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UNIVERSITY OF ALBERTA

CORRELATES OF CAREGIVER BURDEN

BY

KAREN KERR ©

A THESIS
SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE
DEGREE OF MASTER OF SCIENCE
IN
FAMILY LIFE EDUCATION

DEPARTMENT OF FAMILY STUDIES

EDMONTON, ALBERTA
FALL, 1990

ISBN 0-315-65116-4

UNIVERSITY OF ALBERTA

RELEASE FORM

NAME OF AUTHOR: Karen F. Kerr

TITLE OF THESIS: Correlates of Caregiver Burden

DEGREE: Master of Science

YEAR THIS DEGREE GRANTED: 1990

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The undersigned certify they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled CORRELATES OF CAREGIVER BURDEN submitted by KAREN F. KERR in partial fulfillment of the requirements for the degree of MASTER OF SCIENCE in FAMILY STUDIES.

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ABSTRACT

The fact that Alzheimer's disease has a very long course and that much of the caregiving occurs at home suggests that there is a need to better understand the context and consequences of caregiving, especially the difficulties encountered by family caregivers in providing care to their ill relative. Realization of this has prompted research on what is typically referred to as the burdens experienced by caregivers of Alzheimer's patients.

There is a paucity of research that separates the emotional or subjective aspects of burden from the situational or objective aspects of burden when assessing the burden of caring for an elderly relative with Alzheimer's disease. The purpose of this study was to examine the relationship between six factors (income, caregiver age, caregiver health, the ill relative's ability to perform activities of daily living, family support to the caregiver and service utilization) and objective burden and the relationship between five factors (caregiver age, caregiver health, family support to the caregiver, the ill relative's behavior/cognitive capacity, objective burden) and subjective burden. Choice and exchange theory was the conceptual framework used for this investigation.

The study involved multiple linear regression analysis of secondary data from a research project involving family caregivers of relatives with Alzheimer's disease. The sample consisted of 58 primary caregivers from the original research. The two dependent variables, subjective and objective burden, were measured using scales developed by Montgomery, Gonyea and Hooyman (1985).

Results indicated that higher utilization of services is associated with lower levels of objective burden experienced by caregivers. It was also found that the worse the caregiver's health, the higher the level of objective burden experienced by the caregiver. Both family support and objective burden were found to be positively related to subjective burden. In addition, caregivers who reported being in fair health experienced higher levels of subjective burden than caregivers who reported being in excellent health. However, no significant relationship existed between good caregiver health and subjective burden or poor caregiver health and subjective burden.

Results of this study suggest that attention should be paid to the health of the caregiver as well as to the care of the relative with Alzheimer's disease. Information about and accessibility to service utilization may also aid in reducing the levels of subjective and objective burden experienced by family caregivers.

ACKNOWLEDGEMENTS

I wish to extend my sincere appreciation to my advisor, Dr. Norah Keating for her guidance and support throughout this research endeavor. The early morning coffee meetings and her unflagging ethusiasm and energy were invaluable.

To Dr. Janet Fast, I wish to express my gratitude for her statistical expertise, her support as a committee member and her unending patience with my "just one more quick question..."

I further extend my thanks to Dr. Sharon Warren not only for her participation as a committee member, but also for her challenging questions and constructive advise.

Finally to my friends and colleagues, thank you for listening, for the laughs, the encouragement and generally "being there" for me.

TABLE OF CONTENTS

LIST OF TABLES

I. INTRODUCTION

Alzheimer's disease occurs in 2%-3% of the population over age 60, and in over 20% of those aged 80 years and over. It is estimated that in Canada, at least 10,000 deaths per year are attributable to Alzheimer's disease and that as many as 100,000 to 300,000 people may be affected at any time (Health and Welfare Canada, 1984). Aronson (1985) makes reference to the fact that, in Canada, the proportion of people over age 75 will increase sharply from comprising 3.2% of the total population in 1976 to a projected 5.2% in 2001 and 8.3% in 2051. These statistics imply that in the future, Alzheimer's will be affecting even more people than current estimates suggest.

Although the course of Alzheimer's disease is described as stage-related by some (Health and Welfare Canada, 1984), the rate of progression is both variable and unpredictable (Ortof & Crystal, 1989). There are large individual differences in both the rate of change and the course of illness, with some patients declining abruptly and then reaching a plateau, while others remain relatively stable with only small changes and then experience rapid deterioration (Eisdorfer & Cohen, 1981).

Despite different perspectives as to the course of the illness, there is considerable agreement that there is a progressive impairment of memory and orientation with generalized deterioration in intellectual functioning and inevitable decline in physical health (Teusink & Mahler, 1984). As the disease progresses, emotional and behavioral problems (wandering, repetitious behavior, sleep and night time problems, aggressive behavior) of the Alzheimer's patient may worsen (Health and Welfare Canada, 1984). As the person becomes increasingly unable to take care of her/himself, families most often provide care to their uninstitutionalized relative (Brody, 1985; George & Gwyther, 1986; Pratt, Schmall, Wright &

Cleland, 1985; Shanas, 1979a, 1979b; Zarit, Reever & Bach-Peterson, 1980; Zarit, Todd & Zarit, 1986). The spouse or an adult child, usually a daughter or daughter-in-law, is most often the primary caregiver (Fitting, Rabins, Lucas & Eastham, 1986; Poulshock & Deimling, 1984; Pratt et al., 1985; Stoller, 1983; Zarit et al., 1980).

Due to the continual cognitive and physical decline which is characteristic of Alzheimer's disease, the primary caregiver (the person responsible for the provision of care) increasingly must do more for her/his relative. Findings from a recent study by Keating and Warren (1988) show that relatives with Alzheimer's disease are kept at home an average of three years after diagnosis, with some maintained for as long as 10 years. The demands and responsibilities involved in caring for someone with this disease, coupled with the long period of caring for an A.D. relative, can have negative consequences. Some examples of these consequences are that the caregiver "often faces the prospect of social isolation; lack of time for self, family and friends; career interruptions; financial drain; and unrelieved heavy physical labour in caregiving" (Pratt et al., 1985, p. 27). Realization of this has prompted research on what is typically referred to as the burdens experienced by caregivers of Alzheimer's patients.

Poulshock and Deimling (1984) state that burden is often the term used to denote the variety of effects families or family members experience when caring for an impaired relative. They consider burden a general term that covers a breadth of issues associated with caregiving. The concept of burden includes a large range of definitions although, in the gerontological literature, burden has tended to be seen as a unidimensional concept which emphasizes the subjective emotions or feelings experienced by the caregiver. Some recent studies have separated burden into two separate dimensions, subjective and objective burden (Montgomery, Gonyea & Hooyman, 1985). This dichotomous conceptualization allows for the separate examination of emotional and situational outcomes of caregiving.

Researchers concerned with the consequences of caregiving of mentally ill family members have shown that a difference exists in the incidence of subjective and objective burden (Thompson & Doll, 1982). Furthermore, in the gerontological literature, it has been found that differences exist in the variables associated with these two types of burden. For example, Montgomery et al. (1985) found that income and caregiver age were correlates of subjective burden while certain personal care tasks such as bathing and dressing were related to objective burden.

STATEMENT OF THE PROBLEM

There is a paucity of research that separates subjective and objective burden when assessing the burden of caring for an elderly relative with Alzheimer's disease. Consequently, there has been little systematic evaluation of variables associated with each type of burden. Most of the research to date has examined variables associated with a unidimensional concept of caregiver burden. Based on the assumption that subjective and objective burden are indeed separate entities, (Montgomery et al., 1985) the project described in this thesis was undertaken. The research question for the thesis was: what is the relationship between certain variables (income, caregiver age, caregiver health status, activities of daily living, family support, service utilization and behavior/cognitive impairment) and caregiver burden? The research question was further subdivided into the following two specific questions: What variables are associated with objective burden? What variables are associated with subjective burden?

JUSTIFICATION

The fact that Alzheimer's disease has a very long course and that much of the caregiving occurs at home suggests that there is a need to better understand the context and consequences of caregiving, especially the difficulties encountered by family caregivers in providing care to their ill relative. The identification of two separate elements of caregiver burden has been a great step forward as it has provided a framework to examine emotional and situational aspects of burden. Understanding the factors that contribute to each of these types of burden in caregivers of Alzheimer's relatives would provide additional information on the exigencies of caregiving.

Establishing the relationship between the previously stated variables (income, caregiver age, caregiver health status, physical and instrumental activities of daily living, family support, service utilization and behavior/cognitive impairment) and the levels of subjective and objective burden could prove useful in the following ways. First, it could add to the understanding of the concept of burden in general and provide additional information about the more recently discussed components of subjective and objective burden. Second, by increasing knowledge with respect to the variables associated with each type of caregiver burden, practitioners can plan interventions more effectively in an attempt to alleviate some of the burden caregivers experience. Third, the identification of an association between certain variables and a specific type of burden may be helpful in planning preventive measures. By identifying caregivers "at risk" of experiencing higher levels of a particular type of burden, interventions can be implemented in an attempt to prevent the level of burden from increasing. Fourth, the few studies that have examined caregiver burden have been conducted primarily in the United States. Canada's health care system is different than the system in the United States. In Canada, more medical services are covered by public health insurance plans. People in a Canadian sample might bear less financial responsibility for their relatives' care. Therefore, differences may be found in the association between income and either type of caregiver burden. Caserta, Lund, Scott, Wright and Redburn (1987) note that the discrepancy between the need for services and the utilization of services has usually been attributed to the perceived lack of availability of, or access to services. Availability, accessibility and affordability of service utilization may also be different in the United States compared with Canada because the health care systems are so different.

II. CONCEPTUAL FRAMEWORK

In this study, caregiver burden is conceptualized using choice and exchange theory. In this chapter the theory that the conceptualization is based on is introduced and some of the basic assumptions are discussed. The key concepts are defined and examples are provided. A discussion of family caregiving is included to provide the context for an understanding of burden.

It is important to distinguish between the concept of caregiver burden and the act of caregiving. Caregiving is the responsibility for the provision of care taken on by the relative of the A.D. patient. Caregiver burden is a consequence or outcome of caregiving, determined by such factors as the amount of resources a caregiver has and the number of difficulties or costs she faces in caring for her relative.

A basic assumption of the choice and exchange framework is that humans avoid costly behavior and seek rewarding statuses, relationships, interactions and feeling states to the end that their profits are maximized or losses minimized (Nye, 1979). Caring for a relative with Alzheimer's disease is a situation in which this general assumption applies. Caregiving in this situation is assumed to be costly. Thus, the outcome of caregiving known as caregiver burden can be seen as the loss incurred in providing care to a relative with the disease. Prior to discussing family caregiving and caregiver burden within a choice and exchange perspective, it is necessary to define the key concepts: costs, rewards, resources and profit/loss and choice.

COSTS, REWARDS AND RESOURCES

Choice and exchange theory is based on costs and rewards, with a person's intent being to reduce costs and maximize rewards for most profits (or least losses).

Some studies have recently begun to address the problems (or costs) and resources of the caregivers (Pratt et al., 1985). According to Nye, (1979) a cost is, "any status, relationship, interaction, milieu or feeling, disliked by an individual" (p. 2). Costs also refer to a negative value or an unpleasantness actually experienced in the course of obtaining a reward (Dowd, 1975).

Following are some examples of factors that are considered to be costs associated with caring for a relative with Alzheimer's disease. Having to assist impaired relatives with physical activities of daily living (ADL) such as eating, dressing, bathing; and instrumental ADL such as shopping, preparing meals and getting around, are considered costly (Hooyman, Gonyea & Montgomery, 1985). The A.D. relative's cognitive impairment and inability to perform ADL are seen here as costs to the caregiver because having to care for a relative who is confused is difficult emotionally, and there are concomitant time pressure and constant care demands (Wilson, 1989).

Under "normal" circumstances, certain kinds of instrumental activities of daily living such as meal preparation, shopping and so forth might tend to be looked after by one family member without being considered costly. This is because family members are typically involved in constant exchanges such that if one person does certain kinds of tasks, it is likely that the other member(s) perform other kinds of tasks. Edwards (1969) notes that the need to exchange lies at the very root of family formation. However, this kind of exchange no longer exists in the caregiving situation of the caregiver-A.D. patient relationship.

Cognitive and ADL impairment necessitate that the caregiver spend much time and energy in the caregiver role. It seems likely then, that a caregiver of a relative with cognitive and ADL impairment would have more responsibility for tasks and a lack of exchange, thereby reducing the caregiver's autonomy. Autonomy is a reward and as such, is considered a valuable situation (Nye, 1979). Cogritive and ADL impairment are considered costs since the caregiver's reward of autonomy is forgone and the previous exchanges involved in the relationship no longer exist.

From an exchange theory perspective, age is seen as a cost because as people age (spouse caregivers tend to be elderly), their power resources decrease (Dowd, 1975) and their physical health may be impaired due to the fact that they are older. Poor caregiver health status resulting from the caregiving role is also seen as costly (Pratt et al., 1985). When the caregiver's health status is poor, caregiving will likely be all the more difficult. Since poor health is obviously an unpleasant feeling that is disliked by an individual, poor health is seen here as a cost. In addition, poor health may perpetuate the negative status of older persons as necessarily frail beings who lack independence. In contrast, age may also be considered a cost for younger caregivers as they are often employed and have demands that conflict with the caregiving role (Robinson, 1983).

In contrast to costs, rewards are "statuses, relationships, interactions, experiences other than interaction, and feelings which provide gratifications to people" (Nye, 1979, p. 2). Nye considers all things physical, social and psychological that an individual would choose in the absence of added cost, to be a reward. Exchange theorists often use the concepts of rewards and resources interchangeably. For example, Nye (1979) points to money, and social approval (including, but not limited to, love, respect, prestige and admiration) as two sources of rewards. Blau (1964) includes money along with approval, esteem and respect, as examples of what he refers to as power resources, which he considers to be types of rewards. Therefore, in accordance with the burden literature, the concept of reward will be referred to using the term resource.

Resources to caregivers are pointed out in the caregiver burden literature. For example, Pratt et al. (1985) state that the caregiver's social resources include extended families and community services. Family support is an example of a resource for caregivers of relatives with Alzheimer's disease (Zarit et al., 1980). Family support and access to various types of services (i.e. in-home services, community services and government-sponsored programs) are considered resources because they may alleviate some of the caregiver's emotional and physical problems resulting from the caregiving role and are thereby rewarding. By relieving the caregiver of some of the provision of care, both informal and formal support may allow the caregiver to gain a degree of autonomy which as previously stated, is viewed as a reward.

BURDEN AS LOSS

A concept central to choice and exchange theory is profit/loss. Profits "can be determined in terms of rewards and punishments in a contemplated sequence of actions" (Nye, 1979, p. 2). The most profitable outcome is an outcome which provides the best relationship of rewards to costs. In contrast, a loss is incurred when the costs outweigh the rewards. Although in certain situations emphasis is placed on maximizing profit, it is assumed here that costs associated with caregiving outweigh the rewards. Therefore, it is more appropriate to apply the assumption of minimizing losses to the situation of caring for an impaired relative. However, regardless of whether a person is maximizing profits or minimizing losses, the same principle applies: human beings will attempt to obtain the most favourable outcome available (Nye, 1979).

Caregiver burden has been broadly defined (Poulshock & Deimling, 1984) in the gerontological literature. Some definitions use neutral terms in defining burden. An example of this is the general notion of caregiver impact, "the impact of the changes in cognition and behavior of the Alzheimer's patient on the family, and the patient's subsequent need for care and supervision" (Ory et al., 1985, p. 631). From an exchange theory perspective, this definition is based on the assumption that caregiving could have a positive or a negative impact on the caregiver. That is, profit and loss are both possible outcomes. However, much of the research being done in this area now refer to the burden, stress or strain of caregiving, which carries with it negative connotations with respect to the caregiving role.

Literature on caring for mentally ill family members also generally define burden as "the presence of problems, difficulties, or adverse events which affect the life (lives) of the psychiatric patient's significant other(s)" (Platt, 1985, p. 383). Discussions tend to focus on problems or difficulties the caregiver faces. Perhaps this is due to the recognition of the physical and emotional costs of caring (Goodman, 1986). For example, Thompson and Doll (1982) examined the emotional and social costs of families caring for their mentally ill kin.

In the gerontological literature, Given, Collins and Given (1988) describe caregiver burden as the physical, psychological, emotional, social and financial problems that can be experienced by family members caring for older relatives with dementia. Pett, Caserta, Hutton and Lund (1988) refer to caregiver burden as a constellation of negative affects (such as guilt, anger, financial stress, alienation) arising from the care of a chronically ill relative. Burden is viewed as loss because the costs of caring for a family member that has a disease, the nature of which is progressive cognitive impairment and eventual death, are high in spite of resources available to the caregiver. In their descriptive study of middle-aged female caregivers, Pett et al. (1988) found that caregivers described feeling resentful and devastated in terms of the turmoil and psychic pain involved when the personality of a parent loses its constancy and coherence. One caregiver was quoted as saying she felt a great loss (Pett et al., 1988). This again is illustrative of the emotional costs associated with caring for a cognitively impaired relative.

It would appear from these examples, that caregiving costs do outweigh the rewards. The definitions of burden therefore, tend to focus on the negative outcomes or loss resulting from the costs of caregiving, as loss was previously defined. This assumption is adopted by this author. Although the phenomenon of burden is not universally conceptualized or consistently operationalized, the fact that "the term is generally used to refer to the hardships, costs or effects that ill relatives have on their families" (Gilewich, 1987 p. 34) lends support to the view that burden is a loss experienced by caregivers.

There may be rewards within the caregiving context, such as caregivers' satisfaction of knowing that they have cared for their relative to the best of their ability. However, the burden which is the overall outcome or consequence of caregiving, is seen as the loss that comes from the excess of costs over rewards. The level of caregiver burden, may be more or less, depending on the extent to which costs exceed resources. Caregiver burden as conceptualized here, can never have a positive value.

Stoller (1985), in discussing intergenerational exchanges, points out that costs and rewards associated with the exchanges involve psychological as well as instrumental factors. As has been noted, caregivers incur different types of costs including physical, emotional, social and financial. Therefore, burden in this study, is divided into two components as it is important to distinguish between the different kinds of loss in which caring for an impaired relative can result. Recent advances in the conceptual clarity of caregiver burden have lead to a model which includes two separate dimensions, subjective and objective burden (Montgomery et al.,1985). Subjective burden includes the feelings, emotions and attitudes associated with the caregiving. In contrast, events, happenings, and activities associated with caregiving are aspects of objective burden.

Because caregivers are dealing with different types of loss, it may be that the costs and resources associated with subjective and objective burden vary. For example, ADL impairment necessitates that the impaired relative receive help with physical personal care tasks. Providing physical help requires time and energy from the caregiver. Therefore, it may be that ADL impairment which was previously defined as a cost, is associated with the level of objective burden and not subjective burden. For the purposes of this research, subjective burden, the loss that results from the total of the emotional costs of caregiving, is defined as "the respondents' attitudes towards or emotional reactions to the caregiving experience" (Montgomery et al., 1985, p. 21). Objective burden, the loss resulting from the total of the situational costs, is defined as "the extent of disruptions or changes in various aspects of the caregiver's life and household" (Montgomery et al., 1985, p. 21). Therefore, objective burden (loss) = resources - costs, and subjective burden (loss) = resources - costs.

THE CONTEXT OF FAMILY CAREGIVING

An assumption of choice and exchange theory is that, "if no profitable alternative is perceived as available, the one promising to be least unprofitable will be chosen" (Nye, 1979, p. 7). That is, there are some situations in which a person does not wish to choose any available alternative. However, if a person must choose among primarily costly alternatives, the person will choose the alternative in which the smallest loss is anticipated. The above statement is illustrative of the concept of choice, which is also a significant component of choice and exchange theory. Choice is defined as making a decision among available alternatives. An assumption of choice and exchange theory, that humans are rational beings, necessitates that the concept of choice be central in a discussion of family caregiving.

Families and/or family members often must make choices regarding the provision of care the impaired relative will receive. From this perspective, it is not only a matter of weighing the rewards and costs, but rather it becomes a matter of choosing the best alternative available to the caregiver(s). When making a choice, the level of alternatives is evaluated. In evaluating the level of alternatives, the family or certain family members compare the outcomes in a given relationship or position to those of the alternatives to the relationship or position that is involved (Nye, 1979). Most often, no alternative viewed as desirable is open to the primary caregiver or the family in deciding how to best care for an elderly relative with Alzheimer's disease. With respect to caregiving, family members may choose to accept the burden (loss) associated with the caregiving role rather than choose other alternatives such as institutionalization. In a study by Pett et al. (1988) for instance, nursing home placement was seen only as a last resort.

Choosing to be a caregiver may be attributed in part, to the cost of uncertainty or ambiguity. Nye (1979) points out that uncertainty concerning the nature and extent of rewards and costs in an alternative situation can create anxiety and unpredictability for the individual or group who may be considering an alternative course of action. An example in the case of a person caring for a relative with Alzheimer's disease might be the uncertainty or ambiguity the caregiver experiences if she is considering institutionalization as an alternative to providing care for the relative at home. At home, the caregiver exercises control and more independence over care the impaired relative will receive. Institutionalizing a relative may create fear and worry about what is going to happen once the relative is institutionalized. These costs - uncertainty and ambiguity - operate to keep persons or groups in their current status or situation when they might otherwise try a new avenue that would perhaps be more rewarding, or in this case, less burdensome.

From an exchange theory perspective, social approval which includes love, respect, prestige and admiration, is considered a central source of reward (Nye, 1979). Fulfilling feelings of marital obligation, and filial responsibility (Brody, 1985; Reece,Walz & Hageboeck, 1983), facets of the concept of social approval, may be rewarding when taking care of an impaired elderly member of the family. When making decisions whether or not to assume the role of primary caregiver, rewards such as social approval may outweigh the costs (ie. physical, emotional, social and financial strain) involved in the caregiving. From an exchange theory perspective then, regardless of the burden or loss associated with caring for an A.D. relative, the above rewards may explain *why* caregivers choose to stay in the caregiving relationship.

There are other possible reasons why caregivers enter and remain in the caregiving role. The generalized norm of reciprocity , that people should help those who now need the type of help that they themselves may need from others someday (Nye, 1979), may encourage caregivers to provide support without immediate reciprocity (Stoller, 1985). Also, the caregiver-patient relationship itself can be rewarding from the feeling of satisfaction that comes from caring for someone you love, even though there may be a lack of rewarding or comforting reciprocal exchanges while in the caregiving situation (Pett et al., 1988). In addition, Nye notes that the cost of terminating relationships in the family is very high. Therefore, even if caregiving provides few rewards, the cost of not providing care may be too great, thereby keeping the caregiver in the caregiving role. From an exchange theory perspective, the caregiver will choose what is perceived to be the least costly alternative, that is, providing care to the impaired relative.

In summary, it is important to recognize that the context of family caregiving is not the same as the burden experienced by caregivers of relatives with Alzheimer's disease. There are costs and rewards associated with decisions as to whether or not to provide care to the impaired relative. Once the choice has been made to assume or continue the caregiving role, there are different costs and resources which are associated with the levels of subjective and objective caregiver burden a caregiver experiences. It is important to distinguish between the caregiving role and caregiver burden which results from the caregiving role. Although it was necessary to provide a context for family caregiving, this research focused on the consequence of caregiving, that is, burden.

With respect to caregiver burden, it was hypothesized that certain caregiver costs and resources would be associated with both the level and type of burden (subjective or objective) experienced by the caregiver. In the next section, research concerning some of the factors that represent the costs and resources associated [illegible] burden are reviewed. Findings from these studies in conjunction with this [illegible] of burden were used to develop the rationale for the specific [illegible] burden which are used in this study.

III. LITERATURE REVIEW

The following review of literature identifies pertinent variables that have been investigated as possible correlates of burden experienced by caregivers of relatives with Alzheimer's disease. Each variable is discussed in terms of its relationship to subjective and/or objective burden as identified by or inferred in the literature. Whether the variable is viewed here as a cost or a resource is based on the conceptualization previously explained. The order in which the variables are discussed is not indicative of the expected strength of their association with the level of burden. It should be noted that there is a paucity of literature relating to the factors which may be correlated specifically with subjective and/or objective caregiver burden. Most of the research thus far has used scales that represent [illegible] a unidimensional concept.

The lack of consistency in findings of correlates of burden is due, in part, to the lack of operational clarity of the concept of burden. As Poulshock and Deimling (1984) note:

> Burden has been broadly defined and differentially measured. The definitions range from burden as emotional costs qua feelings of embarrassment and overload (Thompson & Doll, 1982) to specific changes in caregivers' day-to-day lives such as disruption of daily routine (Fatheringham et al., 1972). Other areas include financial difficulties, role strain, and physical health deterioration (Robinson, 1983; Zarit et al., 1980)(p. 230).

It appears that some of the literature that refers to caregiver strain/stress is actually investigating the same phenomenon as the literature on caregiver burden. Robinson (1983), using Pearlin and Schooler's (1978) definition in the development of a caregiver strain index (CSI), defines strain as, "those enduring problems that have the potential for arousing threat, a meaning that establishes strain and stressor as interchangeable concepts" (p. 344). Robinson's stressors such as physical strain, financial strain and confinement are the same types of factors, viewed here as costs, that are presently being studied as possible correlates of caregiver burden. The fact that the indices developed to measure strain and stress as well as a majority of the burden scales do not separate the emotional and the situational dimensions of burden further adds to this lack of agreement.

Given et al. (1988) present a model of what they refer to as "sources of stress experienced on family members caring for a demented family member" (p. 70). Their summary begins with the statement, "we have described the different sources of stress and burden that are imposed by caring for a family member with A.D." (p. 80) without differentiating between stress and burden. As Montgomery et al. (1985) note, in the gerontological literature, caregiver stress, problems, adverse effects and burden are all terms used to describe the consequences of caregiving. These terms also point to loss resulting from the caregiving role. Therefore, this literature review will include studies describing caregiver strain and stress, in addition to those on caregiver burden.

INCOME

Of the studies that have investigated the association between income and burden, the findings are inconsistent. Pratt et al. (1985) sampled 240 caregivers drawn from support groups and those who attended a one-time educational workshop on Alzheimer's disease. They found that the caregiver's income was not significantly related to the level of burden experienced by the caregiver. Pett et al.'s (1988) descriptive study consisted of 181 middle-aged women who, in addition to caring for their own families, were also primary caregivers for impaired relatives. They found no differences in income level between what they referred to as their high-risk caregivers (who reported the highest levels of burden and lowest life satisfaction), medium- risk (medium burden, medium life satisfaction) and low-risk (lowest levels of burden and highest life satisfaction) groups of caregivers.

Both of the above studies used the caregiver burden scale (Zarit & Zarit, 1982) that operationalizes burden as a unidimensional concept based on the caregiver's subjective sense of burden. In contrast, in a study of 80 female and male caregivers, Montgomery et al. (1985) found income to be significantly associated with subjective burden. The relationship with subjective burden was negative so that when caregiver income was low, the level of subjective burden was high.

Perhaps these inconsistent findings are due to a discrepancy between the conceptual and operational models of what variables are related to caregiver burden. Conceptually, some of the literature appears to hypothesize a relationship between the level of caregiver burden and financial problems. However, operationally, income which is a resource, is what is measured with respect to caregiver burden. For example, Pett et al. (1988) found no differences between low, medium and high-risk groups with respect to income level. However, they did find that "high-risk caregivers reported the highest percentage of caregiving responsibilities in terms both of hours of direct care and money expended" (p. 412). The amount of money expended proportionate to the amount of household income the caregiver has may prove to be a more useful measure in attempting to establish this relationship.

It is not clear from the literature whether income is associated with the level of burden a caregiver experiences nor, with what type of burden income is correlated. Further, it may be that financial expenditure proportionate to household income, rather than income itself, may present a more consistent picture of the relationship between financial problems and burden.

CAREGIVER AGE

Similar to income, caregiver age has not been examined extensively in terms of its relationship to caregiver burden. Pett et al. (1988) examined a sample of 181 daughters and daughters-in-law who were caregivers whose mean age was 47.3. Approximately one-third of the impaired relatives lived with the caregiver, one-third in the community and one-third in institutions. In contrast, Pratt et al.'s (1985) sample included 240 caregivers with a mean age of 61.3 years. Sixty-two percent of the impaired relatives lived in the community, 38 percent resided in institutions. Pett et al. and Pratt et al., both using burden as a unidimensional concept focusing on the subjective component, found no significant differences for burden scores among caregivers of different ages.

In contrast, Robinson (1983) found a significant negative correlation between what she referred to as "caregiver strain" and age. It should be noted that Robinson's sample consisted of caregivers to elderly hip surgery and heart patients, not to Alzheimer's patients with mental impairment. Robinson attributed the negative correlation between caregiver strain and age to the fact that younger caregivers are more likely to be employed and thus have multiple demands that conflict with the caregiver role. These women, referred to by Brody (1981) as "women in the middle", are likely to experience high levels of strain (burden).

Montgomery et al. (1985) examined the relationship between caregiver age and subjective and objective burden using a sample of 80 primary caregivers (primarily adult children) that lived within a one hour drive from their impaired relative. The median caregiver age was 56, but the the age range and mean age and standard deviation were not stated. Correlations were run with age and each type of burden. Caregiver age was found to be significantly related to subjective burden.

If it is the case that the middle aged (younger) caregivers referred to above are experiencing higher levels of burden, then based on the previous conceptualization and definitions, younger age with its multiple roles has been viewed as a cost.

CAREGIVER HEALTH

In the literature, poor health has consistently been inferred as a cost of the caregiving role. Haley, Levine, Brown, Berry and Hughes (1987) compared caregivers with a control group when examining the specific effects of the stress of caregiving on caregiver health. These authors found that the health status of the caregivers was significantly poorer than that of the control group. Not only did the caregivers seek out more medical controls and use more medications, but these caregivers perceived their health as poor.

Self rated health has been found to be a strong correlate of objective measures of health (LaRue, Bank & Jarvik, 1979; Mossey & Shapiro, 1982). Pruchno and Potashnik (1989) examined the impact of caregiving on the physical health of spouse caregivers. They found that compared to a general population matched for age and gender, caregivers of spouses diagnosed as having Alzheimer's disease did not rate their own health as excellent as frequently as did the general population. In addition, women caregivers over age 65 were more likely to report their health as fair or poor than were older women who lived in the community. Pruchno and Potashnik note that specific statistical comparisons of means for caregivers with means for non-caregivers were not possible and therefore, caution should be taken in interpreting the results. However, they point out that the results suggest differences between caregivers and non-caregivers.

Goodman (1986) makes the interesting comment that" it is debatable how valuable establishing a causal relationship between caring and ill health is when the majority of studies agree that carers undoubtedly do experience a level of physical exertion in their daily living far above that experienced by other people" (p. 708). Perhaps as well as the physical cost which Goodman (1986) point to, the caregiver's perception of poorer health resulting from the caregiving role could be interpreted as a different type of cost, that is, an emotional cost. Whether or not this is the case, there does appear to be agreement in the literature that the caregiving role is associated with poor health. Poor health is a cost of caregiving and considered here as a possible contributing variable to the outcome or the level of burden a caregiver experiences. What is far less clear is the relationship between poor health and subjective or objective burden.

Pratt, Wright and Schmall (1987) in comparing caregivers of community patients to those of institutionalized patients, found that in both groups, burden scores were significantly higher for caregivers who rated their health as fair to poor. In assessing the relationship between caregiver health status and caregiver burden, studies once again, tend to conceptualize burden as a unidimensional concept, which leans toward an emphasis on what is referred to in this research as subjective burden. If this is the case, there appears to be agreement that caregiver's health status is negatively correlated with subjective burden. The poorer the caregiver's health, the more likely she is to feel upset and depressed. It should be noted however, that there is a paucity of literature in which the relationship between burden and caregiver health is examined. Rather, poor health is often examined as an outcome of the caregiving role.

ACTIVITIES OF DAILY LIVING

Activities of daily living (ADL) include physical tasks such as bathing, dressing, eating, or instrumental tasks such as shopping, housework and meal preparation that people must perform in their daily lives. The impaired relative's lack of ability to perform ADL have been identified as variables positively associated with caregiver burden (Hooyman et al., 1985; Montgomery et al., 1985; Zarit et al., 1980). Implicit in the literature are two different ways of operationalizing ADL. Studies either look at the tasks caregivers must perform for the impaired relative or they assess the impaired person's ability to perform ADL. In both cases, a relationship between ADL impairment and caregiver burden is expected. However, when studies examine the tasks caregivers must perform for the impaired relative, the relationship is hypothesized to be positive whereas when they assess the impaired person's ability to perform ADL,a negative relationship is hypothesized.

Montgomery et al. (1985) and Hooyman et al. (1985), using the same sample of 80 caregivers consisting primarily of adult children found specific types of personal care tasks involving the dressing, bathing and nursing of the impaired relative to be significantly related to objective burden. Montgomery et al. (1985) also found tasks involving assistance with walking, transportation and errands to be significantly related to objective burden. These authors suggest that it is not so much the amount of time spent performing tasks, but rather, the freedom or lack of freedom associated with certain tasks that may be associated with an increase in the level of objective burden. It is inferred then, that certain types of tasks could be considered costs of caregiving.

Poulshock and Deimling (1984) also found a positive correlation between elder ADL impairment and burden (r=.46). In this case, burden was not separated into its two entities. Burden was defined as a subjective filter associated with the tasks affiliated with physical dependence and mental incapacity. "The burden measure associated with ADL impairment incorporated caregiver responses to several questions on the tiring, difficult, or upsetting nature of caregiving tasks" (p. 233). These authors note that a patient with high ADL impairment requires constant attention. Therefore, they speculate that the correlation between ADL impairment and burden is probably due to the perceived pervasiveness of the tasks required to care for a physically impaired elderly person. It should be noted that Poulshock and Deimling considered burden to play a mediating role between the elder relative's impairment and caregiver "impact". Two impact measures were used. One measure consisted of items that reflected the negative changes in elder-caregiver/caregiver-family relationships. The other measure represented the restrictions in caregivers' activities resulting from the caregiving.

Zarit et al. (1980) used mean scores for measuring physical and instrumental activities of daily living, rather than looking at specific tasks performed by the caregivers. This was accomplished by having a scale for each type of ADL which consisted of multiple items and summing these items such that an index score was obtained for each scale. These authors suggest that looking at the tasks as an aggregate may be the reason they did not find a correlation between instrumental and physical ADL and caregiver burden. It might also be that correlations were not significant because whereas the relationship may actually be between ADL and objective burden, burden in this study was a unidimensional concept with the focus on subjective burden. Other studies have found a positive relationship between ADL impairment and objective burden.

There is some agreement in the literature that the level of capability of the impaired relative in performing physical and instrumental ADL may be related to the level of objective burden caregivers experience. If the amount of ADL assistance caregivers must provide for their impaired relatives is associated with an increase in the level of objective burden, the implication is that respite care or caregivers' utilization of other types of services could be considered resources. Services to relieve caregivers of some of the responsibility of certain tasks may reduce the level of objective caregiver burden. It would seem, then, that service utilization may also be a possible correlate of objective burden.

BEHAVIOR/COGNITIVE INCAPACITY

Findings regarding the relationship between caregiver burden and the severity of behavior problems and the level of cognitive impairment lack agreement. Behavior checklists and items pertaining to level of cognitive functioning such as memory and confusion typify the instruments used to measure this concept. Eagles et al. (1987) used separate measures of mental status (memory and orientation) and behavior. Their sample consisted of 79 caregivers of relatives with no dementia, mild, moderate and severe dementia. Stress was measured using a scale with items related to the effect the impaired relative was having on the relative's social life and mood state and assessed the negative feelings of the caregiver toward the impaired relative. Also, a mood scale measured how tired, irritable, tense, worried and depressed caregivers were. This is similar to many of the subjective burden items. These authors found that both caregivers' stress scores and mood scores were significantly related to both the measure of the relatives' cognitive impairment and with their level of behavioral disturbance.

Deimling and Bass's (1986) symptoms of mental impairment included social functioning and the presence of disruptive behavior in addition to the traditional measure of cognitive incapacity. Path analysis was used to test the effects of each of the three symptoms of mental impairment on caregiver stress, both directly and indirectly. Stress was measured using four "impact" measures: negative changes in elder-caregiver/caregiver-family relationships, restrictions in caregivers' activities, changes in physical health and level of depression. They found "cognitive incapacity to have a less important direct effect on caregiving stress than disruptive behavior and impaired social functioning. Cognitive incapacity does have an important indirect effect through its influence on disruptive behavior and social functioning" (Deimling & Bass, 1986, p. 778).

In contrast, Zarit et al. (1980) and Fitting et al. (1986) both found that the behavioral problems caused by Alzheimer's disease were not related to the caregivers' feelings of subjective burden. Zarit et al.'s sample consisted of 29 subjects. A limitation noted in this study was that caregivers did not report high levels of burden. Fitting et al., examining a sample of 54 spouse caregivers, reported that severity of behavioral problems of dementia sufferers was not related to the caregiver's perceived sense of burden. However, they found that burden did increase with higher levels of dysfunction when there was control for sex and age of the spouse.

The main obstacle in investigating the relationship between problems arising from the behavior and/or level of cognitive impairment of the A.D. relative and caregiver burden is the ambiguity in operational definitions and the instruments used to measure these variables. Consequently, literature that describes the research is difficult to interpret. Fitting et al. (1986) note that the disparity between their study and previous research may have been due to different measures of functional impairment.

Some researchers address cognitive impairment and behavioral problems separately, some combine the two dimensions, and many include some of the same components as the ADL scales. The main feature of dementia common to some ADL and behavioral/cognitive impairment scales is incontinence. In spite of the inconsistency in the operationalization of behavioral/cognitive incapacity, there appears to be an implicit agreement that dealing with the A.D. relative's cognitive impairment is a cost. Conflicting findings make it difficult to assess whether this cost is associated with subjective caregiver burden.

INFORMAL SUPPORT - FAMILY

Family support is a commonly measured correlate of caregiver burden. This type of informal support has been operationalized in diverse ways. Zarit et al. (1980) measured family support as the frequency of visits by family members to the household. They found that the level of subjective burden experienced by the primary caregiver was negatively related to frequency of visits from other family members. George and Gwyther (1986) found that caregivers who reported that they did not need more social support had higher well-being than those who desired more assistance from their friends and kin. Similarly, Gilhooly (1984) found that satisfaction with help from relatives, and not just help itself, was significantly related to caregiver well-being.

Pratt et al. (1985) examined social support resources including spiritual support, extended families, friends, neighbours and community services with respect to the level of burden experienced by the caregivers. The unidimensional caregiver burden was found to be significantly related in a negative direction to spiritual support and to family support. The level of burden experienced by caregivers was not significantly related to assistance from friends, neighbours, or the use of community services. As Pratt et al. state, "burden may be abated by the presence, or exacerbated by the absence, of affective support from the caregiver's family" (p. 31).

Caserta et al. (1987) measured informal support received by their sample of 597 caregivers of non-institutionalized impaired relatives. Informal support was operationalized by using an index score comprised of the number of people the caregiver reported as assisting with the caregiving tasks, the frequency of contact with network members and the perceived satisfaction with the support received. Caserta et al. also found an inverse or negative relationship between informal support and their measure of caregiver burden, the focus of which is subjective burden.

Montgomery et al. (1985) measured family support by asking how many other family members assisted with the caregiving. The variable concerning number of others who assist was correlated with both subjective and objective burden. A significant negative correlation existed between the number of others who assist and objective burden only. This variable was also found to be negatively related to objective burden when it was subsequently regressed on objective burden.

The literature seems to suggest that informal support, and specifically family support, when available and satisfactory, is a resource for caregivers which is associated with a decrease in caregiver burden. The majority of studies investigated family support in relation to a unidimensional concept of burden. Therefore, it is not clear whether family support is associated with a reduction in the emotional burden, the situational burden or both types of burden that caregivers experience.

FORMAL SUPPORT - SERVICES

Formal support can include a variety of services offered through the community, the hospital system, or government agencies. Respite care, day care or chore service programs taking place both in and out of the home have been examined in terms of their relationship to caregiver burden. Respite, adult day care, and chore service programs all have a common goal which is to provide the necessary care to the A.D. relative while at the same time allowing the primary caregiver needed time away from the caregiving role (Caserta et al., 1987). Caserta et al. found in their study on utilization of community services, that caregivers' definitions of respite, day care, or in-home care were often interchangeable. However, most of the research on service utilization has been accomplished by examining the three above mentioned types of services separately.

Morris, Morris and Britton (1988) note that although it would seem that more formal support received should alleviate the level of subjective burden, the relationship between these two variables is not that straightforward. Contradictory findings are evident throughout the literature with respect to whether a particular type of service may be a correlate of caregiver burden. Morris et al. (1988) report results of a study done by Morris (1986) that did in fact find a positive relationship between the amount of strain a caregiver experiences and the amount of service utilization.

Burdz, Eaton and Bond (1988) examined the effect of respite care on dementia and non-dementia patients and their caregivers. They hypothesized that the transition to and from the community to a respite facility within a short time period would be more stressful for the dementia patients since people suffering from dementia can get confused and disturbed in response to unfamiliar situations (Mace & Rabins, 1981). Unexpectedly, they found the respite care program to have a positive influence on both the cognitive and physical functioning of the dementia patient and on the perceived caregiver burden. Respite care has also been reported as helpful in terms of improving caregivers' physical and mental health and relationships (Scharlach & Frenzel, 1986).

As with other forms of formal support, it is assumed that day care should be perceived as beneficial both to the A.D. relative and to the caregiver (Gilleard, Gilleard & Whittick, 1984). Programs vary but tend to offer patients structured physical and recreational activities, as well as providing support and support groups for the caregivers and other family members (Panella, Lilliston, Brush & McDowell, 1984; Winogrond, Fisk, Kirsling & Keyes, 1987). Winogrond et al. (1987) found that over a six month period, behavior problems did not increase significantly.

In contrast, Panella et al. (1984) found that repeated evaluation of behavior after the initial three months showed a steady decline in the A.D. relative's functional abilities. These authors note that the continued decline suggests that day care for dementia does not halt or change the downward decline of the patients. However, the respite time for the caregivers was seen as beneficial and it appears that this program has made it possible for families to keep their relatives at home longer. In contrast, Gilleard et al. (1984) note that even caregivers who feel the day care programs are beneficial are not more likely to keep their relative at home. In addition, caregivers deriving the most benefit are simply those who can see the most advantages of that type of a service for themselves from the beginning.

Support groups for caregivers of the A.D. relative are often offered in conjunction with day care programs. In addition, various agencies and associations such as the Alzheimer's Society also have support groups. The emergence of support groups for caregivers of Alzheimer's patients illustrates the movement to "fill the large gaps in service that exist for families of dementia victims" (Aronson & Yatzkan, 1984, p. 6). Discussion groups have, in the past, been reported to be effective in helping relatives of stroke and asphasic patients, (Lazarus, Stafford, Cooper, Cohler & Dysken, 1981) but are a more recent phenomena to be researched for caregivers of Alzheimer's patients.

Group curative factors are defined by Zarit, Orr and Zarit (1985) as the qualities of the group interactions which result in benefit to the participants. Particularly relevant to these support groups are the following five curative factors: the imparting of information, universality (seeing that you are not alone), imitative behavior (observing others' reactions and modelling them), interpersonal learning (having someone to talk to, learning from others to accept the disease and so forth), and group cohesion. These qualities constitute the majority of positive aspects expressed by caregivers in these support groups (Barnes, Raskind, Scott & Murphy 1981; Clark & Rakowski, 1983; Glosser & Wexler, 1985; Wright, Lund, Pett & Caserta, 1987).

Pagel, Erdly and Becker (1987) say that: "most theories of social support implicitly assume that social networks are supportive" (p. 793). Social support groups as a type of social network are often based on this same assumption. Hepburn and Wasow (1986) note that negative outcomes of support groups are often ignored. Wright et al. (1987) did include caregiver dislikes in their study. They stated that, "one of the most revealing negative reactions related to support group participants was that some caregivers found the meetings to be depressing and discouraging due to the nature of the subject matter" (p. 53). Lack of systematic research, empirical data and evaluation of these Alzheimer's caregivers support groups is often noted in the literature (Barnes et al., 1981; Clark & Rakowski,1983; Glosser & Wexler, 1985; Haley, Brown & Levine, 1987; Lazarus et al., 1981).

Hooyman et al. (1985), investigating the impact of termination of in-home services on family caregivers, found that the loss of chore services was not associated with caregivers' perceptions of objective burden or with the level of subjective burden measured by a single question on stress. The types of tasks provided by the chore service consisted of impersonal tasks such as shopping, laundry, and house cleaning. Hooyman et al. (1985) found that it was the personal care tasks such as bathing, feeding and toileting that were strongly correlated with what was implicitly measured as objective burden. They speculated, therefore, that the lack of a significant relationship between termination of the service and "perceived" burden may have been due to the nature of the service rather than having or not having the service itself.

It is unclear from the literature whether service utilization actually reduces the level of caregiver (subjective) burden. Because of the continual cognitive and physical deterioration, caregivers may feel just as upset, worried, and depressed as they did previous to service utilization. However, it appears that caregivers do find these services beneficial in terms of respite time and, following the conceptual framework, formal support is seen here as a resource.

In the absence of consistent measures of burden, it is not possible to compare many of these studies. Thus, researchers do not have a clear idea which of the variables are correlates of objective burden and which of the variables are correlates of subjective burden. However, based on the conceptual framework and the literature review, the following hypotheses were tested in this research:

HYPOTHESES

OBJECTIVE BURDEN

Hypothesis #1: Income is negatively related to objective burden.

Contrary to Montgomery et al.'s (1985) finding that income is correlated with subjective burden, it is hypothesized that income is related to objective burden, and that the relationship will be negative. It seems likely that income will be a correlate of objective burden because as a generalized reward (Nye 1979) a higher income allows access to other kinds of help (e.g. respite care). The utilization of services would allow the caregiver to have more freedom, more privacy and so forth, which are components of objective burden. Therefore, a negative correlation is hypothesized for the relationship between income and objective burden.

Hypothesis #2: Caregiver age is positively related to objective burden.

Older caregivers tend to have fewer resources such as money (Dowd, 1975) and tend to have more time to do the caregiving as they are more likely to be retired. Therefore, they may be responsible for the personal care tasks. This implies having less freedom, consequently feeling more drained, more socially isolated, and may be more burdened financially as income following retirement is often less than before retirement.

Hypothesis #3: The worse the caregiver's health, the higher the level of objective burden.

The poorer the caregiver's health, the more difficult it would be for the caregiver to perform the caregiving role, thus leaving less time for self, less time or energy for social activities and so forth. Therefore, the caregiver in poor health may experience an higher level of objective burden than the caregiver in excellent health.

Hypothesis #4: The need of the ill relative for help with physical activities of daily living is positively related to objective burden.

The higher the physical ADL score (the more unable the patient is to perform the physical ADL), the more tasks the caregiver will have to perform. The more shopping, meal preparation and driving the caregiver must do for her impaired relative, the less time, energy, freedom and so forth (greater objective burden) the caregiver will have for her/himself.

Hypothesis #5: Instrumental activities of daily living is positively related to objective burden.

The higher the instrumental ADL score (the more unable the patient is to perform the instrumental ADL), the more tasks the caregiver will have to perform. The more the caregiver must do for her impaired relative in terms of personal care tasks such as bathing and dressing, the less time, energy, freedom and so forth (greater objective burden) the caregiver will have for her/himself.

Hypothesis #6: Family support is negatively related to objective burden.

Hypothesis #6a: The receiving of help from relatives is negatively related to objective burden

If the caregiver receives help from other family members, the caregiver is likely to encounter less situational disruption, and the caregiver may have fewer household tasks to perform. Therefore, the more help the caregiver receives from family members, the lower the level of objective burden s/he is likely to experience.

Hypothesis #6b: Frequency of help received from relatives is negatively related to objective burden.

The more frequently the caregiver receives help from relatives, the less disruption the caregiver is likely to encounter and the caregiver may have fewer household tasks to perform. Therefore, the more frequent the help the caregiver receives from family members, the lower the level of objective burden s/he is likely to experience.

Hypothesis #7: Formal support, particularly service utilization is negatively related to objective burden.

The more services the caregiver uses, and the more assistance s/he receives, the more time, freedom and energy s/he will likely have, thereby decreasing the level of objective burden s/he experiences.

SUBJECTIVE BURDEN

Hypothesis #1: Caregiver age is negatively related to subjective burden.

The hypothesis is based on findings from the literature that feelings of guilt, being overwhelmed, distressed and so forth are expected to result from the numerous conflicting demands faced by younger caregivers.

Hypothesis #2: Caregiver health status is negatively related to subjective burden.

It is suggested here that the poorer the caregiver's health, the more overwhelmed, distressed, and upset (subjective burden) the caregiver is likely to be. For example, caregivers in poor health may be less able to performs tasks and therefore feel guilty. Caregivers may also be more easily overwhelmed due to their poor health.

Hypothesis #3: Informal support, particularly family support is negatively related to subjective burden.

Hypothesis #3a: The receiving of help from relatives is negatively related to subjective burden.

If the caregiver receives help from other family members, s/he will feel less anxious, guilty, worried, upset and so forth (subjective burden).

Hypothesis #3b: Frequency of help from relatives is negatively related to subjective burden.

The more often the caregiver receives help from other family members, the less anxious, guilty, worried, upset and so forth (subjective burden) the caregiver will feel.

Hypothesis #4: Behavior/cognitive Incapacity is positively related to subjective burden.

The more mentally impaired the elderly relative is, the more the deterioration becomes a reality to the caregiver. Seeing a family member that you love getting more confused and behaving erratically will tend to increase the caregiver's feelings of sadness, of being upset, worried and so forth.

Hypothesis #5: Objective burden is positively related to subjective burden.

The higher the level of objective burden experienced by the caregiver (that is, the less time, energy, freedom and so forth), the more likely the caregiver is to experience a higher level of subjective burden (that is, feeling depressed, overwhelmed and so forth).

IV. METHODOLOGY

This chapter begins with a presentation of the research design, a description of the sample, and the method of data collection used in the primary research. Data analysis techniques used in the secondary analysis follow. Finally, the empirical models tested are presented along with the operational definitions of the variables under investigation.

DESCRIPTION OF SAMPLE AND METHODS OF DATA COLLECTION FOR THE ORIGINAL STUDY

This research used data generated by a research project involving family caregivers of Alzheimer patients conducted by Dr. Norah Keating of the Department of Family Studies, and Dr. Sharon Warren of the Faculty of Rehabilitation Medicine, University of Alberta. The study, Factors Which May Predict the Institutionalization of Alzheimer's Patients, was funded by the Senior Citizen's Secretariat. The purpose of their study was to determine the factors which predict whether a family member diagnosed as having Alzheimer's disease will be institutionalized soon after the diagnosis or cared for at home over an extended period of time (Watson, 1988).

The sample for this study consisted of 77 caregivers of relatives with Alzheimer's disease. To be eligible, an individual had to be a primary caregiver (the person most involved in caring for the patient) to a diagnosed Alzheimer's patient and had to reside in Alberta for interview purposes. Sample members were drawn mainly from two sources: The Geriatric Outpatient Clinic of the Edmonton General Hospital and the Edmonton Chapter of the Alzheimer's Society. A small number of caregivers were identified through day hospitals and organizations like the YMCA which provide in-home respite care on a limited basis.

The source and selection of the sample in this research may limit generalizability of the findings since random sampling was not possible. This was a convenience sample. It is not possible to identify the population of people with Alzheimer's disease as there is no central registry of those with the disease. Many A.D. patients in the early phases of the disease may not have been diagnosed because of the insidious nature of the disease. For the same reason, physicians may also be cautious in giving a diagnosis of Alzheimer's disease to the patient or the family (Watson, 1988).

The major concern expressed by Keating and Warren (1988) regarding possible biases in the sample is that caregivers of Alzheimer's patients more likely to experience extremely high levels of burden may not be included in this sample. That is, caregivers at highest risk for having the highest levels of burden may have been "too burdened" to participate in the study.

DATA ANALYSIS AND EMPIRICAL MODELS

DATA ANALYSIS

Multiple regression, which analyzes the common and separate influences of two or more independent variables on a dependent variable (Kerlinger, 1986), was employed to analyze the data in this research. Using multiple linear regression, both the direction and magnitude of the relationship between burden and each of the independent variables can be measured, holding the effects of other regressors constant. Regression was the method of choice since this investigation focused on assessing the relationship between several potential explanatory variables and each dependent variable (objective caregiver burden and subjective caregiver burden).

Multiple linear regression was preferred to step-wise regression as the purpose of this research was to examine how costly each variable was with respect to each type of burden rather than determining the order of importance of each variable. In addition, using step-wise regression reduces the power of statistical tests.

Caregiver age, caregiver health status, family support and service utilization were regressed on objective burden. Caregiver age, caregiver health status, family support, behavior/cognitive incapacity and the actual objective burden index score were regressed on subjective burden.

EMPIRICAL MODELS

The empirical model for estimating the regression equation for objective burden is:

Objective Burden =
$a_0 + a_1$ caregiver age + a_2 good health + a_3 fair health +
a_4 poor health + a_5 receiving help + a_6 some help +
a_7 frequent help + a_8 instrumental ADL + a_9 physical ADL +
a_{10} number of services used

where the a_i represent the regression coefficients corresponding to explanatory variable i.

The empirical model for estimating the regression equation for subjective burden is:

Subjective Burden =
$a_0 + a_1$ caregiver age + a_2 good health + a_3 fair health +
a_4 poor health + a_5 receiving help + a_6 some help +
a_7 frequent help + a_8 behavior/cognitive incapacity +
a_9 objective burden

where the a_i represent the regression coefficients corresponding to explanatory variable i.

OPERATIONAL DEFINITIONS OF THE DEPENDENT VARIABLES

1. Objective burden of the caregiver was measured using a 5 point Likert scale for each of 9 items in an inventory of personal changes in the caregiver's life that had occurred since s/he began caring for her ill relative (Montgomery et al., 1985). The responses for the nine items were summed to create an index for which the possible range of values is 1-45. Montgomery et al. (1985) used Chronbach's alpha to test the reliability of the inventory. The alpha was equal to .85 (See Appendix A for the inventory that measured this variable as it appeared in the questionnaire).

2. Subjective burden of the caregiver was measured using a 5 point Likert scale for each of 13 items. The scale was adapted from Montgomery et al. (1985). The items ask about feelings like nervousness, depression, guilt, and others. The responses for these 13 items were summed to create an index of values for which the possible range is 0-52. An alpha of .86 was computed for Montgomery et al.'s (1985) scale. (See Appendix B for the inventory that measured this variable as it appeared in the questionnaire)

   Montgomery et al. (1985) state that, "while the data show that subjective and objective burden are correlated (r=.34), the two types of burden share only 12% common variance. This finding further supports Thompson and Doll's contention that the factors contributing to subjective burden are different from those contributing to objective burden" (1982, p. 22). The above quote lends further justification to the use of two different measures of burden.

OPERATIONAL DEFINITIONS OF THE INDEPENDENT VARIABLES

1. Caregiver age was operationalized by asking the caregiver her/his age in years.

2. Caregiver physical health was measured by asking the caregiver, "Would you say that your physical health in the last few months before your relative entered a long-term care facility was

   1..excellent 2 good 3 fair 4. poor"?

   This categorical variable was entered into the regression as a set of dummy variables: good health (0 = no; 1 = yes), fair health (0 = no; 1 = yes) and poor health (0 = no; 1 = yes). The category "excellent" represents the null condition.

3. Activities of daily living (ADL) measured the caregiver's assessment of her/his relative's ability to perform two types of everyday tasks.

3a. Instrumental ADL represents the impaired relative's ability to perform such tasks as using the telephone, shopping for groceries or clothes, preparing meals, and housework. This variable was measured using an inventory from the Duke University Multidimensional Functional Assessment or OARS methodology (1978). The reported reliability is .87. One item (taking medicine) was omitted from the scale as it was a missing value for a significant proportion of the sample. It was not possible to distinguish for which respondents this question was not applicable and those who simply failed to respond to this item. For this study, then, instrumental ADL consisted of six items, each item having three choices (0 = without help; 1 = with some help; 2

= completely unable to). These items were summed to create an index for which the possible range was 0-12 (See Appendix C for the inventory that measured this variable as it appeared in the questionnaire).

3b. Physical ADL measured the impaired relative's ability (or lack thereof) to perform such tasks as eating, dressing, grooming and bathing by her/himself. This variable was measured using an inventory from the Duke University Multidimensional Functional Assessment or OARS methodology (1978). The reported reliability is .84 (the item on incontinence was not included in the reliability coefficient). For this study, then, physical ADL consisted of seven items, each item having three choices (0 = without help; 1 = with some help; 2 = completely unable to). These items were summed to create an index for which the possible range was 0-14 (See Appendix D for the inventory that measured this variable as it appeared in the questionnaire).

4. Family Support was operationalized in two ways: by measuring whether relatives helped provide care ("Did any of your relatives help with providing care?" 0 = no; 1 = yes) and by the frequency of help received from family members. The frequency of help measure of family support was based on face-to-face help from nearby relatives. This variable was transformed into dummy variables with "none" (no help) as the null condition. The "sometimes" category (0 = no; 1 = yes) indicated whether the caregiver received help from relatives biweekly, once a month, or occasionally. The "frequent" category (0 = no; 1 = yes) indicates that the caregiver received daily or weekly help from relatives.

5. The service utilization variable was operationalized by first summing the number of services the caregiver utilized (total possible number of services listed was 18) and then dividing the caregivers into two groups, low users and high users. The decision as to what constituted low vs. high service use was determined by the mode, which was 3 services used. Individuals who used less than 3 services were classified as low users and coded as 0, while those who used 3 or more services were classified as high users and coded as 1. (See Appendix E for the list of services as they appeared in the questionnaire)

6. Behavior/Cognitive Incapacity - was operationalized using an instrument developed by the Benjamin Rose Institute (1980) called Family Assessment of Caregiving to Seniors (FACTS). The inventory consists of 27 items about the A.D. relative's behavior and mental status for which there were three possible responses (0 = not at all; 1 = some of the time; 2 = most of the time). The items were then summed to create an index score for behavior/cognitive incapacity. The possible range for this variable was 0-54. (See Appendix F for this inventory as it appeared in the questionnaire)

7. Objective burden - was operationalized in the same way as was done for objective burden as a dependent variable.

Income was to be included among the independent variables. However, there were too many missing values (over half of the sample) to include this variable in the statistical analysis. Therefore, this variable was omitted from the data analysis. Income is a sensitive and private issue for many people. This may be one reason why so many of the caregivers did not answer the question.

V. RESULTS

This chapter begins by listing some of the limitations of this study that should be kept in mind when interpreting the results. Next, the characteristics of the sample used in this research are described. Means and standard deviations for continuous variables and frequencies for categorical variables are presented. This section concludes with the results of the regression analyses.

LIMITATIONS OF THIS STUDY

The fact that the sample used in this research was not random and that it included a relatively small number of subjects make generalization of the findings somewhat limited. Cross-sectional data make it impossible to know whether the types and levels of burden caregivers experience change over time. In addition, this secondary analysis has a different focus than that of the original study. Consequently, while measures available were adequate for the purposes of this study, more detailed information would have enhanced the scope of the measures.

SAMPLE CHARACTERISTICS

The original objective of the research for which the data used in this study were collected, was to investigate factors which may predict institutionalization. Zarit (1989) notes that pressure to maximize sample size when testing multivariate models of stress and caregiving may lead researchers to include subjects without consideration of such factors as the minimal level of involvement of the caregiver. Since the members of the population of interest in this research are direct care providers only, 15 subjects who listed someone other than her/himself as the relative who provided the major source of assistance to the impaired relative were excluded from this sample. Four other caregivers were eliminated from the sample as a majority of the data were missing from the objective or subjective burden scales since these subjects considered the scales as not applicable.

As a result, the sample for this research consisted of 58 primary caregivers. Forty -three of the caregivers were female, 15 were male. This group of caregivers included 23 wives, 16 daughters, 11 husbands, 3 sons, 2 daughters-in-law, 2 sisters of A.D. patients and 1 interview in which the caregiver's relationship to the impaired relative was not identified. The caregivers ranged in age from 26 to 93 years old, with a mean age of 64.51. Means and standard deviations for the dependent variables and for continuous independent variables are reported in Table 1. Frequencies for categorical independent variables are reported in Table 2.

TABLE 1: MEANS, STANDARD DEVIATIONS AND RANGES OF THE DEPENDENT AND INDEPENDENT VARIABLES

Dep. Var.s	Range	Mean	St.Dev
objective burden	13	36.64	3.37
subjective burden	46	22.71	10.15

Indep. Var.s	Range	Mean	St.Dev
caregiver age	67	64.36	13.32
physical ADL	10	3.91	2.68
instrumental ADL	9	9.44	2.16
service utilization	8	3.97	1.99
behav./cog. incapacity	32	23.38	6.64

TABLE 2: FREQUENCIES OF CATEGORICAL INDEPENDENT VARIABLES

	VARIABLE	FREQUENCY	PERCENT
Caregiver Health[1]			
	Excellent	8	14
	Good	22	38
	Fair	18	31
	Poor	10	17
Receiving Help from Relatives			
	No	17	29
	Yes	41	71
Frequency of Help[2] from Relatives			
	None	20	35
	Sometimes	14	24
	Frequent	24	41
Service Utilization[3]			
	Low Users	26	45
	High Users	32	55

[1] Caregiver Health - "excellent" is the null condition

[2] Frequency of Help from Relatives - "none" is the null condition

[3] low users = 3 services or less, higher users = more than 3 services

Simple correlations among the independent variables were estimated prior to estimating each regression equation in order to check for collinearity among the independent variables. The correlation matrix for the correlates of objective burden is displayed in Appendix E. The correlation matrix for the correlates of subjective burden is displayed in Appendix F. The correlation between whether relatives help and the frequency of relatives' help, the same in both matrices, suggests a small amount of collinearity between these variables ($r=.54$). This moderate correlation was expected as the variables are measuring different dimensions of the same concept, that is, family support. The estimates of the coefficients, however, remain unbiased. Variance estimates are biased upwards which results in the t-values associated with the variables that are highly correlated being biased downwards (Studenmund & Cassidy, 1987). That is, the t-values may be smaller than they would be in the absence of collinearity thereby strengthening any significant findings.

REGRESSION ANALYSES

Results of the regression analyses will be discussed by examining each of the previously stated hypotheses for both objective and subjective burden. The discussion will address primarily individual coefficients found to be statistically significant at the .05 level or better, which is indicated by a t-statistic of 2.00 or higher for the size of the sample in this study. Each coefficient represents the magnitude of the association between the corresponding independent variable and the dependent variable. The coefficients can also be interpreted as representing the expected change in the dependent variable associated with a one unit change in the independent variable.

TABLE 3: RESULTS OF OBJECTIVE BURDEN REGRESSION

VARIABLES	COEFFICIENT	HYPOTH SIGN	T-STAT
Caregiver Age	-0.003	+	0.10
Caregiver Health			
Good	1.37	+	1.20
Fair	4.26	+	3.61**
Poor	5.03	+	3.83**
Receiving Help from Relatives	1.21	-	0.83
Frequency of Help from Relatives			
Sometimes	-1.09	-	0.75
Frequent	-2.25	-	1.59
Instrumental ADL	-0.38	+	1.89
Physical ADL	0.30	+	1.74
Services Used	-1.48	-	2.00*

**p<.01 *p<.05

F-value for Regression = 4.416
R-squared = .484
N = 58

Significance of F = .0002
Adjusted R-squared = .375

Table 3 illustrates results of the multiple regression in which objective burden is the dependent variable. The F-test, is most commonly used to test the overall fit or significance of a regression model (Studenmund & Cassidy, 1987). As can be seen in Table 3, F= 4.416 suggests that this regression is statistically significant.

The coefficient of determination (R-squared), represents the proportion of variation in the dependent variable that is explained by the independent variables taken together. The higher the R-squared, the more variance in the dependent variable is explained by the independent variables included in the model (Studenmund & Cassidy, 1987). The R-squared of .484 shown in Table 3 means that about 48% of the variation in objective burden experienced by caregivers of relatives with Alzheimer's disease is explained by the independent variables caregiver age, caregiver health, family support, the level of capability of the impaired person to perform activities of daily living, and caregivers' service utilization.. Adjusted R-squared represents the proportion of the variation explained by the statistically significant variables (Studenmund & Cassidy, 1987). The adjusted R-squared means that about 38% of the variation in objective burden experienced by caregivers of relatives with Alzheimer's disease is explained by the independent variables fair and poor caregiver health and caregivers' service utilization.

As the income variable had to be omitted from this research due to missing data, hypothesis #1 does not apply. Therefore, the discussion will begin with the second hypothesis.

Hypothesis #2, stated that caregiver age is positively related to objective burden. This hypothesis is not supported by the regression equation as the coefficient is not statistically significant even at the .05 level.

Hypothesis #3 stated that the worse the caregiver's health,the higher the caregiver's level of objective burden. The results reported in Table 3 support this hypothesis. The dummy variable for good health, was found to be positively related to objective burden. That is, caregivers with good health experienced higher levels of objective burden than did caregivers with excellent health. This relationship, however, is not statistically significant, at the .05 level. Fair health and poor health were also found to be positively related to objective burden, and were statistically significant at the .01 level or better thereby lending support to the notion that the poorer the caregiver's health, the higher the level of objective burden s/he will experience. The coefficient for fair health is 4.26 indicating that a caregiver whose health is fair scores 4.26 points higher on the objective burden scale than a caregiver in excellent health. The coefficient for poor health, indicates that caregivers who report poor health have burden scores 5.03 points higher than caregivers in excellent health. Again, supporting the notion that the poorer the caregiver's health, the higher the level of objective burden s/he will experience.

Both the physical and instrumental activities of daily living index scores were coded such that a higher score means that the impaired elderly person is less capable of performing the activities of daily living. Hypothesis #4 stated that physical activities of daily living were expected to be positively related to objective burden. Hypothesis #5 stated that instrumental activities of daily living were expected to be positively related to objective burden. These hypotheses imply then, that the more unable the A. D. relative is to carry out the tasks of daily living, the higher the level of objective burden experienced by the caregiver will be. Physical activities of daily living was found to be positively related to objective burden, but contrary to what was hypothesized, instrumental activities of daily living was found to be negatively related to objective burden. However, neither of these relationships were statistically significant.

Hypothesis #6, family support was tested in two ways. Hypothesis #6a that help from relatives to the caregiver in providing care (one of the measures of family support) is negatively related to objective burden was not supported by the results reported in Table 3. Although the Beta coefficient indicates a positive relationship, the result is not statistically significant. Hypothesis #6b was tested using the other measure of family support, frequency of help from relatives to the caregiver. The sign on the coefficient corresponding to this variable is negative as was expected. However, this finding is not statistically significant either.

Hypothesis #7 stated that service utilization is negatively related to objective burden. It can be seen by the results reported in Table 3 that the sign was consistent with what was expected. The coefficient of -1.48, which is statistically significant, suggests that an increase in caregiver service utilization is associated with a decrease in the level of objective burden.

TABLE 4: RESULTS OF SUBJECTIVE BURDEN REGRESSION

VARIABLES	COEFFICIENT	HYPOTH SIGN	T-STAT
Caregiver Age	-0.10		1.22
Caregiver Health			
Good	3.81	+	1.13
Fair	9.31	+	2.39**
Poor	7.01	+	1.61
Receiving Help from Relatives	-4.64	-	1.11
Frequency of Help from Relatives			
Sometimes	5.94	-	1.43
Frequent	8.85	-	2.08 *
Behavioral/Cognitive Incapacity	0.30	+	1.84
Objective Burden	1.16	+	2.83 **

**p<.01 *p<.05

F-value for Regression = 5.207
R-squared = .494
N = 58

Significance of F = .0001
Adjusted R-squared = .399

Table 4 illustrates the results of the multiple regression in which subjective burden is the dependent variable. In terms of the overall fit or significance of this regression equation, F=5.207 which is significant at the .0001 level. The R-squared of .494 indicates that 49% of the variation in subjective burden experienced by relatives caring for impaired elderly family members is explained by the independent variables, caregiver age, caregiver health status, family support, the impaired relative's mental capacity/behavior, and objective burden. The adjusted R-squared indicates that 40% of the variation in subjective burden experienced by relatives caring for impaired elderly family members is explained by the independent variables fair caregiver health status, frequent help received from relatives and objective burden.

Hypothesis #1 stated that age and subjective burden are negatively related. While the relationship indicated by the negative coefficient associated with this variable is of the expected sign, it is not a statistically significant finding.

Hypothesis #2, stated that the worse the caregiver's health, the higher the level of subjective burden. Again, because caregiver health was coded such that the higher the value, the worse the caregiver's health, a positive coefficient suggests that subjective burden increases as caregiver health deteriorates. Of the three dummy variables, only the coefficient responding to "fair" health is statistically significant at the .05 level. The coefficient (9.31) suggests that caregivers who have "fair" health have subjective burden scores 9.31 points higher than caregivers who have "excellent" health.which was expected. However, as the hypothesis was that subjective burden increases as caregiver health decreases, it was expected that the coefficient responding to "poor" health would be significant and that it would be greater in magnitude than the coefficient responding to the category of "fair" health.

As can be seen from Table 4, the coefficient corresponding to "poor" health is 7.01, smaller than that corresponding to "fair" health but is not statistically significant even at the .05 level.

It was hypothesized that family support is negatively related to subjective burden. Hypothesis #3a stated that merely receiving help from other relatives would reduce caregivers' subjective burden. Similarly, hypothesis #3b stated that the more frequently these other relatives provided help, the lower the subjective burden experienced by caregivers. The coefficient associated with the dummy variable representing whether the caregivers had relatives helping with the provision of care, does have a negative coefficient. However, this relationship is not statistically significant, even at the .05 level.

The results for the second measure of family support, the frequency of help to the caregivers from other relatives, is an interesting and surprising result. Although the result is not statistically significant, the "sometimes" category of help from other relatives yielded a positive coefficient. For the "frequent" category of help to the caregiver from other family members, the coefficient also indicates that the direction of the relationship is positive. In addition, this relationship is statistically significant at the .05 level. This result then, indicates that caregivers who frequently receive help from other family members have higher subjective burden scores than caregivers who receive no help from other family members. Caregivers who receive help frequently have a burden score 8.85 points higher than caregivers who receive no help from other relatives. This finding is contrary to what was hypothesized.

Hypothesis #4 was that behavior/cognitive incapacity is positively related to subjective burden. While the direction of the relationship between behavior/cognitive incapacity and subjective burden is positive, as expected, this finding is not statistically significant.

Hypothesis #5 stated that objective burden is positively related to subjective burden. This hypothesis is supported by a positive coefficient that is statistically significant at the .01 level. The coefficient of 1.16 denotes that a one point increase in [illegible] caregiver's objective burden score is associated with an increase in subjective burden of 1.16 points.

VI. DISCUSSION

This chapter begins with a discussion of the significant findings reported in the previous chapter. Beginning with objective burden, results from each regression equation will be dealt with separately. Implications of the findings in terms of public policy, programming and future research conclude the discussion.

OBJECTIVE BURDEN

It was hypothesized that caregiver age, caregiver health,family support, physical and instrumental activities of daily living, and service utilization would be associated with objective burden. Of the hypotheses relating to correlates of objective burden, only those pertaining to caregiver health and utilization of services were supported. This section begins with a discussion of these two variables.

CAREGIVER HEALTH

Most of the literature notes that poor health seems to result from the caregiving role (Haley et al., 1987; Pratt et al., 1985; Pratt et al., 1987). However, the question of whether poor health is associated with the caregiver's level of burden has not received as much attention. The relationships hypothesized between fair caregiver health and objective burden, and poor caregiver health and objective burden were both found to be statistically significant. In the context of choice and exchange theory, this finding suggests that poorer health is costly with respect to the caregiving role and contributes to the overall level of loss experienced by the caregiver. The cost of fair or poor health compared to excellent health is associated with less time, energy and freedom for the caregiver. It may be that as caregiver health deteriorates, the caregiver's required tasks become more time consuming and more exhausting, which raises the level of objective burden.

SERVICE UTILIZATION

Service utilization, a form of formal support, was also found to be statistically significant when regressed on objective burden. In choice and exchange theory terms, the fact that caregivers who utilized more services had lower objective burden scores, lends support to the view that service utilization is a resource for the caregiver (Panella et al., 1984; Scharlach & Frenzel, 1986). Services allow caregivers a break from the caregiving role. Whether it provides the caregiver time away from the impaired relative or whether the service provides relief from some of the specific caregiving tasks, the caregiver likely benefits from more time, energy and freedom for her/himself.

It makes sense then, that service utilization is associated with a decrease in the caregiver's level of objective burden. Because this independent variable was operationalized by summing the number of services used by a caregiver, it is not possible from this study to determine whether certain services are more valuable resources than others. For instance, it might be useful to know whether caregivers utilizing adult day care have objective burden scores different from caregivers who use respite care. It could also be beneficial to know whether there were differences in the relationship between caregivers who sought out institutional respite care and objective burden compared to those who used respite care at home.

In this research, services providing instrumental support were not differentiated from services more focused on providing psychological support. As it was argued here that objective and subjective burdens are different, it may be useful to differentiate between the types of formal support in order to get a more clear picture of how to reduce each type of burden.

PHYSICAL AND INSTRUMENTAL ADL

In agreement with Zarit et al. (1980), but contrary to what was hypothesized here, neither physical nor instrumental activities of daily living were found to be significantly related to objective burden. Specific types of physical tasks such as nursing care, bathing, dressing and specific types of instrumental tasks such as assistance with walking, transportation and errands were correlated with objective burden in previous literature (Montgomery et al, 1985). Rather than scrutinizing specific tasks in this research, both physical ADL and instrumental ADL were operationalized using index scores of the sum of the tasks associated with each category. The reason for this method of measuring the ADL was the sample size (n = 58). That is, the small sample size restricted the number of variables that could be regressed on objective burden without compromising the explanatory power of the model. For this reason, it was decided that an index score of each type of ADL would be appropriate.

Using index scores on the ADL measures may be one possible reason why neither physical nor instrumental ADL were found to be significantly related to objective burden. Therefore, although these findings suggest that the impaired relative's capacity to perform ADL is not as costly to the caregiver as was originally hypothesized, it should be noted that specific types of tasks may be considered more costly to the caregiver than others (Montgomery et al., 1985). It might be valuable then, in future research, to further investigate whether it is indeed the case that certain types of caregiving tasks are more costly and consequently, related to objective burden.

FAMILY SUPPORT

The negative direction of the relationship hypothesized between family support and objective burden was supported in this research. However, neither of the coefficients corresponding to the two measures of family support, receipt and frequency of help from relatives, was found to be statistically significant. These findings suggest that the frequency of help from relatives is not as much of a resource as was hypothesized with respect to the amount of objective burden the caregiver experiences. However, it may be that it is the nature and/or satisfaction of help from relatives that is associated with a reduction in objective burden, rather than merely receiving help or the frequency of help received.

An open-ended question relating to the nature of help received from relatives was asked in the questionnaire. In a great number of cases, caregivers did not go into much detail about the help they received from their relatives. Many of the caregivers responded vaguely by stating that the relative visits. Since it is difficult to determine whether visiting included physical help, emotional help or both, this data was difficult to code and not considered reliable for analysis.

Gilhooly (1984) assessed factors associated with the psychological well-being of caregivers of an impaired relative in the community. She found that the frequency of contact with relatives was not significantly related to the caregiver's morale or mental health, but satisfaction with help from relatives was significantly related. Gilhooly (1986) also examined factors associated with caregivers' preference for institutional care. She found that although the amount of help given by relatives as indexed on the social resources scale was not associated with the caregiver's preference for institutional care, satisfaction with help given by relatives was significantly related. For instance, even if a relative helps twice a week, if the caregiver is not satisfied with the help, or if the kind of help s/he is receiving is not time or energy saving, or allowing the caregiver more personal freedom, then the caregiver's level of objective burden may not be reduced. Again because of the purpose of the original study, there were no data pertaining to the satisfaction with help from relatives.

The lack of a significant relationship between family support and objective burden may then be due to the ways in which family support was measured in this research. It is possible that other measures would support the argument that family support is an important resource for a caregiver (Morris et al., 1988). If this is the case, in future research it may be beneficial to specify the amount of helped received while controlling for the various types of help received from relatives and then examining the relationship between family support and objective burden. It would also be useful to include a measure of satisfaction when assessing the relationship between family support and objective burden.

SUBJECTIVE BURDEN

It was hypothesized that caregiver age, caregiver health, family support, behavior/cognitive incapacity and objective burden would be related to subjective burden. Objective burden, caregiver health and family support which were all found to be significantly related, are discussed prior to some of the other variables.

OBJECTIVE BURDEN

Montgomery et al. (1985) distinguished between the two types of burden caregivers experience and found that the different concepts of burden have distinct sets of correlates. Based on this argument, some of the variables regressed on subjective and objective burden were different. Objective burden was one of the independent variables regressed on subjective burden. That the relationship between these two variables was significant, suggests that, although different variables are associated with the levels of objective and subjective burden, it is important to recognize that reducing the level of objective burden may also be associated with a reduction in the level of subjective burden.

Because caregivers experience both physical and psychological consequences of caregiving, it may be valuable when planning interventions focused on either treatment and/or prevention to keep in mind that although the different types of burden have some different correlates, there appears to be an association between the two. So although each type of burden should be addressed separately, the relationship between objective and subjective burden should not be neglected. For example, reducing some of the disruption in the household and caregiver's life, that is situational loss that results from caring for an impaired elderly relative, may in turn reduce the level of emotional burden that the caregiver experiences.

CAREGIVER HEALTH

As previously cited, the majority of literature in the area of caregiver burden appears to concur that lack of health is a cost of caregiving. That fair caregiver health was found to be significantly related to subjective burden in this study further supports this conclusion. Perhaps even more insightful however, this finding indicates that fair health compared to excellent health, is associated with the level of subjective burden the caregiver experiences. Fair health then, compared to excellent health, may play a role in increasing the caregiver's subjective feelings of being overwhelmed, upset, irritated and depressed, reinforcing the argument that caregiver health is a cost of the caregiving.

It was hypothesized that the worse the caregiver's health, the higher the level of subjective burden would be. The fact that poor health was not found to be significantly related to subjective burden in this study is an unexpected yet interesting finding. One possible explanation might be that the relationship between caregiver health and subjective burden assumed to be linear might, in fact, be curvilinear. That is, caregivers in both excellent health and poor health experience lower levels of subjective burden. It might be that caregivers' own poor health status provides a reason to focus on their own frailty and not feel as upset about the burdens associated with caring for their impaired relative. Caregivers in poor health may experience a low level of subjective burden if they feel they are providing care to the best of their capabilities considering their own state of health

Another possible explanation for the lack of significance of the estimated relationship between poor caregiver health and subjective burden might be because of the significant relationship between objective and subjective burden. Since utilization of services was found to be significantly related to objective burden, perhaps utilizing more services would reduce the objective burden which may in turn reduce the level of subjective burden experienced by the caregiver. Caregivers in poor health may be more likely to utilize more formal services, thereby decreasing the negative emotional feelings about the caregiving role. Despite poor health, an alternative such as increasing their resources, that is, use of formal services, may be seen as less costly to caregivers than institutionalization, the alternative of changing the context of caregiving.

FAMILY SUPPORT

One of the family support variables, frequency of help from relatives, was significantly related to subjective burden. The direction of the relationship is contrary to that hypothesized. The positive coefficient indicates that frequent help received from relatives is associated with the caregiver experiencing a higher subjective burden score. In contrast, findings from much of the research that has examined the relationship between family support and subjective burden suggest that family support is an important resource for caregivers of impaired elderly relatives (Pratt et al., 1985; Zarit et al., 1980).

In this research, family help is unexpectedly significantly related to subjective burden in a positive direction. This finding suggests that family help may be associated with more feelings of being overwhelmed, irritated, upset and guilty. However, this unexpected finding may be understood if it is in fact the case that caregivers tending to experience higher levels of subjective burden are more likely to call upon relatives for help more frequently. In support of this reasoning, Scott, Roberto and Hutton (1986) note that perhaps their second most burdened group of caregivers "received increased family support because they were most at risk for dysfunction" (p. 353).

Another possible explanation exists for the unexpected positive relationship found between the family support variable and subjective burden. Most of the caregiver burden literature shows consistently that family support is related to lower levels of caregiver burden. It is important to note, however, that with few exceptions (such as Montgomery et al., 1985), these findings have been based on the the unidimensional concept of caregiver burden. A unidimensional concept of caregiver burden clusters the subjective and objective dimensions of burden together. Therefore, it is impossible to detect whether the frequency of family help is necessarily associated with lower levels of subjective burden or whether it is actually associated with helping to perform the physical and instrumental tasks, thereby reducing the time and energy spent in the caregiving role (the level of objective burden).

Stoller (1985), in discussing intergenerational exchange, points out that, "while instrumental support from children may be seen as evidence of their affection and concern, an exchange perspective implies that help from children will undermine morale unless the elderly parents are able to reciprocate" (p. 336). This argument concerning the lack of reciprocity is one possible explanation as to why frequency of help from relatives was found to be positively related to subjective burden. Lack of reciprocity when receiving help from relatives may also occur even when the caregiver is someone other than a spouse. Also, caregivers may perceive themselves as having a lack of autonomy when receiving frequent help from relatives. Therefore, although the assistance may be helpful in reducing the caregiver's number of caregiving tasks, it may be costly to the caregiver emotionally.

It is often assumed that support, by its very nature, is positive and beneficial. However, depending on the history of a family's interactions and exchanges, it is possible that family support is not seen as supportive by the caregiver. This may be one more reason for the positive relationship found in this study between family support and subjective burden. For example, if family members are critical of the caregiver's way of doing things and make comments when they come to help, the caregiver could end up feeling more guilty, overwhelmed, irritated and upset. Or, if when family members come to help, they are constantly attempting to pressure the caregiver into seeking an alternative form of care that the caregiver does not consent to, this could also contribute to increasing the level of subjective burden experienced by the caregiver.

It may be that with regard to subjective burden, family support is not as valuable a resource as was hypothesized. However, all of the above explanations as to why these two variables may have been found to be positively related suggest that the relationship between family support and subjective burden is still not clear. Therefore, the usefulness of the family as a resource for caregivers should not be overlooked.

CAREGIVER AGE

Caregiver age was not significantly related to either objective or subjective burden as was originally hypothesized. A possible explanation is that caregiving at any age may be costly for different reasons. As was previously cited, adult children caregivers are often faced with multiple demands that conflict with the caregiving role. In contrast, it is more likely that older caregivers (who are usually spouses) are in poorer health. The correlation between caregiver age and poor health approached significance ($p<.07$). Therefore, it may be that age per se is not related to burden, but other costs that come with certain age groups are related to each type of burden. If this is the case, it is not surprising that caregiver age was not found to be significantly related to objective or subjective burden.

IMPLICATIONS FOR FUTURE RESEARCH, POLICY AND PRACTICE

The two variables found to be significantly related to objective burden were caregiver health and caregiver service utilization. Both preventative and maintenance measures can be taken to ensure caregiver health is optimum. It would seem that the focus of care often is on the relative with the Alzheimer's disease. The literature does focus on the caregiver's health, but only as it appears to be a cost of the caregiving. It is important to investigate how poor caregiver health resulting from the caregiving role effects each type of caregiver burden and what can be done both to improve or at least maintain the caregiver's health status and to reduce the objective burden. Perhaps more time needs to be taken by the caregiver to monitor her/his own health. This may be difficult for the caregiver since s/he has the responsibility of caring for the impaired relative. Perhaps the caregiver's family and the formal care system should also take responsibility for making sure the caregiver has regular check ups and/or whatever is necessary to maintain optimum health.

Perhaps if more time is taken to maintain or improve the caregiver's health status, the caregiver's level of objective burden may be reduced. It makes sense that if the caregiver is in better health, s/he may have more time and energy for the provision of care. It is interesting to note that the caregiver health variable was not examined by Montgomery et al. (1985) as a possible correlate of either types of burden while in this study, poor caregiver health significantly related to both objective and subjective burden .

With respect to service utilization, it would appear that use of a larger number of services is associated with a decrease in objective burden. Therefore, it is important that a variety of services including help with chores, respite care and adult day care, should be made available to caregivers. Part of the availability of these types of services includes making sure that caregivers know that this type of formal help exists. Caserta et al. (1987) noted that the discrepancy between the need and utilization of community services has usually been attributed to perceived lack of availability of or access to services. Unfortunately, the amount of missing data on the income variable, and the lack of a measure of relative expenditure made it impossible in this research to establish if money is a factor in terms of the caregiver's perceived availability of these services.

That objective burden is associated with subjective burden implies that reducing the level of objective burden experienced by caregivers may also reduce the level of subjective burden they may be experiencing. With regard to service utilization then, the implication is that availability, accessibility and affordability of services to caregivers may indirectly reduce their level of loss in terms of feeling overwhelmed, irritated and upset resulting from the caregiving role. In support of this notion, Pett et al. (1988) found in their descriptive study, that feelings of guilt, anger, resentment and so forth, seemed to be directly related to the perceived lack of available and economically feasible respite services and alternative options for care.

Montgomery et al. (1985) found a statistically significant negative relationship between family support and objective burden. While in this research the relationship between frequent help from relatives and objective burden was not statistically significant, the negative coefficient is in keeping with Montgomery et al.'s (1985) findings that receiving frequent help from relatives might be related to lower levels of situational loss resulting from the disruptions in the caregiver's household and lifestyle.

It is difficult to assess the relationship between family support and subjective burden experienced by caregivers. If it is the case that some aspects of family support are positively related to subjective burden, perhaps emphasis on alternative resources such as social support groups may be important in reducing the level of subjective burden experienced by the caregiver. In addition, as Scott et al. (1986) report, many caregivers desire the opportunity to talk and to share their problems with persons who have had or are currently in the same situation. This form of support was not investigated in detail in this research as it was only measured as one of the possible services caregivers utilized. A review article by Morris et al. (1988) suggests that research investigating support groups show positive results. These authors point to a study by Kahan et al. (1985) who found that caregivers who participated in support groups reported a reduction in burden and level of depression. In contrast, people who did not receive an intervention reported increased burden after four months of study. It may be then, that support groups are a valuable resource in terms of reducing the subjective burden experienced by the caregiver.

To summarize, researchers need to recognize that caregivers experience two types of burden and measure them accordingly. It would be useful for future research to recognize apparent differences in the correlates of both the situational and emotional loss that are consequences of caring for a relative with Alzheimer's disease. Some possible directions for future research are as follows. One useful direction would be to focus on comparing community services in order to determine whether certain services might be more valuable resources for caregivers than others. This will enable us to target scarce resources more effectively. Also, more detailed measures of family support, level of satisfaction with the support, and how the type of family support is related to each type of burden are needed in future research. Having a more clear picture of the relationship between family support and subjective and objective burden would be beneficial when integrating the findings with planning interventions. Further study on whether certain types of caregiving tasks are more costly to caregivers than others and therefore associated with a higher level of objective burden, might also provide insight in the future.

Interventions, should focus on reducing the caregiver's costs and increasing the caregiver's resources. Particular attention should be paid to some of the more costly consequences of caregiving, namely, the caregiver's health. As well, to help reduce the levels of subjective and objective burden, it is critical that the government and community agencies consider it a priority to provide caregivers with information about and accessibility to valuable resources such as various types of services, particularly respite care and support groups.

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NOTE:

All Appendices are excerpts from the original questionnaire

Please note: Items in Appendix C (Instrumental ADL), Appendix D (Physical ADL), Appendix E (Service Utilization), Appendix F (Behavior/Cognitive Incapacity) were recoded such that one endpoint was 0 instead of 1.

For example: in Appendices C and D — responses were recoded from 1-3 to 0-2; in Appendix E — responses were recoded from yes=1, no=2 to yes=1, no=0; in Appendix F — responses were recoded from 1-3 to 0-2.

APPENDIX A
IX. PERSONAL CHANGES IN CAREGIVER'S LIFE[1]

The objecive burden scale has been removed because of the unavailability of copyright permission.

---

[1] Source: Montgomery, R.J.V., Gonyea, J.G., Hooyman, N.R. (1985) Caregiving and the experience of subjective and objective burden. <u>Family Relations, 34</u>, 19-26.

APPENDIX B

XI. TYPE AND FREQUENCY OF BURDEN[2]

The subjective burden scale has been removed because of the unavailability of copyright permission.

---

[2] Source: Montgomery, R.J.V., Gonyea, J.G., Hooyman, N.R. (1985) Caregiving and the experience of subjective and objective burden. Family Relations, 34, 19-26.

APPENDIX C

VII. ACTIVITIES OF DAILY LIVING[3]

The instrumental ADL Scale has been removed because of the unavailability of copyright permission.

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[3] Scale: ADL scale from: The Duke University Centre for the Study of Aging and Human Development (1978). Multidimensional functional assessment: The OARS Methodology, Durham, NC.

APPENDIX D

B. PHYSICAL ADL[4]

The physical ADL Scale has been removed because of the unavailability of copyright permission.

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[4] Scale: ADL scale from: The Duke University Centre for the Study of Aging and Human Development (1978). Multidimenstional functional assessment: The OARS Methodology, Durham, NC.

APPENDIX E

XV FORMAL SERVICES

1. Since the onset of your (relative's) illness, have you used any of the following services?
Please indicate "yes" or "no".

213	a.	Society for the Retired and Semi-Retired	yes 1	no 2
214	b.	Alberta Mental Health Services	yes 1	no 2
215	c.	Catholic, Jewish or Family Services	yes 1	no 2
216	d.	Office of the Public Guardian	yes 1	no 2
217	e.	Public Trustee	yes 1	no 2
218	f.	Senior Citizens Bureau	yes 1	no 2
219	g.	Central Placement (District 24)	yes 1	no 2
220	h.	Auxiliary Hospital	yes 1	no 2
221	i.	Nursing Home	yes 1	no 2
222	j.	Extended Day Care	yes 1	no 2
223	k.	Day Hospital	yes 1	no 2
224	l.	Active Treatment Hospital	yes 1	no 2
225	m.	Alzheimer's Society	yes 1	no 2
226	n.	(Edmonton) Home Care	yes 1	no 2
227	o.	Private nursing	yes 1	no 2
228	p.	Meals on Wheels	yes 1	no 2
229	q.	Respite care (at home)	yes 1	no 2
230	r.	Respite care (institutional)	yes 1	no 2
231	s.	Others (please describe)	yes 1	no 2

APPENDIX F

VIII. CAREGIVER ASSESSMENT OF RELATIVE'S BEHAVIOR, MENTAL INCAPACITY[5]

The behavior/cognitive incapacity scale has been removed because of the unavailability of copyright permission.

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[5] Source: Benjamin Rose Institute (1980). Family Assessment of Caregiving to Seniors (FACTS). Primary caregiver interview schedule. Cleveland.

APPENDIX G

CORRELATION MATRIX OF THE INDEPENDENT VARIABLES
REGRESSED ON OBJECTIVE BURDEN

	CAREGIVER AGE	GOOD HEALTH	FAIR HEALTH	POOR HEALTH	SOME HELP FROM RELATIVES	FREQUENT HELP FROM RELATIVES	RECEIVING HELP	INSTRUMEN- TAL ADL	PHYSICAL ADL	SERV. USED
Caregiver Age	1									
Good Health	-.226	1								
Fair Health	-.007	-.524	1							
Poor Health	.24	-.357	-.306	1						
Some Help	.012	.057	-.03	.063	1					
Frequent Help	-.065	.065	-.11	-.013	-.474	1				
Receiving Help	.115	.113	-.223	.093	.275	.541	1			
Instrumental ADL	.185	-.014	-.158	.011	-.062	.053	.099	1		
Physical ADL	.145	-.082	-.006	-.071	-.148	.067	.136	.521	1	
Services Used	-.078	.062	.005	-.139	.103		-.047	-.022	.166	1

APPENDIX H

CORRELATION MATRIX OF THE INDEPENDENT VARIABLES REGRESSED ON SUBJECTIVE BURDEN

	CAREGIVER AGE	GOOD HEALTH	FAIR HEALTH	POOR HEALTH	SOME HELP FROM RELATIVES	FREQUENT HELP FROM RELATIVES	RECEIVING HELP	MENTAL INCAPACITY	OBJECTIVE BURDEN
Caregiver Age	1								
Good Health	-.226	1							
Fair Health	-.007	-.524	1						
Poor Health	.24	-.357	-.306	1					
Some Help	.012	.057	-.03	.063	1				
Frequent Help	-.065	.065	-.11	-.013	-.474	1			
Receiving Help	.115	.113	-.223	.093	.275	.541	1		
Mental Incapacity	-.033	.053	-.042	.09	.018	.064	.04	1	
Objective	.121	-.352	.352	.337	.049	-.213	-.093	.177	1