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An investigation of the dimensions of burden in family caregivers of Alzheimer's disease patients.

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AN INVESTIGATION OF THE DIMENSIONS OF BURDEN IN FAMILY CAREGIVERS OF ALZHEIMER'S DISEASE PATIENTS

by

© Carol S. Guest

B.A. University of Winnipeg, 1984

A Thesis
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ABSTRACT

Broad definitions of caregiver burden frequently employed in the literature result in a lack of precision in research results. Therefore, this study took a multi-dimensional approach to the operationalization of burden. A total of 101 caregivers of demented dependents participated in the study.

The first objective of the study was to identify some of the dimensions underlying the construct of caregiver burden. Items generated by a literature review were presented to over 500 subjects. Through factor analysis, five dimensions of burden were isolated: Time-dependence; Physical and Emotional Costs; Family Conflict; Role Strain; and Negative Affect.

The second objective of the study involved obtaining a preliminary estimate of the validity of the obtained dimensions. Only Physical and Emotional Costs correlated significantly with a measure of Global Burden. Multiple regression of demographic and situational variables on each of the five dimensions followed expected patterns and, generally, indicated the validity of the dimension labels.

The final objective was to explore differences between various sub-groups of caregivers on the dimensions of burden. The dimensions did not distinguish clearly between male and female caregivers, however significant discrimination was obtained between spouse caregivers and adult child caregivers and between caregivers who were sharing a residence with their dependent and caregivers whose dependent resided in a nursing home. Based on differences in dimension scores, profiles of two types of caregivers who are highly burdened emerged.

The results obtained from this study support further work towards the development of a scale to measure the dimensions of burden. The implications for interventions in caregiving situations using such a scale are discussed.

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CHAPTER I

Introduction

Alzheimer's Disease (AD) is the most common of a group of diseases known as Senile Dementias. The disorder commonly becomes apparent when an individual is in their sixties and is characterized by progressive loss of memory, general decline of intellectual functions, disorganization of the personality, and increasing inability to perform the activities of daily living (Teusink & Mahler, 1984). There is no known cause for the disorder, no cure, and no treatment which can halt its progression (Heckler, 1985).

Moderate to severe AD afflicts approximately five percent of individuals over 65 years of age (Rabins, 1984). In the U.S. it is estimated that approximately one million elderly suffer from AD, and in Canada there are approximately 300,000 such cases. It is projected that, with the increase in the numbers of elderly in the population, the prevalence of AD will double in the next 45 years (Rickards, Zuckerman, & West, 1985).

For every elderly person with AD who resides in an institution, there are two who reside in the community (Wilder, Teresi, & Bennett, 1983). It is estimated that over one half million severely demented patients in the U.S.

are cared for at home (Pratt, Schmall, Wright, & Cleland, 1985). These elderly persons are most often cared for by family members, usually a wife or daughter (Niederehe & Fruge, 1984).

The experience of caring for a relative with AD is a stressful one (George & Gwyther, 1984; Heckler, 1985; Kahan, Kemp, Staples, & Brummel-Smith, 1985; Morycz, 1980, 1985; Pagel, Becker, & Coppel, 1985; Rabins, 1984). Indeed, caring for a relative with AD is more stressful than caring for a relative with a physical impairment (Gilhooly, 1984). For every elderly individual affected by AD, two or three family members, including the primary caregiver, will be immediately affected by the stress of caregiving (Oliver & Bock, 1985).

Family burden has been shown to be associated with a variety of indicators of stress, including decrements in physical health, life satisfaction, and mental health. Although they did not measure burden, Gilleard, Belford, Gilleard, Whittick, & Gledhill (1984) found that approximately 50 percent of their sample of caregivers of the elderly mentally infirm were suffering from a psychiatrically significant level of disturbance. Similarly, Fiore, Becker and Coppel (1983) found that the majority of their sample of AD caregivers met RDC criteria for diagnosable depression. George and Gwyther (1984) compared caregivers of AD dependents with a representative community sample and found that the AD caregivers displayed significantly lower levels of mental health, as indicated by stress-related psychiatric symptoms, psychotropic drug and alcohol use, and decreased life satisfaction. Other studies have measured burden and have found it to be correlated with reported negative changes in health (Pratt, et al., 1985) and with depression (Poulshock & Deimling, 1984). Thus, the stress experienced by caregivers has serious implications for their physical and mental health.

Two current trends indicate that the demand on AD caregivers will increase in the future. The rapid increase in the proportion of the population over 65 means that there will be a greater number of elderly affected by AD and, therefore more families will contain a member requiring care. Also, the current climate of economic restraint is likely to result in insufficient expansion of institutional beds to meet the needs of this growing population, with the result that more AD patients will have to be cared for at home. Both of these trends indicate that in the future there will be a larger population of family caregivers who will be experiencing the stress of caregiving. Thus, it is important that we develop an understanding of the experience of AD caregivers so that we are able to help them cope with the stress of providing care.

The Concept of Caregiver burden

The ill effects or costs to the family that occur as a result of giving care to the impaired family member have been referred to as Family Burden or Caregiver Burden. The concept of families' reactions to the presence of a patient in the household originated in response to concerns about the consequences of deinstitutionalizing mental patients. The pioneering work of Grad and Sainsbury (1963) defined burden as any costs to the family which resulted from having a mental patient in the home. Hoenig and Hamilton (1969) expanded on this work by dividing burden into objective and subjective types. Objective burden was defined as disruption of the daily life of the household due to the abnormal behavior of the patient or to effects that were secondary to the patient's illness, such as financial strains, poor health, family separation, or distress of a family member. Subjective burden was defined as the perception that one was burdened by having the patient in the household.

In that AD involves cognitive impairment, disorientation, delusions, and disorganization of the personality, it is similar to mental illness and can be presumed to have similar effects upon family caregivers. Therefore, the concept of caregiver burden, as defined in early work on deinstitutionalization, is appropriate for use in understanding the experience of family caregivers of AD dependents. The concept has also been applied to families who are giving care to any elderly individual.

Several studies done in the late 1970's first applied the concept of caregiver burden to families who were giving care to an elderly person, or to an individual who was ill. Zarit, Reever, and Bach-Peterson (1980) and Morycz (1980) were the first to apply the burden concept to the family caregivers of demented dependents.

Morycz (1980; 1985) relates burden to aversive behaviors of the dependent, to financial strain, family conflict, or other environmental problems, and to "limitations of the caregiver" (1980, p. 21). This last category includes the caregiver's attitudes towards and expectations of the dependent, physical problems, and emotional reactions such as depression or anxiety. An amount of burden is assumed to be attached to each of these circumstances and the burdens are cumulative, with the assumption of some point at which no more burden can be tolerated by the family, the point at which institutionalization procedures are begun.

Zarit et al. (1980) defined burden operationally by asking caregivers what situations were problematic and combining these items into a 29-item scale. Items dealt with caregivers' health and well-being, finances, social life, and their relationship to the cared-for person. It was assumed that discomfort caused by these situations placed a burden upon the caregiver.

Other authors view burden as one extreme of a continuum of caregiver well-being. George and Gwyther (1984) define burden as the decrements in well-being which result from the demands of caregiving. Niederehe and Fruge (1984) view burden as the clinical impact of dementia on others and regard this impact as resulting in a loss of caregiver well-being. Gilleard, et al. (1984) operationalized burden with a scale designed to measure emotional distress related to a diagnosable psychiatric condition. The impact of caregiving has also been defined in terms of the caregivers' morale and mental health (Gilhooly, 1984) Burden, therefore, has been understood as a stress-related condition which results in decrements in a caregiver's physical and mental health.

A multidimensional approach to the definition of burden is taken by Montgomery, Gonyea, and Hooyman (1984) and by Poulshock and Deimling (1984). Montgomery et al. believe that it is necessary to divide burden into subjective and objective components. Subjective burden involves caregivers' attitudes toward and emotional reactions to caregiving. Objective burden involves the disruption of caregivers' lives which results from giving care. Poulshock and Deimling differentiate between burden and impact. Burden is defined as the subjective interpretation of the caregiver that certain caregiving tasks or behaviors of the elderly person are stress-producing. Impact is regarded as replacing the concept of objective burden and involves alterations to the lifestyle of the caregiver.

It is evident from this review of the definition of burden that a single, universal conception of burden has not yet been developed. For purposes of this study burden is defined as a global concept of costs to the primary caregiver of an AD dependent. It includes the caregiver's perceptions of the impact of caring on his or her life. These lifestyle changes may or may not have actually occurred: what is important is the caregiver's perception that her or his lifestyle has been altered. Also included in the concept of burden are the primary emotional reactions of caregivers to the experience of giving care to their relative. Reactions which could be considered secondary to the stress of providing care, for example, depression, have not been included. Inclusion of such symptoms can result in confounding between measures of burden and measures of psychological distress (Dohrenwend, Dohrenwend, Dodson, & Shrout, 1984).

Role Theory

One way to understand caregiver burden is in terms of role theory. The position of primary caregiver meets the criteria for a role in that caregiving involves a cluster of rights and obligations (Banton, 1965) which are recognized by society (Thomas & Biddle, 1966).

Goode (1960) introduced the concept of role strain which he defined as "felt difficulty in fulfilling role obligations" (p. 483). Role strain is conceptualized as having two components: Role overload and role conflict. Role overload involves being unable to perform satisfactorily in any given role because of an overwhelming number of obligations attached to the totality of roles an individual occupies (Barnett & Baruch, 1985). Role conflict reflects the situation in which satisfactory performance in one role jeopardizes adequate performance in all other roles (Sieber, 1974; Barnett & Baruch, 1985). These concepts led Goode to formulate the theory that role accumulation would inevitably result in the experience of stress for individuals who occupied many roles concurrently.

Sieber (1974) and Marks (1977) questioned the stress-producing aspects of role accumulation. Sieber's theoretical analysis proposed that occupation of multiple roles resulted in a number of benefits which arose, not from the roles themselves, but from possession of many roles. However, he excluded from consideration roles which were "intrinsically offensive or deprivational" (p. 569). Marks emphasized the importance of commitment to a role, pointing out that role conflict and role overload emerge when an individual over-commits him or herself to some roles and under-commits time and energy to other roles.

Stoller (1983) discusses the "complex time allocation decisions" (p. 852) faced by family caregivers. Her analysis indicates that some caregivers, especially women, may be over-committing themselves to the caregiver role at the expense of other roles. She found that marriage decreased time commitment to caregiving for both sexes, but that paid employment decreased time commitment to caregiving only for males, a fact which may help explain the finding that female caregivers experience more burden than do male caregivers (Marcus & Jaeger, 1983).

Barnett & Baruch (1985) tested role accumulation theory as it applied to women's involvement in multiple roles. They found that the quality of experience in a role predicted role overload and role conflict. That is, if costs associated with a role outweighed the benefits derived from occupancy of that role, then women were more likely to report high levels of role conflict and role overload.

Additionally, they found that roles differed in their ability to predict overload and conflict. For example, they found that the parent role was related to role strain, regardless of employment status. The caregiver role has often been described as putting family caregivers in the role of parent to the AD dependent (Teusink & Mahler, 1984). Parent roles are associated with many more obligations than rewards in our society (Barnett & Baruch, 1985), and this would also seem likely for the role of caregiver. Thus, occupancy of the caregiver role would be expected to be related to role strain.

A study by Thoits (1983) provides further insight into the origins of caregiver burden. She tested the social isolation hypothesis, which is derived from a symbolic interactionist perspective of role theory. The social isolation hypothesis contends that isolation from intimate social relations may lead to psycholgical distress. Indeed, Stryker and Statham (1985) maintain that "role occupancy is critical for self-definition and hence for positive feelings toward self and life in general" (p. 349).

Thoits found that the greater number of roles accumulated, the less distress suffered by an individual. She also found that the loss of roles was more distressing for the individual who had previously possessed many roles than it was for the individual who possessed few roles. The social isolation of AD caregivers was examined by Novak and Guest (1985) who found that perceived decrease in activities other than caregiving was significantly correlated to feelings of burden in AD caregivers, and that the strength of desire to engage in alternate activities was strongly and significantly correlated with burden. This indicates that AD caregivers feel socially isolated, and that this perception is related to their feelings of burden.

Role theory suggests three explanations why individuals who are caring for a family member with AD would feel burdened. First, the caregiving role, especially in the case of AD, tends to have more obligations than it does rewards. Thus, the quality of experience in the role will be poor, and the role can be expected to be associated with feelings of role strain and role overload. Second, the nature of AD and the tasks required by caregivers makes it inevitable that an individual will commit much of her or his time and energy to the caregiver role, perhaps at the expense of becoming under-committed to other roles. This time commitment factor has also been implicated in role strain. Finally, the caregiving role often results in feelings of social isolation that would be likely to be associated with feelings of burden, especially for those who had to discard previously held roles in order to meet the demands of the caregiver role.

Limitations of Research on Caregiver burden

Research on caregiver burden as experienced by caregivers of the impaired elderly and by caregivers of AD dependents contains a number of inconsistencies and unexplained findings. Several studies (Gilhooly, 1984; Wilder, et al., 1983; Zarit, et al., 1980) found that caregiver burden was not related to several measures of dementia, such as confusion, disruptive behavior, or memory problems. On the other hand, Kraus (1984) found a "striking difference" (p. 50) in perceived difficulty of providing care between caregivers of AD dependents who displayed noxious behaviors and caregivers of AD dependents who displayed no behavior problems. A relationship between the behavior problems of the AD dependent and psychiatric symptomology of the caregiver was found in the caregivers of the elderly studied by Gilleard et al. (1984). Novak and Guest (1985) found that the functional decline of the AD dependent gave a low, but significant correlation with burden.

Relationships of social support measures with burden have also been inconsistent. Number of family visits was the single significant correlate of burden in the Zarit, et al.(1980) study. However, other measures of social support, such as presence of a confidant, number of close friends, or membership in a support group have failed to show a significant relationship to caregiver burden (Gilhooly, 1984; Novak & Guest, 1985; Pratt, et al., 1985). Fiore, et al. (1983) also found that measures of the helpfulness of the support network of AD caregivers did not give the expected negative correlations with a measure of caregiver depression.

Research on the effects of provision of services to AD caregivers has also resulted in findings of no effect, or effects that were not in the expected direction. Kraus (1984) found that receipt of community care services did not affect caregivers' perceptions that caring for their AD dependent was very difficult, and Pratt et al.(1980) found a similar result with AD caregivers' feelings of burden. Several studies (Gilleard, et al., 1984; Pratt, et al., 1985) found no difference between levels of distress or burden experienced by caregivers of dependents who were institutionalized or living in the community. In their longitudinal study of AD caregivers George and Gwyther (1984) found that caregivers who had institutionalized their dependent during the course of the study showed a decline in five of six measures of well-being.

Most studies (Cantor, 1983; Gilleard, et al., 1984; Marcus & Jaeger, 1983; Novak & Guest, 1986) have found that female caregivers experience greater levels of burden than do male caregivers. However, Pratt, et al. (1985) found no differences in burden between the sexes, and Gilhooly (1984) found that male caregivers had higher morale than did female caregivers, but that there was no difference between the sexes on a measure of caregivers' mental health.

A number of authors have suggested that inconsistencies in research results stem from inadequate conceptualization of the burden construct. Montgomery et al. (1985) believe that the absence of consistent findings in the research on caregiver burden is attributable to differences in the definition and operationalization of the consequences of caregiving. Poulshock and Deimling (1984) state that the precision of research findings will continue to be in doubt as long as burden continues to be broadly defined. Wilder, et al. (1983) explain their finding of no relationship between dementia and burden by speculating that their narrow operationalization of burden as inconvenience may have failed to detect other areas of the relationship.

Research on caregiver burden has been criticized for employing a variety of definitions and operationalizations of the construct, for employing broad, global definitions, and for overly narrow operationalizations of the construct. It would appear that caregiver burden is poorly understood. One way to better understand a concept is to break it down into its component parts and to discover the ways in which these components relate to each other and to exogenous variables. Thus, to better understand caregiver burden, the construct must be operationalized in a multi-dimensional manner. An understanding of the dimensions of caregiving and the ways in which they relate to relevant variables can help to clarify the inconsistencies in research on caregiver burden.

The Dimensions of Caregiver burden

Burden has been operationalized in a number of ways. Robinson (1983) has developed a measure of caregiver strain. In this case, caregiver strain is regarded as "enduring problems that have the potential for arousing threat" (p. 344). Thus, stressors and the resultant strain are regarded as interchangeable concepts. The items of the scale were derived from open-ended interviews with adult children who were caring for their elderly parents who were physically impaired. Items cover 13 potential stressors, such as family, emotional, and work adjustments, inconvenience, disturbed sleep, and upsetting behaviors. The scale correlates moderately with the degree of physical and mental impairment of the elder, but more highly with the caregivers' perceptions that caregiving was difficult, that help was needed with the caregiving, and that lifestyle changes, especially negative ones, had resulted from giving care to the elder. The concept of strain is regarded as being uni-dimensional.

Zarit, et al., (1980) developed a scale to measure the feelings of burden of caregivers who were caring for a demented dependent. They included items which represented areas most frequently mentioned by caregivers as problems. These problems were assumed to result in discomfort to the caregiver which represented feelings of burden. Zarit et al.'s inventory includes 29 items dealing with the caregivers' physical health, their cognitions about caregiving, their affective reactions to the caregiving situation, their mental health, their social life, their financial situation, and their relationship with the person they are caring for. However, the concept of burden is regarded as a uni-dimensional one.

Morycz (1985) measured the strain of AD caregivers with a 14 item scale which deals with caregivers' affective reactions, changes to relationships, changes in social activities and personal freedom, and perceived changes in physical health. A stepwise regression analysis was used to determine the predictors of strain. Several objective variables (availability of help, getting someone to stay with the dependent, dependent's problem severity, and the amount of vigilance required of the caregiver) were found to predict 61 per cent of the variance in strain scores. Thus, in Morycz's analysis, strain is regarded as a uni-dimensional construct, and is considered to result from objective stresses on the caregiver.

Other authors, however, have theorized that burden is a multi-dimensional construct. Montgomery, et al. (1985) point out that, since the literature concerned with the burden of caring for a mentally ill individual indicates that the incidence and correlates of the events of caregiving and the perceptions of caregiving are different, this objective/subjective division should be of use in understanding the burden experienced by caregivers of the frail elderly. In their study, Objective burden was described as the extent to which caregiving had resulted in changes or disruptions to the caregivers life. This was operationalized by asking subjects about changes in the amount of free time available to them, financial changes, changes in activities, changes in relationships, and changes in health since they had become caregivers. Subjective burden was conceptualized as the caregivers' emotional reactions to and attitudes toward the caregiving role. This concept was measured with 13 items relating to attitudes and feelings toward caregiving selected from Zarit et al's (1980) scale. Objective and subjective burden were found to have distinct sets of correlates and to share little of their variance, implying that the two concepts should be considered independently in the examination of causes of caregiver burden.

Thompson and Doll (1982) carried out a study of the burden experienced by families of the mentally ill. They found that many of the families that they studied experienced psychological burdens in addition to objective burdens such as financial strains and disruption of the household. Further, they found that these emotional burdens were nearly universal across families of different composition, race, and social class. They suggest that burden should be, at minimum, separated into subjective and objective components since these concepts shared less than ten per cent of their variance in this study. Additionally, they defined four theoretical dimensions of subjective burden: Overload; feelings of entrapment; resentment; and exclusion. Overload represents the extent to which the ill person interferes with the family and is an emotional drain. Entrapment describes the degree to which the caregiver feels trapped or helpless in the caregiving role. Resentment covers a continuum from sympathy for the care receiver to resentment towards the care receiver. Feelings of exclusion refer to the caregiver's wish to withdraw emotionally from the dependent and to insulate oneself from the situation.

The Caregiver Stress Scale (CARES) (Worcester & Quayhagen, 1983) is composed of three situational stress scales reflecting three types of stress which, they hypothesize, are experienced by caregivers. All three sub-scales are scored on five-point Likert-type rating scales ranging from high stress to low stress. The first two sub-scales, medical-physical and psychological-behavioral, refer to stress on the caregiver resulting from these aspects of the dependent's condition. The final sub-scale, environmental-personal, measures environmentally related stresses of the caregiver, such as having competing demands on one's time, worries about the dependent, and the need for caregiving assistance.

A different approach toward identifying theoretical dimensions of the caregiving experience was taken by Clark and Rakowski (1983). Based on an extensive review of the literature, they developed three clusters of tasks required of caregivers. Tasks associated with the caregiver as provider of direct assistance relate to the time-dependency of the care receiver on the caregiver. This category includes such items as evaluation and supervision of treatment, monitoring the care receiver's condition, performing basic activities of daily living for the care receiver, and management of the care receiver's resources. A second category, Personal tasks faced by family caregivers, contains items reflecting the costs to the caregiver's personal life. Examples of these items are resolving guilt, compensating for loss of personal time, and dealing with the possibility of institutionalization. The final category, Family and societal tasks of the caregiver role, includes items reflecting the need for the caregiver to arrange for the availability of family and societal services to supplement the care provided by the primary caregiver. For example, caregivers must designate other family caregivers, manage feelings towards family members who do not help, and interact with medical, health, and social service professionals. Clark and Rakowski postulate that these categories are dimensions of the caregiving role, not dimensions of caregiver burden. However, many of the items that they use reflect items used to operationalize burden, indicating a parallel between their conception of the dimensions of caregiving tasks and dimensions of subjective feelings about caregiving. If one accepts the assumption made by Poulshock and Deimling that "burdens caregivers experience are the result of their highly personal and individualized responses to specific caregiving contexts" (1984, p. 231), these task divisions would have related types of burden.

Finally, George and Gwyther (1984) measured four aspects of caregiver "well-being". The four dimensions examined in this study were financial resources, physical health, participation in and satisfaction with social and recreational activities, and mental health. Caregivers were found to give significantly lower ratings of social participation and mental health than did representative community samples. Over a one-year period, caregivers showed significant declines in physical health, satisfaction with social activities, and mental health, especially those caregivers who were living with the care receiver or who had recently institutionalized their care receiver. George and Gwyther state that these changes "suggest increased burden" (p. 8), indicating that they view burden as consisting of low levels of well-being measures.

Only two empirical studies of the dimensions of CG burden have been carried out. The first of these was conducted by Niederehe and Fruge (1984). They developed a scale to assess several dimensions of the impact of caring for a demented dependent on the caregiver's emotional status and on the functioning of the family unit.

The dimension of "Subjective Strain" was measured by 36 questions describing costs and benefits of the caregiver role. Principal factors analysis was used to confirm the presence of two factors which were associated with the positive and negative aspects of caregiving.

The dimension of "Impact on Family" was described by 45 items. Principal factor analysis indicated the presence of four factors: Problems in other family members; social restriction; emotional and interpersonal effects; and positive family effects.

Niederehe and Fruge's (1984) study provides interesting results. However, it has one severe limitation: The number of items used in the factor analyses exceeded the number of subjects from whom data was obtained. Unless the number of subjects is much greater than the number of items, factor analysis can take great advantage of chance. When the number of items is approximately equal to the number of subjects the clusters of correlations which make up the factors occur purely by chance. Therefore factors obtained in this manner cannot be considered to be reliable (Nunnally, 1967).

The second study which takes an empirical approach, Poulshock and Deimling (1984), urges a multidimensional approach to the study of burden, but suggests that a simple objective-subjective division is insufficient to categorize the multiplicity of factors which determine caregivers' feelings of burden. The authors propose that burden is an intervening or moderating variable between the cared for elder's impairment and the degree of impact or change in the caregiver's life that results from giving care. Burden is regarded as the subjective view that certain caretaking tasks are stressful. Their analysis indicates that different types of burden can be distinguished as being associated with different types of elder impairment: Sociability impairment burden; disruptive behavior burden; cognitive incapacity burden; and Activities of Daily Living (ADL) impairment burden. Impact or change in a caregiver's life is suggested as a substitute for what other authors call objective burden. To examine the dimensionality of the impact construct items dealing with potential impact on caregiver's lives in the areas of job conflict, financial hardship, caregiver's physical and mental health, family relationships, and social activities were subjected to factor analysis. Two factors of Impact were derived: the first factor referred to changes in the relationship between the caregiver, the caregiver's family, and the cared-for elder; and the second factor was composed of items dealing with restrictions in the caregiver's activities.

There are a number of limitations to Poulshock and Deimling's (1984) study for the purposes of understanding the burden of a caregiver of an AD dependent. First, the study was conducted on a general group of caregivers. Although some of these were undoubtedly dealing with a demented dependent, there are no separate analyses for this group. Second, relatively few items were submitted to the factor analysis, and much overlap exists between those items. For example, of eight items which loaded on the factor describing caregiver activity restriction, six items are listings of various types of social activities. More information about the experience of caregivers could be obtained from a more diverse group of items.

Overview

To summarize, Alzheimer's Disease is a disease of later life which results in a progressive inability to perform the activities required by daily living. Individuals who develop this disease require increasingly larger amounts of assistance and, finally, total care. Most often, the person who provides the majority of this care and assistance is the ill person's wife, daughter or other family member.

Providing care to an AD dependent is stressful for the caregiver, and high incidences of stress-related physical and mental illnesses have been reported for this population. Most commonly, the impact of this stress on the caregiver's daily life and emotions has been referred to as burden. These consequences of giving care to an AD dependent have been variously defined as inconvenience, emotional distress, strain, stress, and lack of well-being or caregiving satisfaction.

Research which has explored the correlates of burden has produced inconsistent results. Studies which have defined and operationalized burden in different ways have indicated different relationships between burden and dependent variables such as the presence of dementia, availability of social support, provision of community services, and sex of the caregiver.

One explanation of the inconsistency of research results in the study of burden is the failure to use a multi-dimensional approach in the definition of the burden construct. Thus, different definitions of the construct may include different dimensions of burden, and thereby may produce different results.

An examination of the literature on the dimensionality of burden shows that it is often treated as a uni-dimensional construct. When a dimensional approach is used, dimensions are frequently based on intuition, rather than on an emprical foundation. Additionally, all hypothesized dimensions are considered to be equally important and the ways in which background characteristics of caregivers relate to the dimensions has not been clearly explained.

Only two emprical studies of the dimensions of the impact of caring for an impaired elderly dependent have been carried out. The first of these studies suffered from severe methodological problems. The second, while methodolgically more rigorous, had some limitations in that it did not deal with AD caregivers, used relatively few items in the analysis, and used items which contained much overlap in their content.

Statement of the Problem

This study focuses on the construct of caregiver burden. Of particular interest are the caregivers of AD dependents, their perceptions of lifestyle changes due to caregiving, and their emotional reactions to these changes and to the situation.

The primary purpose of this study is to take an empirical, multi-dimensional approach to the measurement of burden. Previous research has lacked an empirical examination of the dimensions of burden, with the exception of two studies.

A second purpose of the study is a preliminary attempt at validation of the dimensions obtained in the study. An important component of this objective would be to assess the relative importance of each dimension by regressing the obtained factors on a global measure of burden. Additionally, regression of the background variables would provide additional information about the dimension and indicate the validity of the dimension labels.

The final purpose of the study is to examine the different characteristics of caregivers along the dimensions of burden. Burden is not equal among individuals, therefore an objective of the study would be an examination of how scores on dimensions differ as a function of various background characteristics such as sex of the caregiver, the relationship of the caregiver and dependent, and the living arrangements of the caregiver and dependent.

Chapter II

METHOD

Subjects

The sample consisted of 101 family caregivers of demented or confused elderly individuals drawn from two main sources. Sixty-four cases were obtained through the Windsor and Essex County chapter of the Alzheimer's Society. Another group of 37 subjects was obtained through the University of Winnipeg, where they were taking part in a study of caregivers of confused elderly individuals.

The total sample consisted of 81.2% female caregivers and 18.8% male caregivers. Ages ranged from 25 to 87 years, with 50.5% of the caregivers falling between 51 and 68 years of age. In terms of relationship to the dependent individual, 53.5% of the caregivers were the dependent's spouse, 35.6% of the caregivers were caring for a dependent parent, and the remaining 10.9% of caregivers were caring for a parent-in-law, a sibling, an aunt or uncle, a friend, or another individual. A detailed description of the sample as well as a description of the dependents for whom they were caring is presented in Appendix B.

Description of the Instrument

A major focus of this study was to take an empirical, multi-dimensional approach to the construct of caregiver burden. The final instrument used in the study included a number of items designed to measure the burden construct. As well, three criterion items, questions on demographic variables, items measuring situational variables, and an assessment of the role occupancy of the caregiver were included. The instrument is presented in Appendix A.

Burden Scale Construction

An instrument to measure caregiver burden was constructed for use in this study. Items were gathered from the relevant literature, including studies of caring for the elderly and caring for an AD dependent (Cantor, 1983; George & Gwyther, 1984; Morcyz, 1980; 1985; Montgomery, et al., 1985; Poulshock & Deimling, 1984; Rabins, 1982; Robinson, 1983; Soldo & Myllyluoma, 1983; Strong, 1984; Thompson & Doll, 1982; Worster & Quayhagen, 1983; Zarit, et al., 1982; Zarit, 1983). These items were then grouped according to content and duplications were deleted. The author's judgment was the criterion for grouping and deletion. Ninety-five items remained after this process was completed.

A questionnaire was constructed using the 95 items. Items were rewritten to be as short and to the point as possible. A short description of family caregiving and the purpose of the study was followed by the question: "How well does each of the following statements describe your experience in caring for your elderly relative?". Subjects were asked to answer on a five-point scale ranging from "Not at all descriptive" to "Very descriptive".

This preliminary version of the instrument was completed by 242 Introductory Psychology students, who received partial course credit for their participation. Students were given a short introduction describing AD. They were then asked to imagine that they were in the position of caring for a family member with the disease, and to complete the questionnaire in the manner in which they supposed a family caregiver would.

The data gathered in this manner were then submitted to a principal components analysis with Varimax rotation. Correlations were also calculated between each item and the remainder of the scale items, to obtain an item/total correlation for each item. Items were retained if they had a factor loading of greater than 0.50 and if they had an item/total correlation of greater than 0.50. Forty-three items were deleted in this analysis, leaving 52 items.

A second preliminary analysis was conducted on the remaining 52 items to reduce the item pool still further. This version of the questionnaire was completed by 176 senior undergraduate students from the faculties of Social Work, Nursing, and Psychology. Many of these subjects had completed field work placements and were therefore more likely to be aware of the problems faced by family caregivers than were the Introductory Psychology students who responded to the first version of the questionnaire. Participation was voluntary and students did not receive course credit for their participation. Again, subjects were given a brief introduction about the nature of Alzheimer's disease and asked to imagine themselves in the position of providing care to an AD dependent relative as they completed the questionnaire.

Data were again submitted to principal components analysis with Varimax rotation and item/total scale correlations were computed. As well, item/factor correlations were computed. Items for the final scale were chosen on the basis of these analyses. Items which were retained met two of the following three criteria: Factor loadings greater than 0.50; item/total scale correlations greater than 0.50; and item/factor correlations greater than 0.45. As well, three items that appeared to have duplication of content with other items were deleted, even though they met the criteria for inclusion. The final scale, which is presented in Appendix A, contained 30 items.

Criterion variables

Three criterion items were also added to the scale to provide a preliminary measure of the validity of the obtained factors of caregiver burden.

Global burden (Morcyz, 1985): Overall, how burdened do you feel in caring for your elderly relative?". Responses to this item were rated on a five-point scale ranging from "Not at all" to "Extremely". This item was used to give an estimate of the validity of the obtained dimensions.

Role Overload (Barnett & Baruch, 1985): How often do things you do add up to being just too much? A five-point scale ranging from "Never" to "Almost always" was provided for responses. This item was included since it was felt that role overload was an important variable influencing the experience of caregiver burden.

Role Conflict (Barnett & Baruch, 1985): How often do you have to juggle different obligations that conflict with one another and give you a pulled-apart feeling? This question was answered on a five-point scale ranging from "Never" to "Almost always". The item was included to gauge the degree to which role conflict was associated with each of the dimensions of caregiver burden.

Demographic data

In addition to the burden and criterion items, the final scale contained a number of questions on demographic data. Respondents were asked to indicate their age, sex, and marital status and the age, sex and marital status of the dependent individual. Demographic data is reported in detail in Appendix B. The dependents ranged in age from 51 to 93 years with 53.5% falling between 67 and 80 years of age. Dependents were approximately equally divided among the sexes with 53.5% females and 46.5% males.

Situational Variables

An additional purpose of the study was to examine the variation in scores on the dimensions of burden between caregivers in different situations. Important aspects of the caregiving situation were the relationship of the caregiver to the dependent, and the living arrangements of the caregiver and the dependent individual.

Type of relationship. Subjects were asked to indicate the way in which they were related to the person they were caring for. A detailed breakdown of these relationships is given in Appendix B. Since most of the caregivers were caring for either a spouse or a parent, the 12 relationship categories were collapsed, for purposes of analysis, into two groups: Spouse caregivers (_n_ = 54); and Adult child caregivers (_n_ = 36).

Involvement in the caregiver role. The caregivers' degree of involvement in the caregiving role was measured by asking what percentage of the total assistance and care provided to the dependent was provided by the respondent. A detailed analysis of responses to this item is provided in Appendix B.

Living arrangements of the caregiver and dependent. An additional variable of interest was the living arrangement of the dependent person. Respondents were asked to indicate if their dependent lived by him or herself, in the caregiver's home, in a nursing home or care facility, or in some other living arrangement. All responses fell into the first three of these categories and the responses are reported in Appendix B.

Role Occupancy of the Caregiver

Role theory indicates that an important variable in this study would be the degree to which caregivers were involved in multiple roles. Caregiver's occupancy of eight roles was measured: Spouse role, for currently married caregivers; Parent role, for caregivers with one or more children; the Employee role, for caregivers who were employed on a full or part time basis; Church member role, as indicated by regular attendance of church services; Neighbor role, as indicated by visiting one or more neighbors; Friend role, as indicated by the possession of at least two close friends; and Organization member role, as indicated by attendance of the meetings of any club or organization other than the Alzheimer's Society. The Alzheimer's Society was excluded as it was felt that this activity belonged to the Caregiver role. All subjects were automatically considered to be occupying the Caregiver role. Caregivers in this study occupied between two and eight roles. The frequencies with which caregivers occupied each of these numbers of roles is reported in Appendix B.

Procedure

Since subjects were drawn from two different sources, different procedures were used to administer the final questionnaire to each sample.

Windsor Sample

Subjects were caregivers of AD dependents living in Windsor and Essex County. A list of subjects was obtained with the cooperation of the Windsor and Essex County

Alzheimer's Society. Potential subjects were those who were defined as primary caregivers of a family member with AD who was still living. Potential subjects were contacted by telephone or by letter by a member of the board of the Alzheimer's Society, the purpose of the study was explained, and the subject's cooperation was requested. If the subject agreed to participate they were told that the investigator would contact them by telephone. Seventy caregivers were approached in this manner. Three potential subjects refused to participate and eight did not respond to letters.

Of the remaining 59 subjects, 16 had indicated that it would be inconvenient for them to participate in the study by telephone. Therefore, a questionnaire was mailed to these subjects, along with a stamped return envelope. Eleven of these questionnaires were returned.

The remaining 43 subjects were telephoned by the investigator. The introduction to the questionnaire was read ~~to the~~ subject and the investigator confirmed that they were willing to participate. Three additional subjects refused to participate at this point.

The demographic and situational questions were read and the subject's response was noted. The burden and criterion items were then read to the subjects, with the five response categories for each item being read after each item. If a subject was uncertain or did not understand the question the item and response categories were repeated. After the interview was completed the subject was thanked and informed that a summary of the results would be included in the Alzheimer's Society newsletter in the fall of 1986. On average, the telephone interviews took 15 minutes to complete.

Additional responses were gathered at the meetings of the Alzheimer's Society. As people entered the meeting they were asked if they had participated in the study. If they had not already completed the questionnaire, the study was explained to them and their participation was requested. All 13 individuals approached in this manner completed the questionnaire on their own and returned it to the investigator at the end of the meeting.

In total, of 83 potential subjects approached in various ways, 64 individuals completed the study. The return rate for the Windsor sample, therefore, was 77%.

Winnipeg Sample

An additional 37 responses were obtained in Winnipeg, Manitoba. Subjects were family caregivers of confused elderly individuals. The questionnaire used in the present study was embedded in a larger questionnaire which was administered in a face-to-face interview taking approximately one and one-half hours to complete.

The first 37 of 150 interviews were selected for the present study. This number was predetermined to bring the sample size to approximately 100.

Subjects in the Winnipeg study were identified and approached by workers with home care services, day care programs, and nursing homes. Only the names of those subjects who had agreed to participate were given to the investigator and no data on refusals to participate were available. The investigator contacted subjects by telephone and arranged to interview the subject in his or her home at a convenient time. None of the subjects approached in this manner refused to participate.

CHAPTER III

Results

The Dimensions of Burden

The main objective of this study was to carry out a multi-dimensional examination of the construct of caregiver burden. Factor analysis was used to determine the dimensions underlying a set of items relating to the burden construct.

A preliminary step involved assessment of the homogeneity of the sample. This was necessary because data were collected from individuals who lived in two cities and who were derived from different sources. A statistical comparison was made using t tests and few differences were found between the two samples. Based on this assessment it was concluded that the samples were sufficiently similar to be combined in all subsequent analyses.

Factor Analysis

Principal component analysis with Varimax rotation was performed on the 30 burden items. Fourteen of these initial items were eliminated, based on this preliminary analysis, because they failed to correlate higher than 0.45 with any factor, or because their loadings were complex.

The remaining 16 items were submitted to a second principal components analysis with Varimax rotation. Intercorrelations between these 16 items are included in Appendix C. Two subjects were dropped from the analysis due to missing values, leaving 99 cases. Five factors were retained, based on the Eigenvalue one criterion. The five factors accounted for 66% of the total variance in the set of items. This solution was moderately successful in accounting for the variance in the individual items as indicated by the communality values. Loadings of variables on factors, communalities, and percents of variance and covariance are shown in Table 1. Variables have been ordered and grouped by size of loading to facilitate interpretation. Loadings under 0.30 have been deleted.

Factor 1 (Time dependence) includes five items. These items, followed by their factor loadings, were: "My care receiver is dependent on me" (.81); "My care receiver needs my help to perform many daily tasks" (.76); "I have to watch my care receiver constantly" (.75); "I must be available when my carereceiver needs me" (.66); and "Caring for my care receiver ties me down" (.59). This factor represents the extent to which the dependency of the care receiver results in restrictions on the caregivers' time. Since Alzheimer's disease and other forms of dementia result in

Table 1

Factor Loadings, Communalities (h^2), Eigenvalues, and Percents of Variance and Covariance for Five Factor Principal Components Analysis with Varimax Rotation

Item	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	h^2
1	.81	–	–	–	–	.70
7	.76	–	–	–	–	.64
2	.75	.39	–	–	–	.74
19	.66	–	–	–	–	.61
21	.59	.36	–	.36	–	.63
27	–	.73	–	–	–	.61
26	–	.73	–	–	–	.62
23	–	.72	–	–	–	.59
5	–	.50	.30	–	.33	.53
3	–	–	.89	–	–	.82
4	–	–	.85	–	–	.76
17	–	–	–	.76	–	.59
8	–	–	–	.75	–	.58
15	–	.34	–	.59	–	.56
16	–	–	–	–	.89	.82
14	–	–	–	–	.84	.78
Eigenvalue	4.25	2.21	1.60	1.38	1.27	
Percent of variance	26.56	13.83	10.03	8.64	7.05	66.11
Percent of covariance	25.59	23.31	17.30	17.25	16.55	100.00

Note. *N* = 99. Two cases were dropped from the analysis due to missing values.

the dependents' inability to perform the tasks of daily living, the caregiver must perform these tasks for the dependent. As well, with the increasing forgetfulness of the dependent, the caregiver must increase his or her vigilance to ensure that the dependent is not engaging in any potentially injurious activity. Thus, the increasing inability of the dependent to care for his or her self means that the caregiver must be physically present and aware of the dependent at all times.

Factor 2 (Physical and emotional cost) was composed of four items: "My health has suffered" (.73); "I expected that things would be different at this point in my life" (.73); "I wish I could escape from this situation" (.72); and "I feel uncomfortable when I have friends over" (.50). This factor is defined by considerations of Physical and emotional costs: To health; of loss of an anticipated future; to personal freedom; and to the ability to relax and feel comfortable with one's friends. This factor represents the caregivers' internal reactions to the negative aspects of the caregiving role. Much of this reaction seems to be tied up with the idea that the caregiver did not expect to be in the caring situation, was therefore not prepared for it, and, possibly does not feel capable of handling the various aspects of the role. Thus the caregiver mourns for the loss of freedom that he or she expected to have at this time of his or her life and desires to escape from a situation which is difficult to deal with.

Factor 3 (Family Conflict) is defined by two items: "I don't get along with family members as well as I used to" (.89); and "My caregiving efforts aren't appreciated by others in my family" (.85). Both of these items reflect caregivers' perceptions that the quality of family interactions has suffered due to their caregiving. This would naturally contribute to feelings of burden, since family members are regarded as a source of support, especially in times of illness or trouble. The feeling that one's efforts are not appreciated by others may give rise to feelings of resentment, and possibly may cause the caregiver to question his or her own efficacy in the role.

Factor 4 (Role strains) is composed of three items: "I don't do as good a job at work as I used to" (.76); "I've had problems with my marriage/intimate relationship" (.75); and "I can't pay as much attention to my family as I used to"(.59). This dimension represents caregivers' perceptions that their involvement in the caregiving role is interfering with their ability to fulfill their obligations in other roles. The time demands of a demented dependent are heavy, and would naturally limit the quantity of time available to caregivers to expend on other roles. As well, worry about the dependent and emotional and physical tiredness arising from caregiving may affect the quality of the caregivers interactions in their other roles.

Factor 5 (Negative Affect) consists of two items: "I resent my care receiver" (.89); and "I feel ashamed of my care receiver" (.84). This factor is defined by the caregivers' feelings that the caregiving role has resulted in negative thoughts toward the dependent individual. Given the feelings which define the other factors, it is not unnatural that caregivers would feel some degree of anger towards their dependent. Also, especially for caregivers who do not understand the nature of dementing illness, the caregiver may be ashamed of the dependents' bizarre behaviors, inability to control bowels, etc.

Since Factors 3 and 5 were defined by so few variables an examination of their reliability was carried out. The sum of squared factor loadings (SSL) for each factor was examined after rotation. All SSL values were greater than one, indicating reliable factors. As well the patterns of correlations for the two variables defining each factor with each other and with the other variables in the data set were examined. In both cases the two variables defining the factors were highly correlated with each other and had no high correlations with any other variable. This suggests that these factors can be regarded as reliable ones.

Intercorrelations between the five obtained dimensions are contained in Table 2. Intercorrelations for Factors 1, 2, 3, and 5 range from 0.04 to 0.39 indicating that between 0.2% and 15% of their variance is shared. Factor 4, however, shows two large correlations with other factors. Factor 4 and Factor 2 correlate 0.45 (p < .0001), indicating that 20% of their variance is shared. Thus, the Physical and emotional cost dimension and the Role Strains dimension share a significant, though small, portion of their variance. The large correlation between Factor 4 and Factor 1 (0.71, p < .0001) indicates a more serious problem. These two dimensions share 50% of their variance indicating that Role Strains and Time-dependency share many of the same attributes. However, since it is reasonable to suppose that role strains would arise when substantial time was being allocated to one of may roles a caregiver occupies and, given the exploratory nature of the study, the decision was made to proceed with further analysis using all five dimensions. Coefficient Alpha was calculated for the total reduced set of items and for each of the dimensions to give an estimate of their internal-consistency reliabiltiy. These estimates are included in Table 2.

Correlates of the Dimensions of Burden

In order to establish the validity of the interpretations of the obtained dimensions of burden

Table 2

Intercorrelations Between Five Obtained Factors and Alpha Reliabilities for the Total Item Set and Factors

Factor	Coefficient Alpha	Factor 1	2	3	4	5
1	0.79	1.00				
2	0.77	0.38***	1.00			
3	0.79	0.04	0.29***	1.00		
4	0.53	0.71***	0.45***	0.20*	1.00	
5	0.76	0.14	0.39***	0.09	0.13	1.00
Total	0.82	0.78***	0.79***	0.42***	0.79**	0.39***

Note. *N* = 101

*** $p < 0.001$

correlational analyses were carried out. Canonical correlation was performed to analyze the relationships between the set of dimensions and the set of demographic and situational variables. To understand the relationships between the individual dimensions and the demographic and situational variables better, stepwise multiple regression was conducted.

Canonical Correlation

Canonical correlation is used to determine the magnitude of the relationship between two sets of variables, to derive linear combinations of the variables that are maximally correlated, and to explain the nature of the relationship by indicating the contribution each variable makes to the obtained function. Both correlations and weights are obtained from the analysis, however, correlations are more appropriate for interpretive purposes, as the weighting procedure can distort the relative importance of the variables in the attempt to maximize linear prediction.

A canonical correlation analysis was performed between the five obtained dimensions of burden (Time-dependence, Physical and emotional cost, Family Conflict, Role Strains, and Negative Affect) and a set of demographic variables

(Caregivers' and dependents' sex, age, and marital status) and situational variables (type of relationship, percentage of care provided, living arrangements of the dependent, the number of children, neighbors, and friends of the caregiver, and the caregivers involvement with work, clubs, and church). Table 3 presents the results of the analysis.

Of the five canonical correlations obtained, the first two were significantly different from zero. The first canonical correlation was 0.69, ($p < 0.0001$), and accounted for 42% of the variance shared by the canonical variates. The second canonical correlation had a magnitude of 0.63 ($p < 0.05$) and accounted for a further 30% of the shared variance.

Inspection of the loadings greater than 0.30 on the first pair of canonical variates indicate that variables relevant to the first canonical variate in the set of dimensions were, in order of magnitude, Factor 1 (Time-dependence), the negative of Factor 3 (lack of Family Conflict), and Factor 4 (Role strains). Among the demographic and situational variables, greater percentage of care provided, dependent residing with the caregiver, greater age of caregiver, possession of fewer friends, and married status of the dependent were relevant to the canonical variate. Taken as a pair, the first canonical variates indicate that strong feelings of time-dependence, moderate feelings of role strain, and lack of family conflict are associated with older individuals who are caring for their spouse at home, providing a large percentage of the total care received by the dependent, and who have few close friends.

The second canonical variate in the set of dimensions was composed of Factor 1 (Time-dependence) and Factor 3 (Family conflict) and, to a lesser extent Factor 2 (Physical and Emotional Costs). The corresponding canonical variate from the set of demographic and situational variables consisted of percentage of care provided, living arrangement of the dependent, number of friends of the caregiver, sex of the caregiver, and type of relationship. Taken as a pair, these variates suggest that high perceptions of time-dependence of the elder and of family conflict combined with moderate levels of physical and emotional costs are associated with male caregivers who are caring for a spouse or parent in the community, providing a large proportion of the total care the dependent receives, and who have a relatively large number of close friends.

Multiple Regression Analyses

Several multiple regression analyses were done to assess the relationship between the demographic, situational, and criterion variables and each of the

Table 3

Canonical Correlation Analysis Between the Obtained Dimensions and the Demographic and Situational Variables

	First Canonical Variate		Second Canonical Variate	
	Correlation	Coefficient	Correlation	Coefficient
Demographic and Situational Set				
Caregiver Age	0.56	0.69	0.22	-0.27
Caregiver Sex[a]	-0.06	-0.32	0.43	0.51
Caregiver marital status[b]	-0.03	0.31	-0.03	-0.02
Type of relationship[c]	-0.17	0.27	-0.42	-0.37
Number of CG's children[d]	0.13	0.28	-0.14	-0.06
Caregivers work status	-0.21	0.01	-0.06	0.18
Caregivers club membership[e]	0.06	0.19	-0.16	-0.21
CGs' Church attendence[f]	-0.15	-0.17	-0.18	0.01
Number of neighbors	0.27	0.26	-0.21	-0.18
Number of friends	-0.35	-0.29	0.44	0.40
% of care provided	0.66	0.60	0.59	0.50
Dependent Age	-0.04	-0.16	0.21	0.25
Dependent marital status[g]	-0.34	-0.22	-0.16	0.10
Dependent living situation[h]	0.58	0.01	0.54	0.07

Table continued

Table 3 continued

	First Canonical Variate		Second Canonical Variate	
	Correlation	Coefficient	Correlation	Coeffficient
Dimension Set				
Factor 1 (Time-dependence)	0.70	0.48	0.69	1.06
Factor 2 (Personal Loss)	-0.00	-0.25	0.32	0.08
Factor 3 (Family Conflict)	-0.64	-0.63	0.59	0.68
Factor 4 (Role Strains)	0.54	0.39	0.29	-0.54
Factor 5 (Negative Affect)	0.18	0.25	0.04	-0.12
Percent of Variance	0.32		0.31	
Redundancy	0.15		0.12	
Total Redundancy = 0.27				
Percent of Variance		0.20	0.07	
Canonical Correlation		0.69^{***}	0.63^{**}	

Note. N = 89

*** $p < 0.001$

** $p < 0.01$

a Female=1, Male=2
b Married=1, Widowed=2, Divorced=3, Separated=4, Single=5
c Spouse=1, Parent=2, Parent-in-law=3, Sibling=4, Aunt/Uncle=5, Friend=6, Other=7
d Not working=1, Working part time=2, Working full time=3
e No membership=1, Club or organization membership=2
f No regular attendence=1, Regular attendence=2
g Married=1, Widowed=2, Divorced=3, Separated=4, Single=5
h Nursing home=1, Own home=2, Caregiver's home=3

dimensions of burden. Stepwise multiple regression analyses were performed using Global burden as the dependent variable and the five dimensions of burden as independent variables and the five dimensions of burden as dependent variables and the set of demographic and situational variables and the criterion variables as independent variables. The Stepwise technique was used since it is a model-building rather than a model-testing technique and, as such, is useful for eliminating superfluous variables from consideration. The significance levels for entry of removal from the equation were set at 0.15 and Mallows' C_p statistic was used to determine the best model. A value of C_p which is near the number of variables entered into the equation indicates that the parameter estimates (regression coefficients) are unbiased. Results of the regression analyses are presented in Appendix D.

Only one of the dimensions of burden was a significant predictor of Global Burden. Factor 2 (Physical and emotional cost) predicted 23% of the variance in the feeling that the caregiver was burdened by the care of their dependent. No other dimensions met the criteria for entry into the equation, indicating that they have little in common with the feeling of being "burdened" by care.

Factor 1 (Time-dependence) was best predicted by two variables: Percentage of total care provided to the dependent by the caregiver and role overload. These two variables accounted for significant variance in Factor 1 ($\underline{R}^2 = 0.40$) and indicate that the label is appropriate.

Factor 2 (Physical and emotional cost) was best predicted by two of the criterion variables: Role overload and global burden. The combination of these two variables gave an $\underline{R}^2$ of 0.36. Thus, the feelings of things being "too much" to handle and the feeling of being burdened by care are moderately related to feelings that the costs of the caregiving role outweigh the benefits.

Factor 3 (Family Conflict) had only a small proportion of its variance accounted for ($\underline{R}^2 = 0.30$) by five variables. They are, in declining order of magnitude: Role Conflict; number of caregivers' friends; number of neighbors caregiver visits; caregivers' age; and caregiver sex. More variables were needed to reach a satisfactory value of C_p; however no further variables met the significance level for entry into the equation. To a limited degree, however, Family Conflict is predicted by the feeling of being "pulled apart" by conflicting obligations, by possession of many friends, by relatively few visits to neighbors, by relatively younger caregivers, and by a larger proportion of male caregivers.

Factor 4 (Role Strains) was accounted for to a moderate degree ($\underline{R}^2 = 0.38$) by a set of six items. From most to least important, these are: Role overload; percent of care provided; Global burden; number of caregivers' friends; age of caregiver; and employment status of caregiver. The number of caregivers' children and caregivers' marital status also met the criteria for entry into the equation, but the C_p statistic indicated that they introduced bias into the parameter estimates. The dimension of Role strain, therefore, was partly accounted for by the perception that things were "too much" to handle, by greater percentage of care provided, by the perception that the caregiver must juggle conflicting obligations, by a smaller number of friends, younger age of the caregiver, and by employed (full or part time) status of the caregiver.

Three variables met the entry criteria for the equation with Factor 5 (Negative Affect) as dependent variable. They were: Role overload; caregiver sex; and visits to neighbors by the caregiver. However, only 17% of the variance in Factor 5 was accounted for by these variables and C_p indicates that none of the models have unbiased parameter estimates. Tentatively, therefore, Negative affect is associated with role overload, female sex, and visits to many neighbors.

Variation in Dimensions Between Sub-groups

A further purpose of the study was to examine the variation in scores on the obtained dimensions between various sub-groups in the caregiver population. Variables of particular interest in this study were caregiver sex, the relationship of the dependent person to the caregiver, and the living arrangements of the dependent and the caregiver.

Tests of Mean Differences

To assess the differences between subgroups of caregivers t tests and one-way Analysis of Variance were carried out.

Caregiver Sex. Only one of the differences between the sexes was significant. Males scored significantly lower ($M = 0.16$) on Factor 5 (Negative Affect) than did females ($M = 0.61$), $t\ (76) = 2.47$, $p < 0.05$. This difference disappeared when only spouse caregivers were compared.

Relationship of dependent to caregiver. A significant difference was found between Factor 1 (Time-dependence) scores for the groups, $t\ (67) = 3.39$, $p < 0.01$, with spouse caregivers reporting significantly more feelings of time-dependence ($M = 12.50$) than did adult child caregivers ($M = 8.50$). As well the scores on Factor 3 (Family Conflict) differed significantly between the two groups,

t (88) = -1.97, $p < 0.05$. Adult child caregivers reported significantly higher levels of family conflict ($M = 2.00$) than did spouse caregivers ($M = 1.01$). A final difference between the groups was found on Factor 4 (Role Strain) scores, t (81) = 2.26, $p < 0.05$. Spouse caregivers reported significantly more role strain ($M = 3.98$) than did adult child caregivers ($M = 2.63$).

Living arrangements of dependents and caregivers. One-way analysis of variance for unbalanced samples was used to assess mean differences, with the three levels of the dependent's living arrangements (dependent in own home, dependent in caregiver's home, or dependent in Nursing Home) as the independent variable and the estimated scores of the five dimensions as dependent variables. This analysis revealed main effects for Factor 1 (Time-dependence), F (2,98)= 18.83, $p < 0.001$ and for Factor 4 (Role Strain), F(2,98) = 7.20, $p < 0.01$. Post-hoc analysis of means (Tukey's HSD) indicated that Factor 1 and Factor 4 scores were significantly higher for caregivers who were caring for their dependent in their home (M Factor 1 = 14.5, M Factor 4 = 4.41)and caregivers whose dependent resided in a nursing home (M Factor 1 = 7.85, M Factor 4 = 2.35) with the nursing home caregivers reporting lower levels of burden on both dimensions.

Canonical Discriminant Function Analyses

Discriminant function analysis was used to determine the best combination of predictor variables (factor scores) which would maximize differences between the various naturally occurring sub-groups in the sample. The procedure produces a linear combination of variables that will discriminate among existing groups and assigns a weight to each variable to indicate the relative importance of each variable to the solution.

Caregiver Sex. A canonical discriminat analysis was performed using the five factors as predictors of membership in the two groups. One canonical discriminant function was calculated, however it failed to discriminate between the sexes.

To further examine the differences between male and female caregivers the set of 16 items which composed the five factors was submitted to a canonical discriminant analysis as predictors of caregiver sex. One canonical function was derived which accounted for 32% of the variance between the sexes. The canonical correlation between the groups and the set of predictor variables was 0.49 (F (16,82) = 1.65, $p < 0.07$) indicating that the canonical function approached significance. Given the exploratory nature of the present study, the canonical function was interpreted and is presented in Appendix D.

Relationship of caregiver to dependent. Canonical discriminant analysis was performed using the five factors as predictor variables of membership in one of two groups: Spouse caregivers or Adult child caregivers. One canonical discriminant function was derived, which discriminated significantly between the groups ($R = 0.45$, $F(5,184) = 3.18$, $p < 0.001$.

The loading matrix of correlations between predictor variables and the discriminant functions, presented in Table 4, indicates that Factor 1 (Time-dependence) was the most important variable in discriminating between spouse caregivers and other caregivers. Spouse caregivers scored higher ($M = 12.5$) on this factor than did Adult child caregivers ($M = 8.5$). Also important in discriminating among the groups were Factor 2 (Physical and emotional cost), the negative of Factor 3 (lack of Family Conflict), and Factor 4 (Role Strains).

Table 4

Canonical Discriminant Analysis of Relationship Groups on the Basis of Five Dimensions of Burden

Predictor Variable	Correlations with Discriminant Function	F Value
Time-dependence	0.77	12.10^{***}
Physical and Emotional Costs	0.41	3.16
Family Conflict	-0.46	3.88^{*}
Role Strain	0.50	4.85^{*}
Negative Affect	-0.16	0.48
Canonical R	0.45^{**}	
Eigenvalue	0.25	

Note. $N = 90$,

*** $p < 0.001$

** $p < 0.01$

* $p < 0.05$

Living arrangements of dependents and caregivers. Canonical discriminant analysis was also used to determine whether the five burden dimensions could effectively discriminate between three types of living arrangements of dependents: Living in their own home; living in the caregivers' home; or living in a nursing home. One significant canonical discriminant function was obtained. The results of the analysis are presented in Table 5.

Inspection of the loading matrix of correlations between the predictor variables and the first discriminant function indicates that Factor 1 (Time-dependence) is the most important variable in discriminating between the groups. Additionally, Factor 4 (Role Strains) contributes to the discriminatory power of the function. Inspection of the Mahalanobis distances indicated that the first canonical function significantly discriminated between all three groups ($p < 0.0001$).

Summary

Factor analysis was used to derive five factors from a set of items pertaining to the construct of caregiver burden. The factors were named Time-dependence, Physical and Emotional Costs, Family conflict, Role strain, and Negative affect.

Table 5

Canonical Discriminant Analysis of Relationship Groups on the Basis of Five Dimensions of Burden

Predictor Variable	Correlations with Discriminant Function	F Value
Time-dependence	0.97	18.83^{***}
Physical and Emotional Costs	0.24	1.02
Family Conflict	-0.07	0.87
Role Strain	0.62	7.19^{**}
Negative Affect	0.27	1.36
Canonical R	0.54^{***}	
Eigenvalue	0.42	

Note. $N = 100$

*** $p < 0.001$

** $p < 0.01$

Regression analyses indicated that only Factor 2 (Physical and emotional cost) was a significant predictor of global burden. Additional regressions indicated the important predictors of the five dimensions and, to a certain extent, validated their labels.

Canonical correlation indicated that time-dependence, feelings of role strain, and lack of family conflict are associated with older caregivers who are caring for their spouse or parent at home, providing a large proportion of the total care received by the dependent, and who have few close friends. As well, this analysis suggested that time dependence and family conflict are associated with male caregivers who are caring for a spouse or parent in the community, providing a large amount of the dependent's care, and who have a large number of friends.

Chapter IV

DISCUSSION

This study was designed to examine the dimensions of the construct of caregiver burden in caregivers of Alzheimer's Disease or other demented dependents. Previous attempts in this direction have either not focused on this particular population, or have had methodological limitations. The major objective of the study was to identify the dimensions underlying the construct of caregiver burden in order to better understand the dynamics of the experience of burden. The second objective was to provide a preliminary estimate of the validity of the obtained dimensions. The final objective of the study was to examine the ways in which various groups of caregivers differed in their scores on the various dimensions of burden. Each of these objectives will be dealt with in this chapter.

The Dimensions of Burden

Five burden dimensions emerged from the analysis: Time-dependence; Physical and Emotional costs; Family Conflict; Role Strains; and Negative Affect. These dimensions are listed in order of their importance, as indicated by the study results, with the first two factors carrying more weight in the overall feeling of being burdened than do the last three dimensions. Previous studies have identified variables similar to these dimensions as important elements of the caregiving experience (Chenoweth & Spencer, 1986; Clark & Rakowski, 1983; Greene, Smith, Gardiner & Timbury, 1982; Poulshock & Deimling, 1984; Rabins, Mace, & Lucas, 1982; Worcester & Quayhagen, 1983).

Validity of the Dimensions

The validity of the obtained dimensions requires a much more intensive examination that was given in this study. However, the preliminary attempts at validation indicate that the dimensions have, for the most part, been appropriately labeled. Significant amounts of the variance in four of the five dimensions were accounted for by variables that would be expected to correlate with the dimensions as named.

The dimension of Physical and Emotional costs was the only one associated with the measure of Global burden, indicating that, for this sample of caregivers at least, the feeling of being burdened by care is associated with decrements in physical and emotional costs. However, the failure of the other dimensions to correlate with the global measure should not be regarded as a failure to validate these dimensions as part of the burden construct. The correlations of the burden items and the background variables tended to be low, possibly reflecting different interpretations by the individual caregivers of what being "burdened" by care meant. Also, the mean response to this item was low, suggesting that caregivers did not feel that their dependent was a burden, or that it was not acceptable for them to admit to these feelings.

Differences Between Caregivers

In light of mixed findings regarding sex differences in the literature it was interesting to note that the only difference which emerged between the sexes was the greater likelihood that females would score higher on the dimension of Negative affect than would males, a finding supported by Richman (1984). This difference disappeared when only spouse caregivers were examined. Zarit, Todd, and Zarit (1986), in a two-year follow up of a sample of male and female spouse caregivers, found that their initial finding of significantly higher levels of burden for female than for male caregivers had disappeared two years later. They suggest that females may change their attitudes towards caring or may learn to cope better with the caring situation with increased time in the role.

The effectiveness of a dimensional approach to the construct of caregiver burden was indicated by the ability to differentiate between sub-groups of caregivers based on their scores on the five dimensions. Caregivers showed patterns of burden which were distinct for two different types of relationship to the dependent person and for two different types of living arrangements. In both cases the dimension scores indicate special needs of sub-groups of caregivers.

Two profiles of highly burdened caregivers emerged from the analysis. Older individuals who cared for their spouse at home, provided a large percentage of the total care received by the dependent, and who had few friends were likely to suffer high levels of time-dependence and role strain and low levels of family conflict. Middle-aged caregivers who were more likely to be male, had many friends, cared for a spouse or a parent in the community, and provided a large proportion of the care that the dependent received were likely to experience high levels of time dependence and family conflict and to report moderate degrees of physical and emotional costs.

Similarities between the two types of caregivers are of note. Both caregiver profiles indicate a relationship between community care and burden, a finding that has been supported in the literature (George & Gwyther, 1986).

Previous studies (Cantor, 1983; George & Gwyther, 1986) have found that closer relationships are associated with higher levels of caregiver burden. Thus, spouse caregivers suffer higher levels of distress than do adult child caregivers who are, in turn, more burdened than caregivers of other relatives or friends. Burden is increased for all groups when they are sharing a residence with their dependent.

The differences between the two high-risk caregivers raise some interesting questions for further research. The two types of caregivers vary in the number of close friends that they reported. This may indicate differences in levels of social support received, although this would have to be examined in further depth. Additionally, the number of friends reported is negatively correlated with level of family conflict burden between the two caregiving types, indicating that friends may only be appealed to for support when family support fails. Again, an in depth study of family and social network interactions would be required to understand the dynamics of caregiving in a social context. A further interesting finding is that higher levels of family conflict burden are associated with a relatively larger proportion of male caregivers. Role theory would propose that, since the male caregiver is engaged in a non-normative role, role partners, in this case the family, may not know how to react appropriately, causing strain. Again, a study of family dynamics would be required to understand the presence of family conflict burden.

Additional future research could involve the development of a scale, based on the dimensions of burden, which could be used to assess levels of caregiver burden. Such research would involve the addition of items to strengthen the obtained dimensions, estimations of the scales reliability over time, and validation of the scale using standardized instruments. An important aspect of validating the scale would be the identification of the consequences of high scores on the various sub-scales or dimensions. It could be speculated that high levels of time-dependence would be related to early institutionalization of the dependent due to "burn out" of the caregiver. Another possibility is that high levels of physical and emotional costs could be related to depression in the caregiver. There is also a potential association between high levels of negative affect and abuse of the dependent.

Limitations of the Study

There are a number of limitations to the present study which have implications for interpretation of the present study and for further research.

Sampling

There were a number of sampling problems with the study. The largest problem concerns the multiple sources of subjects. Not only were subjects gathered from two, considerably different, geographic locations but individuals in those locations were recruited in very different ways. Variables relevant to source, such as self-help group membership or receipt of services, were not assessed. Hence, it is unknown how the samples differ in these respects or whether these factors influence levels of burden.

A related issue is the different data collection techniques employed in the study. Subjects may have responded differently to filling out a questionnaire on their own with complete confidentiality, answering the questions of an unknown individual over the telephone, and verbally responding to a long and varied interview about caregiving.

A further concern is that the sample may not be representative of caregivers of demented dependents. However, due to the small refusal rate in both locations, the groups would seem to be representative of Alzheimer's society members and community care recipients. No attempt, however, was made to determine the composition of the population of such caregivers, or to sample representative sub-groups within that population.

A final sampling issue concerns the use of university students in reducing the size of the item pool. Students were much younger than the actual subjects and had not shared many of the caregivers' life experiences. They could not therefore be expected to rank items in the same order of importance. While overall patterns of correlations were similar for the students and the caregivers, the possibility exists that the item pool was biased by the pre-selection procedures.

Measurement Issues

One drawback of the study was that it employed self-report measures exclusively. The limitations of such measures are well known and have already been highlighted elsewhere in this discussion. It would have been helpful to have included a number of more objective, external types of measures to validate the subjects perceptions.

Additionally, the use of a global measure as a criterion for validation was not successful. This may have been due to varying interpretations of the phrase "burdened by care". Future research in this area should include more objective criterion measures.

Statistical Analyses

Overall, the sample size was small, considering the employment of factor analytic techniques in the study. In the initial factor analysis the ratio of items to subjects was small enough to allow some room for chance to operate in the clustering of items. Thus, the possibility exists that items that would have been retained in a larger sample were deleted, or that items that were not truly correlated with the dimensions were retained

The study relied heavily upon multivariate analyses. While these techniques are useful in exploring complex relationships, problems in biasing of results can occur due to high intercorrelations between variables. One particular problem in this area concerned the high correlation between Factors 1 and 4. The problem of small sample size is also important, since many of the analyses used many variables and, thus, had a small variable to subject ratio, increasing the possibility that the analysis could capitalize on chance.

Implications for Interventions

The dimensions of burden which emerged in the study are potentially useful for interventions with a population of caregivers of demented dependents. The gerontological literature has indicated that consequences of burden can include depressive illness of the caregiver (Coppel, Burton, Becker, & Fiore, 1985), early institutionalization of the dependent (Zarit, et al., 1986), and abusive behaviors towards the dependent by the caregiver (Kosberg & Cairl, 1986). Thus it is important to identify and intervene in high-risk situations. Since a scale including the obtained dimensions of burden has not been developed or validated, the following discussion is speculative in nature.

High scores on the time-dependence dimension would indicate that programs which provide an opportunity for respite, for example day care or home care programs, would be appropriate interventions. Caregivers who registered highly on the dimension of physical and emotional costs would appear to be at risk for depression and interventions could be targeted in that area. A great deal of family conflict could be identified by examination of the dimensions and family counselling could be used to aid in resolution of dissension. Role strains could probably be best dealt with by providing respite care, as indicated by the high correlation between factors one and four. However, some caregivers may require additional counselling on role management. The Negative affect dimension is potentially important for intervention, since it may be speculated that these feelings lead to elder abuse. High levels of negative affect would seem to warrant a closer examination of the caregiving situation.

The present study indicates that areas for intervention can be targeted on the basis of background variables. Caregivers who are caring for the dependent in their own home would be more likely to score highly on the dimensions of time dependence and role strain. Spouse caregivers tend to be higher on these two dimensions than do adult child caregivers, whereas adult child caregivers are more prone to score highly on family conflict. Awareness of these issues on the part of professionals dealing with this population, coupled with appropriate interventions has the potential to improve caregiver well-being through reduction of burden.

APPENDIX A

QUESTIONNAIRE

CAREGIVER EXPERIENCE QUESTIONNAIRE

More and more people are living to old age in recent years. Since Alzheimer's Disease affects 5 to 10 percent of persons over 65 years of age, this means that more families are having to provide care to a family member who has this illness (the care receiver).

The primary purpose of this research is to contribute to a better understanding of the experiences of family members who are caring for individuals with Alzheimer's Disease or a related disorder. This knowledge is necessary in order to design programs that can help caregivers cope with the demands of their role. An additional purpose of the study is to gather information about your needs so that the Alzheimer Society can serve you better. A copy of the report of this study will be provided to the Alzheimer Society to help them improve their service.

You have been asked to participate in this resarch because, by providing information about yourself, your care receiver, and your feelings about providing care, you can help researchers better understand the types of problems that caregivers face.

I want to assure you that everything you tell me in this interview will be kept strictly confidential. Names, or any information by which a particular individual could be identified will not be used in any reports of the information gathered in this study.

Thank you for your co-operation in completing this questionnaire.

I'd like to know some things about you, the caregiver. Please fill in the blanks or circle the answer that applies to you.

What is your age? __________

Are you: Female Male

Are you: Married Widowed Divorced Separated Single

How are you related to the person you are providing care to?
The person I am caring for (the care receiver) is my __________

How many children do you have? 0 1 2 3 4 5 more than 5

Do you work outside the home (full-time or part time)? Yes No

Do you attend the meetings of any club or organization (other than the Alzheimer's Society)? Yes No

How often do you attend church services? __________

How many of your neighbors do you visit? __________

How many close friends do you have? __________

Approximately what percentage of the total assistance and care provided to the care receiver is provided by you?

100% 75%-99% 50%-74% 25%-49% none-25% none

If you provide less than 100% of the care, who provides the rest?

____

____

Now, I'd like to know about the person you are providing care and assistance to (the care receiver):

How old is the care receiver? __________

Is the care receiver: Female Male

Is the care receiver: Married Widowed Divorced Separated Single

Where does the care receiver live? (check one)
In his or her own home?
In your home?
In a nursing home or care facility?
Other (please specify) __________

Think of your experiences as a family caregiver. To what extent would each of the following statements describe your experiences in providing care to an individual with Alzheimer's Disease or a related disorder (the care receiver)? Since everyone reacts to this situation in different ways, there are a variety of statements below, some of which will reflect your views of the caregiving situation better than others. Please answer according to the scale below and indicate your answers by circling the letter that corresponds to the answer that best describes your feelings.

How well does each of the following statements describe your experience in caring for your care receiver?

A	B	C	D	E
Not at all Descriptive	Slightly	Moderately Descriptive	Quite	Very Descriptive

1. My care receiver is dependent on me.
   A B C D E
2. I have to watch my care receiver constantly.
   A B C D E
3. I don't get along with other family members as well as I used to.
   A B C D E
4. My caregiving efforts aren't appreciated by others in my family.
   A B C D E
5. I feel uncomfortable when I have friends over.
   A B C D E
6. I feel that I've lost control of my life.
   A B C D E
7. My care receiver needs my help to perform many daily tasks.
   A B C D E
8. I've had problems with my marriage/intimate relationship.
   A B C D E
9. I feel guilty because I find caring inconvenient.
   A B C D E
10. I need relief from the continual pressure of caring.
    A B C D E
11. Household routine has been disrupted.
    A B C D E

How well does each of the following statements describe your experience in caring for your care receiver?

A	B	C	D	E
Not at all Descriptive	Slightly	Moderately Descriptive	Quite	Very Descriptive

12. I feel emotionally drained due to caring for my care receiver.
A B C D E

13. Caring restricts the amount of time I can devote to my friends.
A B C D E

14. I feel ashamed of my care receiver.
A B C D E

15. I can't pay as much attention to my family as I used to.
A B C D E

16. I resent my care receiver.
A B C D E

17. I don't do as good a job at work as I used to.
A B C D E

18. I feel that I am missing out on life.
A B C D E

19. I must be available when my care receiver needs me.
A B C D E

20. My care receiver just isn't him/herself anymore.
A B C D E

21. Caring for my care receiver ties me down.
A B C D E

22. I have less personal freedom than I used to.
A B C D E

23. I wish I could escape from this situation.
A B C D E

24. My social life has suffered.
A B C D E

25. My relationship with my care receiver is poor.
A B C D E

How well does each of the following statements describe your experience in caring for your care receiver?

A	B	C	D	E
Not at all Descriptive	Slightly	Moderately Descriptive	Quite	Very Descriptive

26. I expected that things would be different at this point in my life.
A B C D E

27. My health has suffered.
A B C D E

28. My only purpose in life is to care for my care receiver.
A B C D E

29. I feel a sense of duty to care for my care receiver.
A B C D E

30. I feel guilty because I could do more for my care receiver.
A B C D [✓ E]

31. Overall, how burdened do you feel in caring for your care receiver?

A	B	C	D	E
Not at all	A little	Moderately	Quite a bit	Extremely

32. How often do things you do add up to being just too much?

A	B	C	D	E
Never	Seldom	Occasionally	Usually	Almost Always

33. How often do you have to juggle different obligations that conflict with one another and give you a pulled-apart feeling?

A	B	C	D	E
Never	Seldom	Occasionally	Usually	Almost Always

The Alzheimer Society would like to be able to serve you better. One of the main goals of the Alzheimer Society is to help families of people with Alzheimer's Disease or a related disorder cope with the many demands placed on them in their individual situations. To do this they must know what your needs are. What are the most important unmet needs you are facing because of the disease?

APPENDIX B

BACKGROUND INFORMATION ON CAREGIVERS AND ON DEPENDENTS

Table B-1

Background Information on Caregivers

	Frequency	
	n	Percent
Source of respondent		
Windsor	64	63.4
Winnipeg	37	36.6
Sex of respondent		
Female	82	81.2
Male	19	18.8
Age of respondent		
25 - 34	3	3.0
35 - 44	12	11.9
45 - 54	21	20.8
55 - 64	29	28.7
65 - 74	21	20.8
75 - 84	14	13.9
85 and older	1	0.9
Marital status of respondent		
Married	90	89.2
Widowed	1	0.9
Divorced	4	4.0
Separated	1	0.9
Single	5	5.0
Percent of dependent's care provided by caregiver		
none	4	4.0
0 - 24	43	42.6
25 - 49	12	11.9
50 - 74	10	9.9
75 - 99	18	17.8
100	14	13.8
Role occupancy of caregiver		
2	3	3.0
3	6	5.9
4	15	15.9
5	34	33.6
6	22	21.8
7	18	17.8
8	3	3.0

Note. *n* = 101

Table B-2

Background Information on Dependents

	Frequency	
	n	Percent
Sex of dependent		
Female	54	53.5
Male	47	46.5
Age of dependent		
50 - 59	4	4.0
60 - 69	28	27.7
70 - 79	35	34.6
80 - 89	30	29.7
90 and older	4	4.0
Marital status of dependent		
Married	62	61.4
Widowed	36	35.7
Divorced	2	2.0
Separated	0	0
Single	1	0.9
Relationship of dependent to caregiver		
Husband	40	39.6
Wife	14	13.9
Mother	30	29.8
Father	6	5.9
Mother-in-law	2	2.0
Father-in-law	1	0.9
Brother	0	0
Sister	3	3.0
Aunt	2	2.0
Uncle	0	0
Friend	2	2.0
Other	1	0.9
Place of residence of dependent		
Own home	13	12.9
Caregiver's home	34	33.7
Nursing home or care facility	54	53.4

Note. n = 101

APPENDIX C

INTERCORRELATIONS BETWEEN THE FINAL SET OF BURDEN ITEMS

Table C-1

Intercorrelations Between the Final Set of Burden Items

	Item															
Item	1	2	3	4	5	7	8	14	15	16	17	19	21	23	26	27
1	1.00															
2	.52	1.00														
3	-.14	.01	1.00													
4	-.07	.14	.66	1.00												
5	.07	.40	.21	.21	1.00											
7	.63	.57	-.04	-.02	.21	1.00										
8	.10	.16	.16	.20	-.07	.12	1.00									
14	.09	.05	.16	.09	.33	.07	.03	1.00								
15	.08	.25	.34	.21	.27	.13	.34	.24	1.00							
16	.16	.09	.05	.00	.28	.02	.11	.63	.02	1.00						
17	-.01	-.07	.10	.07	.08	.10	.36	.11	.40	.08	1.00					
19	.35	.35	.09	.07	.06	.33	.21	.02	.19	.05	.02	1.00				
21	.39	.52	.12	.09	.34	.37	.29	.21	.49	.20	.20	.47	1.00			
23	.04	.26	.16	.28	.39	.23	.07	.25	.23	.32	.16	-.01	.39	1.00		
26	.11	.29	.07	.19	.20	.18	.33	.24	.33	.14	.12	.15	.42	.48	1.00	
27	.06	.34	.26	.21	.35	.23	.24	.34	.39	.23	.11	.02	.32	.38	.53	1.00

Note. *N* = 101

APPENDIX D

CANONICAL DISCRIMINANT ANALYSIS OF MALES AND FEMALES BASED ON SIXTEEN BURDEN ITEMS

Table D-1

Canonical Discriminant Analysis Between Males and Females Based on Sixteen Burden Items

Predictor Variable	Correlation with Discriminant Function	F Value
Item 1	0.24	1.43
Item 2	0.19	0.87
Item 3	0.15	0.57
Item 4	0.22	1.15
Item 5	0.03	0.02
Item 7	0.12	0.34
Item 8	-0.37	3.32
Item 14	-0.22	1.23
Item 15	0.18	0.79
Item 16	-0.32	2.47
Item 17	-0.07	0.11
Item 19	0.27	1.79
Item 21	0.43	4.58*
Item 23	0.28	1.83
Item 26	0.14	0.50
Item 27	-0.36	3.21
Canonical *R*	0.49[a]	
Eigenvalue	0.32	

Note. *N* = 99

* $p < 0.05$

[a] $F(16,82) = 1.65$, $p = 0.07$

Table D-2

Mean Scores for Females and Males on Sixteen Burden Items

	Means	
Item	Females	Males
1	1.74	2.10
2	0.51	0.74
3	0.51	0.74
4	0.59	0.95
5	0.54	0.58
7	1.80	2.05
8	0.51	0.05
14	0.31	0.11
15	0.90	1.21
16	0.29	0.05
17	0.15	0.10
19	2.41	2.89
21	1.39	2.21
23	1.15	1.63
26	2.38	2.68
27	1.43	0.79

Note. *N* = 99

APPENDIX E

STEPWISE MULTIPLE REGRESSION OF DIMENSIONS ON GLOBAL BURDEN AND OF DEMOGRAPHIC, SITUATIONAL, AND CRITERION VARIABLES ON FIVE DIMENSIONS OF BURDEN

Table E-1

Stepwise Multiple Regression of Five Dimensions of Burden on Global Burden

Predictor	B	F	R^2	Overall F
Physical and Emotional Cost	0.15	29.74***	0.23	29.74

Note. N = 100

*** $p < 0.001$

Table E-2

Stepwise Multiple Regression of Demographic, Situational, and Criterion Variables on Time-dependence

Predictors	B	F	R^2	Overall F
Percent of care	1.66	42.93^{***}		
Role overload	0.96	10.73^{***}		
			0.46	29.31^{***}

Note. *N* = 89

$^{***}p < 0.001$

Table E-3

Stepwise Multiple Regression of Demographic, Situational, and Criterion Variables on Physical and Emotional Costs

Predictors	B	F	R^2	Overall F
Role Overload	1.29	36.18***		
Global Burden	1.00	9.15***		
			0.36	24.91***

Note. $N = 89$

*** $p < 0.001$

Table E-4

Stepwise Multiple Regression of Demographic, Situational, and Criterion Variables on Family Conflict

Predictors	B	F	R^2	Overall F
Role Conflict	0.61	13.01***		
No. Caregivers' Friends	0.08	10.55***		
No. Neighbors	-0.31	8.77***		
Caregiver's Age	-0.04°	7.77***		
Caregiver's Sex	0.97	6.96***		
			0.30	7.11***

Note. *N* = 89

*** $p < 0.001$

Table E-5

Stepwise Multiple Regression of Demographic, Situational, and Criterion Variables on Role Strain

Predictors	B	F	R^2	Overall F
Role Overload	0.44	15.57***		
Percent of Care	0.48	15.08***		
Global Burden	0.48	12.04***		
No. Caregiver's Friends	-0.08	10.28***		
Caregiver's Age	0.05	9.32***		
Caregiver Working	0.50	8.67***		
			0.38	7.48***

Note. *N* = 89

*** $p < 0.001$

Table E-6

Stepwise Multiple Regression of Demographic, Situational, and Criterion Variables on Negative Affect

Predictors	B	F	R^2	Overall F
Role Overload	0.33	8.65**		
Caregiver's Sex	-0.65	6.26**		
No. Neighbors	0.17	5.92**		
			0.17	5.77**

Note. N = 89

** $p < 0.01$

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