PERCEIVED STRESS AMONG ALZHEIMER SUPPORT GROUP MEMBERS: A BROADER PERSPECTIVE

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ABSTRACT

This study examines the experience of Alzheimer caregiver support group members in relation to their perceived levels of stress. Thirty-three participants from the six Alzheimer Society sites in the jurisdiction of Northern Ontario participate in the study. The research tool consists of a 26-item self designed survey assessing characteristics of the support group, the caregiver, the care receiver, and outside assistance. These independent variables are examined to outline their probable influence on a caregiver's perceived stress. The survey incorporates Cohen's 4-item *Perceived Stress Scale* along with a question measuring self-identified caregiver stress which collectively created the dependent variable perceived stress. Additionally, these caregivers are given the opportunity to express through open-ended survey questions how they view their role as a caregiver, what contributes to their stress and service ideas that they have for the future. Significant relationships are found between the independent variables of self-care, gender, marital status, and difficulty asking for help with the dependent variable perceived stress. No significant relationships are found between perceived stress and the independent variables, length of support group attendance, employment status, living arrangements, stage of disease, use of respite, barriers to respite, and regular help from family and friends. This may be a result of the sample size of this study. Through a Structural Functional, Feminist, and Contextual Fluidity framework, caregiving is discussed in relation to the influence of political and sociological forces.

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Chapter 1

Introduction

Overview.

> *This experience has been the most difficult thing I have had to handle. I feel very lonely at times. This disease has changed our lives in many ways and I feel this will only get worse.* -Alzheimer Caregiver

Caring for someone with Alzheimer disease or a related dementia is a uniquely stressful experience due to the irreversible cognitive decline and behavioral problems exhibited by care receivers. The inability of care receivers to reciprocate or validate those that care for them exacerbates feelings of stress among caregivers. Alzheimer disease and related dementias have proven to be long-term chronic diseases with the general life span of this disease ranging from one to twenty years with an average of eight years of symptoms (Barclay et al, 1985). Family members and friends are most likely to carry out the informal caregiving role and inevitably are exposed to an alarming array of adverse consequences. Informal caregivers have a sixty-three percent higher mortality rate when compared to non-caregivers (Schulz & Beach, 1999) and are at least twice as likely to experience depression (Health Canada, 1997-1998; Canadian Study of Health and Aging Working Group, 1994a) and other decreases in physical and mental health (Max, Webber, & Fox, 1995; Brodaty & Green, 2000). However, as outlined by the Canadian Association for Community Care (n.d.), support initiatives are constantly geared to the person requiring care while less attention is paid to the person providing care. In light of the importance of understanding stress triggers among Alzheimer caregivers, this study specifically investigates factors that influence stress for Alzheimer caregivers who attend support groups. Understanding these factors that augment stress for caregivers is becoming increasingly important due to the normalization of informal caregivers as a central feature in the national health care system. (Romanow, 2002). While there is a wealth of literature that has investigated support groups and its influence on reducing the stress levels of Alzheimer caregivers, this study adds to the literature by including the independent variables of length of attendance in a support group, frequency and type of self-care and outside support systems.

The literature speaks to three compelling reasons as to why there is a need to better understand caregivers and their perceived level of stress. The first factor is the growing number of people who are being diagnosed with Alzheimer disease and related dementias. Most well known is the impact that these diseases have on the aging population. In fact, age is stated to be the greatest risk factor of acquiring Alzheimer disease and related dementias (Small et al, 1997). The absolute growth of an aging population relative to other segments of the population further substantiates the importance of this study. For example, the 2003 Statistics Canada figures show that approximately thirteen percent of the Canadian population is over the age of sixty-five. This percentage is projected to grow to approximately nineteen percent by 2021. The Canadian population over the age of sixty-five has been growing at approximately two to three percent per year while the population over the age of eighty-five has been growing at approximately four percent per year (Moore & Rosenberg, 2001). As noted by Hooyman & Gonyea (1995) the increase in the average life expectancy of the 'oldest old' (those eighty-five years and over) is likely to be met with an increasing number of people living with multiple physical and mental ailments which increases reliance on both formal and informal care. According to the Canadian

Study of Health and Aging (1994b), one in thirteen Canadians over the age of sixty-five and one in three over the age of eighty-five have Alzheimer disease or a related dementia. These numbers are projected to grow by over fifty percent in just over two decades (O'Rourke & Tuokko, 2000). Perhaps more alarmingly is the recent awareness that Alzheimer disease is not exclusively a disease of the aging. An increasing number of people are being diagnosed before the age of sixty-five, which is referred to as early-onset Alzheimer disease (Padgen, 2003).

The second factor is the high costs for formal and informal sectors of care which will predictably increase as this segment of the population increases relative to other age groups. In comparison to other age groups, the age bracket of eighty years and over typically adds the most stress onto the Canadian health care system (Statistics Canada, 1999). The net economic cost of Alzheimer disease and related dementia care in Canada is estimated to be $3.9 billion annually, with $636 million of this portion attributable to indirect costs bore by informal caregivers comprised of family and friends (Ostbye & Crosse, 1994). This calculation does not account for lost opportunity and emotional costs by caregivers which are significant but more difficult to measure (Ostbye & Crosse, 1994). Of particular significance is the recent findings from a Health Canada report on a national profile of family caregivers which stated that caregivers were found in various income strata yet on average still have household incomes below the national average (Health Canada, 2002). Although this Health Canada report did not just examine Alzheimer caregivers, it generally shows the financial burden felt by the general population of informal caregivers.

The third factor is the growing support for informal caregivers as an essential component for homecare as a normalized feature of the national health care system. The Romanow Report signals a significant change in the composition of Canada's national health care system by proposing that homecare services be integrated into the Canada Health Act. Although Romanow is referring to a formal homecare service approach, it still reflects a shift in responsibility from hospitals and institutions to the home which essentially puts more pressure on the informal care sector (family members and friends) who will inevitably continue to provide care. This is a result of what Estes (1993) refers to as the "paradox of the demographic imperative." Advances in medicine which has lead to increased longevity has also led to the shrinking availability of community and long-term medical services due to growing demand. This has placed growing pressure on the informal care sector comprised of family members and friends of those that require care. The Romanow initiative may appear to be meeting the needs of the elderly in light of the finding that they desire to remain at home for as long as possible (Health Canada, 1997-1998), yet this unavoidably puts more pressure on the informal care sector whom is already providing 85 to 90 percent of homecare to people in need (Ontario Coalition of Senior Citizen Organizations, 2002). An estimated 50 to 80 percent of people with Alzheimer disease in Europe and Canada are cared for at home (Bosanquet et al, 1997), by family members and friends (Nicoll et al, 2002; Jackson et al, 1991; Malonebeach & Zarit, 1991; Stone, Cafferata, & Sangl, 1987; Baumgarten et al, 1992; Kiecolt-Glaser et al, 1991). People with Alzheimer disease are commonly cared for by one identified primary caregiver as opposed to a network of people (Isenhart, 1992), with female caregivers, primarily spouses and adult daughters providing the majority of care (Max, Webber, & Fox, 1995; Rice et al, 1993; Roberts et al, 1999). As indicated by Romanow (2002), "Informal caregivers play an essential role in the delivery of homecare services and in the health and care of their families and friends."

One of the catalysts for a growing reliance on the informal care sector stems from the 1950 and 1960's where a process of deinstitutionalization took place. People experiencing Alzheimer disease and other mental health problems were transferred out of psychiatric institutions into the community or long-term care facilities (Roberts et al, 2000). The twenty-first century continues to feel the effects of this trend as care continues to be transferred out of hospitals and mental health institutions to the home. These factors coupled with family loyalties have resulted in family and friends taking on a substantial responsibility through their unpaid role as informal caregivers. Of most relevance is the how the informal care sector has become one of the cornerstones of Canada's health care system in the government's pursuit of future health care sustainability.

This leads to another significant catalyst stemming from the 1990's where increasing demands for healthcare care services has lead to a scarcity of health care resources. In other words, increases in life expectancy have not been met with an increase in services and funding. In response to this, informal caregivers have been and continue to be the key players in keeping those who would otherwise be institutionalized in the community (Brodaty, Green & Koschera, 2003). Informal caregivers play an essential role in the sustainability of Canada's health care system as homecare results in massive costs savings due to decreases in hospital admissions and delayed institutionalization (Romanow, 2002). As a result, homecare is commonly described as a "cost effective strategy" which can serve to cut back on future health care expenditures

(Hollander & Chappell, 2002). However, in light of the adverse consequences of informal care provision, the universal homecare initiative may potentially lead to an increase in negative caregiving outcomes. The reality behind the universal homecare initiative is it will likely lead to an increasing reliance on family and friends causing further deterioration of the informal care sector. As stated by Lefley (1987) "caregiving for one group at the expense of another can scarcely be considered a desirable mental health objective."

However, to a certain extent, the Canadian government recognizes the needs among informal caregivers. One indication that the government is recognizing the severe stress felt by informal caregivers is reflected in the implementation of the Caregiver tax credit for low income earners as well as in the recent 2004 federal budget which outlines the allowance of caregivers to claim up to $5000 on medical related expenses when looking after a dependent relative. The six week Compassionate Leave Program which is also a recent development will likely not apply to Alzheimer Caregivers since the narrow definition of what qualifies to be compassionate leave renders this program of little help to caregivers of Alzheimer disease and related dementias.

Meeting the needs of Alzheimer caregivers is strongly supported by the Alzheimer Society of Canada which is a not-for-profit organization founded over twenty-five years ago (Alzheimer Society of Canada, 2004). Besides the national head office, 140 Alzheimer chapters and ten provincial organizations are operating across Canada (Alzheimer Society of Canada, 2004). The Alzheimer Society takes an inclusive approach and offers support to caregivers who are looking after those with related dementias. The three major goals of providing family support, education and undergoing research has served to increase awareness of the disease and ease the adverse consequences of care provision. Of most relevance to this study is that the Alzheimer Society of Canada represents a symbol of national recognition to an important and overlooked population of informal caregivers. The society was formed in response to researchers from the University of Toronto and Surrey Place Centre becoming deeply concerned over the lack of available support systems for people who suffer from Alzheimer Disease and their families (Alzheimer Society of Canada, 2003a). Today, the Alzheimer Society's mission statement is two-fold; "to alleviate the personal and social consequences of Alzheimer Disease" and "promote the search for a cause and cure for the disease" (Alzheimer Society of Canada, 2003a). In 1986 the support group was officially established and is now one of the most widely used interventions by Alzheimer caregivers (Mace & Rabins, 1999; Zarit, Anthony, & Boutselis, 1987; Aronson & Yatzkan, 1984; Barnes et al, 1981; Glosser & Wexler, 1985; Lazarus et al, 1981; Ory et al, 1985; Schmall, 1984; Steuer & Clark, 1981). The support group provides a safe place for caregivers to receive validation, reciprocation and education in a supportive environment.

This study is based on a sample of Alzheimer disease caregivers who attend support groups offered by the Alzheimer Society in six Alzheimer Society sites in the Northern Ontario jurisdiction. This study seeks to understand the relationship between support group characteristics (length of support group attendance), victim characteristics (gender, stage of the disease, living arrangements), caregiver characteristics (gender, age, marital status, employment status, and relationship to the care recipient), use of outside assistance (utilization of respite care, barriers to respite care, levels of self-care, assistance from family members and friends, perceived difficulty in asking for help when stressed) and perceived levels of stress.

Additionally, this study, through open-ended questions gives caregivers the opportunity to outline their experiences as caregivers and their suggestions for future service.

Studies on support groups generally conclude that although rated positively by caregivers, it is inconclusive as to whether or not support group attendance helps to relieve adverse psychological symptoms. However, a segment of the literature has outlined the benefits of support groups on caregivers psychological functioning. Studies by Fung & Chien (2002), Otswald et al (1999), Zanetti et al, (1998), & Greene & Monahan, (1989) all demonstrate the potential of support group membership in relieving feelings of stress among caregivers. However, very few identified studies capture the full essence of the support group experience by including both caregivers of institutionalized and non-institutionalized elderly and controlling for factors such as length of support group attendance, frequency of self-care practices among caregivers, and use of outside interventions such as assistance from family and friends and utilization of respite care. Only one identified study by Gonyea & Silverstein (1991), was identified which examines the relationship between support group attendance on formal service use. Other studies by Larrimore (2003) and Cuijpers, Hosman & Munnichs (1996) investigates the support group experience among caregivers of institutionalized and non-institutionalized care receivers outlining the importance of support groups for caregivers after the care receiver is admitted into long-term care. These studies offer a piece of the complex puzzle of the experience of Alzheimer caregivers who attend support groups. Examining the larger picture by accounting for such factors such as use of respite care help from family and friends, and practices of self-care can help to understand the roles that these variables play and how they potentially influence perceived stress among Alzheimer support group members.

Importance of this Study.

This study examines the experience of Alzheimer caregiver support group members in relation to their perceived levels of stress. Characteristics of the support group, the caregiver, the care receiver, and outside assistance are used as independent variables in the study to outline their probable influence on a caregiver's perceived stress. Additionally, these caregivers are given the opportunity to express through open-ended survey questions how they view their role as a caregiver, what contributes to their stress, and service ideas that they have for the future. This study may provide the Alzheimer Societies across Northern Ontario with information to help them better serve those who need help in dealing with the impacts of caring for those with Alzheimer disease.

The Purpose Statement.

The purpose of this survey study is to analyze the experience of Alzheimer support group members by examining the various factors which potentially contribute to levels of perceived stress. The dependent variable (caregiver stress) is defined in this study by ten signs as identified by the Alzheimer Awareness Campaign (1999). The signs are as follows: denial that the person has the disease, anger at the person with the disease and others, emotional sensitivity, social withdrawal, depression, lack of sleep, lack of concentration, exhaustion, anxiety and an increase in health problems. Any or all of these signs may be experienced.

The independent variables used in this study are support group characteristics (length of support group attendance), victim characteristics (stage of the disease, living arrangements), caregiver characteristics (gender, age, marital status, employment status and relationship with the care recipient), and use of outside interventions (respite care, barriers to respite care, practices of self-care, help from family and friends, and perceived difficulty in asking for help when feeling stressed).

Theoretical Perspectives.

Structural Functional Theory. In formulation of an umbrella theoretical perspective for the study of Alzheimer caregiver support group members and their perceived levels of stress, Structural Functionalism provides a useful model. This positivist theory is outlined in the early works of Talcott Parsons (Jaffee, 2001) and has been used in the social sciences to examine social organizations. This theory has been applied to frame the experience of informal caregiving networks (Doress-Worters, 1994).

This theory is used to study how events or people operate within a larger system and how they work to maintain balance within that system. According to Parsons, networks within the larger social order are responsible for carrying out certain functions. For example, historically the government has been responsible for ensuring the sustainability of health care. Thus, when this becomes threatened, changes take place to regain balance. Society is constantly changing and growing, thus adaptations and temporary disruptions take place to keep society in equilibrium (Neuman, 2003). For example, due to our struggling health care system, informal caregivers are valued because their role fulfills what formal healthcare struggles to carry out. As a result of a continued threat to the sustainability and longevity of universal health care, a shift in the national agenda is taking place which puts more emphasis on informal care. Consequently, the further reliance on home care to maintain health care costs coupled with the socially ingrained expectation of familial obligation has made informal care a socially accepted and encouraged phenomenon. As mentioned earlier, this places undue pressure on those with family members and friends who need this type of care. Additionally, the number of informal caregivers in Canada is estimated to be at the three million mark and projected to increase substantially (Canadian Association of Community Care, 2001).

This theory holds that I would expect my independent variables (support group characteristics, caregiver and care receiver characteristics, and use of additional outside support) should influence or explain my dependent variable (perceived stress). The importance of understanding the various factors which contribute to stress among Alzheimer caregivers is increasingly important as a result of the current shift in Canada's healthcare system which places increasing reliance on the informal care sector. As a result of structural functionalism, societal expectations and political agendas tend to shape the caregiving experience creating a negative outcome due to the lack of connection between the formal and informal systems. Additionally, the shift of emphasis from formal to informal care can be understood within a structural functionalism theoretical framework.

Feminist Theory. This study uses feminist theory to add understanding to the significant role that women play in the caregiving system for Alzheimer disease and related dementias. This theory grew out of the feminist movement of the nineteenth century but was not widely incorporated into studies of the social sciences until the late 1980's (Neuman, 2003; Hooyman & Gonyea, 1995). As indicated by Hooyman & Gonyea (1995), in their extensive literature on caregiving as a gendered role, feminists began to challenge the expectation of women as caregivers in the 1960's and 1970's. Population aging coupled with the societal expectation of informal care provision which continues to be driven by policy has led to this increase in research (Hooyman & Gonyea, 1995). The division of labor as shown by the ingrained responsibilities of men and women became social norms following the industrial revolution (Erhreneich, 1983) and has created lasting impacts as evidenced by current caregiving research which outlines the dominant role of women as care providers.

Feminist theory shapes much of the caregiving literature as studies generally conclude that women continue to provide the role of caregiving in the private sphere despite gains in participation in the public sphere which makes their daily living experiences multi-faceted and challenging. Male caregivers are growing in number yet the level of expectation between genders to perform the role of caregiving is far from balanced. While societal expectations for men may be changing, they are not expected to provide care all by themselves (Hooyman & Gonyea, 1995). For example, men are more likely to make financial sacrifices through their support initiatives while women are more likely to sacrifice themselves (Dalley, 1988).

Feminist theory is used extensively in the caregiving literature as indicated in studies by Doress-Worters (1994), Harrison & Neufeld (1996), Hoffmann & Mitchell (1998), Logsdon & Robinson (2000) , Strang (2001) and Hooyman & Gonyea (1995) whom all use a feminist approach to study the informal caregiving experience and its various impacts on women.

This theory focuses on the role of women in society, which is shaped by particular assumptions and expectations derived from a long history of women providing the nurturing role of care. As a product of historical and political forces, the responsibility of caregiving has been assigned largely to women (Miller, 1976). Informal care is an example of the "privatization of care" as a shift has taken place from societal responsibility to a private responsibility (Hooyman & Gonyea, 1995), which primarily affects women as care providers. Although women have gained a significant amount of independence over the last several decades as exemplified in the workforce and increasingly in the policy arena, women are finding themselves in multiple and taxing roles as the expectation of providing care still weighs largely on their shoulders. Providing unpaid informal care in the home is still viewed as "women's work" (Stoller, 1993). As described by sociologist, Robert J. Brym (1998) as a society we have come to look at roles as either being inherently "masculine" or "feminine" which strongly influences how people view themselves and how they interpret their world. Female spouses provide the majority of informal care to people in their later years (Glasgow, 2000), including those suffering from Alzheimer disease and related dementias. This responsibility of care largely falls on the shoulders of wives, daughters and daughters-in-law (Aronson, 1998), and due to the unwavering socially ingrained expectations of women as caregivers, this appears likely to remain (Hooyman & Gonyea, 1995). As applied to my study, this theory particularly speaks to the dependent variable of perceived stress which may be influenced or explained by the gender characteristics of my independent variables.

Contextual Fluidity. Contextual Fluidity is a model of helping in which the person who gives help is embedded in the same system as the person receiving help. Other practice theories focus on formal helping in which the helper is outside and objective to the caregiving system. Since informal caregivers work in the same system, a theory was needed that addressed how to provide help from within. This emerging practice theory founded by Nelson & McPherson (1985, 2003, 2004) grew out of the realization that there is a missing link in social work's current spectrum of practice theories. The positivist, problem-focused approaches to giving help perpetuates a hierarchical helping process. Contextual Fluidity acknowledges that equal partnerships between people giving and receiving help coupled with acknowledging the relevancy of the context of the person in need is essential for mutual understanding and a mutual helping system to be created (Nelson & McPherson, 2003). Trying to understand an individual outside of their context posits the inevitable outcome of not fully understanding them to the degree possible.

As applied to my study, this theory holds that one would expect the independent variables (support group characteristics, caregiver and care receiver characteristics, and additional outside support) to influence or explain the dependent variable (perceived stress) because the Contextual Fluidity theoretical framework emphasizes the need to understand someone by taking into account the various social and environmental factors which ultimately influence their experience. Investigating a range of factors which speaks to the various aspects of the informal care system compliments the driving force of the Contextual Fluidity theoretical framework.

Chapter 2

Review of the Literature

Introduction.

There is an extensive and growing body of literature that deals with different aspects of the Alzheimer disease experience. This literature includes research on various forms of support to meet the needs of those both providing and receiving care. One of the most favored caregiving interventions is the support group which enables caregivers to receive education, validation and reciprocation in a supportive environment. A variety of characteristics of support groups are explored in the literature to understand the caregiving experience at a broader level. A large emphasis is placed on caregiver characteristics (gender, age, type of caregiver, employment status, marital status), care receiver characteristics (living arrangements, stage of disease), while smaller emphasis has been placed on support group characteristics (length of support group attendance) and use of outside interventions (e.g., use of respite care).

On this later point there has been a considerable amount of attention given in the literature on the impact of respite care because it was perceived as a pivotal point in delaying institutionalization, and meeting the psychosocial needs of both those providing and receiving care. However, literature on respite care displays ambiguous findings in terms of its positive influence on any of its desired objectives. Despite these indefinite findings, growing evidence suggests that respite care is one piece of a complex puzzle which may potentially influence the caregiving experience. Additionally, multiple intervention strategies have been shown to decrease perceived levels of stress. Since utilization of support groups and respite care falls under the category as a multiple intervention, this study initially placed more emphasis on the connection between support group attendance and utilization of respite care justifying the in depth literature presented on this formal service. Nonetheless, this study supports the research findings that respite care is an underutilized service which is reflected in the current low utilization rates within the sample used in this study. Thus, while initially researched as a central feature to caregiving, it became necessary to explore respite care as only one of the array of independent variables related to caregiver stress. Looking into the multitude of factors which potentially influence the role of Alzheimer care helps to explain the overall caregiving experience to a greater degree.

Independent Variables.

This section briefly explains background information on support groups and is followed by a review of the literature as related to the following independent variables: support group characteristics (length of support group attendance), caregiver characteristics (gender, age, caregiver status, marital status, employment status), care receiver characteristics (stage of disease, living arrangements), and outside assistance (use of respite care, the influence of respite barriers, help from family and friends, perceived difficulty in asking for help when stressed, and self-care). The independent variables, age, caregiver status, and marital status are grouped together as a result of the clustering of these variables in the literature.

Support Groups Background Information.

Support groups were introduced in the late 1970's (Fuller, Evans, & Massam, 1979; Hausman, 1979; Silverman, Kahn, & Anderson, 1977). In response to the growing awareness of the stress associated with the role of Alzheimer caregiving, the support group intervention was adopted a decade later in 1986 by the Alzheimer Society of Canada. The literature confirms that caregiver support groups exist with the intent of lessening the degree of caregiver burden, of teaching valuable coping skills, of allowing the caregiver a break from caregiving duties, and of providing emotional and practical support (Biegal, Sales, & Schulz, 1991; Gonyea, 1989; Toseland & Rossiter, 1989; Toseland, Rossiter, & Labrecque, 1989). Although inconsistencies have been found in the effectiveness of support groups in terms of eliminating objective measures such as stress and depression, support groups have been found to be successful in helping caregivers gain awareness about what to expect as the disease progresses, how to seek out community resources and how to effectively manage their role as a caregiver. Furthermore, participation in a support group enables caregivers to increase their social networks and have the opportunity to experience reciprocation, validation and reassurance from other caregivers. These outcomes have special value in light of the fact that care receivers' ability to reciprocate becomes compromised due to the nature of the disease (Adler, Kuskowski, & Mortimer, 1995). Alzheimer support groups comprise a significant portion of support groups that are offered to caregivers due to the growing number of people who are faced with the devastating and complex impacts of this disease (Gonyea, 1989, 1990).

Support groups are rated quite highly by caregivers that attend them (Gonyea, 1989; Gonyea, 1990; Gonyea & Silverstein, 1991; Green & Monahan, 1987; Green & Monahan, 1989; Haley, 1989; Toseland & Rossiter, 1989; Toseland, Rossiter, & Labrecque, 1989) but objective measures have not shown any consistent psychological benefits as measured by standardized tools (Haley, Brown, & Levine, 1987; Lazarus et al, 1981). In a study by Toseland & Rossiter (1989), fifty-six participants are randomly assigned to experimental or control group conditions.

Findings conclude that there is no significant difference on support group attendance on perceived burden. However, studies by Zanetti, Metitieri, Bianchetti, & Trabucchi (1998), and Ostwald et al (1999), demonstrate significant decreases in perceived stress when compared to matched controls. Reasons for these mixed findings as indicated by Smith et al (1991) may be that the objectives of these groups may not coincide with caregiver needs. Despite the appropriateness of content, Cuijpers, Hosman, & Munnichs, (1996) outline that support groups tend to be more effective for caregivers who are caring for care receivers who display signs of apathy and reside in long-term care. Additionally, in a study by Garity (1997) which compares stress levels among male and female support group members, female caregivers experience more burden and personal strains when compared to male support group members.

Attendees of support groups include caregivers of institutionalized and non institutionalized elderly and of care recipients who are deceased. It has been a common misconception that the negative consequences of caregiving diminish following institutionalization or death of the care recipient (McCarty, 1996). Caregivers usually remain involved in the care of their loved ones following institutionalization (Jensen, 2001). A process of adjustment takes places following institutionalization of the care recipient and many issues may surface such as guilt, grief, depression, and anxiety around the quality of care that the care receiver is getting. This is supported in a study by Zarit & Whitlatch (1992) and Beck (1998). Following the institutionalization of care receivers, caregivers feel a decrease in overload and tension and increases in well being; however, other stress related symptoms remain unchanged. Consequently, caregivers commonly continue to feel the stressful effects of there role regardless of institutionalization of the care receiver. In addition, following the death of a care receiver, caregivers may reflect on their role as a care provider and may need further support as they undergo the grieving and reflection process (Petronela-Juozapavicius & Weber, 2001). Following the death of the care receiver, caregivers have been shown to display an increase in well-being (McGartland Rubio et al, 2001), or to show higher levels of depression when compared to current caregivers (Bodnar & Kiecolt-Glaser, 1994). Consequently, many other factors potentially influence the post-caregiving experience and need to be studied further in future investigations.

Support Group Characteristics.

Length of Support Group Attendance. Gonyea & Silverstein (1991) introduce the connection between characteristics of support groups and formal service utilization among Alzheimer caregivers. One of these support group characteristics is length of support group attendance. These authors compare 301 Alzheimer Disease families who attend support groups with seventy-five non-support group member controls. Their findings conclude that caregivers who have been attending support groups for a longer period of time use more formal services. However, their study did not look at the linkage between length of support group attendance on psychological measures. As a result, it is the work of Gonyea and Silverstein (1991) that influenced the inclusion of psychological measures as a support group characteristic in this present study. Specifically, this present study takes Gonyea & Silverstein's (1991) findings one step further and looks at the relationship between length of support group attendance and perceived levels of stress among caregivers.

Another convincing argument for the inclusion of length of support group attendance as an independent variable arises from the high degree of variability of both content and type of Alzheimer support groups. As a result, length of support group attendance turns out to be one feature of support groups that is common to all regardless of content and type.

Caregiver Characteristics.

Gender. Although the twenty-first century is marked by a continued emphasis on the gained independence of women, the earlier socialized trends are still strongly imbedded in the North American culture. Although these socializing influences may not be as visible, they still have a substantive effect on the population of female informal caregivers. Female spouses and adult daughters of those in need most often provide care (Max, Webber, & Fox, 1995; Rice et al, 1993; Roberts et al, 1999). Although males are increasingly taking on the caregiving role, females still largely outnumber males in the subpopulation of informal caregivers since providing unpaid care to those in need is still viewed as “women’s work” (Stoller, 1993). When comparisons have been made, women and men tend to have different caregiving experiences. For example, female caregivers are more likely to experience stress in their role as care providers (Bass et al, 1994; Biegel, Sales & Schulz, 1991; George & Gwyther, 1986; Pruchno & Resch, 1989; Schulz et al, 1993; Barusch & Spaid, 1989). Furthermore, female caregivers are less likely to seek help unless they feel they are able to reciprocate (Logsdon & Robinson, 2000; Belle, 1982). An ethics of care as outlined by Henderson & Allen (1991), explains how the psychological development of women influences the caregiving experience for females. Women are socialized to meet the needs of others and often define themselves through the happiness and health of their family. As a result, women may experience guilt if they try to meet their own needs before meeting the needs of others.

Additionally, Harrison & Neufeld (1996) propose that women generally want to avoid conflict within the family and consequently take over the caregiving role without challenging this gendered expectation. As a result, women may develop the perception that maintaining healthy relationships takes precedence over their personal needs (Harrison & Neufeld, 1996). Stemming from this, women as caregivers often try to meet other people's needs before meeting their own and do not feel entitled to leisure activities (Strang, 2001; Deem, 1986; Harrington, Dawson & Bolla, 1992).

The Clustered Characteristics: Age, Marital Status and Type of Caregiver. As caregivers age, their chances of acquiring their own chronic illnesses unavoidably increases making the act of caregiving much more challenging. According to the Canadian Study of Health and Aging (1994a), people with dementia are typically cared for by a spouse who are elderly themselves. As a result of this age factor, caregiving for a spouse tends to be much more difficult (Pruchno & Resch, 1989; Rankin, Haut, & Keefover, 1992). Due to advanced age, spousal caregivers may have poorer cognitive functioning (Caswell, et al, 2002), are more likely to be in poorer physical health and generally partake in fewer social activities (Barber & Pasley, 1995; Barnes et al, 1992; Cohen et al, 1990). This commonly leads to feelings of social isolation which potentially leads to increased feelings of stress (Antonucci, 1989; Shumaker & Brownell, 1984). Consequently, spousal caregivers are commonly referred to as the "hidden victims" of Alzheimer disease and related dementias (Zarit, Orr & Zarit, 1985). According to the Canadian Study of

Health and Aging (1994a), 69 percent of the spousal caregivers in this study do not make use of formal sources of support. This is of concern because studies indicate that social support goes hand in hand with improved physical health and well-being (Cohen & Willis, 1985; Pierce, Sarason & Sarason, 1996). Spouses generally receive minimal help from formal services and other family members (O'Byrant, Straw, & Meddaugh, 1990) leading to heightened difficulties in their role.

Besides spousal caregivers, the literature also outlines the role of adult children as caregivers. According to Gonyea (1995), it is this generation that is the most involved in maintaining contact and unity across generations. Adult children caregivers are more likely to be apart of the sandwich generation (looking after children and parents simultaneously), and fulfill multiple roles which may lead to role strain. According to Fitting et al (1984), younger caregivers are more likely to show signs of resentment and unhappiness than older caregivers. However, they are more likely to utilize services (McCabe et al, 1995) and institutionalize the care recipient when compared to spousal caregivers (McFall & Miller, 1992) which may potentially lead to decreases in stress. Nevertheless, in summary, caregiving can be stressful for spouses and adult children for a variety of both similar and different reasons.

Employment Status. Employment adds a twist into the already complex and busy role in which many caregivers find themselves involved. Whether or not employment eases or adds adversity to the caregiving role remains ambiguous in the literature. On one hand, caregivers who are employed often have to make sacrifices to fulfill caregiving duties. The results of an employee survey in 1989 indicates that in comparison to employed non-caregivers, employed caregivers miss 50 percent more days of work and are 40 percent more likely to state that caregiving interferes with their work in the formal sector (Scharlach & Boyd, 1989). This holds true in two recent profiles on Canadian caregivers by Statistics Canada. These reports on employed caregivers indicate that caregiving duties affect the caregivers work in the formal sector (Cranswick, 1997, Statistics Canada, 2002). As a result, the competing demands of employment and caregiving often interfere with each other (Aneshensel et al, 1995; Barling, MacEwen, Kelloway, & Higginbottom, 1994; Gignac, Kelloway, & Gottlieb, 1996; Gottlieb, Kelloway, & Fraboni, 1994; Neal, Chapman, Ingersoll-Dayton, & Emlen, 1993; Scharlach, 1994). Caregivers may even be forced to retire as a result of the competing demands of the workplace and informal caregiving duties.

On the other hand, various studies which have examined the impact of employment on caregiving duties indicate that employment does not have a direct or significant impact on aversive psychological symptoms (Dautzenberg et al, 2000; Edwards et al, 2002; Orodenker, 1990; Martire & Stephens, 2003; Lee, Walker & Shoup, 2001). Reasons for this are summarized by Martire & Stephens in their research on adult daughters who are employed and provide care to a parent in need. Findings conclude that holding these two roles can reap many benefits. For example, caregivers who have multiple roles may experience mental health benefits from having greater access to rewards attached to these roles leading to positive feelings from increased productivity. Coinciding with this perspective, in comparison to non-employed caregivers, some studies show that employed caregivers experience less caregiver strain and better emotional health (Brody et al, 1987; Giele, Mutschler, & Orodenker, 1987; Miller, 1989; Skaff & Pearlin, 1992; Stoller & Pugliesi, 1989).

As outlined by Edwards et al (2002), due to conflicting findings of the effects of employment on caregiving and the mental health of caregivers, it is safe to assume that all caregivers adapt differently to having multiple roles. A caregiver's experience in one role may carry over to the other role. Thus negative work experiences and lack of support from employers may lead to increased strain and role overload while caregiving and vice versa (Edwards et al, 2002; Martire & Stephens, 2003).

Since women occupy the majority of caregiving roles, the majority of studies which examine the effect of multiple roles involve the experience of women. Women's historical role of being sole care providers has carried to a lesser, yet still significant degree to the present. An increasing amount of women hold jobs in the formal sector; yet are still held responsible to provide unpaid care to family members in need (Joseph & Hallman, 1998). Research by Hooyman & Gonyea (1995) note that although the workplace has seen a dramatic increase in women, policies within the workplace has not changed along with this trend. For example, currently no policies exist which fully meet the demands of women who occupy both roles. Furthermore, employment does not significantly affect a daughter's assistance to a parent while it significantly decreases assistance from a son to his parent (Health Canada, Winter 1997-1998; Dautzenberg et al, 2000). This coincides with caregiving expectations in relation to gender as women are generally expected to provide care themselves while it is more socially acceptable for men to receive assistance with caregiving duties (Hooyman & Gonyea, 1995).

Care Receiver Characteristics.

Stage of the Disease. There is overwhelming evidence in the literature to support the hypothesis that the stage of the disease that the care receiver is in has an effect on the caregiver's experience. As Alzheimer disease progresses, a decrease in cognitive ability takes place which essentially leads to physical and behavioral changes among care receivers. While the early stage of Alzheimer disease is characterized by mild forgetfulness, poor concentration, mild coordination problems and difficulty making conversation, this becomes exasperated in the middle and late stages of the disease (Alzheimer Society of Canada, 2003b). The middle stage is generally characterized by an inability to recognize family and friends, disorientation of time and place, daily living impairments (impaired ability to eat, dress, etc, independently), restlessness, mood changes, and a change in appetite and sleep patterns (Alzheimer Society of Canada, 2003b). The later stage is characterized by a continued loss of cognitive and physical abilities to the point where the Alzheimer victim becomes immobile and unable to speak. As a result of progressive cognitive and behavioral changes, the care receiver becomes unable to display validation or reciprocation to the caregiver. Thus, the relationship between the caregiver and care receiver becomes increasingly unilateral leading to increased stress (Aneshensel, Pearlin, & Schuler, 1993). Needless to say, the impacts of the disease on those who give and receive care are devastating. Caregivers generally provide care to those with Alzheimer disease throughout a significant duration of the disease (Clyburn et al, 2000).

Although stress is experienced by caregivers who are caring for someone in the early stages of the disease, stress generally increases in the middle and late stages. Behavioral problems which characterize the middle and late stages of the disease are commonly associated with elevated stress levels and often leads to institutionalization of the care recipient (Swearer, 1994). Several studies support the notion that behavioral problems exhibited by care receivers lead to increases in stress (Baumgarten, 1989; Deimling & Bass, 1986; Eagles, Craig, & Rawlinson, 1987; George & Gwyther, 1896; Gilleard et al, 1984; Hamel et al, 1990; Kiecolt-Glaser et al, 1987; Poulshock & Deimling, 1984; Pruchno & Resch, 1989; Wilder, Teresi, & Bennett, 1983; Bedard et al, 1997; Chappell & Penning, 1996; Stuckey, Neundorfer, & Smyth, 1996; Irvin & Acton, 1997; Coen et al, 1997). For example, in a study by Chappell & Penning (1996) which examines specific behavioral problems of care recipients with dementia, the symptoms of aimlessness, aggressive behaviors, forgetfulness, and restlessness which are characteristic of the middle to late stages of Alzheimer disease are correlated with increased feelings of burden.

In addition to behavioral problems among care receivers, the caregivers perceived inability to handle these problems also leads to increased stress (Baumgarten, Battista, Infante-Rivard, Hanley, Becker, & Gauthier, 1992; Gallagher-Thompson, Brooks, Bilwise, Leader, & Yeasavage, 1992; Montgomery & Kosloski, 1994; O'Donnell, Drachman, Barnes, Peterson, Swearer, & Lew, 1992; Pruchno, Michaels, & Potashnik, 1990; Teri, Rabins, Whitehouse, Berg, Reisberg, Sunderlans, Eichelman, & Phelps, 1992; Winogrond, Firk, Kirsling, & Keyes, 1987; Winslow, 1997).

Living Arrangements. Although Alzheimer caregiving is a particularly taxing experience, the majority with this disease are cared for in the community. Among Canadian women and men aged sixty-five and over, only 7.3 percent and 3.7 percent respectively live in long-term care (Moore and Rosenberg, 2001). Hence, the majority of people who suffer from Alzheimer disease and related dementias continue to live in the community and are cared for by family members and friends (Jackson et al, 1991; Malonebeach & Zarit, 1991; Stone, Cafferata, & Sangl, 1987; Baumgarten et al, 1992; Kiecolt-Glaser et al, 1991). Overwhelming evidence indicates that caregivers who reside with the care recipient will experience more stress than care recipients who do not reside with the caregiver (Bass et al, 1994; Biegel, Sales & Schulz, 1991; George & Gwyther, 1986; Pruchno & Resch, 1989; Schulz et al, 1993; Aneshensel, Pearlin & Schuler, 1993; Zanetti et al, 1997; Zarit & Whitlach, 1992). In a population based study by Grafstrom et al (1992), it is hypothesized that dementia caregivers who live with the care receiver experience a high degree of stress and burden. Furthermore, Alzheimer caregivers who live with a care receiver who is in the later stages of Alzheimer disease experience more anxiety and depression when compared to the general population (Meyers, et al, 1984; Bland, Newman & Orm, 1988).

Nevertheless, the elderly commonly express the desire to "age in place", meaning they wish to remain in the community for as long as possible (Health Canada, 1997-1998; National Advisory Council on Aging, 1986). This includes the sub-population of Alzheimer care receivers (Schulz et al, 2002). Similarly, informal caregivers (spouses and adult children), express the desire to care for their loved ones in the community, only resorting to long-term care when all coping strategies have been exhausted. In the recent report by Health Canada (2002) on family caregivers, as few as nine percent of informal Canadian caregivers feel that their loved ones would be better cared for in an institution. Even at the breaking point, the step from community to institutionalized care is usually taken with undiminished reluctance (Brody, 1995; Wenger, Scott, & Seddon, 2002). Informal caregivers continue to provide care at home for as long as possible (Armstrong, 2000; Mittelman et al, 1996; Chenoweth & Spencer, 1986; Morycz, 1985), even when they are risking their own health and well-being (Deimling & Bass, 1986; George & Gwyther, 1986; Haley et al, 1987; Moritz, Kasl, & Berkinan, 1989). In fact, dementia caregivers are at an increased risk of acquiring serious mental health problems (Cuijpers, Clemens & Munnichs, 1996) as well as physical health problems (Petronela-Juozapavicius & Weber, 2001) such as sleep disorders, cardiovascular disease chronic fatigue and hypertension (Burns et al, 1996). Not surprisingly, caregivers report seeking medical care on a frequent basis (Draper et al, 1992; Kiecolt-Glaser, et al, 1991). In summary, although caregivers may want to continue to provide care at home, it appears to have a devastating effect on their mental and physical health and well-being.

The use of outside interventions.

Use of respite care. Respite care is a specialized program designed to allow caregivers to have a break while care receivers acquire supervised care. Respite care has the objectives of lessening the adverse consequences of care provision (Rosenheimer & Francis,1992). As identified by Gottlieb & Johnson (2000), respite may enable caregivers to stay in their role longer which may delay institutionalization (role endurance) or may be used as a stepping stone into institutionalized care (role-bridging).

Respite care generally falls into three categories: in-home respite, day programs and institutional respite care. Table 2.1 provides a summary of the literature on these three types of respite programs. This includes some of the pros and cons of each type of respite program along with information on caregiver utilization and preferences.

Table 2.1: Summary of Aspects of Different Types of Respite Care

Type of Respite Program	Description	Pros	Cons	Caregiver Utilization and Preference
In-Home Respite	A service in which health care workers, support workers, or respite volunteers provide basic nursing and personal care, housecleaning and/or visiting/supervision in the caregivers or care receivers home.	Caregivers do not have to worry about respite preparation and the effects of changing the environment on the care receiver. Hours may be predetermined by caregiver, providing more flexibility.	It is usually the most costly form of care and may not always be readily available.	Utilization is high compared to other forms of respite (Family Caregiver Alliance, 1997) Most preferred (Montgomery, 1988; Lawton, Brody, & Saperstein, 1989b; Roberts, Browne, & Denton, 1995; Ashworth 2000).

Day Programs	Care is provided in a designated facility where a combination of basic care, meals and activities are provided during designated hours during the day.	Ideal for caregivers who are working or need an extended break during the day. Set cost is generally lower than in-home or institutionalized respite.	Preparing care receiver for out-of- home care can be quite time consuming and take away from the respite experience (Berry, Zarit, & Rabatin, 1991).	Medium
Institutional Respite	Temporary "round the clock" care that is provided for a fixed period of time in long-term care facilities.	The fixed extended break that this care offers tends to relieve adverse psychological symptoms of caregivers during periods of respite (Larkin & Hopcroft, 1993;	Care receivers may show increased behavioral problems/agitation initially upon the return home (Aldrch & Menkoff, 1963; Lieberman, 1983; Hirsch et al, 1993).	Utilization is low (Canadian Study of Health and Aging Working Group, 1994a).

		Homer and Gilleard, 1994; Grasel, 1997).		

Respite care and support groups when used individually are identified as unsuccessful interventions in studies by Chappell et al (2001) and Brodaty et al (2003) respectively. This finding coupled with the conclusion that the mere availability of services does not guarantee utilization has given rise to the importance of providing a more comprehensive system of care (Lawton, Brody & Saperstein, 1989b; Strang & Haughey, 1999) comprised of multiple intervention strategies that aim to work through barriers to respite utilization. To date, various studies that integrate multiple intervention strategies are proving to be effective in achieving the desired outcome (Bourgeois, Schulz, & Burgio, 1996; Lawton, Brody, & Saperstein, 1989; Cox, 1997; Greene & Monahan, 1989; Haley, 1989; Mohide et al, 1990; Toseland, Labrecque, Goebel, & Whitney, 1992). Furthermore, multiple intervention strategies have been shown to decrease perceived levels of stress (Acton & Kang, 2001), improve caregiver quality of life, increase satisfaction with nursing care (Mohide, et al, 1990), and delay institutionalization (Mittelman, Ferris, Shulman, & Levine, 1996). Coupled with providing a comprehensive system of care is the need to provide a variety and flexible array of services. Providing services that foster diversity as opposed to offering care in an inflexible and rigid manner tends to be more effective in achieving the desired outcome (Chiverton & Caine, 1989; Lovett & Gallagher, 1988; Mittelman et al, 1996; Zarit, Anthony, & Boutselis, 1987). Zarit et al (1993) document that rigid and inflexible service provision may create more harm than having no services.

Barriers to Respite Care. Although caregivers identify the need for respite (Caserta et al, 1987; Mace, 1986) and rate the service quite positively, utilization rates are generally low (Canadian Study of Health and Aging Working Group, 1994a; Wenger, Scott, & Sendon, 2002; George, 1998; Gibson et al, 1996; Lawton, Brody, & Saperstein, 1989a; Oktay & Volland, 1990; Kosloski, Montgomery, & Youngbauer, 2001; Saperstein, 1988; Smyer & Chang, 1999; Caserta et al, 1987; Wright, 1993; Stone, Cafferata, & Sangl, 1987; Dorfman et al, 1998; Logan & Spitz, 1994; Malone Beach et al, 1992; McCabe et al, 1995; Winslow, 1997). As a result, reasons for low utilization of respite care have been explored extensively in the literature. An increasingly substantiated conclusion is that available services do not meet the diverse needs of the caregiving clientele (Middelman et al, 1993). Most literature focuses on the barriers that impinge on the utilization of such services. Some of these barriers have been identified as lack of knowledge of services, the negative feelings that accompany the mere contemplation of the use of services (e.g., feelings of guilt which may lead to difficulty in asking for help, worrying that the care receiver will not receive the care they need, refusal of the care receiver to use respite), lack of funds to afford the out-of-pocket costs that respite usually requires, and problems with accessibility of respite due to structural barriers (e.g., transportation problems, and government enforced "red tape"). In the present study the barriers that are examined are: lack of knowledge, guilt, and financial and other structural barriers.

Lack of Knowledge

To overcome the barrier of lack of knowledge, the literature almost exclusively examines this in terms of formal service providers educating informal caregivers about formal services. This is a top down approach which carries the assumption that educating caregivers is the key to increases in service utilization. Although, this appears to be true as indicated in the literature, this approach provides a much narrower window on the findings of the impact of knowledge about Alzheimer disease on the caregiving experience. This unilateral approach from formal to informal care does not allow Alzheimer caregivers to educate formal caregivers on appropriate practical services which may yield more benefits. Even though an emphasis on formal education is limited, the findings are still instructive in terms of types of formal care and the impact of education on Alzheimer caregivers.

For example, the literature emphasizes that dementia caregivers often lack information on available services (Della-Buono et al, 1999; McCabe et al, 1995). Properly educating caregivers on available services has been linked to increased service use (Roberts et al, 2000). According to Damon-Rodriguez et al (1998), being aware of available services strongly increases service use when compared to other factors such as health status or available finances.

Interventions that take place in the earlier stages of Alzheimer disease have been shown to be more effective in reducing adverse psychological symptoms among caregivers and delaying institutionalization of care receivers (Mittelman, Ferris, Shulman & Levine, 1996; Chu et al, 2000; Mohide, Pringle, & Streiner, 1990). For this reason, there is a need for caregivers to be educated at an early stage of the availability and benefits of using respite services (Lawton, Brody, & Saperstein, 1991). However, caregivers generally do not utilize respite until the later stages of their caregiving experience, when it is absolutely necessary such as following a crisis and/or emergency situation (Lawton, Brody & Saperstein, 1989a; Morgan et al, 2002; Fine & Thompson, 1993; Nankervis et al, 1997; Vetter et al, 1998). Unfortunately, respite is found to be less effective for addressing these acute situations and tends to be more effective before caregiving intensifies. In a study by Deimling (1991) that compares the effectiveness of respite between caregivers of stable and declining dementia patients, caregivers of stable dementia patient's exhibit decreased scores in the psychological symptoms of depression and strain and a decrease in health problems following the respite experience. As identified by Brodaty & Greshman (1992) in their study on temporary institutional respite, it is noted that respite needs to be offered early enough to have an effect but not so early as to decrease the morale of the person receiving it. This calls for the importance of providing innovative types of services tailored towards the specific stage and needs of the care receiver and caregiver.

One source of formal education that can occur at the early stages of the disease is from the primary care physician (the doctor who gives the probable diagnosis) to the caregiver and care receiver. Due to confidentiality, other types of formal service providers are seldom in the position to seek out caregivers to provide education on available services. However, primary care physicians are in a unique role as they are given the opportunity to educate caregivers during the beginning stages of the disease and throughout. Primary care physicians are typically the first formal service provider that caregivers come into contact. Thus, they have been referred to as the initial source of entry into the greater realm of available formal services (Kaye, Turner, Butler, Downey, & Cotton, 2003). It is up to physicians, when meeting with family caregivers, to educate them on the importance and availability of outside services and to make appropriate and timely referrals. However, recent research indicates that physicians themselves are often not aware of services that exist in their communities (Lubben & Damron-Rodriguez, 2003). Cummings & Jeste (1999) finds that physicians generally do not emphasize formal service use as part of treatment plans for those giving and receiving care. A study by Fortinsky (1998) concludes that physicians are most likely to refer dementia patients and their caregivers to long-term care and home health care agencies instead of other formal agencies such as Alzheimer support groups and respite care. In this study by Fortinsky (1998), the importance of following up with caregivers after an initial consultation is noted. Upon hearing the news of an Alzheimer diagnosis, caregivers and care receivers may experience a mix of emotions which may essentially make it difficult to retain information. When caregivers are experiencing stress, limited amounts of information can be retained at any one time (Kaye et al, 2003). Thus, proper follow-up and integration with formal service providers who can assess and educate caregivers on a continual basis may be better received. Information needs to be provided in an appropriate and timely manner, not necessarily at the time of diagnosis. The absence of receiving accurate information in a well-timed manner has been cited as one of the main reasons that caregivers do not seek outside assistance (Schofield, 1998).

Guilt

Caregivers often feel compelled to provide full time care for their loved ones and experience guilt at the mere contemplation of seeking assistance elsewhere. This is particularly evident among spousal caregivers. When compared to adult children caregivers, spouses are less likely to access services when needed and experience a greater degree of guilt when contemplating the use of services (Cotrell, 1996). For most, the act of providing informal care automatically occurs when needed without conscious awareness of the significance of this role or the sacrifices it entails. Informal care is strongly embedded through an ideology of familial obligation shaped by societal expectations and the political agenda of saving health care dollars.

Although the role of informal care is significant, caregivers often fail to see themselves as being notable in the spectrum of care and may undermine their significant contribution to society (Milligan, 2000). Since caregivers frequently act out of a sense of obligation, love, and duty; guilt and familial responsibility may prevent them from seeking formal services or feeling entitled to initiate the use of such services (Milligan, 2000). Thus, education which focuses on working through feelings of guilt, particularly with spousal caregivers, is imperative in order for respite to be utilized (Cotrell, 1996).

Financial and other structural barriers

Since respite care is generally an out-of –pocket service, caregivers may choose not to utilize these services due to expense. It is well documented that caregivers have expressed their concern over the cost of respite care (McCabe et al, 1995; Della-Buono et al, 1999; Liken & King, 1995; Mullan, 1993) and may hesitate to utilize such a service if they do not have sufficient resources to afford it (McCabe et al, 1995). In one particular study, the most frequently cited reason for the discontinuation of respite care is the expense of the service (Cotrell, 1996). Government subsidized support may be available for some caregivers who qualify based on income cut-off eligibility criteria, yet such benefits are usually quite meager at best. Depending on other aspects of eligibility such as of the care receiver's age and limitations due to chronic disabilities, a set number of government subsidized hours are usually available to meet basic survival needs through food delivery programs and in-home assistance with activities of daily living. However, in certain Ontario jurisdictions, long waiting lists and reduced funding has created a problem in meeting the needs of those who are eligible for these services. Long waiting lists have been associated with reduced satisfaction of services (Cryns et al, 1989; Townsend & Kosloski, 2002). Likewise, clients are more satisfied when services are readily available (Safran et al 1998). Services that are shadowed with structural barriers such as long waiting lists, confusing eligibility criteria and multiple steps that need to be taken before services are formally put into place creates a system of care that lacks user friendliness and inevitably creates a further deterrent to utilization. It has been noted that a flexible service that can be accessed quickly is essential particularly for caregivers that are employed (Cotrell, 1996). Additionally, in light of the fact that respite services are not usually accessed until an emergency/crisis situation occurs, having services available in a timely manner becomes increasingly important.

Assistance from family and friends. Lack of outside assistance and support is one of the predominant factors in shaping a stressful experience (Baumgarten, Battista, Infante-Rivard, Hanley, Becker, & Gauthier, 1992; Gallagher-Thompson, Brooks, Bilwise, Leader, & Yeasavage, 1992; Montgomery & Kosloski, 1994; O'Donnell, Drachman, Barnes, Peterson, Swearer, & Lew, 1992; Pruchno, Michaels, & Potashnik, 1990; Teri, Rabins, Whitehouse, Berg, Reisberg, Sunderlans, Eichelman, & Phelps, 1992; Winogrond, Firk, Kirsling, & Keyes, 1987; Winslow, 1997). Likewise, social support has been shown to decrease adverse psychological symptoms such as stress. Specifically, lack of assistance from family and friends has been shown to contribute to stress among caregivers (Clyburn, 2000). Since care is generally provided by one person as opposed to a network of people, lack of understanding from other family members who pay sporadic visits commonly do not understand a caregivers experience let alone there feelings of accumulated stress (Cummings, 1996). Evidence in the literature notes that having other individuals available to provide support helps caregivers to cope more effectively with stress (Hobfoll & London, 1986; Hobfoll & Walfisch, 1984; Collijn, Appels, & Nijhuis, 1995). In a study by Franks & Stephens (1996), sixty-four percent of the women in this study received assistance from their spouses which helped to protect them from the negative impacts of caregiver stress.

Difficulty Asking for Help. The difficulty that caregivers have in asking for help gives rise to the importance of educating caregivers (Petronela et al, 2001) about how to access outside sources of help and to deepen their awareness around their entitlement to such help. Whether it is seeking out formal services in the form of support groups or respite care, seeking out informal help through family and friends, or engaging in self-care strategies (exercising, spending time with other family and friends, etc), caregivers need to understand that by not seeking help the adverse consequences of caregiving will take their toll. Thus, timely information and emotional support is essential to educate caregivers on the benefits of engaging in help through informal and formal services (Winslow, 2003). In a study by Juozapavicius & Weber (2001), which examines post Alzheimer caregivers, the most widely given piece of advice that caregivers wish to pass on to other caregivers was to seek help as soon as possible. Similarly, in a study by Bruce et al (2002) many of the caregivers wish that they had utilized formal support services earlier. Caregivers often do not recognize themselves as a client and accordingly may not view themselves as someone who can use formal services to ease the stress that their role will likely bring. Receiving information at an appropriate pace will help caregivers and care receivers adjust to their role, become aware of what to expect and most importantly know that help is available and accessible.

Due to the stigma that is attached to an Alzheimer disease diagnosis, caregivers may try to protect themselves and the one they care for by isolating themselves from others and potential sources of support (Bedard et al, 1997). Caregivers may also avoid service use due to their own preferences or the preferences of the person for which they care. Caregivers often worry about the quality of care that their loved one will receive (Winslow, 2003; Della-Buono et al, 1999); while care receivers themselves may resist the use of such services.

A study by Rapp et el (1998), which looks at social resourcefulness (ability to seek out and maintain supportive relationships) and its effect on the dementia caregiving experience), found that help seeking is strongly associated with actual receipt of support (Dunkel-Schetter et al, 1987; Hobfoll & Lerman, 1988). Significant relationships were found between social support and depression, quality of life, perceived health status and perceived benefits from caregiving (Rapp et al, 1998). However, when compared to noncaregivers, caregivers are less likely to seek out or enjoy the benefits of social support (Kiecolt-Glaser et al, 1991). Thus, lack of support often leads to adverse caregiving outcomes such as depression and stress.

Self-Care. Self-care practices were not strongly promoted until the 1980's when individuals were encouraged to take responsibility for their own health through proper nutrition, exercise and social involvement. During this time, the attempt at dismantling the harsh stereotypes against elderly people began to take place, which was promoted through healthy aging campaigns and the creation of community wellness centers for senior citizens. Providing this altruistic, yet demanding role of informal caregiving, often leads to compromised physical and mental health among caregivers. It frequently causes caregivers to neglect their own health as they try to fulfill the needs of the person requiring care.

Self-care is identified as effective in containing health care costs and decreasing psychological and physical deterioration (Morrongiello & Gottlieb, 2000). In fact, physical health problems such as sleep disorders, anxiety, chronic fatigue, hypertension and cardiovascular disease result from caregiving (Burns et al, 1996) as this role frequently prevents caregivers from meeting their own health needs through, proper rest, exercise and a well-balanced diet (Petronela-Juozapavicius & Weber, 2001).

Self-care practices and views among caregivers are not heavily documented in the caregiving literature; however it is a topic of interest that seems to be developing as shown in recently published studies. Acton (2002) through her study that compares self-care practices among caregivers and non-caregivers defines self-care as "those actions persons take to improve health, maintain optimal functioning, and increase general well-being." Examples of self-care activities are exercising regularly, getting enough rest, eating nutritiously, and any other activities that lead to a healthy mind, body and spirit (e.g., reading, traveling, meditating, etc). In this study by Acton (2002), family caregivers scored significantly lower on views of the importance of self-care, self-care behaviors, interpersonal relationships, stress management, total health promotion actions, physical activity, spiritual growth, hours of sleep, self efficacy for self-care, and health responsibility when compared to matched non-caregiver controls (Acton, 2002). Alzheimer care recipients need assistance with activities of daily living (eating, bathing, dressing, etc.,) which has been correlated to compromised physical exercise and lack of rest (Burton, et al, 1997) which essentially leads to heightened strain, burden (Shaw et al, 1997; Sisk, 2000) and health neglect (Wright, 1997). Additionally, caregivers who are looking after a care recipient who exhibits behavioral disturbances experience increased amounts of stress and are less likely to look after their health needs (Shaw et al, 1997). When levels of stress become intensified, psychological disturbances such as feelings of hopelessness, a decrease in general well-being and suppression of the immune system can occur (Wilcox, 1999; Wykle, 1994). Alzheimer caregivers tend to experience social isolation, which is also correlated with a decrease in self-care practices (Kaplan, et al, 1987).

As a result, research points to the conclusion that partaking in self-care strategies can potentially lead to increased quality of life and less aversive psychological symptoms in caregivers. From a policy perspective, promoting self-care strategies appears to help to increase caregiver longevity which will lead to decreases in institutionalization and a healthier population of informal caregivers. As noted expressed by Lefley (1987), "Caregiving for one group at the expense of another can scarcely be considered a desirable mental health objective." Initiatives on this policy issue need further research.

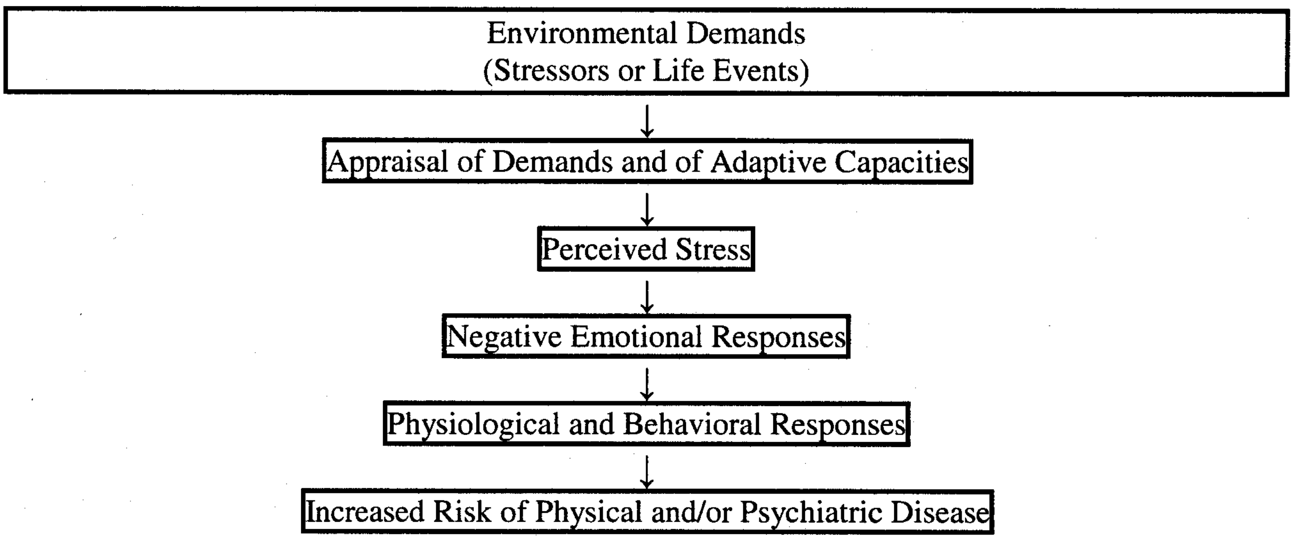
Dependent Variable.

Perceived Stress.

This section examines the dependent variable perceived stress. Although informal caregiving can be characterized by love and loyalty resulting from a combination of familial obligation and altruistic drive to provide for the person in need, the adverse consequences of providing this type of care is generally experienced and is heavily documented in the literature. The high levels of stress experienced by Alzheimer caregivers is emphasized in several studies (Vitaliano, Russo, Young, Becker, & Maiuro, 1991; Schulz, Visitainer, & Williamson, 1990; Wright, Clipp, & George, 1993; Gilhooly, 1994; Motenko, 1989; Novak & Guest, 1989; Gubrium & Lynott, 1987; Bonnel, 1996; George & Gwyther, 1986; Skaff & Pearlin, 1992; Zarit, Todd, & Zarit, 1986; Knight, Lutzky, & Macofsky-Urban, 1993; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Zarit, Gaugler, & Jarrott, 1999). Several factors are associated with the degree of stress a caregiver will experience. Caregiving characteristics (gender, age, marital status, employment status and relationship to the care receiver), care receiver characteristics (stage of disease and living arrangements) and outside interventions (use of respite care, help from family and friends, and engagement in self-care practices) are some of the factors that will likely influence the degree of stress experienced by caregivers. Due to the care receivers gradual loss of memory, deterioration of communication skills (e.g., repetitive questioning, loss of meaningful conversation, etc), and an increase in behavioral disturbances (e.g., wandering, agitation, etc), caregiver stress becomes exacerbated in comparison to caring for someone who is cognitively intact but has physical ailments (Chappell, Reid, & Dow, 2001). The inability of care receivers to reciprocate and/or verbalize appreciation to their caregiver adds to the complexity of this role.

Figure 2.2 adapts Cohen, Kessler & Gordon's (1995) heuristic model of stress to outline the process of stress from a biological, environmental and psychological perspective and how it impacts on the person experiencing it. From their perspective, stress begins with an environmental demand that is identified as a stressor or life event. Caring for a family member or friend with Alzheimer disease tends to be a taxing experience, falling under this category of a "stressor." For example, when the caregiver feels that they are struggling to meet the needs of the person that they are caring for, a negative appraisal of their coping strategies occurs. This ultimately leads to the caregivers "perceived stress." As noted by Reinhard, Rosswurm, & Robinson (2000), when the role of care is accompanied by a lack of sufficient resources, the result is stress. The appraisal of stress may be accompanied by feelings of depression, social isolation, decreased well-being, feelings of helplessness and so forth. These symptoms often lead to compromised and deteriorated objective and subjective measures of health. This model is not unilateral and may change as a result of intervention and outside social support, which may enable caregivers to increase adaptive capacities and effectively deal with negative emotional responses.

Figure 2.1: Heuristic Model of Stress



As indicated by the heuristic model of stress, the symptom of stress essentially has an impact on one's physical and mental health and well-being. Due to these unfavorable stress outcomes, it becomes increasingly important to understand the needs of populations who experience stress due to role demands. Alzheimer caregivers play a vital role in the provision of homecare yet suffer the many adversities of fulfilling this role. Thus understanding the various factors which influence their experience is essential to meeting the needs of this population who are of such value to the Canadian health care system.

Chapter 3

Methodology

Introduction.

The primary goal of this quantitative study is to assess levels of perceived stress among support group members by accounting for factors which potentially influence a caregiver's level of stress. The association is examined between perceived levels of stress and support group characteristics (length of support group attendance), care receiver characteristics (stage of the disease, living arrangements), caregiver characteristics (gender, age, marital status, employment status, relationship to the care recipient), use of outside help (utilization of respite care, barriers to respite care, levels of self-care, assistance from family and friends, and perceived difficulty in asking for help) and the connection to perceived levels of stress is examined.

Sample.

The population for this sample is Alzheimer caregivers who attend support groups. As this population cannot be readily identified, this study chooses to use caregivers who belong to support groups of the Alzheimer Society as a sampling frame. This sampling frame is further narrowed to the six Alzheimer Society sites in Northern Ontario (Thunder Bay, Kenora, Sudbury, Timmins, North Bay and Sault Ste. Marie). From this Northern Ontario sampling frame, the sample is comprised of all Alzheimer caregivers who were currently attending support groups during the time frame of June to October of 2003. This sample, as indicated by the staff of these sites, is 143 caregivers.

A non-random sample was used as all support group attendees who attended the support groups offered by the Alzheimer Society in Northern Ontario during the time frame of June-October of 2003 were given the option of filling out the survey. The staff at these six sites requested, in total, one hundred and forty-three surveys. From these requested surveys, ninety-six surveys were actually distributed to Alzheimer support group members. Thirty-four caregivers completed and mailed the surveys back. One survey was excluded as the caregiver did not match the required eligibility criteria to fill out the survey.

Procedure.

Ethics Review

Once the thesis committee approved the proposal for the study, an application was prepared for ethics review by the Lakehead University Research Ethics Board. This approval was received on February 5, 2003. A copy is included in Appendix A. The cover letter outlining the purpose of the survey as well as the inherent risk factors and confidentiality principles can be found in Appendix B. The following two instruments were also given to the Ethics Committee:

- A self-designed twenty-six item survey comprised of closed ended questions on caregiver and care receiver demographics, outside assistance through respite services, assistance from family and friends, self-care practices and open ended questions on factors leading to stress, and service suggestions for the future (Appendix C).

- The four-item version of Cohen's *Perceived Stress Scale* (Cohen, Kamarck, & Mermelstein, 1983) which consists of questions that pertain to one's view of how stressful they perceive their life to be over the span of the last month. (Appendix D).

Pre-testing the Survey Instrument

This original twenty-six item survey was reviewed and modified many times by myself and my supervisor. Included in this twenty-six item survey is the four-item version of Cohen's Perceived Stress Scale. A penultimate draft was sent to each of the six Northern Ontario Alzheimer Society sites where some combination of the Executive Director, Family Support Coordinator and/or Support Group Leader(s) agreed to critique the self-designed survey. In addition, each site agreed to recruit one caregiver to actually fill out the survey and provide commentary on the readability and relevance of the questions for caregivers who attend support groups. The feedback received was extremely valuable in making last minute adjustments to the survey.

Focus Group

Besides getting the feedback from the staff and caregivers, the survey was also improved by meeting face to face with caregiver support group members at one of the Northern Ontario sites.

In summary, from the feedback from these three sources- Alzheimer Society staff, Alzheimer caregivers who attend support groups and a face to face meeting with four caregivers at one of these sites- the survey was finalized.

Self-administered mail-out survey

As mentioned earlier, the staff at these Alzheimer Society sites indicated a potential sample size of 143. The following chart summarizes the mail-out and distribution numbers and response rates by all six Alzheimer Society sites. Of the 143 requested surveys, ninety-six were actually distributed to caregivers who currently attend these support groups. As indicated in Table 3.1 the overall response rate was thirty-five percent.

Table 3.1: Sample Response Rates

Location	Number of surveys requested	Number of surveys administered	Number of surveys returned	Response Rate (%)
Thunder Bay	39	10	6	60.0%
Kenora	4	4	3	75.0%
Sudbury	56	43	14	32.5%
North Bay	4	4	1	25.0%
Sault Ste. Marie	15	15	7	46.6%
Timmins	25	20	3	15.0%
Total	143	96	34	35.4%

Originally each site was provided with a prepaid envelope for returning the surveys. However, at the request of the Sudbury and North Bay sites, individualized envelopes with prepaid postage were mailed with the surveys to meet the convenience needs of the support group members. This may largely account for the increased response that was received from Sudbury relative to the other sites. Furthermore, in the original design, the staff at the six sites indicated that the caregivers would fill out these surveys at the support group meeting. Nonetheless, at the request and discretion of the caregivers at these meetings, support group leaders allowed caregivers to bring the surveys home to fill out. The researcher had no control over this change in plans. These details are noted to be instructive for future research; and may account for the overall response rate of 35.4 percent.

Research Design.

This study is carried out from a quantitative approach using a self-administered original questionnaire. The advantage of this survey methodology is that a larger sample can be reached at a relatively low cost. This survey includes twenty-six open and closed questions. Factors such as demographics, length of support group attendance, use of outside assistance through respite care, assistance from family and friends, frequency of self-care practices and perceived difficulty in asking for help when stressed were used to examine variables which influence the experience of Alzheimer support group members.

This survey incorporates Cohen's four-item Perceived Stress Scale as well as a question asking caregivers to identify their level of self-identified stress. In order to incorporate all five of these questions into one stress score, each question was weighted according to the findings of the literature. Particular references to the literature for each of these weighted questions are noted below. Due to the inconsistencies in the way the questions are worded in Cohen's Perceived Stress Scale, the response categories were scrutinized to account for any inconsistencies due to the nature of the way the questions were worded. After the responses of the stress questions were weighted, a total score out of ten was tallied for each caregiver, with ten being the maximum possible perceived stress score. In addition, the answer categories for each of these five questions were also weighted. This weighting was done on the basis of looking at the caregiver responses to each of these questions and weighting so as to compensate for misunderstandings in answering the questions. To further corroborate these weightings on the response categories, a random selection check for stress scores was done as illustrated in table 3.2. As noted by Cohen, Kamarck & Mermelstein (1983), the stress measured from these questions may result from a range of aspects other than caregiving. This does not affect the outcome as all caregivers are diverse and carry with them trials and tribulations stemming from other aspects of their lives. In support of a Contextual Fluidity approach, the fact that other aspects besides caregiving may be leading to the caregivers perceived stress does not make the findings of this study questionable. Rather, it supports the realization that a combination of factors lead to perceived stress among caregivers which may or may not specifically be related to caregiving duties.

Question 1:

In the last month, how often have you felt that you were unable to control the important things in your life?

Weighted Value of Question	Weighted Value of Answer Categories
20.0%	Never = 0 Almost Never = 1 Sometimes = 4 Fairly Often = 7 Very Often = 10

Question 1 was weighted at 20 percent because it portrays a strong sense of hopelessness which is significantly linked to chronic stress (Wilcox & King, 1999; Wykle, 1994).

Question 2:

In the last month, how often have you felt confident about your ability to handle your personal problems?

Weighted Value of Question	Weighted Value of Answer Categories
Weighted Value 15.0%	Never = 10 Almost Never = 8 Sometimes = 5 Fairly Often = 2 Very Often = 1

Question 2 was weighted at 15 percent because it is not as definitive as the first perceived stress question. Feeling unable to control something as opposed to feeling confident about doing something will likely measure stress to a lesser degree. Also, after thoroughly examining all of the perceived responses from the thirty-three surveys, some of the answers to this question did not quite fit with the other responses possibly due to a change in wording. For example, the first question uses the word unable while this question uses a different approach by asking if the caregiver is confident about their ability to handle personal problems. The caregiver respondents may have misread this as **not** being confident.

Question 3:

In the last month, how often have you felt that things were going your way?

Weighted Value	Weighted Value of Answer Categories
10.0%	Never = 10 Almost Never = 8 Sometimes = 4 Fairly Often = 2 Very Often = 1

Question 3 was weighted at 10 percent because it is not as significant as the other questions in terms of measuring stress. Life is full of trials and tribulations and although some people will say things have not been going their way it does not necessarily mean they are stressed. Also, after thoroughly reading the responses to the perceived stress answers from all thirty-three surveys, some of the answers to this question did not fit with the other responses justifying the weight of ten percent relative to the other questions.

Question 4:

In the last month, how often have you felt difficulties were piling so high that you could not overcome them?

Weighted Value of Question	Weighted Value of Answer Categories
15.0%	Never = 1 Almost Never = 4 Sometimes = 7 Fairly Often = 9 Very Often = 10

Question 4 was weighted at 15 percent as it also portrays a sense of hopelessness which is linked to chronic stress (Wilcox & King, 1999; Wykle, 1994).

Question 5

Rate your overall experience as a caregiver so far:

Answer Categories	Weighted Value of Question
Very Stressful = 10 Stressful = 8 Unstressful = 3 Very Unstressful = 1	40.0%

This question was weighted at 40 percent because it specifically asks the Alzheimer caregiver to rate their perceived level of stress. Although the Perceived Stress Scale is described as the most widely used tool to measure the perception of stress (Cohen, 1994), no identified caregiving studies used this particular stress scale. Additionally, in light of the possibility that measuring a response to a specific stressor is difficult (Gochman, 1979; Keating, 1979; Worchel, 1978; Worchel & Teddlie, 1976), this question asks in a straightforward manner how the caregiver rates their experience as a caregiver, to ensure that the perceived stress in relation to the caregiving experience is indeed measured.

Table 3.2: Random Selection Check for Stress Scores

Using the random selection process from SPSS version 11.5, five out of the total thirty-three cases were selected to test the consistency and validity of the questions measuring perceived stress.

Case	"In the last month, how often have you felt that you were unable to control the important things in your life?"	"In the last month, how often have you felt confident about your ability to handle your personal problems?"	"In the last month, how often have you felt that things were going your way?"	"In the last month, how often have you felt difficulties were piling so high that you could not overcome them?"	Self-Identified Stress	Total Stress Score
#2	Sometimes	Fairly Often	Sometimes	Fairly Often	Stressful	6.05
#5	Never	Very Often	Very Often	Never	Very Unstressful	0.80
#20	Very Often	Almost Never	Never	Very Often	Very Stressful	9.7
#26	Very Often	Very Often	Sometimes	Very Often	Very Stressful	8.05
#30	Sometimes	Fairly Often	Fairly Often	Fairly Often	Unstressful	3.85

SPSS randomly selected five cases from all thirty-three possible cases. The table indicates that each stress score coincides with each caregivers self-identified level of stress. For example, caregiver #20 scored 9.7 out of 10.0 for perceived stress and rated their caregiving experience to be 'very stressful' while caregiver #5 scored 0.80 out of 10.0 and rated their caregiving experience as 'very unstressful.' Some of the perceived stress questions (the first four questions) did not mesh well with other answers. For example, caregiver #26 stated that they felt unable to control the important things in their life 'very often' and also felt confident about their ability to handle their personal problems 'very often'. The answer for question #2 does not coincide with other answers, however, due to the weighting system, this answer did not appear to skew the overall perceived stress score. The same was evident for caregiver #30, as the answer to question #4 did not coincide with the other answers. However, similarly to caregiver #5 this did not appear to skew the overall perceived stress score.

Variables.

Dependent variable: perceived stress

Independent variables: support group characteristics (length of support group), victim characteristics (stage of disease, living arrangements), caregiver characteristics (gender, age, marital status, employment status, relationship to the care recipient), outside assistance (help from family and friends, self-care practices, use of respite care, barriers to respite care, perceived difficulty in asking for help when stressed).

Hypotheses.

All twelve hypotheses were divided into four independent variable groups (support group characteristics, care receiver characteristics, caregiver characteristics, and outside interventions).

- **Support group characteristics**

  →Caregivers who have been attending the Alzheimer support group for two years or more experience lower perceived stress than caregivers who have been attending the Alzheimer support group for less than two years.

- **Care receiver characteristics**

  →Caregiver support group members who are in the middle to late stages of Alzheimer disease experience higher perceived stress than caregiver support group members of care receiver's in the early stage of Alzheimer disease.

  →Caregiver support group members who live with the care receiver experience higher perceived stress than caregiver support group members who do not live with the care receiver.

- **Caregiver characteristics**

  →Spousal caregiver support group members experience higher perceived stress when compared to adult children caregiver support group members.

→Female caregiver support group members experience higher perceived stress when compared to male caregiver support group members.

→Caregiver support group members who are employed experience lower perceived stress compared to caregiver support group members who are not employed.

→The older the caregiver support group member the greater level of perceived stress reported.

- **Outside Interventions**

→Caregiver support group members who utilize respite care (day programs, institutional respite care, in-home respite/homecare) experience lower perceived stress than caregiver support group member who do not utilize respite care.

→Caregiver support group members who experience barriers to respite utilization experience higher perceived stress when compared to caregiver support group members who do experience barriers to respite utilization.

→Caregiver support group members who have increased or maintained practices of self-care experience lower perceived stress compared to caregiver support group members who have decreased the frequency of practices of self-care.

→Caregiver support group members who receive help from another family member (two or more times a week) experience lower perceived stress compared to caregiver support group members who do not receive help from another family member (two or more times a week).

→Caregiver support group members who have difficulty asking for help in a situation where they feel stressed experience higher perceived stress compared to caregiver support group members who do not have difficulty asking for help in a situation where they feel stressed.

Definitions.

- Dependent Variables

Caregiver Stress: the ten signs of caregiver stress as documented by the Alzheimer Awareness Campaign (1999).

→denial that the person has the disease
→anger at the person with the disease and others
→emotional sensititivity
→social withdrawal
→depression
→lack of sleep
→lack of concentration

→exhaustion

→anxiety

→an increase in health problems

Stress is one of the most commonly used psychological measures in caregiving studies and can be defined in objective or subjective terms. A subjective definition of stress can be defined as an individual's appraisal of the demands in his or her environment, while an objective definition takes on a more environmental perspective with the assumption that stress can be measured depending on the specific life event being experienced. The weakness of this latter definition is that it does not account for the unique personal attributes of individuals which inherently influence their stressful experience. For example, it is assumed that individuals who identify themselves as a primary Alzheimer disease caregiver will experience stress. However, many factors influence the degree of stress they will experience such as their relationship with the care recipient, level of outside support, employment status, gender, and age.

To further understand the subjectivity of caregiver stress, caregivers are asked to document through open-ended questions on the survey what contributes to their stress. Through closed ended questions, caregivers are asked to rate their perceived level of stress on a four-item Likert Scale ranging from *Very Unstressful* to *Very Stressful.* Both items are combined as a dependent variable of perceived stress.

- Independent Variables

Length of Support Group Attendance: how long that the caregiver has been attending the Alzheimer support group. This was divided into two groups: less than two years and two years or more.

Gender: the sex of the caregiver.

Age Group: the age of the caregiver. This was divided into two groups: sixty years and under and over sixty years of age.

Marital Status: whether the caregiver is married, single, divorced, widowed or other.

Employment Status: whether the caregiver is working full time or part time, is retired, not employed at this time, or other.

Caregiver Type: whether or not the caregiver is a spouse or an adult child to the person in need.

Living Arrangements: whether or not the care receiver lives with the caregiver.

Stage of disease: early or middle or late stage of Alzheimer disease. This was divided into three categories, early, middle/late and deceased. See Table 3.3 for a breakdown summary of the different signs of each stage of Alzheimer disease which is based on the findings of the Alzheimer Society of Canada (2003b).

Table 3.3: Stages of Alzheimer Disease

Stage	Signs
Early	→Mild forgetfulness →Poor concentration →Memory problems →In conversation, person has difficulty finding the right words and may be repetitive →Difficulty learning new things →Withdrawal from usual activities →Mild coordination problems →Mood changes (e.g., depression)
Middle	→Inability to recognize family and friends →Disorientation of time and place →Assistance needed with activities of daily living (bathing, dressing, using the washroom)

	→Restlessness (pacing, wandering) →Changes in appetite and sleep patterns →Continued mood changes (anxiety, depression, anger, suspiciousness, etc).
Late	→Loss of ability to communicate, remember, or function →Severe speaking difficulties (may completely lose ability to speak) →Unable to dress, bathe, etc. →May become bedridden →Severely disoriented

Respite care: a specialized program designed to allow caregivers to have a break while care recipients receive supervised care. Respite is generally available in the following three forms: adult day programs, in-home respite, and institutional respite care.

- An adult day program is a service that is provided outside of the home in a designated facility in which a combination of basic care, meals and activities are provided during the day.

- In home respite is a service in which health care workers, support workers or respite volunteers provide aid in the nature of nursing and personal care, housecleaning and/or visiting/supervision in the caregiver or care receivers home to meet the psychosocial and health related needs of care receivers. This is the most costly form of respite yet most preferred among those both providing and receiving care.

- Institutional respite care has been documented as the least preferred yet most ideal for caregivers who need a fixed and extended break for purposes of traveling, working, or catering to their own mental and physical health (e.g., hospital admission, surgery, etc). Institutional respite is temporary "round the clock" comprehensive care that is provided for a fixed period of time (e.g., a few days to a few months) in a designated facility (usually in long-term care facilities which hold designated respite beds).

Barriers to respite care: financial limitations, limited or no information about respite services, no interest in using respite services, lack of transportation to respite service, and respite services not available in home community.

Self-care practices: reading, napping, exercising, watching television, visiting friends and spending time with other family members. Frequency comparisons are made as caregivers are asked to document the difference in frequency of these activities before becoming a caregiver and at present (since they have become a caregiver).

Help from family and friends: receiving assistance with caregiving tasks from family and/or friends two or more times a week.

Perceived difficulty in asking for help when stressed- the self-identified level of difficulty that caregivers have when needing to seek help when feeling stressed.

Delimitations.

This study on Alzheimer caregivers who attend support group offered by the Alzheimer Society was delimited to active Alzheimer support group members between the months of May and October of 2003 who reside in Northern Ontario.

Limitations.

- Due to the sample size and response rate, all results (although some are significant) need to be interpreted with caution.

- Due to the sample size each independent variable was testing individually with the dependent variable. No other variables were controlled for while testing each independent variable. Each of the independent variables (as analyzed separately in relation to the dependent variable) cannot alone account for differences in levels of perceived stress among caregivers as substantiated by a contextual fluidity framework. Examining a combination of various variables is necessary to understand the various contributing factors to perceived stress among Alzheimer caregivers. As a result, using this research with a larger sample is necessary before any definitive conclusions can be drawn.

- When distributing the surveys, originally one extra envelope with prepaid postage was included with the mailed surveys, so the surveys could be returned in one envelope after completion. At the request of caregivers from two of the Northern Ontario sites, separate self-addressed envelopes along with each survey were sent to these sites to meet the convenience needs of the caregivers. As a result, this may have reflected the higher response rates from these sites relative to the other sites.

Chapter 4

Results

Overview.

The data for this survey study was analyzed using SPSS version 11.5. The total sample size was thirty-three; however, some questions were not answered by all participants. When a participant did not respond to a question, any changes in the sample size are in the corresponding tables which note the 'n' value referring to the number of caregivers who answered the question.

As previously mentioned, the twenty-six item self-designed survey examines levels of perceived stress among Alzheimer caregiver support group members. The independent variables support group characteristics (length of support group), caregiver characteristics (gender, age, marital status, employment status, relationship to the care recipient) and care receiver characteristics (stage of disease, living arrangements) and level of outside help (use of respite care, barriers to respite utilization, help from family and/or friends, self-care, and perceived difficulty in asking for help when feeling stressed) are incorporated into the study as factors that potentially influence the level of perceived stress among Alzheimer support group members.

Support Group Characteristics

Length of support group was divided into two groups (less than two years and two years or more). From these two categories 54.8 percent of the caregivers had been attending the Alzheimer support group for two years or more while 45.2 percent had been attending for less than two years.

Caregiver Characteristics

This sample of thirty-three caregiver support group members consisted of 64 percent females and 36 percent males. The average age of these caregivers was sixty-four for both sexes with 70 percent of the caregivers over the age of sixty, and 30 percent sixty years of age and under. Most caregivers identified themselves as adult child caregivers (58.1 percent) which was closely followed by caregivers who were looking after a spouse (41.9 percent). The majority of the caregivers were married (78.8 percent), while a small portion were widowed (12.1%), divorced (6.1%) or single (3.0%). An overwhelming majority of the caregivers were retired (66.7 percent), while a smaller portion were employed full time (15.2 percent), part time (6.1 percent), not employed (6.1 percent) or other (6.1 percent). When grouped together, employed caregivers constituted 27.3 percent of the sample while non-employed caregivers constituted 72.7 percent of the sample.

For a complete list of caregiver characteristics see Appendix E.

Care Receiver Characteristics

All care receivers were identified as having Alzheimer Disease with the exception of one care receiver who suffered from a related dementia (organic brain disorder). An accumulated 37.5 percent of care receivers lived with the caregiver while 62.5 percent did not live with the care receiver. The open-ended responses indicated some of the specific living arrangements of care receivers. When broken down into sub-categories, care receivers who lived with their caregivers constituted 33.3 percent of the sample while 33.3 percent lived in long-term care. A smaller portion of the care receivers had other living arrangements with 6.1 percent of the care receivers living in the community but separate from the caregiver, while the residence of 15.2 percent of the care receivers remained unknown. The majority of care receivers were in the middle and late stages of Alzheimer disease and related dementias (62.5 percent) with 25 percent in the early stage. Deceased care receivers made up 13 percent of the sample.

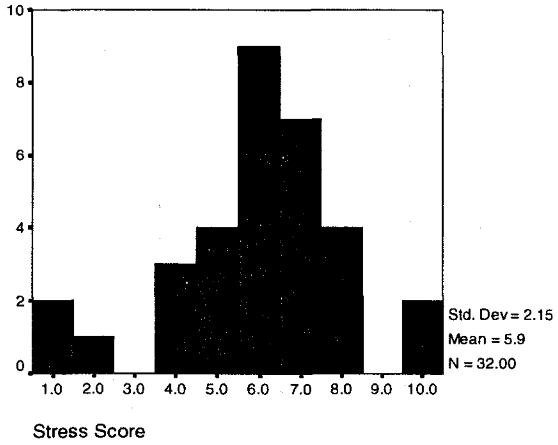
Use of Outside Support

In terms of outside support 51.6 percent of the sample indicated that they use or have used respite care, while 48.4 percent stated that they have never used respite. Current and former users of respite care were grouped together due to the small sample size. However only 9.7 percent of the caregivers were currently using respite care. The majority of caregivers did not identify any barriers to respite utilization (78.1 percent) while fewer caregivers identified barriers to respite care (21.9 percent). The majority of caregivers (71 percent) did not receive help from family and friends two or more times a week while a smaller percentage (29 percent) of the caregivers did receive help from family and friends two or more times a week. When asked to rate the question “I have difficulty asking for help in a situation where I feel stressed”, the majority of the caregivers answered in the affirmative, with 23.3 percent indicating that they ‘strongly agree’, and 46.7 percent indicating that they ‘agree’. A smaller percentage of caregivers did not agree with this statement with 16.7 percent stating that they ‘disagree’ and 13.3 percent stating that they ‘strongly disagree’. When measuring the frequency of self-care before becoming a caregiver and since becoming a caregiver an even split in frequency was evident. Half of the sample (50 percent) maintained or increased self-care behaviors since becoming a caregiver while 50 percent decreased the frequency of self-care behavior.

In Figure 4.1 the findings from the dependent variable are discussed.

Figure 4.1 displays a cross tabulation bar chart of the dependent variable (perceived stress scores) among thirty-two Alzheimer caregiver support group members. One support group member did not answer the perceived stress questions on the survey. Results were continuous from 1 through 10 with 1 equaling caregiving as a very unstressful experience and 10 as a very stressful experience. Thus the higher the score, the higher the perceived stress of the Alzheimer caregiver support group member.

Figure 4.1: Perceived Stress among Alzheimer Caregivers



The mean stress score was 5.9, with the standard deviation of 2.15. Because the distribution is almost normal, the 68-95-99.7 rule tells us that there are about 68 percent of scores one standard deviation from the mean or between 3.75 and 8.05. Thus, the majority of caregivers have some degree of perceived stress in relation to their caregiving experience.

Table 4.1 summarizes a list of the level of significance for each of the independent variables which were analyzed using independent samples t-tests and One-Way ANNOVAS. Due to the sample size, significant correlations were flagged at the 10 percent, 5 percent and 1 percent levels.

Table 4.1: Summary of Significance among the Independent Variables

Independent Variable	**Significance**	**Test Used**
Length of support group attendance	0.816	Independent Samples T-Test
Caregiver Gender	0.021**	Independent Samples T-Test
Age Category	0.087*	Independent Samples T-Test
Marital Status	0.085*	One-Way ANOVA
Employment Status	0.59	Independent Samples T-Test
Type of Caregiver (adult child or spouse)	0.840	Independent Samples T-Test
Living Arrangements	0.777	Independent Samples T-Test
Stage of Disease	0.506	One-Way ANOVA
Use or Have Used Respite Care	0.156	Independent Samples T-Test
Have Experienced Barriers to Respite Utilization	0.428	Independent Samples T-Test
Perceived Difficulty in Asking for Help	0.069*	Kendall's Tau B Correlation
Regular Help from Family and Friends	0.160	Independent Samples T-Test
Self-Care Frequency	0.004***	Independent Samples T-Test

* = significant at the 10 percent level

** = significant at the 5 percent level

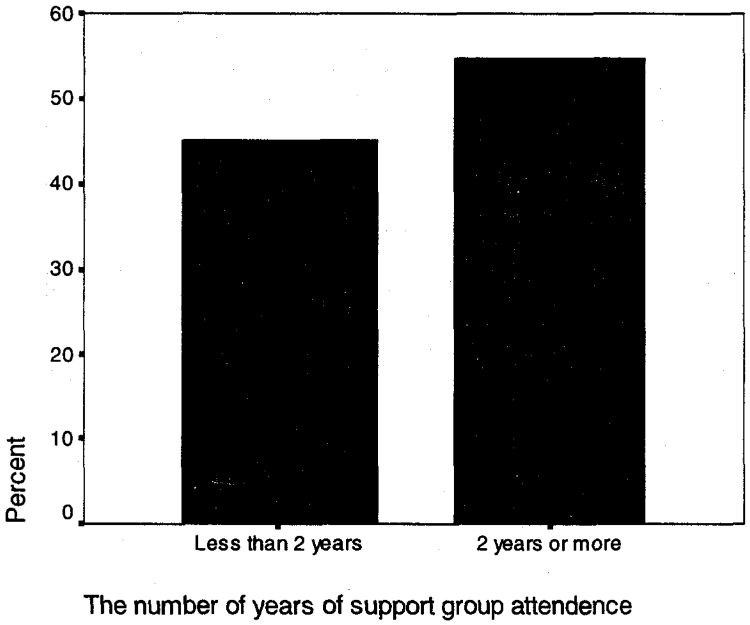
*** = significant at the 1 percent level

In summary significance at the 10 percent level was found for the independent variables age category, marital status, and perceived difficulty in asking for help when stressed. Significance at the 5 percent level was found for caregiver gender while significance at the 1 percent level was found for self-care frequency.

Number of Years of Support Group Attendance

Figure 4.2 displays a visual representation of length of support group attendance among the caregivers in this sample.

Figure 4.2: Number of Years of Support Group Attendance



The majority of the caregivers in this study have been attending the support group for two years or more (54.8%) while a slightly smaller percentage of caregivers (45.2%) have been attending the support group for less than two years.

An independent samples t-test was performed to test the significance of the mean perceived stress score and length of support group attendance. Table 4.2 displays the results of this test.

Table 4.2: Independent Samples T-Test for Perceived Stress Score and Length of Support Group Attendance

Group Statistics

	The number of years of support group attendance	N	Mean
Stress Score	Less than 2 years	14	5.8179
	2 years or more	17	5.6412

There was very little difference between the mean stress score of caregivers who had been attending a support group for less than two years with caregivers who had been attending a support group for two years or more. The mean stress score was slightly higher for caregivers who had been attending a support group for less than two years (5.81 out of 10.0). The mean stress score for caregivers who had been attending a support group for two years or more was slightly lower at 5.64 out of 10.0.

Independent Samples Test

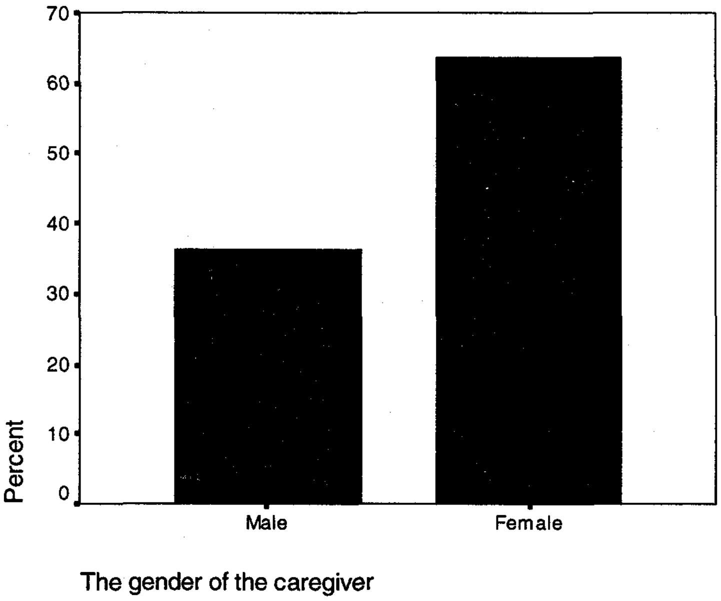
		Levene's Test for Equality of Variances		t-test for Equality of Means		
		F	Sig.	T	Df	Sig. (2-tailed)
Stress Score	Equal variances assumed	.071	.792	.235	29	**.816**
	Equal variances not assumed			.233	26.545	.818

The difference between variances was not significant; therefore, the t-test for independent samples of equal variances was used. No statistical significance was found between mean stress score and length of support group attendance.

Gender of the Caregivers

Figure 4.3 displays a visual representation of the gender differences in this sample of caregivers.

Figure 4.3: Gender of the Caregivers



The majority of caregiver support group members were female (64 percent) while male caregiver support group members constituted 36 percent of the sample.

An independent samples t-test was performed to test the significance of the mean stress scores between genders. Table 4.3 displays the results from this test.

Table 4.3: Independent Samples T-Test for Perceived Stress Score and Gender

Group Statistics

	The gender of the caregiver	N	Mean
Stress Score	Male	11	4.6636
	Female	21	6.4786

When compared to male caregivers, female caregivers were more likely to display higher scores of perceived stress. The mean stress score out of 10.0 for males was 4.66 while the mean stress score for women was significantly higher at 6.47.

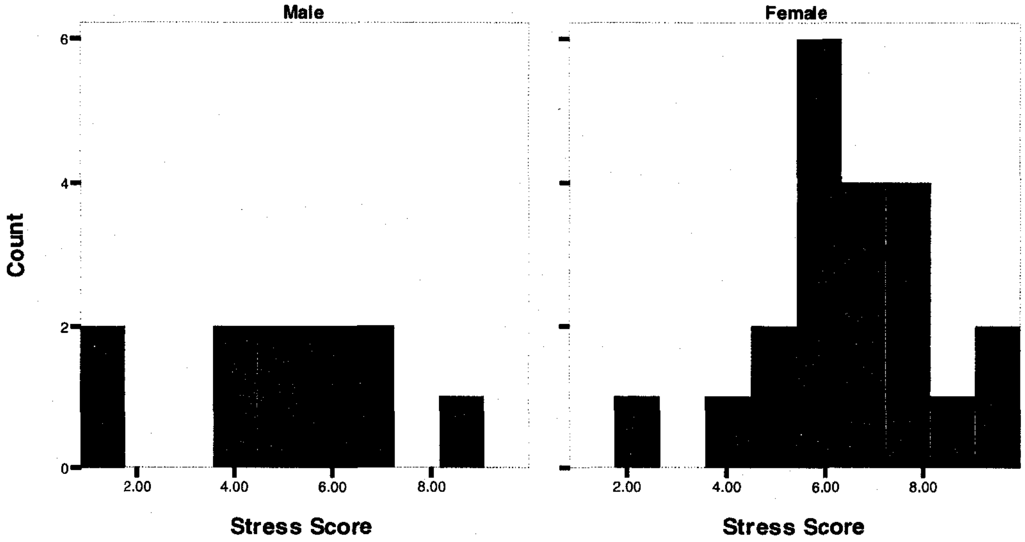
Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means		
		F	Sig.	t	Df	Sig. (2-tailed)
Stress Score	Equal variances assumed	.262	.613	-2.440	30	**.021**
	Equal variances not assumed			-2.288	17.176	.035

The difference between variances was not significant; therefore, the t-test for independent samples of equal variances was used. The difference between means was significant at the 0.05 level.

Figure 4.4 displays a visual representation of perceived stress scores among both genders

Figure 4.4: Perceived Stress Scores According to Gender

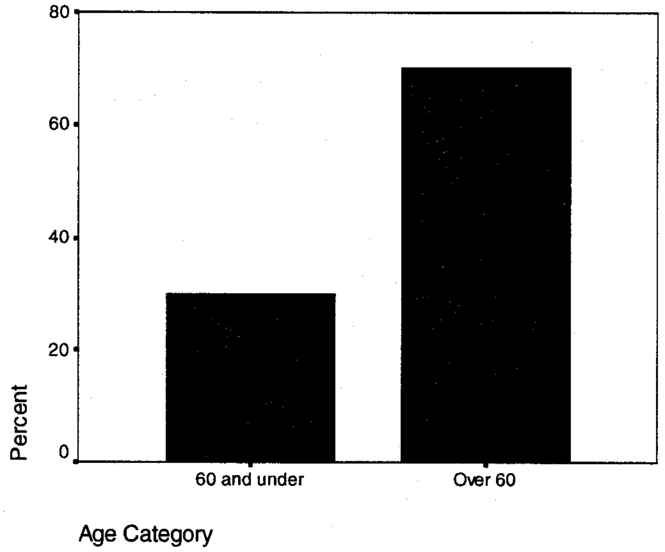


These graphs visually display the higher degrees of stress that female caregivers experience relative to male caregivers. While male caregivers displayed a wide range of perceived stress scores, females consistently displayed higher perceived stress levels.

Age Category of the Caregivers

Figure 4.5 displays a visual representation of the differences between two age groups in this sample.

Figure 4.5: Age Category of Caregivers



The ages of the caregivers were grouped into two categories (sixty years and under and over sixty years of age). Seventy percent of the caregivers were over sixty years of age while thirty percent were under sixty years of age. The average age of the caregivers was sixty-four.

An independent samples t-test was performed to test the significance of the mean perceived stress scores and age category. Table 4.4 displays the results of this test.

Table 4.4: Independent Samples T-Test for Perceived Stress Score and Age Category

Group Statistics

	Age category2	N	Mean
Stress Score	60 and under	9	6.9667
	Over 60	20	5.4225

Caregivers sixty years of age and under displayed a higher mean stress score of 6.96 out of 10.0, while caregivers over the age of sixty had a mean stress score of 5.42 out of 10.0, concluding that caregivers sixty years of age and under have a higher level of perceived stress than caregivers over the age of sixty.

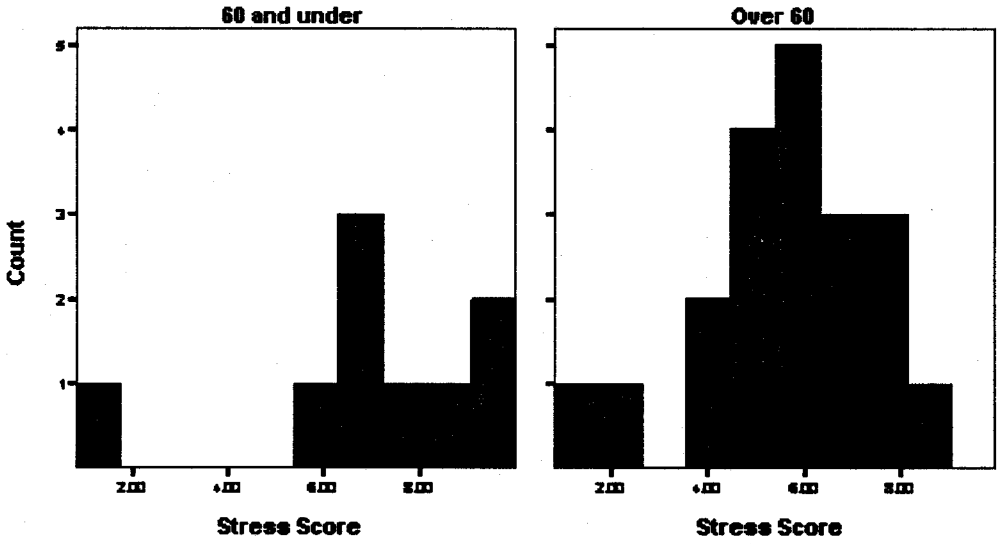
Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means		
		F	Sig.	T	Df	Sig. (2-tailed)
Stress Score	Equal variances assumed	.449	.508	1.778	27	.087
	Equal variances not assumed			1.551	11.680	.147

The difference between variances is not significant; therefore, the t-test for independent samples of equal variances was used. The difference between means is significant at the 0.10 level.

Figure 4.6 displays a visual representation of the perceived stress scores between the age groups (60 years and under and over 60 years).

Figure 4.6: Perceived Stress Scores According to Age Category

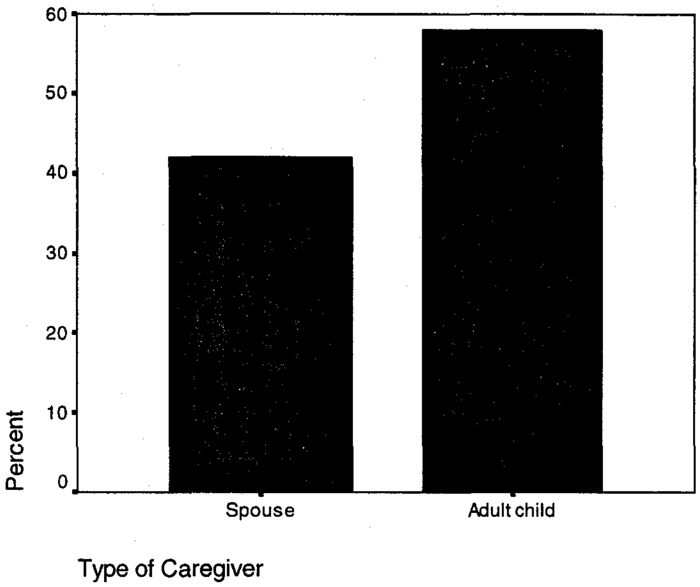


Although a greater number of caregiver were in the over sixty age category, caregivers who were sixty and under consistently displayed higher perceived stress scores.

Type of Caregiver (Adult Child or Spouse)

Figure 4.7 displays a visual representation between two types of caregivers (adult child and spouse).

Figure 4.7: Type of Caregiver



Of the caregiver support group members, 58.1 percent were looking after a parent in need, while 41.9% of caregiver support group members were looking after a spouse.

An independent samples t-test was performed to test the significance between the mean stress scores and type of caregiver (spouse or adult child). The results of this test are displayed in Table 4.5.

Table 4.5: Independent Samples T-Test for Perceived Stress Score and Type of Caregiver

Group Statistics

	Type of Caregiver	N	Mean
Stress Score	Spouse	13	5.8692
	Adult child	18	5.7222

The mean stress scores were very close when comparing spouses to adult children caregivers. The mean stress score for spousal caregivers was 5.86 out of 10.0 and 5.72 out of 10.0 for adult children caregivers.

Independent Samples Test

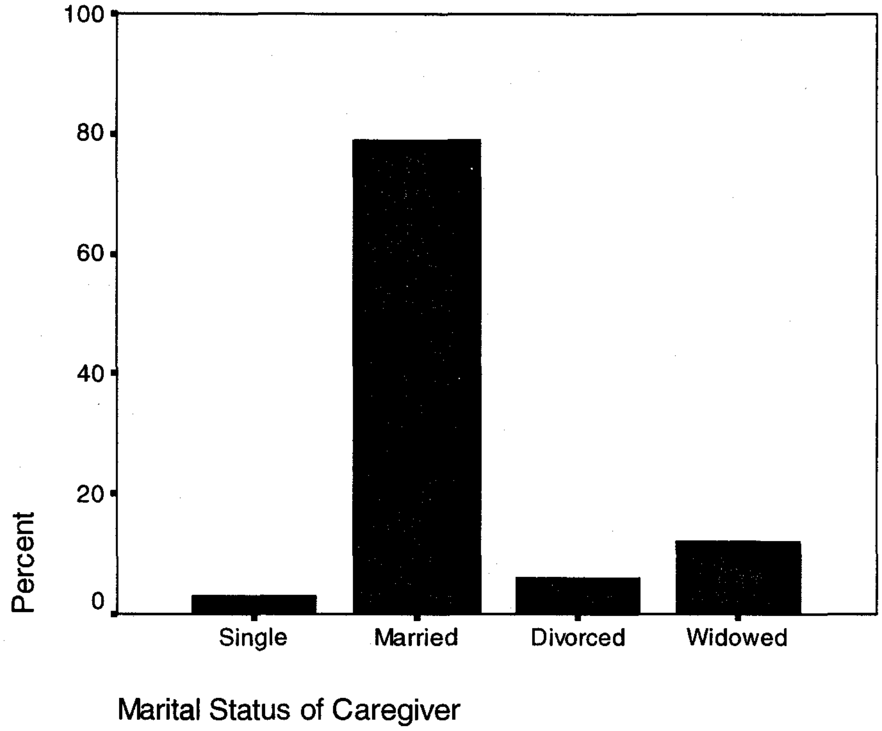
		Levene's Test for Equality of Variances		t-test for Equality of Means		
		F	Sig.	T	Df	Sig. (2-tailed)
Stress Score	Equal variances assumed	3.022	.093	.185	29	.855
	Equal variances not assumed			.204	26.605	.840

Equal variance was significant at the 0.10 percent level. As a result, t-test for equality of means under the category of equal variances not assumed was used. No significance was found between type of caregiver and perceived stress score.

Marital Status of the Caregivers

Figure 4.8 provides a visual representation of the marital status of the caregivers in this sample.

Figure 4.8: Marital Status of Caregivers



The majority of caregiver support group members were married (78.1%), followed by caregivers who were widowed (12.5%), divorced (6.3%) and single (3.1%).

To test for any significant linkages to stress, a One-Way ANOVA was performed to compare the mean stress score for all categories of marital status (single, married, divorced and widowed). Table 4.6 displays the results of this test.

Table 4.6: One-Way ANOVA for Perceived Stress Score and Marital Status

Descriptives

Stress Score

	N	Mean	95% Confidence Interval for Mean		Minimum	Maximum
			Lower Bound	Upper Bound		
Single	1	8.3000	.	.	8.30	8.30
Married	25	5.5380	4.6642	6.4118	.80	9.70
Divorced	2	9.1000	-2.3356	20.5356	8.20	10.00
Widowed	4	5.6000	3.6221	7.5779	4.50	6.75
Total	32	5.8547	5.0787	6.6307	.80	10.00

The mean stress score was highest for caregivers who were divorced (9.1 out of 10.0), followed by 8.3 out of 10.0 for single caregivers. The mean stress score for widowed caregivers was 5.60 and 5.53 for married caregivers. The 95 percent confidence interval for mean stress score was between 4.66 and 6.41 out of 10.0. The minimum stress score was 0.80 out of 10.0 and the maximum stress score was 9.70. Due to the small sample size, individuals who fell into the categories of single, divorced or widowed were minimal. Thus, these higher mean stress scores may be attributable to chance factors.

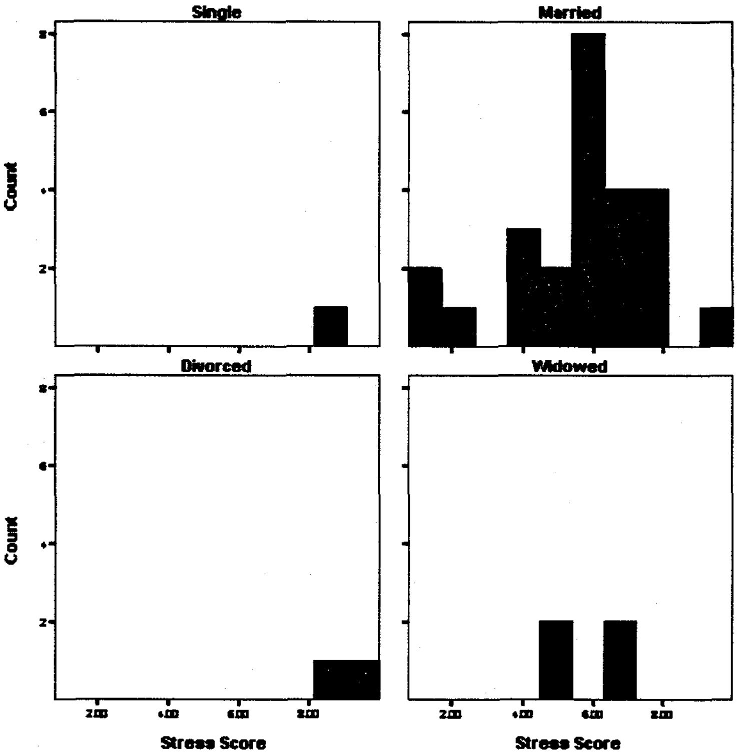
ANOVA

Stress Score

	Sum of Squares	Df	Mean Square	F	Sig.
Between Groups	29.810	3	9.937	2.445	.085
Within Groups	113.806	28	4.065		
Total	143.617	31			

Significance was found between marital status and perceived stress score at the 0.10 level. Figure 4.9 displays visual representations of perceived stress scores in relation to marital status.

Figure 4.9: Perceived Stress Scores According to Marital Status

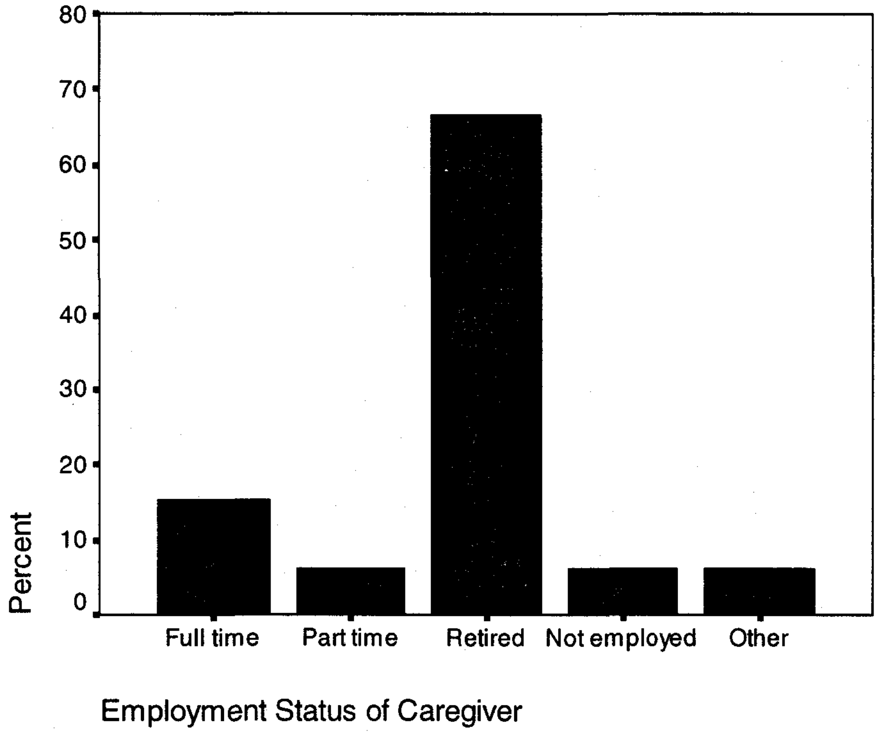


Although higher stress scores were displayed by caregivers who were single, divorced and widowed, very few caregivers are represented in these categories, thus a wider distribution of stress scores is evident for caregivers who are married possible due to the greater number of caregivers who fall into this category.

Employment Status of Caregivers

Figure 4.10 displays a visual representation of the employment status among caregivers in this sample.

Figure 4.10: Employment Status of Caregivers



The majority of the caregivers in this sample were retired (66.7 percent), followed by caregivers who were employed full time (15.2 percent), caregivers who worked part time, were not employed or fell into the "other" category each constituted 6.1 percent of the sample.

To test for significant linkages to stress, a One-Way ANOVA was performed to compare the mean stress scores for all categories of employment status (full time, part time, retired, not employed and other). Table 4.7 displays the results of the One-Way ANOVA test.

Table 4.7: One-Way ANOVA for Perceived Stress Score and Employment Status

Descriptives

Stress Score

	N	Mean	95% Confidence Interval for Mean		Minimum	Maximum
			Lower Bound	Upper Bound		
Full time	5	6.5400	2.2479	10.8321	.90	9.70
Part time	2	3.7000	-33.1480	40.5480	.80	6.60
Retired	21	5.5071	4.8596	6.1547	2.05	7.60
Not employed	2	7.6250	.3189	14.9311	7.05	8.20
Other	2	8.1750	-15.0138	31.3638	6.35	10.00
Total	32	5.8547	5.0787	6.6307	.80	10.00

Caregivers who fell into the “other category” had the highest mean perceived stress score of 8.15 out of 10.0 (these other categories were self-employed (rental landlord) and casual work). The second highest mean stress score (7.62 out of 10.0) was displayed by caregivers who were not employed , followed by caregivers who worked full time, (6.54 out of 10.0) and retired caregivers (5.50 out of 10.0) while the lowest perceived stress score were displayed by part time caregivers (3.70 out of 10.0).

ANOVA

Stress Score

	Sum of Squares	Df	Mean Square	F	Sig.
Between Groups	31.206	4	7.801	1.874	.144
Within Groups	112.411	27	4.163		
Total	143.617	31			

Multiple Comparisons

Dependent Variable: Stress Score

	(I) Employment Status of Caregiver	(J) Employment Status of Caregiver	Sig.
Scheffe	Full time	Part time	.604
		Retired	.902
		Not employed	.981
		Other	.920
	Part time	Full time	.604
		Retired	.836
		Not employed	.464
		Other	.333
	Retired	Full time	.902
		Part time	.836
		Not employed	.742
		Other	.548
	Not employed	Full time	.981
		Part time	.464
		Retired	.742
		Other	.999
	Other	Full time	.920
		Part time	.333
		Retired	.548
		Not employed	.999
LSD	Full time	Part time	.108
		Retired	.318
		Not employed	.530
		Other	.347
	Part time	Full time	.108
		Retired	.242
		Not employed	.065
		Other	.037
	Retired	Full time	.318
		Part time	.242
		Not employed	.172
		Other	.089
	Not employed	Full time	.530
		Part time	.065
		Retired	.172
		Other	.790
	Other	Full time	.347
		Part time	.037
		Retired	.089
		Not employed	.790

* The mean difference is significant at the .10 level.

A significant difference at the 10 percent level was found between the categories "part time" and "other." The homogenous subsets below visually display the significant difference of the two categories "part time" and "other" as each fell into two separate categories.

Stress Score

	Employment Status of Caregiver	N	Subset for alpha = .10	
			1	2
Tukey B(a,b)	Part time	2	3.7000	
	Retired	21	5.5071	5.5071
	Full time	5	6.5400	6.5400
	Not employed	2	7.6250	7.6250
	Other	2		8.1750
Scheffe(a,b)	Part time	2	3.7000	
	Retired	21	5.5071	
	Full time	5	6.5400	
	Not employed	2	7.6250	
	Other	2	8.1750	
	Sig.		.175	

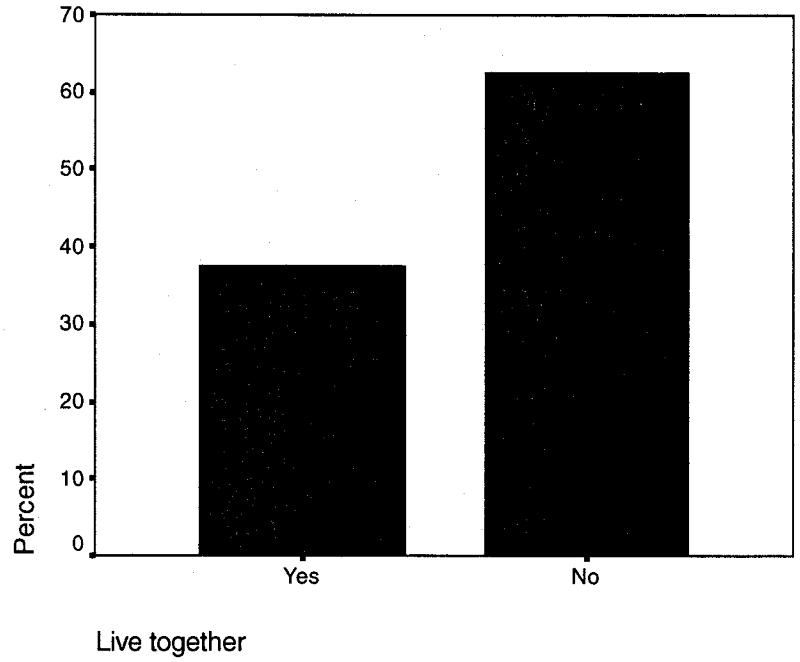
Means for groups in homogeneous subsets are displayed.
a Uses Harmonic Mean Sample Size = 2.861.
b The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

According to the Tukey's B homogeneous subset test, a significant difference was displayed between the categories of part time and other, due to the significant difference of mean stress scores.

Living Arrangements between Caregiver and Care Receiver

Figure 4.11 displays a visual representation of the living arrangements among this sample of caregivers.

Figure 4.11: Living Arrangements between Caregiver and Care Receiver



The majority of caregiver support group members (62.5%) did not live with the care receiver mainly because the care receiver was residing in long-term care. Of this sample, 37.5 percent resided with the care recipient.

An independent samples t-test was performed to test the significance of mean stress scores to living arrangements. Table 4.8 displays the results of this test.

Table 4.8: Independent Samples T-Test for Perceived Stress Score and Living Arrangements

Group Statistics

	Live together	N	Mean
Stress Score	Yes	12	5.9250
	No	19	5.6947

The mean stress score for caregiver and care receivers that live together was 5.92 out of 10.0. Caregivers and care receivers who did not live together followed closely behind with a mean stress score of 5.69 out of 10.0.

Independent Samples Test

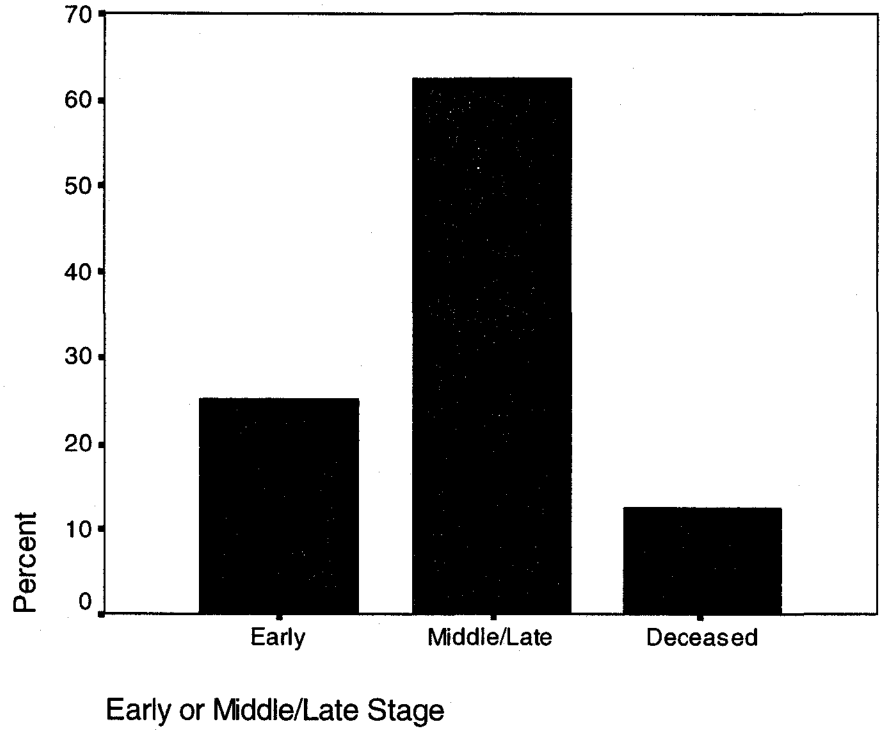
		Levene's Test for Equality of Variances		t-test for Equality of Means		
		F	Sig.	t	Df	Sig. (2-tailed)
Stress Score	Equal variances assumed	.007	.933	.286	29	.777
	Equal variances not assumed			.297	26.233	.769

The difference between variances was not significant; therefore, the t-test for independent samples of equal variances was used. No statistical significance was found between living arrangements and perceived stress score.

Stage of Alzheimer Disease of Care Receivers

Figure 4.12 displays a visual representation of the stage of Alzheimer disease (early, middle/late and deceased) of care receivers in this sample.

Figure 4.12: Stage of Alzheimer Disease of Care Receivers



The majority of care receivers were in the middle to late stage of Alzheimer Disease (62.5%) and 25.0% of care receivers were in the early stage of the disease. A small portion of the sample of care receivers were deceased (12.5%).

To test for any significant linkages to stress, a One-Way ANOVA was performed to compare the mean stress score for stage of Alzheimer disease (early, middle/late, and deceased). Table 4.9 displays the results of this test.

Table 4.9: One-Way ANOVA for Perceived Stress Score and Stage of Disease

Descriptives

Stress Score

	N	Mean	95% Confidence Interval for Mean		Minimum	Maximum
			Lower Bound	Upper Bound		
Early	8	5.5313	4.1729	6.8896	3.75	8.20
Middle/Late	19	5.6395	4.5128	6.7662	.80	9.70
Deceased	4	6.9750	3.3906	10.5594	4.55	10.00
Total	31	5.7839	4.9953	6.5724	.80	10.00

The highest mean perceived stress scores were found among caregivers of deceased care receivers (6.97 out of 10.0), followed by caregivers who were looking after someone in the middle/late stages of Alzheimer disease (5.63 out of 10.0), while the lowest perceived stress scores were displayed by caregivers who were looking after someone in the early stages of Alzheimer Disease (5.53 out of 10.0).

ANOVA

Stress Score

	Sum of Squares	Df	Mean Square	F	Sig.
Between Groups	6.582	2	3.291	.698	.506
Within Groups	132.060	28	4.716		
Total	138.642	30			

Multiple Comparisons

Dependent Variable: Stress Score

	(I) Early or Middle/Late Stage	(J) Early or Middle/Late Stage	Sig.	90% Confidence Interval	
				Lower Bound	Upper Bound
Scheffe	Early	Middle/Late	.993	-2.1560	1.9396
		Deceased	.561	-4.4192	1.5317
	Middle/Late	Early	.993	-1.9396	2.1560
		Deceased	.543	-4.0085	1.3374
	Deceased	Early	.561	-1.5317	4.4192
		Middle/Late	.543	-1.3374	4.0085
LSD	Early	Middle/Late	.907	-1.6653	1.4488
		Deceased	.287	-3.7061	.8186
	Middle/Late	Early	.907	-1.4488	1.6653
		Deceased	.273	-3.3679	.6968
	Deceased	Early	.287	-.8186	3.7061
		Middle/Late	.273	-.6968	3.3679

Stress Score

	Early or Middle/Late Stage	N	Subset for alpha = .10
			1
Tukey B(a,b)	Early	8	5.5313
	Middle/Late	19	5.6395
	Deceased	4	6.9750
Scheffe(a,b)	Early	8	5.5313
	Middle/Late	19	5.6395
	Deceased	4	6.9750
	Sig.		.470

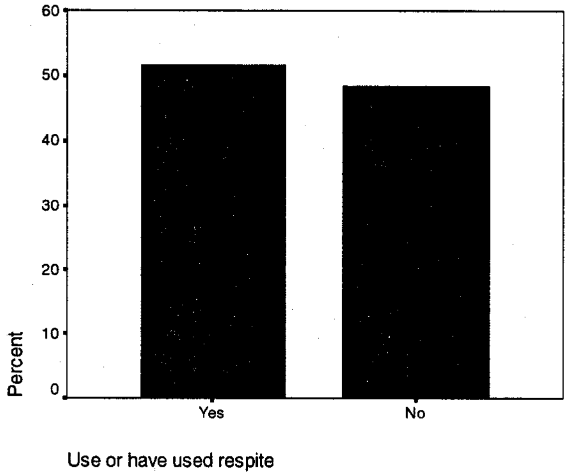
Means for groups in homogeneous subsets are displayed.
a Uses Harmonic Mean Sample Size = 7.015.
b The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

No significance was found between perceived stress score and stage of disease according to the One-Way ANOVA test and Tukey's and Sceffe's homogenous subset tests. As displayed above all stress scores fell into one column due to the closeness of mean stress scores among all stages of disease (early, middle/late and deceased).

Use of Respite Care (Use or Have Used Respite)

Figure 4.13 displays a visual representation of use of respite care among this sample of caregivers.

Figure 4.13: Use of Respite Care



A slightly smaller percentage of caregivers from this sample indicated that they use or have used respite care (51.6 percent), while 48.4 percent indicated that they have never used respite care. Users and former users were grouped together due to the small number of caregivers currently utilizing respite care.

An independent samples t-test was performed to test the significance of mean stress scores to respite utilization. Table 4-10 displays the results of this test.

Table 4.10: Independent Samples T-Test for Perceived Stress Score and Use of Respite Care

Group Statistics

	Use or have used respite	N	Mean
Stress Score	Yes	16	6.3156
	No	15	5.2167

The mean stress score was slightly higher for caregivers who stated that they use or have used respite care (6.31 out of 10.0). For caregivers who have never used respite care, the mean stress score was 5.21 out of 10.0.

Independent Samples Test

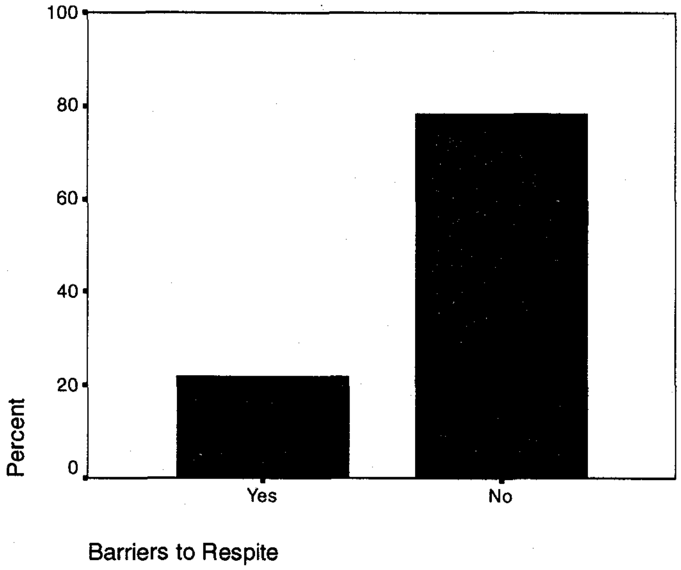
		Levene's Test for Equality of Variances		t-test for Equality of Means		
		F	Sig.	T	Df	Sig. (2-tailed)
Stress Score	Equal variances assumed	.488	.491	1.448	29	.158
	Equal variances not assumed			1.458	28.413	.156

The difference between variances was not significant; therefore, the t-test for independent samples of equal variances was used. No statistical significance was found between utilization of respite care and perceived stress score.

Barriers to Respite Utilization

Figure 4.14 provides a visual representation of caregivers who experienced barriers to respite utilization versus caregivers who did not experience barriers to respite utilization.

Figure 4.14: Barriers to Respite Utilization



Of caregivers in this sample, 78.1 percent did not identify any barriers to respite utilization while 21.9 percent did identify a barrier to respite utilization.

An independent samples t-test was performed to test the significance of mean stress scores to barriers to respite utilization. Table 4.11 displays the results to this test.

Table 4.11: Independent Samples T-Test for Perceived Stress Score and Barriers to Respite Utilization

Group Statistics

	Barriers to Respite	N	Mean
Stress Score	Yes	7	6.4357
	No	25	5.6920

Caregivers who identified one or more barriers to respite utilization displayed a mean stress score of 6.4 out of 10.0, slightly higher than caregivers who did not identify one ore more barriers to respite utilization who displayed a mean stress score of 5.69 out of 10.0.

Independent Samples Test

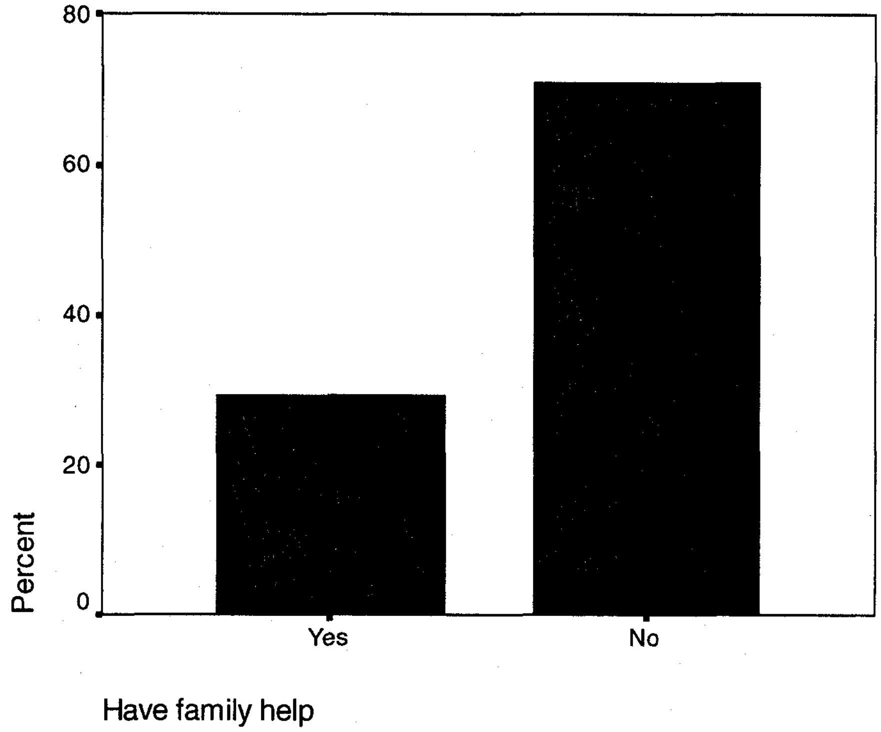
		Levene's Test for Equality of Variances		t-test for Equality of Means		
		F	Sig.	T	Df	Sig. (2-tailed)
Stress Score	Equal variances assumed	1.910	.177	.803	30	.428
	Equal variances not assumed			1.142	20.060	.267

The difference between variances was not significant; therefore, the t-test for independent samples of equal variances was used. No statistical significance was found between barriers to respite utilization and mean perceived stress score.

Help from Family and Friends

Figure 4.15 displays a visual representation of caregivers who have received or have not received help from family and friends two or more times a week.

Figure 4.15: Have Family Help (two or more times a week)



Help from family and friends at least two or more times a week was noted by 29.0% of the caregivers, while 71.0% of the caregivers indicated that they did not get help from family and friends at least two times a week.

An independent samples t-test was performed to test the significance of mean stress scores to caregivers who have and have not received help from family and friends two or more times a week. Table 4.12 displays the results of this test.

Table 4.12: Independent Samples T-Test for Perceived Stress Score and Family Help

Group Statistics

	Have family help	N	Mean
Stress Score	Yes	9	4.9278
	No	22	6.1341

The caregivers that indicated that they did not have help from family and friends two or more times a week displayed the highest mean stress score (6.13 out of 10.0) while caregivers who did have family help two or more times a week had a mean stress score of 4.92 out of 10.0.

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means		
		F	Sig.	t	df	Sig. (2-tailed)
Stress Score	Equal variances assumed	.494	.488	-1.444	29	.160
	Equal variances not assumed			-1.368	13.410	.194

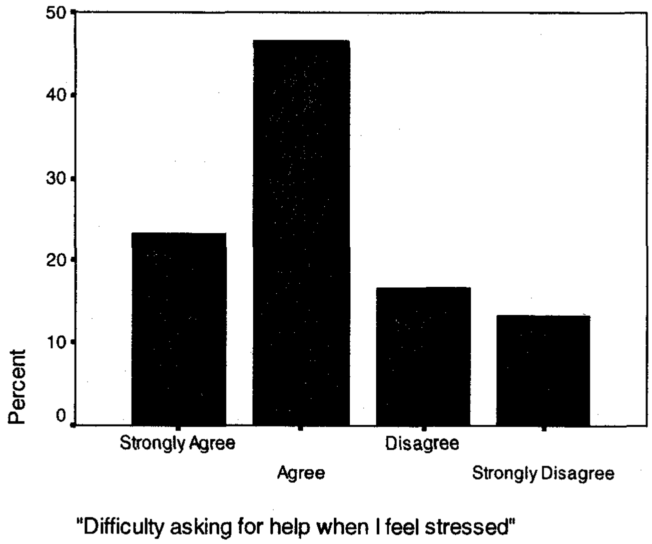
The difference between variances was not significant, therefore; the t-test for independent samples for equal variances was used. No statistical significance was found between family help and mean perceived stress score.

Caregivers Perceived Difficulty in Asking for Help

Caregivers were asked to what degree they agreed or disagreed with the following statement, "I have difficulty asking for help in a situation where I feel stressed"

Figure 4.16 displays a visual representation of the level of perceived difficulty in asking for help when stressed among this sample of caregivers.

Figure 4.16: Caregivers Perceived Difficulty in Asking for Help



When caregivers were asked to rate the question "I have difficulty asking for help in a situation where I feel stressed," 23.3 percent of the sample answered 'strongly agree' with this statement, while 46.7 percent stated that they 'agree' with this statement. Those who noted that they 'disagree' constituted 16.7 percent of the sample, while 13.3 percent noted that they 'strongly disagree'.

A correlation was performed using both the Pearson Method and Kendall's Tau B Method Table 4.13 displays the results from these tests.

Table 4.13: Correlation between Perceived Stress Score and Perceived Difficulty in Asking for Help

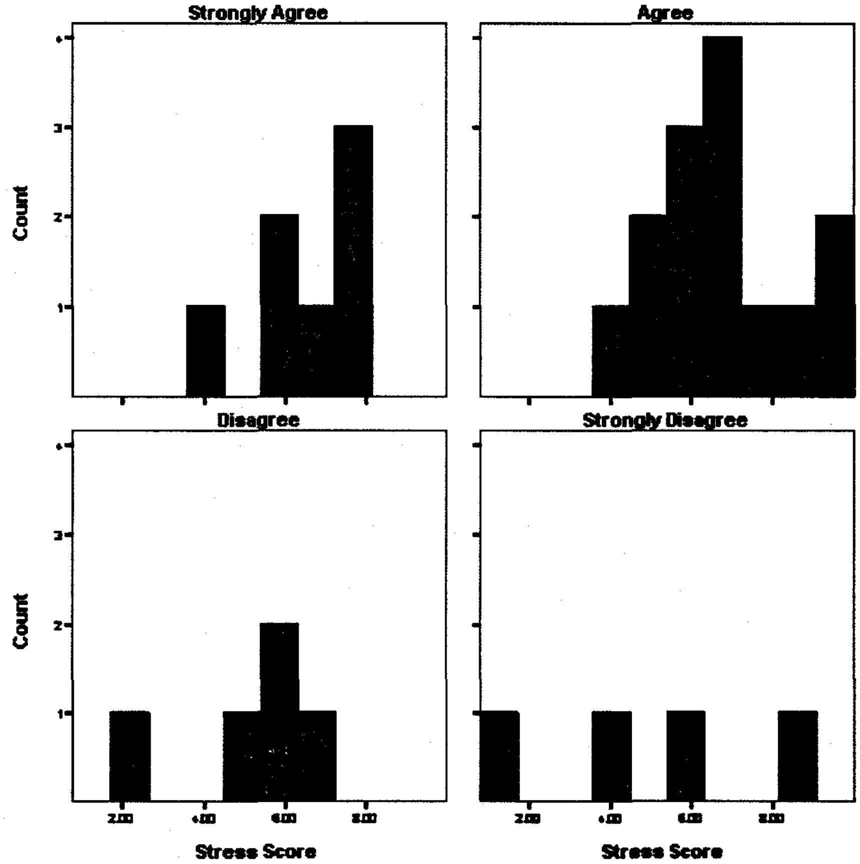
Correlations

			Stress Score	"Difficulty asking for help when I feel stressed"
Kendall's tau_b	Stress Score	Correlation Coefficient	1.000	-.272
		Sig. (2-tailed)	.	.058
		N	32	30
	"Difficulty asking for help when I feel stressed"	Correlation Coefficient	-.272	1.000
		Sig. (2-tailed)	.058	.
		N	30	30

There was a negative correlation found between perceived stress score and difficulty in asking for help when stressed. The answers to the question "I have difficulty asking for help when stressed were coded into SPSS as follows: 1 = Strongly Agree, 2 = Agree, 3 = Disagree, 4 = Strongly Disagree. Hence, since a negative correlation was found this means that the higher degree of perceived difficulty in asking for help is linked to a higher the perceived stress score.

Figure 4.17 displays a visual representation of perceived stress scores among the different levels of perceived difficulty in asking for help when stressed.

Figure 4.17: Perceived Stress Scores According to Perceived Difficulty in Asking for Help

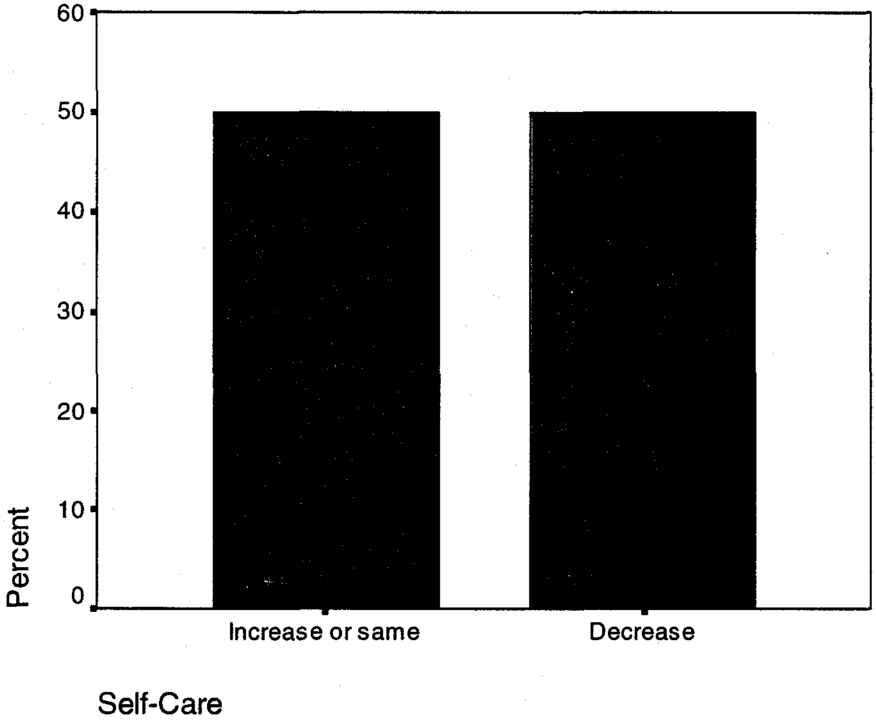


Caregivers that ‘strongly agree’ and ‘agree’ that they have difficulty asking for help when stressed displayed higher perceived stress scores as evident in the top two graphs. Caregivers who ‘disagree’ or ‘strongly disagree’ with this statement were more likely to show lower perceived stress scores with the exception of one caregivers who displayed high stress in the ‘strongly disagree’ chart.

Caregivers Frequency of Self-Care Behaviors

Caregivers were asked to rate their frequency of self-care behaviors (reading, napping, exercising, watching television, spending time with other family members and friends) before caregiving and since becoming an Alzheimer caregiver). Figure 4.18 displays a visual representation of self-care patterns among this sample of caregivers.

Figure 4.18: Caregivers Frequency of Self-Care Behaviors



There was an even split between caregivers who increased or maintained self-care behaviors to caregivers who decreased self-care behaviors (50 percent for each group).

An independent samples t-test was performed to test the significance of mean stress scores to frequency of self-care. Table 4.14 displays the results of this test.

Table 4.14: Independent Samples T-Test for Perceived Stress Score and Frequency of Self-Care

Group Statistics

	Self-Care	N	Mean
Stress Score	Increase or same	14	4.7107
	Decrease	14	7.0643

Caregivers who increased or maintained self-care behaviors a lower mean stress score was evident (4.71 out of 10.0) while caregivers who decreased self-care behaviors displayed a higher mean stress score of 7.06 out of 10.0

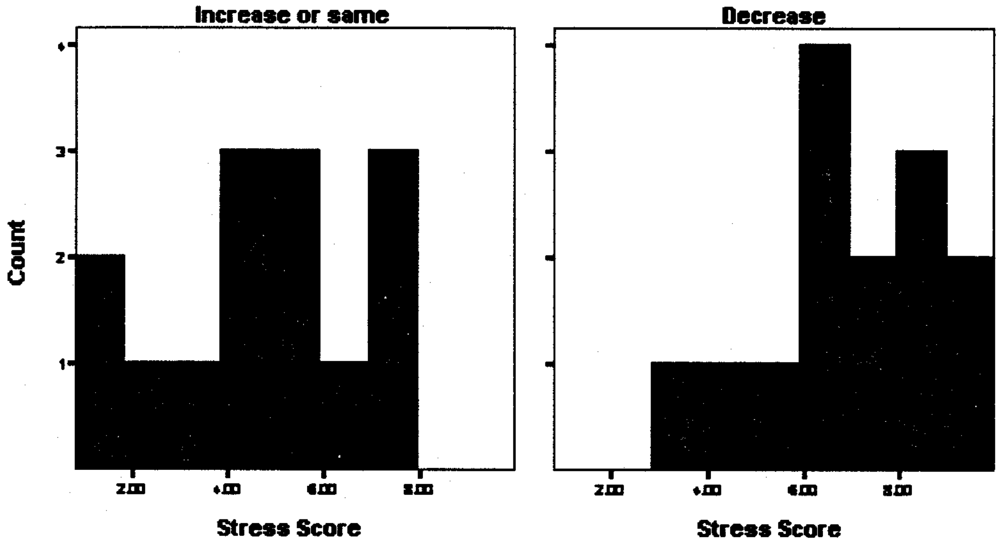
Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means		
		F	Sig.	T	df	Sig. (2-tailed)
Stress Score	Equal variances assumed	.587	.451	-3.137	26	.004
	Equal variances not assumed			-3.137	24.810	.004

The difference between variances was not significant, therefore; the t-test for independent samples for equal variances was used. A significant difference was found at the 0.01 level for self-care and perceived level of stress. Therefore, Alzheimer caregiver support group members who displayed a decrease in self-care behavior were more likely to show higher levels of perceived stress.

Figure 4.19 provides a visual representation of perceived stress scores among caregivers in this sample who increased or maintained self-care behaviors with caregivers who decreased self-care behavior.

Figure 4.19: Perceived Stress Score According to Frequency of Self-Care



The first chart displays the likelihood of lower perceived stress levels among caregivers who maintained or increased self-care behaviors while caregivers who decreased self-care behaviors were more likely to display higher levels of stress as indicated in the second chart.

Open Ended Survey Questions:

Each of the following three open-ended questions were transcribed and grouped into mutually exclusive categories. The left-hand column of each table describes the category name with examples. The number of caregivers which gave responses that fell into the category is listed in the middle column. The right hand column provides examples of caregiver answers to the proposed question. Some caregivers gave responses which categorically fell into more than one column; as a result, the response from each caregiver may be represented in more than one category. For a compete list of all caregiver responses for all three questions please see Appendix F.

Question:

"As a caregiver experiencing Alzheimer Disease, what types of services would you like to see in the future?"

Justification:

This question was asked because formal systems of help have been traditionally formed without consulting informal parties who are the clients of care. Formal services are far from diverse and are classified into neat categories and dominated by eligibility criteria, inflexible hours, waiting lists and other barriers enforced through government bureaucracy. This question provided insight into how to meet the needs in the ever-growing and diverse population of informal Alzheimer caregivers.

Response Categories	**Percentage of Caregivers**	**Selected Caregiver Responses**
Increased education • to staff, general public • education with regards to services available to caregivers • information about long-term care	20.0% (4 out of 20 caregivers)	*"A vigorous attempt to provide education about this disease to family physicians, also to the general public. Social get togethers for those with this disease and their caregivers-for interaction and sharing."* *"Knowledgeable and informed source for everyday coping, and future planning, e.g., placement is required and what to expect. Monthly updates on health both mental and physical of loved one, what resources are available besides busy doctors."* *"An educational link where caregivers can leave a legacy of caregiving situations so that*

		others may use the information and grow."
Increase and improve support - reduce barriers to respite care (increase availability, increase funding, longer hours) - a tool to address care receiver refusal to respite care - increase input from doctors	65.0% (13 out of 20 caregivers)	*"The availability of respite care in our area is inadequate and not readily available. The need for care is an issue. Availability of respite caregivers willing to spend time with the resident when caregivers need a day to relax".* *"Transportation for caregivers and care recipients for shopping, doctors appointments, etc., for caregivers with no vehicles."* *"I am very satisfied that what out there is adequate. The only problem is that too many caregivers either do not or*

		cannot (due to the pressure from the one being cared for) make use of available services."
Long-term care improved • more staff • wider choice of facilities • greater availability of beds • more activities and services within long-term care	30.0% (6 out of 20 caregivers)	*"Increase: Number of beds/openings available; wider choice of facilities. More nurses-gerontology training."* *"One on one care for Alzheimer patient, better physical space for personal visits, cheaper subsidized nursing home space, private rooms."* *"Respite services in a nursing home, visiting on a regular basis (3 to 4 times a week sometimes difficult). If you know a respite person would visit it would give you a day off."*

In summary, the caregiver's responses fell into three mutually exclusive categories, increase education, increase and improve support and improve long-term care. Of the twenty-three respondents, over half placed emphasis on increased and improved support (65 percent). Those wanting aspects of long-term care improved constituted 30 percent, while 20 percent requested increases in education regarding aspects of caregiving.

Question:

"Stress experienced while caregiving may be different for all caregivers. To value your unique experience, please describe what may have contributed to your stress in a few words or sentences below."

Justification:

This provided more insight into the perceived stress of Alzheimer caregivers as they were given a chance to articulate what they thought contributed to the stress experienced in their roles.

Response Categories	**Percentage of Caregivers**	**Selected Caregiver Responses**
Care receiver symptoms • managing challenging behavior • denial from care recipient • behavioral changes	15.0 % (3 out of 20 caregivers)	*"24 hour care and supervision need for creative ideas as symptoms and behavior change, managing challenging behavior, in the advanced stages resistance to care and the physical strength needed to care for your*

		loved one. The early grieving for a loved one who is slowly wasting away."
Caregiver symptoms - lack of sleep - exhaustion - not eating properly - feeling guilty	40.0% (8 out of 20 caregivers)	*"Continued complete care at all hours day and night, causing lack of rest and physical stress."* *"Needing to be there, visit more often, guilt that I cannot look after her at home."*
Lack of support - no help or lack of understanding from family and friends - inability to seek help	20.0% (4 out of 20 caregivers)	*"Family and friends seem to shy away from people with dementia. When they do come around, which my husband really enjoys, he is at his very best. Then they don't understand how I feel so stressed."*

Long-term care • long-term care placement • unsatisfied with long-term care	10% (2 out of 20 caregivers)	*"Mom enjoyed independent living with help until 90 years old. Just seeing our mother in this state and stage of her life is very stressful. She has been a very good mom and having had to place her in a facility was extremely stressful. Although unaware of her surroundings, most of the time she recognizes her children but sometimes remembers us younger than we are."*
Lack of control • unable to control the impacts of the disease • worried about what the future will bring	25.0% (5 out of 20 caregivers)	*"I worry about what the future will bring. I am doing fine so far, but I wonder if the demands from my own family become greater, will I still be able to do a good job."* *"Seeing my mother deteriorate and not be able to do anything about it."*

Instrumental changes - extra errands to run - lack of personal life	10% (2 out of 20 caregivers)	*"Lots of running around trying to straighten things out and work for my mom's best interest. Exhaustion."*

In summary, answers were divided into six mutually exclusive categories (care receiver symptoms, caregiver symptoms, lack of support, long-term care, lack of control, and instrumental changes). The majority of caregivers (40 percent) reported that their own symptoms contributed to their stress. Also reported as stress contributors were lack of control (25 percent), lack of support (20 percent), long term care (10 percent) and instrumental changes (10 percent).

Question:

"In a few sentences, how would you describe your experience as a caregiver?"

Justification:

This question allowed caregivers to articulate their experience from their point of view. This provided further insight into the complex and diverse role of informal Alzheimer caregiving.

Response Categories	**Percentage of Caregivers**	**Selected Caregiver Responses**
Positive	11.0% (3 out of 27 caregivers)	*"I seen this happening slowly to my father over the last year. I am very realistic person always facing the problem head on. This is*

		why I have learned to accept things the way they are and live with them. I have used this philosophy all my life and it works for me."
Negative	48.0% (13 out of 27 caregivers)	*"The experience has been the most difficult thing that I have had to handle. I feel very lonely at times. This disease has changed our lives in many ways and I feel this will only get worse."*
Positive and Negative	37.0% (10 out of 27 caregivers)	*"Each day represents a new outlook and approach to the care you need to give, and care you need to give yourself. Caregiving teaches priorities, to appreciate the 'little things'- like a hearty laugh with the Alzheimer person, family member friend or stranger!! Of course, there are moments one would like to walk away but it is like a job, it gets done. Opportunity to do 'on the spur of the moment' activities are limited."*

Almost half of the caregivers had very mixed feelings as to whether caregiving was a positive or negative experience. While 48 percent of caregivers identified their experience in negative terms, 37 percent described their experience in both positive and negative terms. Only 11 percent of the caregivers gave a truly positive articulation in their response. This exemplifies the trying experience of Alzheimer caregiving and its impact on this population of caregivers.

Conclusions:

Overview of Hypotheses and Results from this Study

Support Group Characteristics

Hypothesis	**Findings from this study**	**Explanation**
Caregivers who have been attending the Alzheimer support group for 2 years or more experience lower perceived stress than caregivers who have been attending the Alzheimer support group for less than 2 years.	Although the finding was not statistically significant, caregivers who have been attending the support group for less than 2 years had a mean stress score that was slightly lower than caregivers who had been attending for 2 years or more.	Although length of support group attendance has been studied minimally in the caregiving literature, this finding supports the common finding that social support leads to positive

		outcomes (e.g., increased well being) (Cohen & Willis, 1985; Pierce, Sarason, & Sarason, 1996; Sarason, Sarason, & Pierce, 1990). From here one can hypothesize that the longer one is the more social support one has, the better the outcome.

Care Receiver Characteristics

Hypotheses	**Findings from this study**	**Explanation**
Caregiver support group members who are in the middle to late stages of Alzheimer's disease experience higher perceived stress than caregiver support group members of care receiver's in the early stage of Alzheimer disease.	Although findings were not statistically significant, caregivers who were looking after someone in the middle and late stages of Alzheimer Disease had higher perceived stress than caregivers who were looking after someone in the early stage of Alzheimer Disease. Interestingly enough, caregivers who had a deceased care receiver displayed the highest perceived stress.	There is overwhelming support in the literature linking disease progression to increased levels of stress (Aneshensel, Pearlin, & Schuler, 1993 Baumgarten, 1989; Deimling & Bass, 1986; Eagles, Craig, & Rawlinson, 1987; George & Gwyther, 1896; Gilleard et al, 1984; Hamel et al, 1990; Kiecolt-Glaser et al, 1987; Poulshock & Deimling, 1984; Pruchno & Resch, 1989; Wilder, Teresi, & Bennett, 1983; Bedard et al, 1997; Chappell & Penning, 1996; Stuckey, Neundorfer, & Smyth, 1996; Irvin &

		Acton, 1997; Coen et al, 1997). Since this study displayed high levels of stress among caregivers of deceased care receivers, this supports the research finding that stress experienced while caregiving is a process which carries into the post caregiving years (Esterling et al, 1994; Bodnar & Kiecolt-Glaser, 1994).
Caregiver support group members who live with the care receiver experience higher perceived stress than caregiver support group members who do not live with the care receiver.	Although findings were not statistically significant, caregivers who live with the care receiver had higher perceived stress when compared to caregivers who did not live with the care receiver.	The linkage between living with the care receiver and higher levels of stress among caregivers is strongly supported in the literature (Bass et al, 1994; Biegel, Sales & Schulz, 1991; George & Gwyther, 1986; Pruchno & Resch, 1989; Schulz et al, 1993;

		Aneshensel, Pearlin & Schuler, 1993; Zanetti et al, 1997; Zarit & Whitlach, 1992).

Caregiver Characteristics

Hypotheses	**Findings from this study**	**Explanation**
Spousal caregiver support group members experience higher perceived stress when compared to adult children caregiver support group members.	Although findings were not statistically significant, spousal caregivers had higher perceived stress when compared to adult child caregivers.	A large portion of the literature supports the finding that spouses experience more stress than adult child caregivers (Antonucci, 1989; Shumaker & Brownell, 1984)
Female caregiver support group members experience higher perceived stress when compared to male caregiver support group members.	Female caregivers experienced significantly higher perceived stress when compared to male caregivers.	This finding coincides with the overwhelming evidence in the literature that supports this finding. (Bass et al, 1994; Biegel, Sales & Schulz, 1991; George & Gwyther, 1986;

		Pruchno & Resch, 1989; Schulz et al, 1993; Barusch & Spaid, 1989)
Caregiver support group members who are employed experience lower perceived stress compared to caregiver support group members who are not employed.	Although findings were not statistically significant, the opposite relationship was found, caregivers who were employed experienced higher perceived stress compared to caregivers who were not employed. However, when employment status was grouped into subcategories, part time workers had the lowest perceived stress scores.	This is supported by studies that have concluded that work in the formal sector and caregiving as an informal role often conflict with one another (Aneshensel et al, 1995; Barling, MacEwen, Kelloway, & Higginbottom, 1994; Gignac, Kelloway, & Gottlieb, 1996; Gottlieb, Kelloway, & Fraboni, 1994; Neal, Chapman, Ingersoll-Dayton, & Emlen, 1993; Scharlach, 1994).
The older the caregiver support group member the greater level of perceived stress reported.	Although findings were not statistically significant, the opposite relationship was found.	This coincides with findings from Fitting et al (1984) that younger

	Caregivers who were 60 years of age and under had higher perceived stress compared to caregivers who were over 60 years of age.	caregivers tend be the least happy in their role and have more feelings of resentment when compared to older caregivers.

Outside Interventions

Hypotheses	**Findings from this study**	**Explanation**
Caregiver support group members who utilize respite care (day programs, institutional respite care, in-home respite/homecare) experience lower perceived stress than caregiver support group member who do not utilize respite care.	Although findings were not statistically significant, just the opposite was found. Caregivers who stated that they use or have used respite care had higher perceived stress when compared to caregivers who stated that they have never used respite.	This finding is supported by Theis, Moss & Pearson (1994), who found similar results in their study on the role of respite in reducing stress among caregivers.
Caregiver support group members who experience barriers to respite utilization experience	Although findings were not statistically significant, caregivers who experienced	This finding is strongly supported in the literature. Barriers to respite care

higher perceived stress when compared to caregiver support group members who do experience barriers to respite utilization.	barriers to respite utilization displayed higher perceived stressed when compared to caregivers who did not experience barriers to respite utilization.	whether they are psychological or structural often lead to feelings of social isolation, guilt and decreased well-being which is all linked to increased stress.
Caregiver support group members who have increased or maintained practices of self-care experience lower perceived stress compared to caregiver support group members who have decreased the frequency of practices of self-care.	Caregiver who decreased practices of self-care experienced significantly higher perceived stress when compared to caregivers who maintained or increased practices of self-care.	This is supported by Vitaliano (1997) who states the association between caregiver stress and decreases in self-care activities.
Caregiver support group members who receive help from another family member (2 or more times a week) experience lower perceived stress compared to caregiver support group	Although findings were not statistically significant, caregivers who received help from family and friends two or more times a week were less stressed when compared to	This finding is supported in the literature, as receiving assistance from others have been found to decrease feelings of stress. (Hobfoll &

members who do not receive help from another family member (2 or more times a week).	caregivers who did not receive help from family and friends two or more times a week.	London, 1986; Hobfoll & Walfisch, 1984; Collijn, Appels, & Nijhuis, 1995; Franks & Stephens, 1996).
Caregiver support group members who have difficulty asking for help in a situation where they feel stressed experience higher perceived stress compared to caregiver support group members who do not have difficulty asking for help in a situation where they feel stressed.	A positive correlation was found between perceived difficulties in asking for help when stressed with perceived stress scores. In other words, caregivers who strongly agreed or agreed with the statement, "I have difficulty asking for help in a situation where I feel stressed" had higher perceived stress when compared to caregivers who disagreed or strongly disagreed with this statement.	This finding is supported in the literature as caregivers who seek out support generally experience more positive caregiving outcomes (Rapp et al, 1998).

Chapter 5

Discussion

Overview.

This study compliments the wealth of caregiving research which heavily emphasizes the stressfulness of the caregiving experience. With the current trend, as outlined in the Romanow report of putting more emphasis on the informal care sector to sustain the future of our healthcare system, this study speaks to the importance of finding a way to meet the needs of one population (the care receivers) without sacrificing the needs of another population (the caregivers). As emphasized by Hooyman & Gonyea (1995) it is necessary to examine public policies and its effect on the family care giving experience. The larger political umbrella which overshadows the caregiving experience has a substantial impact as evidenced by the proposed national health agenda of the Romanow Report.

Findings from this study give rise to the realization that Canada's current structure of formal care services are seldom utilized or effective in meeting the psychosocial needs of caregivers. A rigid array of neatly categorized formal care services which characterizes Canada's current formal care system does not compliment the ever growing and diverse population of informal caregivers.

This study compliments Cohen, Kessler & Gordon's heuristic model of stress (1995) as outlined in Figure 2.1 of Chapter 2. The Alzheimer caregiving experience is outlined by caregivers in this study through open-ended questioning which delineates their adaptive capacities and appraisal of demands. Their perceived level of stress is also measured which is essentially influenced by their caregiving experience. Negative emotional responses such as caregiving symptoms (sleeplessness, anxiety, etc) are noted by caregivers which show the different outcomes of the Alzheimer care experience. In terms of this leading to an increased risk of psychiatric and physical ailments of caregivers, further examination is needed in future studies as this poses a further stress on the current Canadian health care system. As evidenced in Ontario, cuts in health care funding have created a decrease in the availability of formal services causing the further health deterioration among the elderly population. This has lead to an increase in hospital admissions which essentially adds more stress to the health care system (Leydier, 2003).

Findings from this study.

Findings from this study conclude that present and former use of respite care result in increased levels of perceived stress. Although this study has a relatively small sample size, these findings support a study by Theis, Moss & Pearson (1994) which outlines the use of respite care and its connection to increased levels of stress. The effectiveness of respite should not be measured solely on its ability to delay institutionalization but rather by its ability to meet the identified needs of the caregivers utilizing the service. Examining what barriers exist to formal services is one way of explaining the low utilization of services. However, what remains of greater importance is questioning whether or not these services are suitable in the first place. Currently, respite care is designed for the care receiver while, ironically adverse consequences of care are expected to diminish among caregivers. In order to increase the effectiveness and utilization of formal services, examining the types of services that should be offered to meet the needs of this diverse and ever-growing population is essential. This study asks various open-ended questions with the objectives of understanding the experiences of each caregiver, to note what contributes to their stress and what future services should be offered to meet their needs. Of interest, is the fact that caregivers are calling for (through their suggestions on future service), more support in terms of a rigorous attempt to have a strengthened link with the formal care sector (health care staff and respite providers) such as increases in education, better transitional preparation into long-term care, and the removal of rigid respite care practices.

In agreement with Petronela et al, (2001), a stronger and more efficient mechanism needs to be put into place to address the barrier of the difficulty caregivers have in asking for help when stressed. In this study, a significant relationship was found between those caregivers who stated that they 'strongly agree' or 'agree' with the statement, "I have difficulty asking for help when I'm in a situation where I feel stressed" and their perceived stress. In other words, caregivers who are more likely to have difficulty asking for help are likely to have higher perceived stress. A caregiver's guilt and unwavering commitment to their loved ones often causes them to neglect their own health and not seek help when entitled. This strong sense of love and loyalty mixed with the adversity of care provision is evidenced in open ended answers to the question asking caregivers to describe their experience as a caregiver. The majority of caregivers in this study are able to articulate their experience in a positive way while also articulating the hardships and difficulties that render the caregiving situation as a challenging and emotionally draining experience.

This study also displays a significant relationship between age and perceived stress score. The findings from this study conclude that caregivers who are sixty years and under have higher perceived stress scores. Caregivers who are sixty and under are more likely to be in the workforce; thus, are in the position of trying to meet various demands. Suggestions are made by Romanow to encourage workplaces to further support caregivers who take time from work to meet the needs of a loved one. In response, the provincial and federal governments are both showing recognition through tax breaks and the recent Compassionate Leave initiative. Unfortunately, this latter recent policy change provides little help to the growing population of Alzheimer informal caregivers who do not always qualify as a result of rigid eligibility rules. These methods of caregiver compensation which are bounded by government enforced "red tape" parallel that of the formal care system of services.

A statistically significant relationship was found between lower perceived stress and caregivers who maintain or increase practices of self-care. This signals what the true meaning of respite for these caregivers may be. A caregiver's ability to hold onto an important piece of their life through the maintenance of social visits with family and friends, activities that foster relaxation and leisure, exercise, or as simple as watching television, may enable them to keep a piece of normality in their lives. These self-care initiatives serve two purposes; first, these methods of self-care can potentially lead to improved health and well-being among caregivers. Secondly, caregivers can potentially experience a truly rejuvenating experience that is much deserved.

The Influence of Policy.

Canadian policy tends to be based on a very rigid definition of formal care which does not provide the means for caregivers to reap more comprehensive benefits of respite. Although Romanow's proposed homecare initiative may appear to be an example of formal services meeting informal services halfway, one must ask, "Is this really what is happening?" More emphasis is placed on family and friends to provide care in light of the government's desire to control current growing health care expenditures. As a pivotal guide to the future of Canada's health care system, the recent Romanow Report is driven by the political initiative of saving health care dollars by making homecare part of the make-up of our universal health care system. While it appears to meet the needs of those both providing and receiving care who express the desire to remain at home as long as possible, it may potentially lead to an increased population of caregivers who will suffer from the adverse consequences of caregiving resulting in more frequent hospital admissions and an increase in mental health problems.

Romanow (2002) defines the advantages of home care as follows, "People get to stay in their own homes with the assurance that someone will be there to monitor their health." This 'someone' as Romanow refers to is in fact, the informal care network of family members and friends who provide eighty-five to ninety percent of homecare to people in need (Ontario Coalition of Senior Citizens' Organizations, 2002). Additionally, in the same section the Romanow initiative outlines that homecare would be given to those in need on a priority basis such as to terminal patients and patients recently discharged from the hospital. As the full implications of the Romanow Report have not yet been felt it is speculated that the apparent narrow definition may mean that Alzheimer caregivers fall through the cracks and do not fit the criteria of who is considered to be a priority. The only conclusion that one can draw at this time from this report is that Canada lacks a clear policy on understanding the different roles and contributions of both the informal and formal caregiving systems of Alzheimer disease. Furthermore, the issue becomes clouded by indicating that formal home care help for terminal patients and patients recently discharged from the hospital will actually free up homecare workers for others in need. However, the likelihood of an increased availability of formal sector paid homecare workers appears unlikely due to government cut-backs and strict eligibility criteria for formal sector homecare.

Theories.

This structural functionalist initiative has placed informal caregivers into a role that society commonly fails to challenge and merely accepts as an inevitable part of life. However, this responsibility needs to be met through a Contextual Fluidity perspective by working in the informal caregiving system to establish how to best meet the needs of this population. From a Contextual Fluidity framework, we need to understand the needs of these caregivers by getting an "insiders view" of the true caregiving experience and to understand the various factors that shape the role of informal care. Support groups can provide a useful mechanism of getting into the informal caregiving system. It provides the opportunity to investigate what caregivers need to ease their caregiving experience as opposed to enforcing available formal sources of assistance which may not necessarily meet caregiver needs. As outlined by Hooyman & Gonyea (1995), support groups carry the main objective of allowing caregivers to "blow off emotional steam" so they can continue to stay in their caregiving role which does not get at the broader issues that are linked to informal care provision. Formal services need to be built from the ground up with the informal caregiving population laying the foundation for a system of formal services that are unique, practical and diverse. This study gets a first look at this insider's view by asking caregiver support group members to undergo the simple task of documenting what types of services they would like to have in the future.

Particularly affected by the government's structural functionalist approach to health care sustainability are women. As a result of a continued expectation of caregiving as a gender appropriate role, along with the growing number of people being diagnosed with Alzheimer disease, and the continued increase of women in the formal sector, women continue to be put into nearly impossible situations where they are expected to thrive in each and every one of the their challenging and demanding roles. It has become a socialized expectation for women to fulfill caregiving duties despite the devastating physical, mental and financial effects (Hooyman & Gonyea, 1995). This study supports the widely documented finding of the heightened stress experienced by female caregivers relative to male caregivers. Canada is a country which celebrates democracy and places emphasis on equal rights, yet remains unable to change the long lasting effects that history has had in shaping the gendered role of women as care providers.

The three theoretical bases of this study; Structural Functionalism, Feminism and Contextual Fluidity are inextricably fused together as a large umbrella which helps to explain the caregiving experience. Resulting from a Structural Functional value base which created a division of labor following the Industrial Revolution, women became ingrained with the responsibility of maintaining a functional household and providing duties of care. From this rigid frame of reference emerged a feminist approach to unravel the effects of this expectation on women. A logical extension from feminism emerges a Contextual Fluidity outlook which celebrates diversity among all individuals and focuses on understanding people as individuals who are influenced by their environments. As feminism celebrates women as a distinct group who are influenced by a patriarchal past, Contextual Fluidity helps to understand people within their unique environments. In this study, understanding the caregivers within their environment of Alzheimer care is explored. Caregivers within their environments need to be investigated further as the ideas and experiences of these caregivers need to be used as a tool to guide policy as opposed to being studied as a product of policy.

Directions for the Future.

There is a need to re-examine our current structure of formal services including methods of service design. Respite care needs to take on the characteristics of that given by the caregiver, not the formal system that does not fully understand the range of needs of informal caregiving systems. A useful model for future direction towards meeting caregiver needs is exemplified in the recent government legislation known as the Carer's National Strategy which is taking place in London England. This strategy grew out of the recognition of the importance of including caregiving dyads (both the caregiver and care receiver) in the development, delivery and evaluation of respite services (Longshaw & Perks, 2000). The Carers Recognition & Service Act and the NHS & Community Care Act which falls under the National Strategy umbrella recognizes the diverse needs of caregivers and the importance of having a solid partnership between formal and informal spectrums of care. Under the Act, it becomes possible to do a needs assessment to tailor interventions to specifically meet the needs of caregivers (Ashworth, 2000). This type of legislation provides a framework for empowering caregivers by giving them the opportunity to shape their caregiving experience. Evidenced by the immediate success of this strategy, this London initiative provides evidence that trying to meet the needs of informal caregivers by investigating how to better meet their needs and changing the rigid definition of respite care can achieve positive results.

As the Canadian government strives to find balance between controlling growing health expenditures and meeting the needs of informal caregivers, more weight is inevitably placed on the informal caregiving sector who will likely continue to provide care regardless of whether formal homecare becomes a universal service. Thus, finding a way to keep formal services relevant for those in need and available at key moments so that the informal care sector does not become overwhelmed is the key to a truly sustainable healthcare system.

Future studies are needed to achieve more definitive conclusions of the array of factors that lead to stress among Alzheimer caregivers. A Contextual Fluidity framework can assist in the further understanding of the needs of caregivers by taking all potentially influencing aspects to caregiving and using this information to investigate future service needs. Such an approach can help to build a bridge toward a future of care that can potentially meet both the needs of the care receivers and family members and friends who provide care for them. Meeting the needs of care receivers as well as those who provide for them is essential in pursuit of future healthcare sustainability.

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APPENDIX A

Lakehead
UNIVERSITY

Office of Re

Tel. (807) 343
Fax (807) 346

5 February 2003

Ms. Kerry Kuluski
Department of Social Work
Lakehead University
Thunder Bay, ON

Dear Ms. Kuluski:

Based on the recommendation of the Research Ethics Board, I am pleased to grant ethical approval to your research project entitled, "ALZHEIMER DISEASE CAREGIVERS: RESPITE USE AND STRESS LEVELS AMONG CAREGIVERS WHO ARE SUPPORT GROUP MEMBERS."

The Research Ethics Board requests an annual progress report and a final report for your study in order to be in compliance with Tri-Council Guidelines. This annual review will help ensure that the highest ethical and scientific standards are applied to studies being undertaken at Lakehead University.

Completed reports may be forwarded to:

Lynn Stokaluk
Office of Research
Lakehead University
955 Oliver Road
Thunder Bay, ON P7B 5E1
FAX: 807-346-7749

Best wishes for a successful research project.

Sincerely,

Dr. Lori Chambers

Dr. Lori Chambers
Acting Chair, Research Ethics Board

/lms
Encl.

cc: Dr. C. Nelson, Supervisor

955 Oliver Road Thunder Bay Ontario Canada P7B 5E1 www.lakeheadu.ca

APPENDIX B

Lakehead
UNIVERSITY

School of Social Work

Tel. (807) 343-8576
Fax (807) 346-7727

Dear Participant,

Thank-you for volunteering to participate in a study involving respite services and caregiver stress. I am a graduate student in the School of Social Work at Lakehead University. My graduate advisor for this thesis study is Dr. Connie Nelson. The title of the study is: *Alzheimer Disease Caregivers: Respite Use and Stress Levels among Support Group Members.*

As a caregiver who is involved in a support group, you may or may not choose to use respite services for various reasons (for example, lack of availability). Respite services are available in some communities to provide a break for you as a caregiver. For more information on respite care, a definition is provided on the following page.

The purpose of this survey is to see if there is a connection between use of respite care and the degree of stress that you may experience as a caregiver who is also involved in a support group. This study is significant, as it will provide the Alzheimer Societies across Northern Ontario information to help them better serve those who need help dealing with the impacts of caring of those who have Alzheimer Disease. Additionally, the information from these surveys will outline barriers that may exist for you as a caregiver living in Northern Ontario. As a result, these surveys may help to build changes in policy that will cater to your needs as caregivers.

In order to carry out this study, I ask that you fill out the following survey, which will take approximately 20 minutes of your time. All answers are acceptable and will be valued. No names are needed on the survey and all answers are strictly confidential. As you are a volunteer in this research you have the right to withdraw at any time. If you choose to withdraw this will have no effect on the services that you are currently receiving or will receive in the future. All surveys will be kept in secure storage in the School of Social Work at Lakehead University for seven years.

Caregiving can be very stressful and answering this survey may be the catalyst for rethinking some of these challenging aspects of caregiving. As a result, if any questions or concerns arise involving this study feel free to contact myself using the information provided below or speak to your local Alzheimer Society support group leader. The benefit of your participation will help to create a deeper understanding of your unique experience as a caregiver and will add to existing knowledge around the needs and experiences of Alzheimer caregivers.

A copy of the results will be made available at your local Alzheimer Society chapter by May 2004. If you have any questions or concerns feel free to e-mail or contact myself directly at the School of Social Work at Lakehead University at the number listed below.
Thank you for your time and cooperation.

Sincerely,

Kerry Kuluski

Kerry Kuluski
e-mail:
phone: (807) 343-8576

APPENDIX C

"Alzheimer Disease Caregivers: Respite Use and Stress Levels among Support Group Members"

SURVEY

DIRECTIONS:
Please answer the following questions as honestly as possible. Place an X or a checkmark in the appropriate box. Some questions may require you to provide an answer. Lines will be provided for you to answer in sentences or a few words.

DEFINITIONS:
The following definitions may help you understand the terms "caregiver stress" and "respite services." Please read the following definitions before filling out this survey.

Respite Services: A program for care receivers with the aim of providing a break for the caregiver. There are generally three types of respite care:

1. Adult day programs- care is provided outside of the home in a facility in which meals and activities are provided in a supervised environment during the day.
2. In home respite- care is provided in the home during the day or at night.
3. Institutional respite- the care receiver is admitted into a long-term care facility for a specific time period (ie: a few days to a few months) with plans to return home.

Caregiver Stress: Caregiving is a unique experience for all. As a result, all caregivers may interpret caregiver stress differently. However, as identified in the 1999 Alzheimer Awareness Campaign the ten signs of caregiver stress are as follows:

1. Denial that the person has the disease
2. Anger at the person with the disease and others
3. Emotional sensitivity
4. Social withdrawal
5. Depression
6. Lack of sleep
7. Lack of concentration
8. Exhaustion
9. Anxiety
10. An increase in health problems

- Any or all of these signs may be experienced

1. Gender

☐ Male

☐ Female

2. Age__________

3. Marital Status

☐ Single

☐ Married

☐ Divorced

☐ Widowed

☐ Other (please specify)____________

4. Employment Status

☐ Full Time

☐ Part Time

☐ Retired

☐ Not employed at this time

☐ Other (please specify)____________

5. How long have you been attending this support group?__________

6. What is your relationship with the care recipient? In other words, the person you are providing care for is your...

☐ Mother

☐ Father

☐ Wife

☐ Husband

☐ Sister

☐ Brother

☐ Friend

☐ Other (please specify) ___________

7. Check which area applies to you. "I am a caregiver for someone who has been diagnosed..."

☐ one year ago or less

☐ over one year and less than five years ago

☐ five years ago or more

8. Do you live in the same household as the person you are caring for?

☐ Yes

☐ No

9. The following information has been taken from resources provided by the Alzheimer Society of Canada. Using the information provided below, indicate which stage of the disease the person you are caring for falls into.

Early Stage

- Mild forgetfulness
- Poor concentration
- Memory problems become obvious in conversation
- In conversation, person has difficulty finding the right words and may be repetitive
- Difficulty learning new things
- Withdrawal from usual activities
- Mild coordination problems
- Mood changes (ie: depression)

Middle/Moderate Stage

- Inability to recognize family and friends
- Disorientation of time and place
- Assistance needed with activities of daily living (bathing, dressing, using the washroom)
- Restlessness (pacing, wandering)
- Changes in appetite and sleep patterns
- Continued mood changes (anxiety, depression, anger, suspiciousness, etc)

Late Stage

- Loss of ability to communicate, remember, or function
- Severe speaking difficulties (may completely lose ability to speak)
- Unable to dress, bathe, etc.
- May become immobile (ie: bedridden)
- Severely disoriented

The person that you care for is in:

☐ the early stage of Alzheimer Disease

☐ the middle/moderate stage of Alzheimer Disease

☐ the late stage of Alzheimer Disease

10. Respite Services can be used by someone who is experiencing:

☐ the early stages of Alzheimer Disease

☐ middle-late stages of Alzheimer Disease

☐ all of the above

11. Check off what types of resources (if any) besides this support group, that you have used.

☐ Respite Services

☐ Homemaking Services (ie: cleaning and/or nursing care)

☐ Regular assistance from friends or other family members (2 or more times a week)

☐ Other (please specify in the space provided below)

IF YOU HAVE USED RESPITE SERVICES PLEASE ANSWER THE FOLLOWING. IF YOU HAVE NOT, PLEASE SKIP TO QUESTION 12.

a. The following chart examines levels of use for different types of respite care (adult day programs, in home respite, and institutional respite). Please rate your level of satisfaction for the respite program(s) you have used:

Respite Program	**Level of Satisfaction**				
Adult Day Program	**Very Unsatisfied** 1	**Unsatisfied** 2	**Undecided** 3	**Satisfied** 4	**Very Satisfied** 5
In Home Respite	**Very Unsatisfied** 1	**Unsatisfied** 2	**Undecided** 3	**Satisfied** 4	**Very Satisfied** 5
Institutional Respite	**Very Unsatisfied** 1	**Unsatisfied** 2	**Undecided** 3	**Satisfied** 4	**Very Satisfied** 5
Other (please specify)________ ________________ __________	**Very Unsatisfied** 1	**Unsatisfied** 2	**Undecided** 3	**Satisfied** 4	**Very Satisfied** 5

b. If you are currently using respite, how often do you seek these services? Please check the one that best describes your level of use:

☐ On a daily basis

☐ On a weekly basis (1-6 days a week)

☐ On a monthly basis (one or more times a month)

☐ On an yearly basis (one or more times a year)

☐ Other, please explain in the space provided below:

c. If you are no longer using respite services, please explain why in the space provided below.

d. Please indicate what you liked or disliked about the service(s) in the space provided below.

Please go to question 13

12. Please check off ALL of the appropriate answers: "I chose not to use respite services because of..."

☐ Financial limitations

☐ Limited or no information about respite services (unaware of respite services).

☐ No interest in using respite services

☐ Lack of transportation to respite service

☐ Respite services were not available in my home community

☐ Other (Please specify in the space provided below)

13. How did you hear about the availability of respite services?

☐ A support group (such as the one you are attending)

☐ Physician or other medical personnel

☐ A friend, family member, neighbour, etc.

☐ I was unaware of the existence of respite care

☐ Other (please specify in the space provided below)

14. The chart below has a list of different activities (in the left-hand column). Use the scales provided (in the middle and right-hand column) to indicate how often you took part in the activities before you became a caregiver and how often you presently take part in the following activities.

Activity	**Before I became an Alzheimer Caregiver I would...**	**Since I have been an Alzheimer Caregiver I...**
Visit Friends	**Never** 1 **Sometimes** 2 **Often** 3	**Never** 1 **Sometimes** 2 **Often** 3
Spend time with other family members	**Never** 1 **Sometimes** 2 **Often** 3	**Never** 1 **Sometimes** 2 **Often** 3
Run errands	**Never** 1 **Sometimes** 2 **Often** 3	**Never** 1 **Sometimes** 2 **Often** 3
Watch television	**Never** 1 **Sometimes** 2 **Often** 3	**Never** 1 **Sometimes** 2 **Often** 3
Work longer hours (outside of the home)	**Never** 1 **Sometimes** 2 **Often** 3	**Never** 1 **Sometimes** 2 **Often** 3
Complete household tasks	**Never** 1 **Sometimes** 2 **Often** 3	**Never** 1 **Sometimes** 2 **Often** 3
Partake in self-care activities (read, nap, etc)	**Never** 1 **Sometimes** 2 **Often** 3	**Never** 1 **Sometimes** 2 **Often** 3
Exercise (ie: walk, take a yoga class, run, etc)	**Never** 1 **Sometimes** 2 **Often** 3	**Never** 1 **Sometimes** 2 **Often** 3

15. To what degree do you agree/disagree with this statement?
"Respite services tend to be more beneficial if used before an emergency/crisis situation arises. In other words, before the caregiver reaches burnout."

☐ Strongly Agree

☐ Agree

☐ Disagree

☐ Strongly Disagree

16. Please rate the following question as it applies to you: ***"I have difficulty asking for help in a situation where I feel stressed."***

☐ Strongly Agree

☐ Agree

☐ Disagree

☐ Strongly Disagree

17. In the last month, how often have you felt that you were unable to control the important things in your life?

Never	Almost Never	Sometimes	Fairly Often	Very Often
0	1	2	3	4

18. In the last month, how often have you felt confident about your ability to handle your personal problems?

Never	Almost Never	Sometimes	Fairly Often	Very Often
0	1	2	3	4

19. In the last month, how often have you felt that things were going your way?

Never	**Almost Never**	**Sometimes**	**Fairly Often**	**Very Often**
0	1	2	3	4

20. In the last month, how often have you felt difficulties were piling so high that you could not overcome them?

Never	**Almost Never**	**Sometimes**	**Fairly Often**	**Very Often**
0	1	2	3	4

21. Here is a statement regarding caregiver stress: *"The more resources a caregiver makes use of the less stress he or she will experience."*

☐ Agree

☐ Disagree

☐ No Opinion

22. As a caregiver of someone experiencing Alzheimer Disease what types of services would you like to see in the future?

23. Rate your overall experience as a caregiver so far:

☐ Very stressful

☐ Stressful

☐ Unstressful

☐ Very unstressful

24. If you answered unstressful or very unstressful, please skip to question 25. If not please answer the following:

Stress experienced while caregiving may be different for all caregivers. To value your unique experience, please describe what may have contributed to your stress in a few words or sentences below.

25. The following is a question about caregiver stress. You may not have an opinion on this statement, if so indicate below. Here is the statement; *"Caregiver stress tends to increase as the health of the care receiver decreases."*

☐ Agree

☐ Disagree

☐ No Opinion

26. In a few sentences, how would you describe your experience as a caregiver?

This is the end of the survey! Thank-you for your time and cooperation!

APPENDIX D

John D. and Catherine T. MacArthur Research Network on Socioeconomic Status and Health

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Perceived Stress Scale- 4 Item

Instructions: The questions in this scale ask you about your feelings and thoughts during the last month. In each case, please indicate with a check how often you felt or thought a certain way.

1. In the last month, how often have you felt that you were unable to control the important things in your life?

___0=never ___1=almost never ___2=sometimes ___3=fairly often ___4=very often

2. In the last month, how often have you felt confident about your ability to handle your personal problems?

___0=never ___1=almost never ___2=sometimes ___3=fairly often ___4=very often

3. In the last month, how often have you felt that things were going your way?

___0=never ___1=almost never ___2=sometimes ___3=fairly often ___4=very often

4. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

___0=never ___1=almost never ___2=sometimes ___3=fairly often ___4=very often

This scale can be found in the following articles:

Cohen, S., Kamarck, T., Mermelstein, R. (1983). A global

ttp://www.macses.ucsf.edu/research/Psychosocial/notebook/PSS4.html

measure of perceived stress. *Journal of Health and Social Behavior*, *24*, 385-396.

Cohen, S., & Williamson, G. (1988). Perceived stress in a probability sample of the United States. In S. Spacapam & S. Oskamp (Eds.), *The social psychology of health: Claremont Symposium on applied social psychology.* Newbury Park, CA: Sage.

Perceived Stress Scale Scoring

PSS-4 scores are obtained by reverse coding the positive items, e.g., 0=4, 1=3, 2=2, etc. and then summing across all 4 items. Items 2 and 3 are the positively stated items.

The PSS was designed for use with community samples with at least a junior high school education, The items are easy to understand and the response alternatives are simple to grasp. Moreover, as noted above, the questions are quite general in nature and hence relatively free of content specific to any sub population group. The data reported in the article are from somewhat restricted samples, in that they are younger, more educated and contain fewer minority members than the general population. In light of the generality of scale content and simplicity of language and response alternatives, we feel that data from representative samples of the general population would not differ significantly from those reported below.

Conditions of Scale Use

Permission for use of the scale is not necessary when use is for academic reseach or educational purposes.

If you need written permission, please write the letter with a line for signature, along with a self addressed, stamped envelope,and send to:

Laurie Nelson
Department of Psychology
Carnegie Mellon University
5000 Forbes Avenue

Pittsburgh, PA 15213
or email your request with your complete address included:
lanelson@andrew.cmu.edu

(Close this window to return to *Measures of Psychological Stress.*)

Contact: Judith Stewart
Revised 17 February 2000

APPENDIX E

Demographic Information of Caregivers

Caregiver	*Age and Gender*	*Marital Status and Relationship to Care Receiver*	*Employment Status*	*Does care receiver live with caregiver?*
1	63 Female	Married Caring for mother	Retired	No (care receiver lives in long-term care)
2	62 Female	Married Caring for mother	Retired	No (care receiver lives in long-term care)
3	62 Female	Married Caring for mother	Retired	Yes
4	75 Male	Married Caring for wife	Retired	No
5	64 Male	Married Caring for mother	Part time	No
6	? Male	Married Caring for father	Part time	No
7	66 Female	Married Caring for husband	Retired	Yes
8	41 Male	Single Caring for father	Full time	Yes
9	? Female	Married Caring for husband	Retired	No (care receiver lives in long-term care)

10	62 Female	Divorced Caring for mother	Not employed at this time	No (care receiver lives by self)
11	75 Male	Married Caring for wife	Retired	Yes
12	78 Female	Married Caring for husband	Retired	Yes
13	77 Male	Married Caring for husband	Retired	Yes
14	76 Female	Married Caring for husband	Retired	Yes
15	63 Female	Widowed Was caring for mother	Retired	No (care receiver deceased)
16	56 Female	Divorced Was caring for mother	Other (Rental Landlord)	No (care receiver deceased)
17	44 Male	Married Caring for mother	Other (Casual hoping for full time)	No (care receiver lives in long-term care)
18	67 Female	Married Caring for husband	Retired	No (care receiver lives in long-term care)
19	84 Male	Widowed Was caring for wife	Retired	No (care receiver deceased)
20	47 Female	Married Caring for father	Full time	No (care receiver lives in long-term care)

21	76 Female	Married Caring for husband	Retired	No (care receiver lives in long-term care)
22	62 Female	Married Caring for mother	Retired	No (care receiver lives in long-term care)
23	55 Female	Married Caring for mother	Full time	No (care receiver lives in long-term care)
24	55 Male	Married Caring for father	Full time	No (care receiver lives in long-term care)
25	66 Male	Married Caring for mother-in-law	Retired	No
26	56 Female	Married ?	Full time	Living arrangements unknown
27	58 Female	Widowed Was caring for mother	Part time	No (care receiver deceased)
28	77 Male	Widowed Caring for grandparent	Retired	No (caregiver and care receiver live separate)
29	47 Female	Married Caring for father	Not employed at this time	No (care receiver lives in long-term care)
30	70 Male	Married Caring for husband	Retired	Yes
31	74 Female	Married Caring for Husband	Retired	Yes

32	70 Female	Married Caring for husband	Retired	Yes
33	? Female	Married Caring for husband	Retired	Yes

APPENDIX F

Open Ended Responses

Question:
"As a caregiver experiencing Alzheimer Disease, what types of services would you like to see in the future?"

Caregiver	Caregiver Response
2	"Educate people-doctors, nurses. People suffering from Alzheimer's have feelings-they should not be treated like dogs. A bit of patience and compassion goes a long way."
5	"More staff in homes for personal care."
8	"Increased availability of respite services."
9	"I am very satisfied that what is out there is adequate. The only problem is that too many caregivers either do not or cannot (due to pressure from the one being cared for) make use of the available services."
10	"Transportation for caregivers and care recipients for shopping, doctors appointments, etc., for caregivers with no vehicles."
14	"Increase: Number of beds/openings available; wider choice of facilities. More nurses-gerontology training."
15	"An overnight day care, housekeeper (part-time).
16	"A vigorous attempt to provide education about this disease to family physicians, also to the general public. Social get togethers for those with this disease and their caregivers-for interaction and sharing."

17	“More volunteers to support Alzheimer people in the community. Or bring shops to institutionalized people. An educational link where caregivers can leave a legacy of caregiving situations so that others may use the information and grow…”
19	“More in-home care. More intense doctor care and input.”
20	“One on one care for Alzheimer patient, better physician space for personal visits, cheaper subsidized nursing home space, private rooms.”
21	“I would like to see the staff in old age homes have more time and affection and personality. They become very childish and need soft talking to. The people are too busy and not enough of them to spend times with the patients and have more patience with them.”
22	“The availability of respite care in our area is inadequate and not readily available. The need for care is an issue. Availability of respite caregivers willing to spend time with the resident when caregivers need a day to relax”.
23	“More time for personal care workers in home to spend time with resident- not just for needs (feeding/changing/bathing) but social part of day. Even 1 hour a day in intervals just to spend with resident- talking/walking?”
24	“More activities in long term care facilities, better area’s for family gatherings at long-term care facilities, more staffing, possibly more government funding.”
26	“Knowledgeable and informed source for everyday coping, and future planning, ie, placement is required and what to expect. Monthly updates on health both mental and physical of loved one, what resources are available besides busy doctors.”

27	"Improved (more hours) respite hours, volunteer companion, short-term respite beds."
29	"Respite services in nursing home, visiting on a regular basis (3 to 4 times a week sometimes difficult). If you know a respite person would visit it would give you a day off."
30	"More meetings or gatherings for caregivers."
32	"More government money for Respite."

Question:
"Stress experienced while caregiving may be different for all caregivers. To value your unique experience, please describe what may have contributed to your stress in a few words or sentences below."

Caregiver	Caregiver Response
1	"Just the fact that mom does not know me or what I do for her. Can't acknowledge me at all. It's just unfair for such a loving and caring women to end up like a vegetable, and I can't do anything about it."
2	"Seeing my mother deteriorate and not being able to do anything about it."
8	"Lack of sleep is the big one."
9	"Mostly lack of sleep due to worrying about what my husband was doing."
10	"Legal hassles with my brother wanting to sell my mothers house when she is saying no to. Lot's of running around trying to straighten things out and work for my mom's best interest. Exhaustion."
11	"Denial from my husband, irritability, anger, repetition, no help from family or friends so far. I try to manage on my own."

12	"Family and friends seem to shy away from people with dementia. When they do come around, which my husband really enjoys, he is at his very best. Then they don't understand how I feel so stressed."
15	"Learning to lie to my mother. I had no one on the family to help or hinder, ie, I was an only child."
17	"You try harder to work plus be a caregiver. You try to think for the individual, you are so busy thinking 'what if' that your mind does not rest. Guilt sets in when the client blames you fro placement. You keep going due to family obligations, not eating, nor sleeping properly combines to cause 'crash and burn' effect. You do not find outlets for your crisis i.e., exercise, counseling, instead you hide within, Resistance to admit that you need to take a step and seek a little help puts you at a crisis."
19	"Continued complete care at all hours day and night, causing lack of rest and physical stress."
20	"Having to take over family business, father has difficulties coming to terms with understanding his condition (organic brain disease), very little family participation/assistance, unattractive nursing home/physical setting cold and sterile."
21	"I find it hard when I visit my husband and I find he looks so pitiful and would need more compassion from workers and more activity. There is not enough things for them to do. More music, more woodworking and bands to play music. I'm very sure if volunteers would come and play cassette tapes in the afternoon in the dining area people would all be out there. They need to be entertained.

22	“Mom enjoyed independent living with help until 90 years old. Just seeing our mother in this state and stage of her life is very stressful. She has been a very good mom and having had to place her in a facility was extremely stressful. Although unaware of her surroundings, most of the time she recognizes her children but sometimes remembers use younger than we are.”
23	“Needing to be there, visit more often, guilt that I cannot look after her at home.”
26	“The shock and upset of watching the once alert, loving, intelligent person losing mental and physical functions-and the feeling of helplessness I feel when I was once able to do so much to ease this terrible journey we are both experiencing.”
27	“24 hour care and supervision need for creative ideas as symptoms and behavior change, managing challenging behavior, in the advanced stages resistance to care and the physical strength needed to care for your loved one. The early grieving fro a loved one who is slowly wasting away. The lack of personal life.”
28	“I worry about what the future will bring. I am doing fine so far, but I wonder if the demands from my own family become greater, will I still be able to do a good job.”
29	“My highest stress level with my father in a home is upon visiting, question he always asks is “Why and I here and when am I going home?”
31	“Repetitious questions-argumentative-always wants me around, mood swings.”
32	“Lack of sleep.”

Question:
"In a few sentences, how would you describe your experience as a caregiver?"

Caregiver	Caregiver Response
2	"It is very stressful to see your loved one 'die twice.' However you must learn to laugh at certain happenings and enjoy and cherish every moment-every smile."
3	"Each day represents a new outlook and approach to the care you need to give, and care you need to give yourself. Caregiving teaches priorities, to appreciate the 'little things'- like a hearty laugh with the Alzheimer person, family member friend or stranger!! Of course, there are moments one would like to walk away but it is like a job, it gets done. Opportunity to do 'on the spur of the moment' activities are limited."
5	"A real eye opener to the great services available."
8	"Difficult but necessary."
9	"The hardest and most frustrating days of my life. When my husband was home. Now he is in the hospital, very saddening and depressing to see him in such a horrible state, with no quality of life."
10	"I have the Lord in my life. Without this I don't know what I'd do. It's a very lonely place; others don't seem to want to help or even care other than short social visits. Very exhausting."
11	"The experience has been the most difficult thing that I have had to handle. I feel very lonely at times. This disease has changed our lives in many ways and I feel this will only get worse."

12	"I find it hard to do everything even to making all the decisions. I feel that he should be able to do a little bit and try encouraging him to do so. All he really wants to do is sit or lay in bed most of the time sleeping. If I ask him to do something he says he can't or doesn't feel well."
15	"Awful. I had to watch her die day by day for too many years. Just before mom dies a woman told me if I had taken better care of my mother 'she wouldn't be dying' with Alzheimer's if I had been a better caregiver."
16	"A journey that my mother and I experienced together where we faced anger, emotional sensitivity, exhaustion, anxiety and more important love, respect and caring. Being a caregiver for my best friend, 'my mother' I was able to shower her with the love, respect and genuine caring that she bestowed to me. Together we daily faced the trials and tribulations of this disease and we said our good-byes-we won- our undying live is still our together."
17	"As a caregiver it is important to be properly informed i.e., long-term care vs. Respite. Also what services exist in the community that may allow individuals to live in their homes. As a caregiver, I admit that I experienced the hard reality of 'crash and burn.' It is exhausting, and frustrating. The repetition of information, the energy expended trying to provide an outing can be very consuming. You forget to make and take time for yourself. Your ability to balance time is thrown out the window. I support others with Alzheimer's as part of my employment yet find my most difficult client to be the one closest to me."

18	"My experience as a caregiver was very stressful until he was put in the hospital and I was told I should not bring him home. However, since I have spoken with and learned of the problems others have had that I didn't feel somewhat lucky. All in all it is no picnic! I felt a great duty to look after my husband to the best of my ability. It was great help to admit the facts and deal with them. I found people were sensitive and caring."
19	"Though at times very stressful, it was a joy and privilege to help someone you dearly loved-and I would be glad to do it over."
20	"Extremely stressful, unhappy times, stretched beyond abilities, fighting a losing battle, worried about inheriting this or other related diseases."
21	"They sure need meeting and love and caring people to talk with. But I'm sure if the volunteers has a cassette player on each day for 1 to 2 hours the people there would really be much happier because they have something to do. They're too old to get into T.V. and they just lie there when there's music, the activity room is full to the brim with happy people. Please give them some entertainment, every day they deserve it, ok."
22	I feel very special for having my mom for such a long time. Our dad passed at 60 in 1967. I admire her for accomplishing so much after he passed. Every day I have mom is a gift for me and our time with her is special although very stressful as I can't fulfill her wish to 'go home.'
23	"Very gratifying, while being stressful and frustrating at times."

24	"I seen this happening slowly to my father over the last year. I am very realistic person always facing the problem head on. This is why I have learned to accept things the way they are and live with them. I have used this philosophy all my life and it works for me."
25	"Part of life, 'pick up your cross and follow me."
26	"A willing and honored responsibility to one who is loved so deeply. A thankfulness that I am able to be here. A humbling experience. A sense of peace at times when I see the calmness and joy at times. At times hopeless and helpless feeling. A gift of unfailing love."
27	"I cared for my mother for nine years. Each day brought its own challenges. I learned love, patience and an understanding of the processes of the disease. I was fortunate to have a good relationship with Alzheimer's Society, CCAC and our respite care worker who guided and supported me along the way. I feel blessed to have been with her to the end. She died at home on Nov. 5 /03."
28	"Sad to watch a person whom you love go from vibrant and dependable to bored, withdrawn and unreliable and knowing it will only get worse."
29	"No one knows what it is like to have a family member suffer with Alzheimer's and to be in a home with no quality of life, wanting to die, unless they have experienced it. What a difficult thing especially when it is a person who loved and took care of you so well and continued to do so until his terrible disease attacked him. Also when the other parent is still living you now have 2 parents to take care of and 2 homes to visit. Your poor mother out of guilt it going to the home everyday. You ask yourself which one will live the longest. Her stress level is high she is 76 and he is 80."

30	“Need family help more. Less social life.”
31	“I really miss the discussions about every day activities. Always seems to end up in an argument. So the least said the better the mood. Also the lack of his doing small tasks.”
32	“Very demanding. You are on duty 24/7. The Day Program my husband attends 2 times a week is a life saver. Just to be able to go for a walk or shopping alone is a treat as he is slowing down all the time and he gets very disoriented. Our support group is also very important to me.”
33	“My stress is up and down. It depends if my husband day and mood.”