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FAMILY HELP TO FAMILY CAREGIVERS OF ALZHEIMER PATIENTS

BY

DIXIE E. WATSON

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

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research, for acceptance, a thesis entitled FAMILY HELP TO FAMILY CAREGIVERS OF ALZHEIMER PATIENTS submitted by DIXIE E. WATSON in partial fulfilment of the requirements for the degree of MASTER OF SCIENCE.

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ABSTRACT

The purpose of this study was to examine the family help received and the family help desired by the primary family caregiver of a relative suffering from Alzheimer's disease. The two major categories of primary family caregivers included spouses and adult children.

The theoretical perspective through which the research was approached was that of choice and exchange theory. Exchange theorists would suggest that the type of exchange relationships for elderly spouse caregivers would be different than for adult child caregivers. The literature findings were inconclusive.

The sample size included 56 caregivers - 31 spouse and 25 adult child caregivers. Chi-square analysis was conducted on the amount of family help received by the primary caregiver, the frequency of family help provided to the primary caregiver, and the desire for family help expressed by the primary caregiver. Contrary to predictions, the data analyses revealed no difference in the help received and the help desired between the two groups of primary caregivers.

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CHAPTER ONE

INTRODUCTION

Alzheimer's disease is a progressive, irreversible, incurable, degenerative brain disorder. While many theories exist, the origin of the disease is unknown. Insidious in nature, the disease is characterized by "memory impairment, deterioration in general intellectual ability, personality disorganization and impairment of ability to perform self care tasks" (Keating & Gilewich, 1985, p. 17). In Canada, estimates indicate that at least 10,000 deaths per year can be attributed to Alzheimer's disease, with as many as 100,000 to 300,000 people currently suffering from the disease (Health & Welfare Canada, 1982; Government of Canada, 1983). Although frequently not listed on death certificates, Alzheimer's disease is now thought to be the fourth leading cause of death in North America. Recent estimates (Ball, 1984; McHugh, 1982) are that the disease occurs in 5% of the general population over 60 years of age and in more than 20% of those over the age of 80. Life expectancy of an

Alzheimer victim is "4 to 14 years with an average of 6 to 8 years" (Handy & Davis, 1984, p. 3).

The process of Alzheimer's disease can be virulent and merciless for the victims while threatening and heartbreaking for their families who themselves are often in need of help. In discussing assistance to families caring for an Alzheimer patient, a National Advisory Council on Aging (1984) publication entitled Coping and Helping with Alzheimer's Disease, defines helping as the process of:

> enabling the individual and the family to find and use what they have within themselves and their community so that they can emerge more able, not only to cope with what life brings them but to be a purposeful creative force in shaping that life (p. 39).

With this in mind, the purpose of the current research inquiry is to examine the nature of help and assistance to the primary family member caring for a relative with Alzheimer's disease. Of interest here are the two largest groups of family caregivers: spouses and adult children.

Justification

The justification for proceeding with the current inquiry is based upon the following factors: (1) the aging of the Canadian population, (2) ambiguity in research findings regarding the situation of family caregivers, and (3) the need to develop more comprehensive policies regarding the allocation of health care dollars.

The Shifting Age of the Population

The number of elderly Canadians has been steadily increasing and will continue to grow for several decades. The population aged 65 and over is expected to expand from 1.7 million in 1971 to 3.3 million by the year 2001. This segment of the population which comprised 8.8% of the total population in 1976, will increase to 11.9% in the year 2001 and to 20.2% by the year 2031 (Powell & Martin, 1980; Stone & Fletcher, 1986). The first 30 years after the turn of the century will see the largest rise in the number of individuals over 65 years of age.

The greatest increase in the elderly population is expected to be in the number of Canadians aged 75 and over. In 1976 this group represented only three quarters of a million yet demographers indicate this segment of the population will reach 1.5 million in the year 2001 and continue steadily upward to 3 or 4 million by the year 2031. By the year 2031, of all the Canadians 65 years of age and older, 50 to 60 percent will be over the age of 75 (Wigdor, 1986).

These population profiles are important as they indicate an increased number of older Canadians will likely suffer from dementia. There will also be a parallel increase in the number of families having to become involved in caring for these elderly family members with Alzheimer's disease. Not only will there be very elderly spouse caregivers, but many adult child caregivers will be elderly themselves.

Research Ambiguity

There is no consistent body of literature regarding the extent and degree to which family members care for a frail, impaired elderly member. Nor does the literature specify the amount and types of help the primary caregiver receives or would like to receive. Most researchers maintain that the family is a very strong, solid and viable provider of care for its elderly members (Shanas, 1979; Brody, Poulshock & Mosciocchi, 1978; Johnson & Catalano, 1983; Johnson & Johnson, 1983). In the absence of a spouse capable of caring for an ill partner, Shanas (1979) claims that primary provisions are made by the children. Brody (1985) is adamant in her stance that "nowadays adult children provide more care and more difficult care to more parents over much longer periods of time" (p. 21) than ever before. This may be true, but a need exists to examine more fully the ways in which family members help the primary family caregiver of an Alzheimer patient and, in particular, to determine if the patterns of family help differ for spouse caregivers compared to adult child caregivers. Because the extensive nature and demands of caring for an Alzheimer spouse or parent can easily become overwhelming for one caregiver, it is important to learn more about the type of assistance and the extent to which family members help the primary caregiver.

We cannot assume that families will provide an all encompassing caregiving service to their older members. Bengtson and Trea (1980) point out the impact social changes have on family care. The social changes they refer to include the low birth rate; the large number of women employed; and the increased rate of both divorce and remarriage. Aronson (1985), in reviewing the literature on family care in order to compare the traditional view of family care with the more recent findings, states that "the possibility that the family, as presently formulated, is not always the only or most effective form of support is often not countenanced or explored" (p. 120).

Spence (1986) recognizes that the family may very well be an effective and responsive structure, but such a structure is extremely fragile and requires a great deal of "bolstering" in order to provide longterm care to its elderly. Examining the family as a resource to the elderly, Eggert, Granger, Morris and Pendleton (1977) conclude that "families represent a limited resource which can be rapidly eroded" (p. 108). This was based, in part, on findings indicating that in almost 50% of cases in which a frail elderly member was hospitalized for a second time, the family was unwilling to continue the home care upon release of the elderly member from the hospital.

Thus, while a vast majority of the literature supports the premise that the family is a fortress in providing care for their elderly, some of the more recent research findings do not fully support this contention and view such informal help as not always reliable and perhaps precarious in nature. As Aronson (1985) concludes, "the emerging critique of arrangements for the care of the elderly effectively uncovers and challenges some of the assumptions and consequences of the conventional, largely unquestioned use of the term family care" (p. 123).

Aronson (1985) finds that on the one hand researchers such as Brody (1985) are reporting empirical findings that describe how women feel about the task of caring for family members. On the other hand exists a more theoretically oriented body of research criticizing family care in terms of social and sexual divisions. Aronson (1985) claims that the only way to determine the intricacies of family care "is to link these two levels of analysis, examining the way that the ideology of family care is translated into the everyday experience of the frail elderly and the family members that care for them" (p. 118).

If indeed, overall family interdependency is neither stable nor presumable, the role of a family caregiver may be particularly vulnerable in terms of receiving informal help from family members. The extent of help may also vary from spouse caregiver to adult child caregiver.

Public Policy

Of current concern to the government are the health and social policy implications of the aging population. The elderly are traditionally heavy users of health and social services. Increased numbers in this age group will have significant financial ramifications to federal and provincial budgets. Fiscal policies have been geared to reducing public expenditures and there is no evidence to suggest this trend will not continue. In terms of programs to help the elderly and the families caring for impaired elderly, government services are somewhat conspicuous by their absence. "Absence of public provision of care requires the presence of private provision" (Aronson, 1985, p. 121). In times of economic restraint, withdrawal or lack of government intervention, according to Walker (1983), has a profound effect in forcing the care of the elderly onto the family. He notes that:

> the state occupies a dual role in relation to community

> care; it may provide direct support where this is absolutely necessary, but its main concern is to insure the continuance of the prime responsibility of the family for the support and care of its own members (p. 121).

The government does not seem to share, nor acknowledge the research concern regarding the ability, the willingness, and the capacity of the family to care for the elderly. Rather, they are inclined to view family care as a "cheap and attractive solution" (Aronson, 1985, p. 116) to government spending. Part of this bureaucratic philosophy may be a result of the cost factor, but another reason may lie in the government's expectation that societal members should function as independent of government as possible.

Problems usually result when government policy dictating direction is formulated contrary to, or without sufficient data to accurately respond to the needs of the particular policy audience. In terms of coordination, "research, policy and practice are ... not the same, but they are not unrelated ... policy that is not informed by knowledge may be worse that worthless, it may be dangerous" (Kent, 1972, p. 6).

In summary, the predictions for a "greying" of the Canadian population plus the increased longevity of people will result in an increased need for informal sources of help to families caring for a member with Alzheimer's disease. In times of need, often taken for granted is the assumption that assistance will be forthcoming from some source. To date the needs of the elderly have elicited little governmental response which usually necessitates a more active role by the private sector on an informal basis. In commenting on the lack of government involvement in family caring, Aronson (1985) claims such action results in a "distribution of responsibility for caring work that is heavily skewed to the private rather than the public sphere" (p. 123). What is going to happen if steps are not taken to assist families in these very vulnerable situations?

We know from the literature that families caring for a member with Alzheimer's disease usually do so under stressful conditions. Demographic trends indicate that people are living much longer. Because Alzheimer's disease is most prevalent over the age of 80, the number of people suffering from Alzheimer's disease will increase with a concomitant increase in the number of families that will be involved in the care of Alzheimer patients.

The government does not appear to be too accommodating in terms of providing alternate care because of the tremendous costs involved. Rather, the government leaves the bulk of the burden with the family. The problem seems to come full circle and ultimately rests with the family. But research also indicates that families may or may not be in a position to provide the intensive care necessary. Conflicting views exist as to whether the family is a powerhouse or a matchstick in terms of providing intensive long term care. Consistent views support the existence of one family member who will usually assume the duties of primary care.

The situation of caring for an elderly family member with Alzheimer's disease seems fraught with many and varied problems for the family member providing the primary care. The primary caregiver appears to be in the most vulnerable and most precarious position, often shouldering immense responsibilities. It is for these very reasons that we need to learn about the involvement of other family members in helping the primary caregiver. Specific information needs to be gathered on the extent and type of help families provide to the primary caregiver. A need also exists to determine if patterns of family help to the primary caregiver differ for spouse caregivers compared to adult child caregivers. The obstacles that impede the understanding and explanation of family help to a primary family caregiver caring for an elderly member suffering from a dementia such as Alzheimer's disease must be overcome. This research, Family Help to Family Caregivers of Alzheimer Patients, is one such attempt.

CHAPTER TWO

THEORETICAL FRAMEWORK

The intent of this research is to focus on family caregivers. In this study, family is defined as "those persons to whom one is related by blood or marriage" (Rosenthal, 1987, p. 312). Two categories of primary family caregivers are of interest in this research. These are the spouses of an Alzheimer patient and the adult children of an Alzheimer patient. This second category may also include spouses of the adult child, daughter-in-laws and son-in-laws of the Alzheimer patient. The primary caregiver refers to "the family member who bears the major responsibility for care" (Hill, 1984, p. 13).

The behavior under examination is the seeking and receiving of family help by these primary caregivers of Alzheimer patients. Seeking is defined as the act of expressing a desire for help. Receiving is the acceptance of help.

The theoretical approach of the inquiry is Choice and Exchange Theory. In addition, the Developmental Stake (Bengtson & Cutler, 1976) will be used to illustrate and offer further insight into the help sought and help received by spouse caregivers and adult child caregivers of an Alzheimer sufferer.

The underlying assumption of this chapter is that by virtue of the relationship to the Alzheimer patient, spouse caregivers and adult child caregivers will exhibit different help seeking and help receiving behavior. From the perspective of choice and exchange theory, receiving help requires that others be prepared to give. "An important concept for social exchange is the idea that one should reciprocate favors received from others" (Nye, 1979, p. 4). In other words, people should be prepared to assist those who have extended help to them. Thus, a crucial factor in help seeking and help receiving behavior may be the differing exchange relationships of spouses and adult children of Alzheimer patients.

The general principle of exchange theory is that people will pursue rewarding outcomes and avoid costly behavior. Rewards are not always possible without assuming some costs and similarly, some rewards must be forfeited in order to avoid or reduce the costs of a relationship. In assessing the costs and rewards of a relationship, people strive to establish a high reward to cost ratio. As Nye (1979) emphasizes, "whether one is maximizing profits or minimizing losses, the principle is the same - to obtain the most favorable outcome available" (p. 3).

Nye (1979) claims that over time, family members expect to maximize their profits in exchange with one another. A family member will receive, in exchange, something that is deemed equivalent to what that particular family member is prepared to give. Thus relationships are reciprocal. Interactive behavior can be viewed as attempts to maximize rewards and minimize costs.

The Family as Primary Caregivers

From an exchange perspective, caring for an Alzheimer patient appears to represent a situation with many costs and few rewards. Costs are defined as "any status, relationship, interaction, milieu or feeling disliked by an individual" (Nye, 1979, p. 2). Costs can be in the form of punishments, the withholding of rewards, or uncertainty. Uncertainty regarding the risks involved in attaining particular rewards can create anxiety sufficient to deter action or the pursuit of profit. Documented costs associated with caring for an Alzheimer family member include excessive burden (Zarit & Zarit, 1982), little personal time (Pratt, Schmall, Wright & Cleland, 1985), failing health (Archbold, 1983), and fatigue (Provincial Senior Citizens Advisory Council, 1985).

Rewards, on the other hand, are defined by Nye (1979) as "statuses, relationships, interaction, experiences other than interaction, and feelings which provide gratifications to people ... including all things physical, social and psychological that an individual would choose in the absence of added costs" (p. 4). Rewards derived from caring for an Alzheimer relative seem modest in comparison to the costs. From an exchange theory perspective, the situation of caring for a loved one who is sick, fulfilling a family obligation, and social approval should be perceived as rewarding by the caregiver.

In situations where the costs outweigh the rewards, exchange theorists predict a person will withdraw from the relationship. However, it may be very difficult for family caregivers to withdraw. Not only are kinship ties special ties in that "they are the most intimate, supportive and enduring relationships over the life cycle" (Rosenthal, 1987, p. 312), but they are also the most difficult to terminate. To extricate oneself from such a relationship carries a high cost.

This special nature of family ties is central to the analysis of help to primary family caregivers and is related to the nature of reciprocity within families. According to Nye (1979), "one should reciprocate favors received from others" (p. 4). Over time, in relationships, there should be a mutual giving and receiving so that exchanges are equitable. What makes the family ties different from other relationships is long term reciprocity. The relationship and contact among family members usually spans many years. Long term reciprocity exists between the spouse and his or her Alzheimer mate as well as between adult children and their parents. This long term reciprocity may account for family caregivers remaining in what may appear to be non-reciprocal relationships with an Alzheimer patient.

Reciprocity in family relationships should apply to all family members including the family member providing the primary care. Thus all family members, particularly the immediate family, should feel an equal obligation to assist the Alzheimer patient because all family members should be bound by the same degree of reciprocity. Yet frequently family members react differently and often negatively to someone afflicted with Alzheimer's disease. The behavioral manifestations of the disease do not encourage other family members, friends, or neighbors to visit and spend time in the presence of such sufferers (Aronson & Lipkowitz, 1981). For example, Alzheimer patients lose the ability to communicate which may discourage relatives from wanting to seek and/or maintain contact with the afflicted person. How then, does choice and exchange theory account for the adult child primary caregiver continuing to interact and care for his or her parent while the caregiver's brothers and sisters may avoid or withdraw from the situation?

From an exchange perspective, non-involved family members may have a choice not available to the family member who has already assumed the care. Nye (1979) states that "one makes an infinite number of choices so as to reduce his costs and maximize his rewards for most profits" (p. 4). Since the ill relative is already being cared for, the family obligation is being met. Therefore, other family members can choose to remain uninvolved in helping with the care because the costs are not as great as they would be if no family member was caring for the ill relative. The fact that one person assumes primary care may create the opportunity for other family members to evaluate the relationship more in terms of current costs and rewards rather than long term reciprocity. In this case family members, other than the primary caregiver, may choose not to become involved in helping with the care of the Alzheimer relative.

Spouses as Primary Caregivers

Spouses of Alzheimer patients are likely to be in an age group that holds a traditional view of marriage, a view strongly embedded in the concept of the permanent nature of marriage, regardless of the costs. Caring for a spouse can be seen as fulfilling the marital obligation, performing the contractual duties and deriving satisfaction from upholding the marital vows (Ghilhooly, 1986). "These individuals (elderly spouses) usually fulfill the role with little assistance from others even though they may suffer themselves from age-related physical, financial, and social limitations" (Johnson & Catalano, 1983, p. 612). Such care may not be evaluated in terms of the current costs and rewards of caring for the mate with Alzheimer's disease. Rather, reciprocity may be viewed in the context of exchanges over the term of the marriage which may span 25 or more years. Reciprocity may also be viewed in the context of knowing that the elderly caregiver's mate would do the same for him or her if their roles were reversed. Even in cases where the spouse views the relationship as very costly, the likelihood of opting out of the relationship is similarly slim. The spouse of an Alzheimer patient really does not have a choice because the costs of leaving the relationship are too high in terms of social disapproval and family censure. Costs may also accrue in the form of guilt over the very issue of long term reciprocity in that the mate wishing to opt out may feel she or he owes care to the sick partner for past exchanges. Thus, long term reciprocity may unequivocably bind the marriage partner to the caregiver role.

Family Help to Spouse Caregivers

The most likely source of informal help to a spouse caregiver is other family members (Cantor, 1983; Shapiro, 1985; Rabins, Mace & Lucas, 1982). Of the family members, the most likely source would appear to be the grown children. Most of the elderly have living adult children (Brody, 1985). If long term reciprocity exists between adult children and their parents, can it be expected that the adult children are utilized as a resource to the spouse caregiver? By definition, resources refer to "anything which the exchange partner perceives as rewarding and which consequently renders him or her susceptible to social influence" (Dowd, 1975, p. 590). An exchange theorist would suggest that the spouse caregiver is unlikely to seek or receive assistance because of the level of his or her own resources.

Most spouse caregivers are not employed and have reduced incomes (Rosenthal, Marshall & Synge, 1980). Alzheimer's disease usually strikes at a point in the life cycle marked by declining physical health and reduced resources of the patient and his or her spouse. Examples of lower resources include income, strength, health, approval and respect. In an exchange relationship, "the party possessing the greatest degree of social power is the party that controls both the terms of exchange, the rewards, and the profits arising out of the exchange" (Dowd, 1975, p. 593). In the case of a spouse caregiver, he or she is not likely to possess a great deal of power.

The elderly "have precious few resources to exchange. The net effect is an increased dependence upon others and the concomitant necessity to comply to their wishes" (Dowd, 1975, p. 592). This means that an elderly caregiver may perceive the need to exchange compliance to obtain assistance in caring for his or her equally elderly but infirm Alzheimer mate. In a relationship with an adult child, by virtue of long term family reciprocity, the need to exchange may be perceived only on the part of the elderly parent. But that perception of the need to exchange compliance and relinquish independence may represent an unreasonably high relationship cost. The party that has the most power can exert that power by demanding compliance in exchange for the satisfaction of the needs of the other party (Blau, 1964).

The seeking and receiving of help by elderly caregivers is also influenced by the nature of the power positions related to intergenerational relationships. Bengtson and Kuypers (1971), in discussing the Development Stake, recognize the changing power position and the changing interests of the generations over time. As children grow into adults their power increases, at the same time the aging parents' power is diminishing. The importance each generation attaches to the relationship is "directly related to the extent to which each can realize his or her objectives within the relationship" (Knipscheer & Bevers, 1985, p. 146). Emotional involvement is substantial for both generations. The older generation has greater emotional involvement than the younger generation (Bengtson & Black, 1973; Hill, 1970), but fewer resources with which to maintain the relationship. This leaves the elderly caregiver in a more dependent and vulnerable position. To seek or receive help from adult children may jeopardize the balance or the quality of this relationship. Such a risk may be too costly for the elderly caregiver.

Given this theoretical argument, an assumption is drawn that in order to protect intergenerational relationships, elderly spouse caregivers will be reluctant to seek or receive help from children with the care of an Alzheimer parent. Family and in particular adult children constitute the most probable, available, and logical source of help to an elderly parent caregiver. However, if the elderly caregiver does not wish to upset the intergenerational bonds by turning to the adult children in times of need, it is unlikely that an elderly spouse caregiver will seek or receive the same degree of help that an adult child caregiver will obtain.

Adult Children as Primary Caregivers

A spouse may not always be available or able to assume the primary caregiving role to an elderly partner suffering from Alzheimer's disease. In the absence of a spouse, an adult child is the next most likely person to assume the role of primary caregiver to an Alzheimer parent (Johnson & Catalano, 1983).

An adult child would likely assume the primary care of an Alzheimer stricken parent because of long term reciprocity. A grown child may deem care of a sick parent as an opportunity to reciprocate for the many years of nurturing and care received while growing up (Stoller, 1985). The need for an adult child to reciprocate may operate on two levels. The grown child may feel obligated to the parent with Alzheimer's disease and/or to the parent performing the primary caregiving tasks to the other parent.

Opting out of a relationship for an adult child would indeed be difficult, but not as difficult as for a spouse. This may, in part, be due to the fact that children are raised to become independent of their parents and assume separate lives. Thus social disapproval may not be as costly for an adult child as for a spouse. Intimacy at a distance (Rosenmayr, 1984) is socially acceptable behavior for an adult child.

The norm of generalized reciprocity states that "people help those who now need the type of help they themselves may need from others in the future" (Nye, 1979, p. 8). The reward to the adult caregiver may be the provision of a model of family responsibility for his or her own children (Dono, 1978). Help may also be more readily given to a younger caregiver than an elderly caregiver as the chances for reciprocity are better with a younger, more resource powerful caregiver.

Family Help to Adult Child Caregivers

As a primary caregiver of a parent with Alzheimer's disease, exchange theorists would suggest that adult children will behave differently in seeking and receiving help than spouse caregivers. The theoretical support is drawn from the ability of an adult child caregiver to enter an exchange relationship from a stronger resource position.

"Possession of power resources tends to be limited in youth, increasing through later middle age, and decreasing sharply in old age" (Dowd, 1975, p. 592). From the point of view of an exchange theorist, power results from an imbalance in social exchanges. Power as such is an integral part of exchange in that it is synonymous with the dependence of one person upon another. By virtue of being in a more resource rich age group, and by virtue of being able to enter into balanced or profitable exchange relationships, an adult child caregiver ultimately has a large number of choices from which to ask for help. Unlike the spouse caregiver who faces the risk of exchanging compliance, the adult child is independent and is more likely to possess the resources with which to barter for goods and services that are needed. Thus, fewer restrictions would stand in the way of an adult child seeking and receiving help in the care of a parent with Alzheimer's disease.

The cost of dissolving a relationship with an Alzheimer family member may prohibit the spouse and deter the primary adult child caregiver from taking such action. In seeking and receiving help, the assumption is that the adult child caregiver will actively pursue and gain more assistance than a spouse caregiver.

CHAPTER THREE

LITERATURE REVIEW

The intent of this chapter is to review research findings related to the seeking and receiving of family help by the primary family caregiver of an Alzheimer patient. An examination of the choice and exchange theory suggests that spouse caregivers will seek and receive less help than adult child caregivers. The literature review will outline the research conducted in the area of help seeking and help receiving behavior of both spouses and adult offspring in their capacity as primary caregivers of family members suffering from Alzheimer's disease. Ultimately, the determination of what is known, what is not known, and what needs to be learned will guide the specific focus of the current research.

Help Rec [illegible] Asked for by Spouses

Most research [illegible] eived and asked for by elderly spouses has been fo[illegible]n exchanges with adult children who are seen as the major providers of informal assistance

(Stoller, 1985). Rosenmayr (1984) claims that, to some extent, all intergenerational relationships are based upon reciprocal relations even though the highest amount of unreciprocated help also occurs within family relationships.

In her study of a sample of 753 non-institutionalized elderly people, Stoller (1985) found that most sample members were involved in some type of exchange of assistance. However, a small proportion (13.3%) reported that they received unreciprocated help, most of which (72.1%) was provided by children.

Stoller's (1985) findings suggest that this group of elders is particularly vulnerable since older parents who are no longer able to reciprocate for needed assistance may be pressured into relinquishing their authority. She argues that increasing reliance on compliance as an exchange resource generates feelings of low self-worth and can ultimately lead to depression.

It is important to note that Stoller's (1985) sample consists of healthy, independent elderly people. In contrast, the current study includes elderly adults who are providing constant care to their spouses. Although they may not be ill, they are at high risk of becoming ill due to the burden of caring in such a difficult situation (Gilhooly, 1986; Zarit, Orr & Zarit, 1985; Gates, 1986).

In a situation in which one partner suffers from Alzheimer's disease, the caregiving spouse may also be in a diminished position to reciprocate for needed assistance and therefore may be reluctant to ask for or accept that assistance.

Stoller's (1985) findings imply that the group of elders least likely to be involved in reciprocal relationships will be those with the lowest resources, particularly those with high levels of functional impairment. Others have found an inverse relationship between the level of resources of older adults and the amount of help received from children. In a study of factors affecting the ability of family members to engage in intergenerational exchanges, Mutran and Reitzes (1984) found that parents with the most resources received the least amount of assistance. In particular, poor health led to more assistance from adult offspring.

As with the Stoller (1985) research, sample members in the Mutran and Reitzes (1984) study were representative of the general population of older adults. Their sample was derived from a national survey sponsored by the National Council on Aging and included 781 married persons and 723 widows and widowers, all of whom were over the age of 65. Parallels between general samples of older people and samples of those caring for an Alzheimer's spouse must be made with caution. We can assume that the circumstances of the spouse caregivers in the current study have changed in response to having a spouse who is chronically ill. Mutran and Reitzes (1984) argue that a change in the status of an older adult may affect the way in which he or she views exchanges with children. The authors use the example of widowhood which, they say, increases the widow's awareness of the costs and benefits of personal interactions. Similarly, spouses who have a partner with a dementing illness may also revise their view of interactions with their children. A similar view is held by Spence (1986) who states, "it is important to distinguish normal reciprocal relations within the family from those provided in response to long term health care needs" (p. 16).

Elderly people living with their spouses in separate accommodation primarily rely upon each other for help (Stoller, 1985). Spouses provide the most comprehensive form of care (Johnson & Catalano, 1983) but frequently in isolation. In a longitudinal study investigating the effects of long term family care, Johnson and Catalano (1983) focus on methods which enable caregivers to continue care over an extended period of time. Their data reveal that spouses most frequently resort to enmeshing techniques to reduce the tension imposed by long term care. They report two prevalent techniques, both of which serve to increase the interdependence of the dyad. Social regression refers to a form of self imposed isolation resulting from the process of the caregiver relinquishing involvement and interaction with others in order to devote more time to caregiving tasks. The second technique, role entrenchment, refers to a process whereby the caregiver redefines the exchange relationship with the spouse to "exclude some tangible benefits and instead anticipate altruistic rewards which enhance his or her self-esteem and sense of competence" (Johnson & Catalano, 1983, p. 617).

Johnson and Catalano (1983) base their work on a sample of elderly patients, none of whom suffer from dementia, that were discharged from an acute care hospital. Nevertheless, it seems likely that spouses of Alzheimer patients would respond in a similar manner as the long term care is complicated and perhaps more intense due to the problems of Alzheimer caregiving. In a similar manner to the participants in the Johnson and Catalano (1983) study, spouse caregivers may cast off unwanted roles in favor of total investment in the Alzheimer mate. The spouse may choose to devote herself or himself to caregiving to the exclusion of all else.

Investigating factors associated with long term care of senile dementia patients, Gilhooly (1986) states that "many of the spouses in the sample took their marriage vows quite literally and said they would continue with home care until death do us part" (p. 169). The implication drawn from the statement suggests that with or without help, the spouse caregiver will continue to care even at the risk of his or her own health. Such determined dedication can be admired on the one hand but can also expose elderly spouse caregivers to excessive vulnerability. In order to provide care, the spouse caregiver's isolation and enmeshment could conceivably evolve into isolation from others including family members. The question is whether a spouse caregiver is less likely to receive help and concomitantly to ask for family help?

Even in situations in which older parents have relatively high levels of resources, they may be reluctant to ask for help from adult children. Knipscheer and Bevers (1985) studied intergenerational relationships through interviews with 74 elderly parents and one of their adult children. Agreements and disagreements and perceived agreements and disagreements between the parents and their children were examined. Knipscheer and Bevers (1985) found that parents have a strong need to have positive relationships with their children and may ignore evidence that children disagree with them on certain topics. Knipscheer and Bevers (1985) explain these findings in terms of the generational stake. "Because of the strong commitment of the parents to the relationship with their children, it is safest to assume that the relationship is as good as it was before - children are excused in advance" (p. 157). Presumably, children who are excused in advance are not asked for help.

As far as the elderly seeking help from their adult offspring, Knipscheer and Bevers (1985) speculate that parents are cautious, even though a large number of children indicate a willingness to help. Furthermore, the elderly parents in their study emphasize the need for contact with the offspring, but at the same time recognize the vulnerability of depending upon their children. Similar findings of the reluctance of the older generations to "impose" upon or become burdens to their adult children are those of Stoller (1982). If the healthy elderly resist relying on adult children for help, what are the implications for an elderly parent caring for a mate with Alzheimer's disease?

Thus, the literature suggests that some form of reciprocity usually exits between healthy older parents and their adult children with the elderly probably being the more vulnerable partner in the interchange due to his or her diminished power position. The healthy elderly seem to be particularly sensitive to this undesirable position. In the event of unreciprocated exchanges, consensus does not exist as to the consequences to the relationship. Given that much of the research is on the healthy elderly, it is difficult to speculate about the circumstances of long term Alzheimer care. In such situations, the literature suggests that reciprocity operates differently but the differences are not documented. Little information is available regarding the influence unreciprocated interactions may have on the help seeking and help receiving of the spouse providing the care for a husband or wife suffering from Alzheimer's disease. The literature seems to indicate that spouse caregivers will go to extreme lengths to continue to provide care but whether the mechanisms they employ will lead them to seek or receive family help remains undocumented.

Help Received and Asked for by Adult Children

Several researchers have argued that spouses are the primary support for ailing elderly (Stoller & Earl, 1983). However, in the absence of a spouse, the adult daughter assumes this role. The findings of Johnson and Catalano (1983) are consistent with these however they go one step further and describe "in serial order, the spouse functions as the primary caregiver; in the absence of the spouse, a child assumes the role; and in the absence of offspring, another family member is responsible" (p. 612).

There has been relatively little research focused on the amount of help asked for or received by adult child caregivers. This may be in part because children are viewed as having more resources through which to gain the support needed to provide care to ill relatives. For example, Archbold (1983) studied 30 adult caregivers of frail elderly paren[illegible] She was interested in how these caregivers managed the provision of care to their parents. One style of providing care she called 'care managers'. These were caregivers who identified parents' needs and met those needs through arranging for others to provide the needed services. This group of caregivers had a relatively high level of resources since most were employed and relatively well educated.

The study was focused on help asked for and received from the formal, monetized, care system. Archbold (1983) did not explore whether child caregivers asked for or received help from family members. Nonetheless, her findings do provide evidence that child caregivers will ask for and receive help in caring for their parent with Alzheimer's disease.

In a study of family support to the impaired elderly, Johnson and Catalano (1983) also found that children turned to formal supports for help. In addition, they found that children were more likely than spouse caregivers to ask for assistance from other family members.

In the absence of literature on support to child caregivers, the strongest argument remains the conceptual argument presented in Chapter 2. That argument suggests that by virtue of the adult child caregiver likely possessing a higher level of resources such as age, income, and education, he or she may be more willing and able to ask for help in caring for the ill relative. The question remains whether that help will come from informal or formal sources? Adult children are probably not burdened by unreciprocated help from family members or others because of their potential to either reciprocate for informal help received or pay for the necessary formal help.

The concept of distance is also a factor in the work undertaken by Johnson and Catalano (1983) who suggest adult children most frequently use distancing techniques as a method of reducing the stress associated with long term care of a parent. One third of their sample utilize physical distance as a means of coping. Psychological distancing, while much more prevalent among daughters, is effective as a means of prolonging the care of the parent without resorting to institutionalization. If children find it difficult to deal directly with an ill parent, they may look to others for help.

This process of distancing may be important to the caregiver in his or her ability to continue to provide care in a balanced fashion. For adult children assuming care of an ill parent, Rosenmayr (1984) suggests the need to be wary of the costs associated with excessive repayment of what parents have given. Such action can result in heavy burdens that interfere with personal fulfillment. Also the stress related to ambivalent situations can only be endured for a limited time.

Archbold (1983), in studying the impact of caring for frail elderly parents by women, noted that "the costs and benefits are often subtle, indirect, and difficult to calculate" (p. 42). Her study consists of a sample of 30 women, 15 of whom identify their parent's needs and provide t[illegible]ervice themselves, and 15 of whom identify their parent's needs and manage by arranging for others to provide the service. Within this "manager" group of adult caregivers, Archbold (1983) identifies their major costs to include "time limitations, career interruption, financial problems, and guilt" (p. 43).

Archbold (1983) finds that sibling conflicts arise over perceived inequities in the parent caring activities. The sibling assuming the primary caregiver role suffers from a heavier degree of responsibility than other siblings. This occurs even in cases in which other siblings are involved to some degree in caregiver activities. Archbold (1983) concludes that "historically, good sibling relationships tolerate the stress of parental illness better than historically problematic ones" (p. 43). Archbold's findings suggest that siblings may or may not be willing to provide help if asked to do so.

Theoretically, the argument is that child caregivers will ask for and receive more help than spouse caregivers. Research findings on this question are limited. Although there is an assumption throughout the literature that adult children have the necessary resources to obtain help, findings are equivocal.

Based on the theoretical framework and the limited amount of data, the research propositions are:

1. Child caregivers will receive more help from family members than spouse caregivers.

2. Child caregivers will seek more help from family members than spouse caregivers.

CHAPTER FOUR

METHODS

Design

This research is part of a larger research project of family caregivers of Alzheimer patients conducted by Dr. Norah Keating of the Family Studies Department, and Dr. Sharon Warren of the Faculty of Rehabilitation Medicine. The study, Factors Which May Predict the Institutionalization of Alzheimer's Patients, was funded by the Senior Citizen's Secretariat. The purpose of the larger study was to determine the factors which predict whether a family member will be institutionalized soon after a diagnosis of Alzheimer's disease or cared for at home over an extended period of time.

Alzheimer patients were selected from the Geriatric Outpatient Clinic at the Edmonton General Hospital, the nursing homes in Hospital District 24, and the Edmonton chapter of the Alzheimer's Society. The Geriatric Clinic's mandate is to serve only those aged 60 and older. Because some people display Alzheimer's symptoms prior to age 60, patients were also obtained from the other two sources noted.

In recent years, standard procedures have emerged in diagnosing Alzheimer's disease. Alzheimer's Disease: The Standard Reference (Reisburg, Ferris, DeLeon & Crook, 1982) is the accepted guide most frequently used by medical units such as the Geriatric Clinic. The Geriatric Clinic utilized the Reisburg guide along with clinical assessments which serve to minimize the diagnosis of other disorders with similar symptomatology. Not all Alzheimer patients were assessed at the Geriatric Clinic but every patient had been diagnosed as suffering from Alzheimer's disease. Without checking with the doctor involved in each case, it was not possible to determine if all patients diagnosed by someone other than the doctors at the Geriatric Clinic had used the Reisburg methodology. However, the study was examining the family help to caregivers of relatives exhibiting behavior symptomatic of dementia of the Alzheimer's type. The possibility of the relative not having Alzheimer's disease but rather a dementia with similar behavior manifestations would not jeopardize the study.

Sample

The sample studied is that of the relatives who are the primary caregivers for an Alzheimer patient. To identify the sample members, relatives listed as "next of kin" on the Alzheimer patients' files were contacted to determine the identity of the primary caregiver for each patient. In some cases the next of kin was also the primary caregiver, but in other cases the next of kin provided the name of the primary caregiver.

Materials and Procedures

Drs. Keating and Warren, the principal researchers of Factors Which May Predict the Institutionalization of Alzheimer's Patients, developed a questionnaire with a total of 155 questions spanning 18 areas of inquiry. The questionnaire was designed to gather information about characteristics of the Alzheimer patient; caregiver characteristics; circumstances of the family caregiver; caregiver burden; caregiver style; knowledge of available formal supports; informal supports; and, advice from medical personnel and family members. In addition, information describing the types of formal and informal help that would be of assistance to the caregiver was documented.

The next of kin, as determined from the files of the Geriatric Clinic, were sent an introductory letter, jointly endorsed by the primary researchers and the Clinic's physicians. The purpose of the study was described and the participation of the next of kin was requested. The next of kin identified in the files of the nursing homes in Hospital District 24 were similarly contacted by letters jointly endorsed by the researchers and medical personnel from Hospital District 24. The next of kin from the Alzheimer's Society were contacted in person at a meeting and asked if they wished to participate in the study.

Telephone follow-ups were conducted to not only determine the identity of the primary caregiver, but to also ascertain willingness to participate in the study. As part of the larger study, the primary caregivers were interviewed by trained personnel. A total of 59 interviews were completed. Each caregiver was interviewed once. The responses were recorded on the questionnaire by the interviewer. Some interviews were conducted on the University of Alberta campus and some were conducted in the home of the caregiver, depending upon the convenience of the caregiver. The interviews conducted in the home of the caregiver were sometimes conducted under difficult conditions. If the relative suffering from Alzheimer [illegible] disease was in the home at the time of the interview, she or he occasionally reacted adversely to the intrusion. Also, depending upon the progress of the disease, problems were encountered in posing questions about the care of the ill relative with that person in the same room. Conducting the interviews in a professional setting without the presence of the ill relative was more conducive to obtaining objective, accurate, and unbiased data.

Research Design

The purpose of the larger study was to determine what factors contribute to the decision to institutionalize that ill relative. The sample was a convenient sample.

The questionnaire was developed specifically for the larger study. Many of the instruments subsumed within the larger study had been used in previous research. To establish content validity of the questionnaire, the instrument was reviewed by experts in the field of interview research, family studies, and epidemiology. In addition, the complete questionnaire was pretested to further aid the content validity and increase the probability that the questions were testing what they were intended to measure. As a result of pretesting on a sample of three, modifications to the instrument were carried out.

The employment of skilled interviewers enhanced the chances of reducing such random errors as: errors in coding, ambiguous instructions, differential emphasis on certain words, and interviewer fatigue.

The source and selection of the sample may limit generalizability of the findings since random sampling is not possible. The population of people with Alzheimer's disease cannot be identified. There is no central registry of those with the disease. Many, in the early phases of the disease, may not have been diagnosed. Physicians may also be reluctant to give a diagnosis of Alzheimer's disease or to share the diagnosis with the patient or the family.

Sample for this Study

The sample for the study reported here included all participants who met the criterion of being a primary family caregiver who was either a spouse or an adult child of the Alzheimer patient. The three excluded from the study represented relatives other than a spouse or an adult child. The total sample utilized for Family Help to Family Caregivers of Alzheimer Patients consisted of 56 caregivers, with 31 spouse caregivers and 25 adult child caregivers.

Sample bias may have occurred as a result of a number of factors. For example, the total sample resided in the city as opposed to a rural setting. Perhaps the study only attracted a certain type of person. The possibility exists that only the more educated, resourceful, out-going, and active caregiver participated in the study particularly in the case of those caregivers obtained through the Alzheimer's Society. The members of the Society may also more actively seek information and group participation.

Sample limitations may have resulted from the fact that approximately 75% of the next of kin could not be interviewed due to the inability to locate them or their refusal to participate.

Methods for this Study

The writer participated in the primary data collection. This research report is based on secondary analysis of the data.

Measurement

The research propositions for this study were:

1. Child caregivers will receive more help from family members than spouse caregivers.
2. Child caregivers will seek more help from family members than spouse caregivers.

The study from which this report was drawn was not developed specifically to test these propositions. Thus, the operational research propositions for this study were the following:

1(a). A greater proportion of child caregivers than spouse caregivers ~~will~~ receive help from family members.

This research proposition was measured by:

Did any of your relatives help with providing care?

Yes No

1(b). Child caregivers will receive help more frequently from family members than spouse caregivers.

This research proposition was measured by:
How often did they (family members) provide this help? daily weekly biweekly monthly infrequently

2. Of the caregivers not currently receiving help, child caregivers will be more likely to express a desire for help than spouse caregivers.

This research proposition was measured by:
Would you have liked help from any of your relatives?
Yes No

Data Analysis

Data analysis included chi-square calculations to determine the differences between the two groups of caregivers. The purpose of the statistical tests is to compare the results obtained with the results to be expected on the basis of chance. The larger the value of X, the greater the results deviate from the expected chance results.

Chi-square analysis was chosen because chi-square can be used for comparisons between two groups and the testing of two nominal variables. Chi-square tables are basically tables of counts. Such tables are called crosstabulations or crossclassifications. The intent of examining such tables is to determine relationships between the row and the column variables. Chi-square calculations make no assumptions about which variable is independent nor are the results directional.

In response to research proposition 1(a) regarding the amount of help received from family members, a 2 by 2 chi-square analysis was conducted.

In response to research proposition 1(b) regarding the frequency of help received from family members, a 2 by 2 chi-square analysis was conducted. Answers were collapsed into two categories (daily/weekly versus biweekly/monthly/infrequently) in order to perform a 2 by 2 chi-square analysis.

In response to research proposition 2 regarding the caregiver's expressed desire for more help from family members, a 2 by 2 chi-square analysis was computed.

In summary, chi-square calculations were completed for the amount of help received, the frequency of help received, and the expressed desire for help by the caregivers.

CHAPTER FIVE

FINDINGS

In response to the research propositions, the findings derived from the data are presented in this chapter. Chi-square tabulations were performed for each of the research propositions. Additional descriptive data have been included to provide supportive evidence.

Sample Characteristics

The sample was composed of 56 primary family caregivers: 31 spouse caregivers and 25 adult child caregivers. The spouse caregivers ranged in age from 58 to 93 with a mean of 71.6 years of age (Table I). The adult child caregivers ranged in age from 26 to 69 years of age with a mean of 48.3 years of age. The range of ages for the relatives who suffered from Alzheimer's disease was 62 to 89 years.

The yearly income (Table II) of the caregivers ranged from under $10,000.00 to over $50,000.00. Seventy-five percent of the spouses had income between $10,000.00 and

$25,000.00. The yearly income of the adult child caregivers was split into two income groupings with 56% earning between $10,000.00 and $25,000.00 and another 39% earning income in excess of $40,000.00. As a group, the adult child caregivers attained the higher average income.

The education levels also varied between spouse and adult child caregivers (Table III). In terms of high school education, 45% of the spouses had completed some high school while 40% of the adult children had completed all of their high school training. The adult child caregivers had attained a slightly higher level of education than the spouses.

The data in Table IV confirm that not all family units are bound by closely knit kin relationships. In assessing the closeness of the relationship between the caregiver and the Alzheimer patient prior to the onset of the disease, 87.1% of the spouse caregivers reported a very close relationship while only 62.5% of the adult child caregivers reported a similar degree of closeness. A difference was also reported in assessing the lack of closeness in the relationship with only 3.2% of the spouses compared to 16.7% of the adult children reporting a pre-illness relationship as not being very close.

In determining caregiver style, the data in Table V reveal that an overwhelming 90.3% of the spouse caregivers, as opposed to 58.3% of adult child caregivers, determined the needs of the Alzheimer patient and performed most of those caregiving tasks themselves.

As outlined in Table VI, it appears that the spouse caregivers cared for the Alzheimer patient at home for a longer period of time (an average of .9 years) than adult child caregivers.

In using formal sources of help to assist in the caregiving of an Alzheimer patient, the adult child caregivers used an average of 4.2 services, whereas the spouse caregivers used only a average of 3.2 formal services.

Table I

Age of Caregivers

Age	Spouse		Adult Child	
	%	N	%	N
20-30	0.0	(0)	8.0	(2)
30-40	0.0	(0)	16.0	(4)
40-50	0.0	(0)	16.0	(4)
50-60	3.2	(1)	48.0	(12)
60-70	38.7	(12)	12.0	(3)
70-80	48.4	(15)	0.0	(0)
80-90	6.5	(2)	0.0	(0)
90-100	3.2	(1)	0.0	(0)

Table II

Yearly Income of Caregivers

Income in Dollars	Spouse		Adult Child	
	%	N	%	N
Under 10,000.	6.9	(2)	16.7	(3)
10,000.-15,000.	31.0	(9)	11.1	(2)
16,000.-20,000.	27.6	(8)	27.8	(5)
21,000.-25,000.	17.2	(5)	5.6	(1)
26,000.-30,000.	6.9	(2)	0.0	(0)
31,000.-35,000.	6.9	(2)	0.0	(0)
36,000.-40,000.	0.0	(0)	0.0	(0)
41,000.-45,000.	0.0	(0)	11.1	(2)
46,000.-50,000.	0.0	(0)	11.1	(2)
over 50,000.	3.4	(1)	16.7	(3)

Table III

Education Level of Caregivers

Education	Spouse		Adult Child	
	%	N	%	N
Grade school	3.2	(1)	0.0	(0)
Some high school	45.2	(14)	16.0	(4)
All high school	19.4	(6)	40.0	(10)
Trade School	16.1	(5)	16.0	(4)
University	12.9	(4)	28.0	(7)
Post Graduate	3.2	(1)	0.0	(0)

Table IV

Quality of Relationship Between Caregiver and Alzheimer Victim Prior to Onset of Alzheimer's Disease

Type of Relationship	Spouse		Adult Child	
	%	N	%	N
Very close	87.1	(27)	62.5	(15)
Somewhat close	9.7	(3)	12.5	(3)
In-between	0.0	(0)	8.3	(2)
Not very close	3.2	(1)	16.7	(4)

Table V

Caregiver Style

Style Type	Spouse %	Spouse N	Adult Child %	Adult Child N
*Type 1	90.3	(28)	58.3	(14)
**Type 2	6.5	(2)	33.3	(8)
***Type 3	3.2	(1)	8.3	(2)

* I decided what my relative needed and performed most of the caregiving tasks myself.

** I decided what my relative needed and performed some of the caregiving tasks myself.

*** I decided what my relative needed and managed or supervised others in performing the tasks.

Table VI

Years Between First Symptoms of Alzheimer's Disease and Interview

	Spouse In years	Adult Child In years
Range	5.5 - 8.2	4.4 - 7.6
Mean	6.9	6.0

Table VII

Formal Services Used by Caregivers

Number of Services	Spouse		Adult Child	
	%	N	%	N
1	16.1	(5)	8.0	(2)
2	19.4	(6)	20.0	(5)
3	25.8	(8)	16.0	(4)
4	19.4	(6)	12.0	(3)
5	9.7	(3)	16.0	(4)
6	0.0	(0)	12.0	(3)
7	6.5	(2)	8.0	(2)
8	3.2	(1)	4.0	(1)
9	0.0	(0)	0.0	(0)
10	0.0	(0)	4.0	(1)
	mean = 3.2		mean = 4.2	

Answers to Research Propositions

1(a). A greater proportion of child than spouse caregivers will receive help from relatives.

Analysis was computed by using a 2 by 2 Yates chi-square. There was no support for this question ($X_Y^2 = .28$). This means that the spouse caregivers and the adult child caregivers did not differ significantly in the amount of help received from family relatives.

1(b). Adult child caregivers will receive help more frequently than spouse caregivers.

In order to calculate a 2 by 2 Yates chi-square table, the categories that measured frequency of help were collapsed: daily and weekly sources of help from relatives were grouped together in one category; similarly, biweekly, monthly, and infrequent sources of family help were grouped together. The results did not support the research question ($X_Y^2 = .01$). The child caregivers did not differ significantly in frequency of help received than the spouse caregivers.

2. Of the caregivers not currently receiving help, child caregivers are more likely than spouse caregivers to express a desire for help.

Chi-square analysis of the yes/no response did not reveal support for this question ($X_Y^2 = .001$). Adult child and spouse caregivers did not differ significantly in the expressed desire for family help in caring for the relative with Alzheimer's disease.

No significant difference was found in response to each research proposition.

Table VIII

Help Received from Family Members

Caregiver	Yes	No
Spouse	23	8
Adult Child	16	9

$X^2_Y = .28$

Table IX

Frequency of Help Received from Family Members

Caregiver	Weekly	Less Than Weekly
Spouse	14	6
Adult Child	16	5

$X^2_Y = .01$

Table X

Expressed Desire for Help from Family Members

Caregiver	Desire More Help	Do Not Desire More Help
Spouse	12	9
Adult Child	10	9

$X_Y^2 = .001$

CHAPTER SIX

DISCUSSION

The prediction was that the amount of family help provided to a caregiver would differ depending upon whether the primary caregiver was a spouse compared to an adult child of an Alzheimer sufferer. However, no significant differences were found between these two groups of caregivers in the amoun[illegible] family help they receive, the frequency of help they receive, nor in their expressed desire to receive help. Although these were not the expected results, all results bear closer scrutiny and discussion. The discussion of these findings will focus on factors which may have had a bearing on the help received and the help desired by the two groups of primary caregivers.

Help Received by Spouse and Adult Child Caregivers

There are several possible reasons for the finding of no difference in help received. These will be discussed under the headings of family care, heterogeneity, caregiver commitment, and access to institutions.

Family Care

Although it was assumed that spouses and adult children would receive different amounts of help from family members, it may be that neither of these groups of caregivers receive such help. The possibility exists that once the primary caregiver is chosen, relatively little family help is forthcoming from other family members. Family care of the Alzheimer victim may in reality be care by one person. Perhaps no difference was found because as Aronson (1985) has suggested, what families provide is a person, the primary caregiver, rather than a family constellation of help. Once that primary caregiver is in place, other family members have a choice as to whether to help or not to help. Theoretical support, from an exchange theorist such as Nye (1979), would suggest that the family obligation is being met as the ill relative is being cared for. Therefore, other family members are allowed a choice because the costs are not as high as if no family member had assumed the care - to help becomes an option rather than an obligation.

Heterogeneity

A finding of no significant difference in the amount of help received by spouse caregivers compared to adult child caregivers may also be related to heterogeneity within the two sample groups. Spouses and children may be more diverse on various dimensions than was addressed in this study. For example, both spouses and adult children may have been caring for relatives who are at various points in the disease process. Within each group, there may be approaches to care which range from direct care to care management. In addition, there may be more within-group variation in the level of resources than previously expected. These issues are discussed in the next section.

The disease process. The process of Alzheimer's disease can extend from 2 to 19 years (Health & Welfare Canada, 1982). Subjects from [illegible] groups of caregivers had been providing care over a period of time ranging from 1 to 15 years. What cannot be determined from the analysis in this study is whether a spouse caring for a relative who has been ill for a short period of time receives similar amounts of help from family members as an adult child caring for a relative at the same point in the caregiving process. It may be that early in the disease process, caregivers generally receive more help from family members. This may be due to the fact that early in the process the family is more prepared to rally around the caregiver as their energies are higher than they may be after months or years of caregiving. Not all caregivers, in this study, were at the same point in time in terms of disease process as measured from the onset of symptoms. The length of time spouse caregivers had been involved in care ranged from 5.5 to 8.2 years with a mean of 6.9 years. The comparative range for adult child caregivers was 4.4 to 7.6 years with a mean of 6.0 years (Table VI). Thus, this study was not able to determine the caregiver's behavior from a consistent point in the disease process. A longitudinal study, however, could address the changes in family help asked for and family help received over the process of the disease. Such an approach may yield substantive differences between the two groups of caregivers.

Approaches to caregiving. Differences in the overall approach to caregiving within spouse and adult child caregiver groups may also mask differences in the amount of help received. For example, Archbold's (1983) work indicates that the method of care adult child caregivers undertake can range from doing all the work themselves to heavy reliance on the formal system to provide the day to day care for the ill parent. The same range of care provision may also be used by spouses. Information gathered in the present study (Table V) revealed that 90.3% of spouses provided all the care themselves while only 3.2% of spouses classified themselves as care managers. Similar statistics for the adult child caregivers indicated that

58.3% were self proclaimed care providers and 8.3% were care managers. In the end, it may be that care providers in either group are less likely to receive help because of such factors as enmeshment with the ill relative and the consequent isolation from other family members (Johnson & Catalano, 1983). In contrast, those who are care managers may receive more help because they ask for that help.

Levels of resources. Finally, there may also be a good deal of within-group variation in the level of resources of spouse and adult child caregivers. In terms of the absolute level of resources such as assets, income, and education, some spouses may have higher levels of resources than some adult children. Table III indicates that the educational level among spouses ranged from 3.2% having completed only grade school to 3.2% completing post graduate educational levels. The majority of spouses (45.2%) had completed some high school. In comparison, all adult child caregivers had education beyond that of grade school, but none had completed post graduate studies. The majority of adult child caregivers (40%) had completed their high school education.

In terms of income (Table II), spouses reported a range from under $10,000.00 (6.9%) up to $35,000.00 (6.9%) with only one spouse reporting an annual income of over $50,000.00. On the other hand, adult child caregivers reported income ranging from under $10,000.00 (16.7%) up to $25,000.00 (5.6%) with another cluster representing 38.9% falling between $40,000.00 to over $50,000.00. Thus, the level of resources may vary significantly within each group. In future studies, such resources could be either addressed directly or controlled in the analysis.

Caregiver Commitment

The level of commitment to care may also vary within each of these groups, with some caregivers having much higher levels of this resource. Rosenmayr (1984) claims that family reciprocity develops into long term reciprocity only if the family develops a pattern of reciprocal behavior in the early stages of the family's development and maintains this type of relationship throughout the family life cycle. Thus spouses and children may be equally likely to come into the caregiving role with high or low levels of commitment to caring. Similarly, a family history of amicable relationships and mutual support seems much more likely to lead to offers of help to the caregiving relative than one of animosity and lack of support. Differences in the level of commitment to care may be a factor in the current study. Table IV suggests that not all caregivers experienced a similar family history in terms of the caregiver relationship with the Alzheimer relative. Prior to the onset of Alzheimer's disease, 87.1% of the spouses rated their relationship with the Alzheimer mate as very close but 3.2% rated the relationship as not very close. Among the adult child caregivers, only 62.5% rated their relationship with the parent as being very close prior to the disease while 16.7% of the adult child caregivers rated that relationship as not close.

Access to Institutions

The access to formal care alternatives may diminish the need for caregivers to continue to provide burdensome care and for family members to support them in this endeavor. Canada has the highest institutional rate of elderly in the world, two times as high as the United States (Marshall, 1987; Robertson & Reisner, 1982; Spence, 1986). The government in Canada assumes a tremendous portion of the institutional costs in Canada, whereas in the United States, the individual's family must be accountable for providing the financial resources to support institutional care. Compared to the United States, Canadians and families included in the current study have available to them more formal alternatives at a reasonable cost. Unlike American studies (many of which were included in the review of the literature), perhaps families in the present study monitored the caregiving process and suggested formal help when the situation became intolerable as institutional care is a viable Canadian alternative. Although not measured, the possibility exists that one of the ways in which families help the primary caregiver is to give permission to the caregiver to seek formal help. Such action may account for the lack of significant differences between spouse and adult child caregivers in the help receiving and help seeking behavior.

Thus, a number of factors may account for or partially explain the findings of no difference in the amount of help spouse caregivers received compared to adult child caregivers. The issue of family care being equal to care by the primary caregiver is worthy of further inquiry. Heterogeneity within each of the caregiver groups may be a factor in terms of (a) the process of the disease over varying lengths of time, (b) the approaches to caregiving undertaken by the spouse and the adult child, and (c) the level of resources within each group of caregivers may be very diverse. These examples of possible heterogeneity illustrate considerations which may have an influence on the amount of help received by spouse caregivers compared to adult child caregivers. Further considerations such as the commitment to caring for the ill relative and the accessibility to institutional care need to be addressed. If these factors can be addressed, the possibility exists that support may exist for the theoretical argument offered in this research which suggests that the amount of family help the primary caregiver receives will vary depending upon whether that caregiver is a spouse or an adult child.

Help Asked for by Spouse and Adult Child Caregivers

There are several possible methodological reasons for the finding of no difference in help asked for - all of which arise from the fact that this study was a secondary analysis of an existing data set.

Methodological Issues

Since *Family Help to Family Caregivers of Alzheimer Patients* is secondary analyses, some of the ideal questions arising from the theoretical argument could not be pursued. For instance, the current study only determined what the caregivers wished to receive in the way of family help and not what they actually asked for. Exchange theorists would have predicted that the spouse caregiver, due to the diminished resource position, the generational stake, unbalanced reciprocal giving, entrenchment, and isolation would not ask for help. An adult child caregiver, on the other hand, would not be in a reduced bargaining position [illegible] terms of reciprocity and would likely ask for increased amounts of family help than a spouse. Because of the nature of the question, we do not know if this difference exists as there are no data on help asked for. Theoretically both groups wish for help but only children would ask for it.

In addition, analysis was undertaken of help desired only for those people who were not currently receiving family help. Thus, no information is available on either help desired or asked for by those who are already receiving some help. The group receiving no family help may be more isolated, more alienated or in other ways different from caregivers who are receiving some help but would like more. It would be useful to include both groups of caregivers in future research on help desired from family.

Although beyond the scope of this study, it would be useful to have more information about what kinds of help caregivers would like to receive. Such an inquiry would provide further data on whether help that is actually being received matches the perceived needs for help expressed by caregivers. For example, frequencies for spouse and child caregivers in this study suggest that spouses lack emotional/moral support while children lack help in areas such as transportation. Thus, while child and spouse caregivers may be equally needy in terms of help, the kind of help needed may be qualitatively different for each group.

Another methodological implication possibly influencing the findings lies in addressing only a portion of the spectrum of help asked for and received. Formal sources of assistance from formal resources were not examined in depth. Data in Table VII indicate that adult child caregivers used an average of 4.2 sources of formal support while spouse caregivers used an average of 3.2. What is not known is the number of times each formal source was utilized, the duration of time, or the motivation behind the contact. A more extensive examination of the use of formal sources of help might have disclosed a difference in the behavior of family help to spouse caregivers compared to adult child caregivers. The possibility exists that in some situations formal services may substitute for informal services. For example, adult child caregivers may actually be receiving and asking for more help when both formal and informal sources are considered. Such additional data may also lend credence to the theoretical argument, outlined in Chapter 2, which states that adult child caregivers will ask for and receive more help than spouse caregivers. The source of that help, however, may be from the formal system.

Finally, it is also possible that although there is no difference in the amount of help asked for by spouses and children, the reasons for not asking may differ. Spouses may not ask for family help because of a life long commitment to the relationship, because of the generational stake, or because of enmeshment. Children may not ask for family help because they have access to the formal system, because they possess the necessary resources (money, time, or bureaucratic skill), because of distancing from the ill parent, or because of their commitment to their immediate family.

Suggestions for Public Policy

The finding of no difference between spouse and adult child caregivers in the amount of help received and the desired amount of help sought from other family members has implications for policy formation. Because of the projected increase in the number of elderly, and hence the potential number of elderly that will have Alzheimer's disease, there is a need for innovative public policy in the provision of care.

Alberta has no clearly developed policy on the provision of community care nor on help to those providing the care. The assumption is that the family provides this help to the primary caregiver. Aronson (1985) has argued that this is not the case. To presume that families necessarily follow through with such help is naive.

Public policy derived from the data of this study should be based on the assumption that a similar policy will be applicable to both spouse and adult child caregivers. In terms of actual policy, additional knowledge with respect to certain areas would be beneficial. Further research needs to be conducted to delineate the nature of family involvement in the process of care to a relative with Alzheimer's disease.

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