3 4
12.	(_)	gets lost outside.	0 1 2 3 4
13.	(_)	is incontinent of urine (wets himself/herself).	0 1 2 3 4
14.	(_)	is incontinent of stool (wets himself/herself).	0 1 2 3 4

Dementia Behaviour Disturbances continued:

BEHAVIOURS			FREQ
15.	(_)	wakes up at night for no obvious reason.	0 1 2 3 4
16.	(_)	wanders in the house at night.	0 1 2 3 4
17.	(_)	sleeps excessively during the day.	0 1 2 3 4
18.	(_)	overeats.	0 1 2 3 4
19.	(_)	refuses to eat.	0 1 2 3 4
20.	(_)	cries or laughs inappropriately.	0 1 2 3 4
21.	(_)	refuses to be helped with personal care tasks such as bathing, brushing teeth.	0 1 2 3 4
22.	(_)	throws food.	0 1 2 3 4
23.	(_)	wanders aimlessly outside or in the house during the day.	0 1 2 3 4
24.	(_)	hoards things for no obvious reason.	0 1 2 3 4
25.	(_)	destroys property or clothing, breaks things.	0 1 2 3 4
26.	(_)	loses, misplaces, or hides things.	0 1 2 3 4
27.	(_)	asks the same question over and over again.	0 1 2 3 4
28.	(_)	repeats the same action, (e.g. wiping table) over and over again.	0 1 2 3 4

11. ZARIT (Zarit, Reever & Bach-Peterson, 1980)

"Here is a list of ways that people sometimes feel when caring for another person. After I read each question, please indicate how often you have felt that way: Never, Rarely, Sometimes, Frequently, or Nearly Always. Remember thater are no right or wrong answers."

Hand the subject Cue Card

FREQUENCY RATINGS
0 = Never 1 = Rarely 2 = Sometimes 3 = Frequently 4 = Nearly always

HOW OFTEN . . .		FREQ
1.	do you feel that (___) asks for more help than he/she needs?	0 1 2 3 4
2.	do you feel that because of the time you spend with (___) that you don't have enough time for yourself?	0 1 2 3 4
3.	do you feel stressed between caring for (___) and trying to meet other responsibilities for your family or work?	0 1 2 3 4
4.	do you feel embarrassed over (___)'s behaviour?	0 1 2 3 4
5.	do you feel angry when you are around (___)?	0 1 2 3 4
6.	do you feel that (___) currently affects your relationship with other family members or friends in a negative way?	0 1 2 3 4
7.	are you afraid of what the future holds for (___)?	0 1 2 3 4
8.	do you feel (___) is dependent upon you?	0 1 2 3 4
9.	do you feel strained when you are around (___)?	0 1 2 3 4
10.	do you feel your health has suffered because of your involvement with (___)?	0 1 2 3 4
11.	do you feel that you don't have as much privacy as you would like, because of (___)?	0 1 2 3 4

Zarit continued:

		FREQ
12.	do you feel that you social life has suffered because you are caring for (___)?	0 1 2 3 4
13.	(Only where respondent lives with Subject) do you feel uncomfortable about having friends over because of (___)?	0 1 2 3 4
14.	do you feel that (___) seems to expect you to take care of him/her as if you were the only one he/she could depend upon?	0 1 2 3 4
15.	do you feel that you don't have enough money to care for (___), in addition to the rest of your expenses?	0 1 2 3 4
16.	do you feel that you will be unable to take care of (___) much longer?	0 1 2 3 4
17.	do you feel you have lost control of your life since (___)'s condition?	0 1 2 3 4
18.	do you wish you could just leave the care of (___) to someone else?	0 1 2 3 4
19.	do you feel uncertain about what to do about (___)?	0 1 2 3 4
20.	do you feel you should be doing more for (___)?	0 1 2 3 4
21.	do you feel you could do a better job in caring for (___)?	0 1 2 3 4
22.	Overall, how burdened do you feel in caring for (___)?	0 1 2 3 4

12. CENTRE for EPIDEMIOLOGIC STUDIES DEPRESSION SCALE (Radloff, 1977)

"Now I would like to ask you about how you have been feeling. I will read you a list of ways you might have felt or behaved. As I read you each statement, please tell me how often you felt this way during the past week: Rarely, Some of the time, a Moderate amount of time, or Most of the time.

Hand the subject Cue Card

ITEM		FREQ
1.	I was bothered by things that don't usually bother me.	1 2 3 4
2.	I did not feel like eating; my appetite was poor.	1 2 3 4
3.	I felt that I could not shake off the blues even with help from my family or friends.	1 2 3 4
4.	I felt that I was just as good as other people.	1 2 3 4
5.	I had trouble keeping my mind on what I was doing.	1 2 3 4
6.	I felt depressed.	1 2 3 4
7.	I felt that everything I did was an effort.	1 2 3 4
8.	I felt hopeful about the future.	1 2 3 4
9.	I thought my life had been a failure.	1 2 3 4
10.	I felt fearful.	1 2 3 4
11.	My sleep was restless.	1 2 3 4
12.	I was happy.	1 2 3 4
13.	I talked less than usual.	1 2 3 4
14.	I felt lonely.	1 2 3 4
15.	People were unfriendly.	1 2 3 4
16.	I enjoyed life.	1 2 3 4
17.	I had crying spells.	1 2 3 4
18.	I felt sad.	1 2 3 4
19.	I felt that people dislike me.	1 2 3 4
20.	I could not 'get going'	1 2 3 4