Exploring the Experiences of Male Spousal Caregivers for Their Wives with Alzheimer Disease in Their Homes:

The Lived Experience and the Men’s perception of Support Groups

Gloria A. Charles

Department of Graduate and Undergraduate Studies in Education

Submitted in partial fulfillment of the requirements for the degree of Master of Education

Faculty of Education, Brock University

St. Catharines, Ontario

© March, 2002
Abstract

This research is qualitative in nature and has explored, by means of interviews, the experiences of 10 men in their roles in caring for their spouses with Alzheimer Disease (see glossary) in their homes. Additional data were collected by attending 3 formal support group meetings and one informal meeting of a group of men who brought their wives to a support group meeting for their wives with AD. The data retrieved supported the assumption that education about the disease, utilization of formal community support services, and attendance at caregiver support groups or programs can assist healthy male caregivers in caring for their wives with AD in their homes.
Acknowledgments

This Study is dedicated to the memory of my parents, George and Etheline Glasgow, who taught me to set realistic goals and to focus on achieving them. I would like to extend my appreciation to St. Joseph’s Healthcare Administration, the Sisters of St. Joseph’s, and the St Joseph’s Healthcare Foundation for their support during the period of my studies. Also, thanks to the Nursing Education Initiative through the Registered Nurses Association of Ontario (RNAO) and the Hamilton Chapter of RNAO for their support. Thanks also to the staff at the Halton/Wentworth Alzheimer Society, the Victorian Order of Nurses in the Hamilton/Wentworth and Halton regions, the Health for Older Adult Program at the Centre for Ambulatory Health Services, and St. Joseph’s Healthcare in Hamilton for assisting me in obtaining participants for this study. A special thanks to Dr. Jennifer Skelly, my mentor and a member of my thesis committee, for her ongoing encouragement and support, also to my husband, Godwin, and children, Carlos, Culver, and Tanya, and other family members and friends for their support and understanding during this process. I would also like to thank Dr. Carmen Schifellite for acting on my thesis committee and for providing guidance for the pilot study, which was the precursor of this study. Finally, a special thank you to Dr. Richard Bond who, as a thesis advisor, gave me support, encouragement and guidance, and for providing an opportunity for independent growth and flexibility.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Abstract</th>
<th>ii</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acknowledgments</td>
<td>iii</td>
</tr>
</tbody>
</table>

**CHAPTER ONE: INTRODUCTION**

<table>
<thead>
<tr>
<th>Statement of the Problem</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Background to the Problem</td>
<td>2</td>
</tr>
<tr>
<td>Rationale of the Study</td>
<td>4</td>
</tr>
<tr>
<td>Outline of Subsequent Chapters</td>
<td>5</td>
</tr>
</tbody>
</table>

**CHAPTER TWO: REVIEW OF THE LITERATURE**

<table>
<thead>
<tr>
<th>Introduction</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult Learning Principles</td>
<td>7</td>
</tr>
<tr>
<td>Theory of Caring</td>
<td>9</td>
</tr>
<tr>
<td>Death and Dying</td>
<td>12</td>
</tr>
<tr>
<td>Bereavement</td>
<td>17</td>
</tr>
<tr>
<td>Stress Theory</td>
<td>21</td>
</tr>
<tr>
<td>Family Caregiving Systems</td>
<td>26</td>
</tr>
<tr>
<td>Gender Differences in Caregiving</td>
<td>27</td>
</tr>
<tr>
<td>Support Groups and Respite</td>
<td>28</td>
</tr>
<tr>
<td>Respite</td>
<td>30</td>
</tr>
</tbody>
</table>

**CHAPTER THREE: RESEARCH METHODOLOGY**

<table>
<thead>
<tr>
<th>Introduction</th>
<th>31</th>
</tr>
</thead>
</table>

**PILOT STUDY**

| Research Methodology                          | 32|
|Methodological Limitations                     | 33|
|Clinical Assumptions                           | 34|
|Limitations of the study                       | 35|
|Selection of Respondents                       | 37|
|Selection Criteria                             | 37|
|Instrumentation                                | 38|
|The Process of data collection                 | 38|
|The Interview                                  | 39|
|Participant Observer                           | 39|
|Observations                                   | 39|
|Interviews with the 3 Male Caregivers          | 40|
Methodological Assumptions ........................................... 43
Analysis ........................................................................... 44
THE THESIS STUDY: INTRODUCTION ................................ 47
Selection of Respondents ................................................. 47
Selection Criteria .............................................................. 48
Instrumentation ............................................................... 49
The Process ...................................................................... 49
Interview .......................................................................... 50

CHAPTER FOUR: RESULTS OF THE STUDY ......................... 53
Introduction ....................................................................... 53
Data collected from attending the Support Group Meetings ... 54
Identified themes from data collection .............................. 58
Samples of question and answers ..................................... 59

CHAPTER FIVE: DATA ANALYSIS ....................................... 61
Compensating for spousal deficits .................................... 61
Learning to live without conversation,
intimacy and independence ............................................ 65
Grieving the loss of the marital relationship ...................... 68
The men’s perception of Support Groups ......................... 71
Other community resources utilized ................................. 73
Suggestions for use of the data retrieved ......................... 74
Suggestion for educating informal/formal caregivers .......... 75
Supporting the literature .................................................. 79
Reflection ......................................................................... 81
Conclusion ........................................................................ 81

References ........................................................................ 83
Appendix A: What is Alzheimer’s disease? ......................... 92
Appendix B: Signs of Alzheimer’s disease ......................... 94
Appendix C: Stages of Alzheimer’s disease ....................... 97
Appendix D: Diagnostic and Statistical Manual of Mental Disorders
DSM – IV ......................................................................... 99
Appendix E: Questions for the Interview ......................... 101
Appendix F: Consent Form ............................................... 103
Appendix G: Copy of the first letter to the agencies ............ 105
Appendix H: Copy of the second letter to the agencies ....... 106
Appendix I: Copy of the first letter to the participants ....... 107
Appendix J: Watson’s carative factor ............................... 108
| Appendix K: | Caregiving System ................................................................. | 110 |
| Appendix L: | Copy of final letter to the agencies & participants .......................... | 111 |
| Appendix M: | Maslow’s Hierarchy of needs ......................................................... | 112 |
| Appendix N: | Educational sessions ........................................................................ | 113 |
| Appendix O: | Approval Brock ................................................................................ | 114 |
| Appendix P: | Approval St. Joseph’s McMaster University ........................................ | 115 |
| Appendix Q: | Comparison of age and gender caregivers & recipients ......................... | 116 |
| | Cases of Dementia in the 65+ age group in Canada ............................... | 117 |
| | Percentage of persons with AD in institutions by regions 1991.............. | 118 |
| | Comparison of the number of cases of Dementia in 1991 ....................... | 119 |
| | and a prediction for the coming years ................................................ | 120 |
| | Stage I: During caregiving .................................................................. | 120 |
| | Community and Institutionalized persons 65+ ..................................... | 121 |
| | suffering from AD ............................................................................ | 121 |
| | Percentage of persons 65+ with AD in the community and .................... | 122 |
| | in institutions by regions 1994 ....................................................... | 122 |
| Appendix R: | Glossary of terms ............................................................................ | 123 |
| Appendix S: | Data collected from the interviews .................................................... | 126 |
What is caregiving? Garity (1997) states “Caregiving is the provision of direct or managed services by one family member to another” (p. 171). One person assumes responsibility for another, providing for the necessities of life, in a safe, compassionate, knowledgeable, supportive, and financially manageable fashion. Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch (1995) refer to caregiving as the “Unexpected Career.” In describing the concept of career beyond the formal workplace they stated: “The concept of career refers to any sphere of activity in which people move through a series of related and definable stages in a progressive fashion, moving in a definite direction or towards a recognizable endpoint or goal, the unfolding of a social role.” (p.18). Alzheimer Disease (AD) is a progressive disease with a poor prognosis, consisting of several stages, each worse than the previous one (Appendix B, signs of AD and Appendix C, stages of AD). However, it is difficult to diagnose in the early stages, as the symptoms are similar to normal cognitive decline (see glossary for cognitive decline in normal aging). This caregiving career requires caregivers to restructure their responsibilities and activities continually as changes occur through the stages of the disease. The caregiving career is driven by the caregiver’s ability to continue in the role, and this requires education, support from family, formal community service providers, and a healthy caregiver. Caregivers are therefore vital to the health and well-being of the patient, as they provide the necessary duties to their relatives, while also taking care of themselves.

Caregiving at times can be direct or indirect, meaning that it can be hands-on care or care provided in a supportive manner. Family caregivers provide both direct (performing the care) and indirect care (care provided by paid caregivers), making decisions that immediately affect the care receiver’s life or future planning for both of their lives. In Chapter Two, the theory of caring is discussed as presented by Swanson (1991), Ryden (1998) and Piccinato and Rosenbaum (1997). Although many studies have identified the need to care for the informal (family) caregivers of patients with AD,
as many of these caregivers become depressed, complain of ill health and tend to neglect their well-being, further research is still needed in exploring their experience (Connell 1994; Garity 1997; Lynch 1998; Rose-Rego, Strauss & Smyth 1998; Smerglia & Deimling 1997; Wells & Kendig 1997). This chapter presents the statement of the problem, discussion of the background to the problem, the rationale for the study, and limitations to the study. A glossary of terms and an outline of the subsequent chapters are provided.

Statement of the Problem

This study investigated the experiences of 10 men who provide care for their wives with AD in their homes: The lived experience and the men’s perception of Support Groups. Within this context, the study investigated the following foci:

♦ Learning to live without conversation, intimacy and independence
♦ Grieving the loss of the marital relationship
♦ Compensation for spousal deficits

Data retrieved were used to:

(i) identify areas in which agencies may enhance existing services;
(ii) formulate a strategy to enable caregivers to maximize the use of resources
(iii) formulate a teaching plan to assist caregivers in dealing with the diagnosis, understanding the progression of the disease, and to be able to cope with the presenting behaviors in maintaining a high quality of care in the home.

(Appendix N).

Background to the Problem

In my practice as a Nurse Clinician in Geriatrics, I am encountering more and more men caring for their wives with AD. Accepting and dealing with the diagnosis of AD, the stress in caring for their spouses, and the reluctance to access and accept resources seem to be issues of male caregivers in coping with the disease. Traditionally, men are seen as being strong, knowledgeable, and self-sufficient; however, caring for
someone with AD requires a team approach. Factors such as family size, the roles of members in the family, the social support systems available, financial burden and availability of formal services may impact and make a difference in the caregiving role (Shaw et al, 1997). Distance and stress in caring for their family may be issues preventing other family members from providing the support needed by some of these caregivers.

Women traditionally performed the role of caregiving, and in some cultures, it is still uncommon for a man to look after his ailing wife at home; instead, this responsibility falls upon the wife’s side of the family (Spiriopoulos, Brown, & Wright 1999). However, in many societies, including the Western society, both women and men function as informal caregivers (see glossary). Men are acquiring new skills through increasing involvement in childcare and in caring for spouses and aging parents (Mackie 1995). Social class may be a factor in the provision of adequate care for persons with AD in their homes, as the upper-class families and many others are able to purchase caregiving services in addition to what is available to everyone. Many retired spouses do provide care for their spouses if their health is not compromised, and at times are very reluctant to accept services from community service providers. Single sons more than married sons, brothers, and male friends seem to be performing this role and are caring for loved ones with various illnesses, including Alzheimer’s Disease (Appendix A for a summary of AD). As a result of hospital restructuring and shrinking health care dollars, there has been an increase in the number of people being cared for in their homes. The person’s age, the type of illness, and the complexity of the illness determine the level of care to be provided by formal and informal caregivers and agencies in the community. It is vital that we understand the impact of this experience on informal caregivers and find a way to support them.

The results a nation-wide study in 1991, assessing the health of Canadians over the age of 65, showed that 202,560 Canadians suffer from AD, and was rated as the largest study to collect this type of information (Canadian study 1994). Alzheimer
Canada (2000) also noted that 1 in 13 Canadians over the age of 65 have AD and related dementias and agrees with Ostbye and Crosse (1994) who predicted that the total annual net cost of dementia time in Canada is $3.9 billion. The number of people in Canada with dementia is expected to triple by the year 2031 to over ¾ million people (Alzheimer Society Canada 1999). Elliot (1996) provides us with some information relating the impact of AD in the Canadian society (see Appendix Q). She also provides some predicted information for the number of cases in the community and in institutions across the regions (see Appendix Q). In the Hamilton-Wentworth area, the identified number of dementia cases is approximately 6,781 and is predicted to be 8,531 by the year 2010 and 12,398 by 2028 (Hopkins, 1997, p.3).

Comparing Canada to the United States, AD is the major cause of dementia, and there is urgency in finding a response to this disease (Morrison-Bogorad, 1998). She stated that: “The number of Americans who are age sixty-five and older- an estimated 34 million people- will grow dramatically starting in 2011, when the first baby boomers reach age sixty-five” (p.2). This she sees as an issue, as the prevalence of AD doubles every five years after age sixty-five, and that nearly half of all people age eighty-five and older are thought to have some form of dementia (p.2). One can conclude then, that issues related to AD are in Canada as well as in the United States.

Rationale for the Study

Studies comparing female and male caregivers identify differences in areas like communication and emotions, but nothing is noted about the actual experiences of the spousal caregivers (Marks, 1993). It is very important to explore the needs of male spousal caregivers of patients with Alzheimer’s disease and to determine what resources are being utilized to assist them in their role. The need for this study and subsequent ones was noted in the literature. Spiropoulos, Brown & Wright, (1999) stated: “Recent statistics reveal a growth in the incidence of AD and related dementia amongst the elderly. Although women are more likely than men to develop the disease, there is limited literature available on husbands as caregivers for wives with the disease”. Other
researchers agree and noted that although more and more men are acquiring new skills in caring for spouses and aging parents with a long-term health problem, few studies have investigated male caregivers as a distinct group (Fuller-Jonap & Haley, 1995). They also noted that some gerontologists have forecast an increase in the number of males serving as caregivers, with demographic and social changes that are apparent. Statistics Canada estimated that 1 in 8 Canadians are caregivers: 1.1 million men and 1.6 million women (Frederick & Fast, 1999). Marks, (1993) noted that male spousal caregivers of patients with Alzheimer’s disease were the only group within a longitudinal sample to show increases in depression over time, as they do not communicate and express their emotions as much as women do. Fuller-Jonap and Haley (1995) noted that there are as many male caregivers as there are female, and that male spousal caregivers of Alzheimer’s disease patients are of interest, not only because they have been relatively understudied, but also because they are a group vulnerable to the effects of stress. In a comparative study of the differences in perceived well-being of wives and husbands caring for persons with AD Rose-Rego et al (1998) noted that caregiving husbands may experience the same level of distress as caregiving wives, but may not recognize it and therefore would be less likely to report it.

Outline of Subsequent Chapters

Chapter Two deals with the review of the literature as it relates to theories of caring, stress, coping theory, family caregiving systems, support groups and respite, and adult learning. Other areas deal with comparing genders in caregiving, and specifically in dealing with patients with AD.

Chapter Three deals with the methodology, clinical assumptions, the instrumentation with sample questions, information obtained as a participant observer, and analysis of the pilot study done in 1998. It outlines the research methodology of the study with revision from the pilot study. The methodology, the instrumentation with the questions, analysis of the study, and discussion of the themes derived from the study, including the limitations of the study are discussed also.
Chapter Four provides the data collected throughout the study, obtained by attending the support groups and from the interviews with the male caregivers.

Chapter Five provides an analysis and discussion of the data in the previously identified themes, with recommendations and implications for service providers. A program in assisting patients and caregivers to access and better utilize the services available is suggested. In an attempt to empower caregivers, an outline of a four-session educational program for caregivers of persons with Dementia will be included. This could be delivered in collaboration with other agencies or programs. The conclusion includes suggested topics for future research.
CHAPTER TWO: REVIEW OF THE LITERATURE

Introduction

This chapter reviews various theories that relate to the issues of the caregiver and the caregiving role. These include adult learning principles, theories of caring, death and dying, bereavement, stress, and family caregiving systems. A brief comparison of male and female caregivers is discussed, as well as the effect of support groups and respite in the management of AD.

Adult Learning Principles

Fahey Dealy and Bass (1995) agree with Knowles (1975) that adult learning principles are based on a certain readiness to learn relating to a need perceived by the learner. In their research about professional development of nurses, Fahey Dealy and Bass (1995, p. 32F) stated: “Adult learners prefer problem-centred information rather than subject centred.” These principles can apply to the male spousal caregivers coping with the problems of AD, in that they can apply the information to their own situation immediately.

Levels of Adult Motivation

Adults involved in continuing education have the expectation that they will be successful at the level of their ability. Wlodkowski (1985) describes this first level as expectancy for success + a sense of volition. Adult learners need to be successful and have a positive attitude towards the learning process. Given that AD is a progressive disease with an unfortunate prognosis, caregivers need a lot of encouragement to deal with the daily, sometimes unpleasant, issues. Many of them are not aware of their
capabilities, and therefore are afraid of taking risks for fear of failure. Learners need to set realistic goals and organize a plan of activity to achieve these goals. This concept can also apply to caregivers, who should be assisted by professionals in setting realistic goals when coping with a disease such as AD.

The second level of adult motivation to learn is **expectancy for success + a sense of volition + value**. "Adults may not necessarily enjoy the learning activity, but they take it seriously, find it meaningful and worthwhile, and try to get the intended benefit" (Wlodkowski, 1985, p.100). A good example of this would be a husband assuming the role of the nurturer or primary caregiver, which was previously done by his wife who is now ill. Although difficult initially, learning the chores occurs through trial and error at times if the appropriate support is not available. Brophy (1987) suggests that the expectancy + value theory has guided the development and organization of many strategies relating to learning. He states that "the effort that people will expend on a task is a product of the degree to which they expect to be able to perform the task successfully if they apply themselves; and the degree to which they value participating in the task itself or the benefits or rewards that successful task completion will bring to them" (Brophy, 1987, p. 41). Examples of this would be the satisfaction that these caregivers achieve in their daily task, with or without the support from others. Increased self-esteem, self-confidence, and respect from others are also positive rewards that help these caregivers to persevere in their plight.

The third and last level of adult motivation is **expectancy for success + a sense of volition + value + enjoyment**. At this level, the adult enjoys the learning activity and finds it very valuable, delighting in the success or accomplishment of the
activity. This is demonstrated in the ability of the caregiver to fulfill or meet the basic needs of both himself and his ill spouse. (Appendix M, Maslow's hierarchy of needs).

**Intrinsic Factors and Extrinsic Factors**

These are factors influencing the outcome of all situations. *Intrinsic factors* come from within the person and are the driving forces that influence the person's decision to participate in an activity. Examples of these include the learner's needs: attitude, affect, competence, and stimulation, which are all part of the learner's motivation within the learning process. Many adults receive encouragement and support from the environment in which they function, but they must identify their own need for learning before becoming involved, as this will determine the effectiveness of the process.

*Extrinsic factors* are conditions within the learner's environment that impact on the learning experience. Some of the features of the learning process, like the instructor and safety in the beginning of the learning process, are examples of extrinsic factors. Supportive professionals, family, friends, and even past experiences of the caregivers are all extrinsic factors that can impact on their level of success or failure in the role.

**Theory of Caring**

Swanson's mid-range theory of caring (Swanson 1991). This theory discusses five proposed caring processes. These are as follows:

- **Maintaining belief:** This process involves the caregiver's belief that the person being cared for has the determination and strength to endure the illness and look forward to the future with some form of positive expectation (Swanson, 1991). Unfortunately, current knowledge about AD does not give the patient or the caregiver
this option, as it is termed an incurable disease with an unfavourable prognosis (Ryden 1998).

- **Knowing:** "Belief in the individual- as well as compassion, concern and warmth- are vitally necessary, but these things are insufficient without knowing" (Ryden, 1998, p. 205). Knowing relates to having a good knowledge of the disease process skills required to cope with the disease and knowledge of available resources, which are factors necessary in dealing with the person with AD. Swanson (1991) refers to listening skills, sensitivity to nuances of meaning in the communication of the person being cared for, and competence in observing and interpreting behaviours as prerequisites of the type of knowing needed by caregivers.

- **Being with:** This relates to the caregiver not only being physically present to the ill person, but emotionally present also. Ryden (1998) refers to Swanson's mid-range theory of the caring process of "being with" as providing a sense of security for the person with dementia, who feels secure when the caregiver is always near. However, she points out that the caregiver is vulnerable to being "burnt out."

- **Doing for:** This process gradually gets imposed on the caregiver as the demented person loses the ability to perform instrumental and basic activities. However, Ryden (1998) warns of a premature dependency that can occur as the caregiver assumes even the simplest activities instead of encouraging the demented person to maintain the activities that he/she is capable of doing.

- **Enabling:** Swanson refers to this as a positive caring process that facilitates a smooth transition of a person through the changes in life (Ryden 1998). Education is necessary for both the patient and family in the early stage of AD. This prepares
everyone for the potential unfavourable outcome of the disease, and may result in premature retirement for the patient and the caregiver at times. The positive aspect of this process is that the person with dementia is still able at this stage to make appropriate decisions and convey his/her wishes to family members before losing instrumental abilities (see glossary).

Ryden (1998), agrees with Swanson (1991) in defining caring as a nurturing way that one person relates to another to whom they feel a sense of commitment and responsibility. In exploring the applicability Swanson’s theory, she also refers to caring as the predominant treatment currently available in the absence of a cure for diseases such as Alzheimer’s disease and other terminal illnesses. Nurturing, commitment, responsibility, relating, moral and ethical beliefs are words used by Swanson (1991), Ryden (1998), and Piccinato and Rosenbaum (1997) in their reference to caring, and are also used quite frequently in my practice. However, one has to be vigilant that the outcome of caring is favourable to both the patient and the caregiver.

In reviewing caregiver hardiness within Watson’s theory of human caring in nursing, Piccinato and Rosebaum (1997) identify 10 “Carative” factors (Appendix J), and cited Jennings & Staggers, (1994) in saying that “hardiness has become a popular research concept in nursing” (p. 33). Marckx (1995) also talks about these carative factors in validating the dignity and worth of clients, and states: “creative interventions need to be developed that respect the dignity and worth of the person with dementia and recognize the progressive nature of the disorder” (p. 47). Other research on hardiness, describe it in reference to one’s personality and ability to endure high levels of stress without becoming ill. Many caregivers seem to demonstrate this quality of hardiness,
and it is assumed that men, more than women, tend to use this as an avenue to try to avoid failure. This hardiness helps to make families and caregivers resistant in the encounter with stressful life events (Piccinato & Rosebaum, 1997).

In reference to older caregivers, Piccinato and Rosebaum (1997) state: “As society ages, so do caregivers; it is increasingly common for 65-year-old caregivers to be responsible for aged parents or spouses. These older caregivers often experience depression, caregiver burden, and frustration” (p.32). Although Watson’s theory relates to nurses, it also provides a guideline for the practice of caring in nursing and humans in general as they try to deal with end-of-life situations (Appendix J). This theory also encourages nurses to be vigilant and to equip them with the appropriate knowledge required in providing education, support, and guidance in helping to promote hardiness in caregivers.

Death and Dying

Death and dying or grieving is inevitable processes experienced by patients and their caregivers in dealing with any terminal illness. This area is difficult to discuss, and many professionals and caregivers feel very uncomfortable discussing it. The patient diagnosed with AD may not experience all of the stages of the grieving process, depending on how rapid his/her cognitive status declines; however, the caregiver will. Kubler-Ross (1974) identifies five stages: denial and isolation, anger, bargaining, depression, and acceptance.

- **Stage 1: Denial and Isolation:** Whether this stage is short lived or prolonged depends on the severity and prognosis of the illness. There is usually a temporary state of shock and disbelief, from which they recover slowly. “Denial functions as
a buffer after unexpected shocking news, allows the patient to collect himself, and with time, mobilize other less radical defences” (Kubler-Ross 1974, p. 39).

Commonly used statements during this stage are: “No, not me, it cannot be true” or “there must be a mix up,” or “not my wife or husband” as it applies. Many people may also seek a second opinion by engaging in doctor shopping and would say: “to get a better explanation for my troubles” (p. 38). The health professional also experiences some anxiety prior to informing the patient and caregiver of the illness. Kubler-Ross also seems to believe that professionals do not consider the patient’s readiness for the news, and should be there to listen when the patient is ready to talk. Although denial is seen as a buffer for anyone receiving unpleasant news, it is healthy for one to move on and continue with life and the adjustments to be made. Isolation is also a coping mechanism used by patients and caregivers/families until the diagnosis can be accepted. During this stage, one may decrease involvement in activities to avoid others, and may even avoid other family contact for a period of time. The healthier the patient, the better able is that person to deal with impending death. In this stage Kubler-Ross encourages the availability of someone to engage in conversation at the patient’s convenience, to discuss the illness and to make future plans. In the case of Alzheimer’s disease, both the caregiver and the patient require a lot of support during this stage and on an ongoing basis.

Stage 2: Anger follows the denial stage, with rage, envy, and resentment with statements such as: “Why me” or “Why couldn’t it have been him” (Kubler-Ross 1974, p.50). During this period of being angry, the patient wishes it to be
someone else, and displaces the anger on loved ones in trying to understand or comprehend what is going on. The relatives, however, seem to be angry at the system, including the doctors and nurses caring for their loved one. This period is quite difficult to endure, as nothing seems right and no one (patient or family) has a cheerful disposition. Visits are painful events, with grief and tears, guilt or shame, and result in avoidance of future visits. One of the main problems, Kubler-Ross explains, is that few people place themselves in the patient’s position and wonder where this anger might come from. The anger may come from the sudden interruption of the patient’s life, thinking of unfinished business, having someone else enjoy what he or she should have been enjoying, and possibly dying prematurely. Although a counsellor or priest may be effective in dealing with this anger, it should be when the patient is ready or this would not be a productive venture. Kubler-Ross says that one of the biggest mistakes that professionals and others make in dealing with this angry patient is to take the effects of the patient’s anger personally, therefore losing respect and not trying to understand the patient. Once the patient has the opportunity to vent, the anger slowly subsides and the patient becomes more cooperative.

**Stage 3: Bargaining** is a short period, and little is known about it, however it is an equally important stage. The persons involved (patient & family) realize that they have dealt badly with the sad news by denying it initially, then becoming angry, and now feel that there is an opportunity to bargain with God. They also hope that interventions and treatments will be effective and result in a cure. This type of hope helps them to avoid thinking about the sad facts, wishing that they would not
become a reality. The patient may use statements such as: "If God has decided to take me from this earth and he did not respond to my angry pleas, he may be more favourable if I ask nicely" (Kubler-Ross, 1974, p. 82). Others tend to ask for more time to attend special events or to complete unfinished business. Bargaining is mostly done with God and is kept a secret unless told to a chaplain in a private place. The persons try to promise to be good and change things in return for God’s goodness towards them.

Stage 4: Depression is a stage where the persons can no longer deny the reality of the terminal illness, as there may be more hospitalizations or the need for additional medications and treatments. In the case of AD, the patient also goes through a period of depression early in the disease. This is characterized by hopelessness, weight loss, decreased interest in activities, hoping that others may not observe or know about their deficits. Kubler-Ross (1974) identifies two types of depression: reactive and preparatory. Reactive depression is characterized by the patient’s experience of low self-esteem and low self-concept. Self-worth is also questioned, as the patient realizes that he/she is unable to function in the usual role (e.g., in the case of a mother being unable to care for her children, husband or home). Preparatory depression is especially difficult, as it does not deal with the losses already experienced, but the impending losses. Losses such as independence, valuable items, paying insurmountable medical bills which could not be otherwise paid except by parting with valuables, and accepting assistance from others due to increased stress, as in the case of the caregiver for someone with AD are issues faced by patients and their caregivers. Caregivers and others
need to focus on the positive things in helping those involved to overcome the depression. However, caregivers, especially spouses, moan the loss of the person that their relative once was, and at times find it difficult to cope with the existing person, as in AD. Medications may be necessary to treat symptoms. Kubler-Ross noted that although depression is a difficult stage, it is necessary and beneficial if the patient is to achieve a state of acceptance and peace. She also stated: “Only the patients who have been able to work through their anguish and anxieties are able to achieve this stage” (p.88). Many families may be able to cope if this type of reassurance is shared with them. The depression experienced is the result of many losses, past, present, and future ones.

**Stage 5:** Acceptance is the final stage during which the patient is too weak and tired, dozing a lot, and is now neither angry nor depressed. He/she has had enough time and assistance in working through the previous stages and has gained a certain peace, unless death is sudden. However, acceptance should not be mistaken for a happy stage, but as Kubler-Ross (1974) explains, it is a period of almost a void or numb feeling, too weak to struggle, almost painless, and a sense of wanting to be alone. In the case of AD, the patient may seem physically healthy but has no insight into the reality of the situation; therefore it is the family, and especially the immediate caregiver, who requires support in trying to cope with their loved one’s state. In other cases, it has been noted that the patient seems to comfort family members as he/she seems to achieve the state of acceptance or inner peace before the family members. It should be noted that some patients never achieve this state, and unfortunately fight to the end. During
the final part of this stage, when the patient is no longer engaging in conversation, he/she will still need to be loved and not be left alone. A simple touch of the hands or shoulder reassures the patient that someone is with them. The patient should also be treated with continued respect, and dignity preserved. A minister or pastor is very helpful to the patient during this final stage.

**Bereavement**

In reviewing the literature, Lindermann (1944), noted that grief reaction should be completed within weeks. However, later studies proposed a longer period of up to one year (Ramsay (1979), and Mawson, Marks, Ramm & Stern 1981). Other researchers noted that some individuals bear the consequences of this type of stress for the rest of their lives (Osterweis, Solomon & Green, 1984).

Anticipatory grief, however, is grieving prior to the patient’s death, and this type of grieving occurs in caregivers for patients with AD. Dempsey and Baago, (1998) describe anticipatory grief as “the grief process that takes place in anticipation of the actual loss” (p. 87). They also described anticipatory grief as “a psychological response in a person who is becoming more and more aware, not only of his loved one’s impending death, but of the associated losses of past, present, and future “ (p. 87). Jones and Martinson, (1992), agree with Bass and Bowman, (1990), and Saunders, (1982) that the severity of this period depends on the length and severity of the illness. They also suggested that anticipatory grief helps the caregiver to accept and adjust during the bereavement period, and that sudden or unexpected death of a family member is associated with greater psychiatric illnesses than death following a prolonged period of illness prior to the family member’s death. There are, however, conflicting beliefs about bereavement and its effect on caregivers. Researchers such as Saunders, (1982) found that there was no significant difference between the reaction to death following a lengthy illness and that of sudden death. However, others concluded that there was poor adjustment to the patient’s death by caregivers after a lengthy terminal illness, and a
difficult period of bereavement following high levels of stress during caregiving (Bass & Bowman, 1990).

Although little is known about the bereavement of caregivers of AD patients, researchers agree that bereavement following the loss of a spouse from dementia may be more complicated and more difficult than other situations of bereavement (Jones & Martinson, 1992). They identify two stages of bereavement in a study on “The Experience of Bereavement in Caregivers of Family Members with AD”.

The first stage of bereavement occurs while caring for the person with AD, and the other after the person’s death (Appendix Q).

**Stage 1:** This is the beginning of an unfortunate process, starting with the diagnosis of AD, which is the initiation of a 10-year grieving journey that ends with the death of the person with the disease. It is referred to as a “10 year funeral” (Jones & Martinson, 1992, p. 175). During this period, the patient deteriorates, or dies psychologically, losing dignity, cognition, and personhood, resulting in a feeling of powerlessness, loss, and emptiness for the caregiver. The caregiver reluctantly has to let go of the past relationship. This is referred to as the process of detachment, and is characterized by ongoing losses and grief. In this stage, the caregivers try to cope with the grief by overcompensating in different ways. This results in depression, some satisfaction, and increased caregiver stress and burnout at times, if assistance is not accepted. Some caregivers overcompensate due to a feeling of guilt.

**Stage 2:** This stage starts with the physical death of the person, with a period of acute grief and a large empty space in the caregiver. They also experience a complex feeling of relief that forces the caregiver to reflect on the caregiving process before achieving resolution. During this period of resolution, the caregivers try to fill the empty space, move on with their lives, work through the painful memories, and try to resolve the guilt.
However, for some people, this space never gets filled, whereas some achieve a state of full recovery (Jones & Martinson, 1992).

Dempsey and Baago (1998) speak of latent grief as a very unique and hidden grief experience of family caregivers of patients with dementia. Their model identifies three dimensions of loss and other factors contributing to the latency of the grief process. In finding very minimal information on the grieving process in relation to caregivers of patients with AD, they stated: “If the concept of latent grief is valid, it is essential that caregivers and those who provide support for them develop an early awareness of this hidden grieving process” (Dempsey & Baago, 1998, p. 84).

The three dimensions of loss are: ((Dempsey & Baago, p. 85).

♦ The first loss is of the “person” of whom the patient was, in relation to the decline and eventually the loss of cognitive, functional, and social abilities. The person then is no longer able to fulfill the demands of the multiple roles previously held.

♦ The second loss deals with the symbolic loss or psychological death. This relates to the loss of dreams, ongoing losses as the “person” disappears, less hope for the retirement plans, as in the case of a couple. This process is similar to the losses identified by Jones and Martinson (1992) in their second stage of bereavement.

♦ The third loss relates to caregivers’ losses of their own self or previous identity. This stage may result in increased caregiver stress. For example, the husband who is caring for a wife with AD now becomes the person who manages the home, does the cooking, shopping, laundry, provides personal care to his wife, and other vital chores, some of which he may never have done prior to his wife’s illness. As Dempsey and Baago, (1998) noted, there is no time or opportunity for a caregiver of a patient with dementia to redefine or slowly assume the new roles. As the patient deteriorates, the caregiver assumes more and more responsibility to
compensate for their loved one’s deficits. “With every negative loss in his loved one, the caregiver experiences a negative gain for himself” (p. 86).

In an attempt to understand the enormity of the losses for the caregiver, Bowlby (1973) believes that it is crucial to understand human bonding and the reactions when this bond is broken or threatened, and that all relationships stem from that of mother and child. They also view attachment as the basis of the grieving process and that a resolution of the loss of an attachment cannot be achieved until a psychological detachment occurs. Dempsey and Baago (1998) agree with this and state: “When the attachment figure is threatened, the response is one of intense anxiety and strong emotional protest, and clearly these emotions are evident in caregivers, because their attachment bonds are severely threatened by the psychosocial death of their dementing loved one” (p. 86).

Other losses noted by Dempsey and Baago (1998) are ambiguous loss and disenfranchised grief.

- Boss (1991) also talks of ambiguous loss in regard to the dementia patient being physically present but psychologically absent. She also relates ambiguous loss to the caregiver and the lack of clarity of their ever-evolving role and the role of the dementia individual in their relationship and that of society at large. To complicate things, during the process of the disease, the dementia patient has episodes of confusion and lucidity, which at times contribute to caregiver denial of the illness. Many caregivers may say: “Nobody understands what I’m going through, not even my children” (Dempsey & Baago, 1998, p. 86). In this situation, they noted that many caregivers may bury their grief, and there is a sense of disenfranchisement.
Dempsey and Baago (1998) noted that in describing the caregiver loss, disenfranchisement has been referred to as “unacknowledged,” “socially negated,” “unvalidated,” and “unrecognized” and has not been explored enough. Doka (1991) refers to disenfranchisement as the grief experienced by people who cannot publicly mourn a loss, and this loss cannot be openly acknowledged, nor is it socially supported. However, with the emerging of support groups for various illnesses such as AD and the availability of community health service providers, this type of loss is more socially acknowledged and shared in many societies.

**Stress Theory**

In researching the literature on stress, the intent was to obtain current information on the subject; however, work done by Selye in 1926; and 1936 could not be ignored, as this laid the foundation for other researchers (Fernandez, 1983). In discussing his work, Fernandez referred to Selye’s account of his first encounter with what he described as “a series of stereotyped responses,” that were common to patients suffering from the most diverse diseases. These responses he called; “The syndrome of just being sick” (p.227). He later talked about it as: “A syndrome produced by diverse nocuous agents,” which was later named the “General Adaptation Syndrome” (Fernandez, 1983, p. 227). Sethi (1980) viewed studies done by Lazarus, Coffer and Apple, McGrath, and Neuman as modifications to Selye’s definition of stress by emphasizing that; “Stress results from three interrelated parameters: (1) response, (2) stimulus, (3) a combination of stimulus-response reactions” (p.165).

Selye (1974) views the concept of stress as being very old, and possibly dating back to prehistoric man. Everyone has stress, talks about it, works in it, and cannot avoid
it. In his model, Selye defines what stress is or is not, and talks more about physiological stress. However, he recognized the contribution by other researchers, for their interest and activity in stress phenomena and their links to disease, as they looked at the social, psychological, and physiological levels as being separate but interconnected (Selye 1980). In trying to define stress, he argues that stress means different things to different people, and therefore is difficult to define. There are good and bad stressors, which are contributors to the proper functioning of the body and are essential to the survival in life. Selye (1974) identifies few biological functions that are specific stressors, which are necessary for maintaining homeostasis (e.g., the contraction of the blood vessels in our skin to decrease the loss of heat when we experience cold). This is referred to as the Local Adaptation Syndrome (LAS). Other specific biological functions involve pathways reaching the central nervous system (CNS), which activate the hypothalamus-pituitary-adrenals response, called the General Adaptation Syndrome (GAS). This system develops a level of stress in the body to limit all of the internal processes, the LAS that are contributing to the disturbance in homeostasis (Selye, 1983). He nevertheless concludes that all types of stress result in the initiating of the same biological outcome and are the non-specific response of the body to any demand made upon it (Selye, 1974).

The following are statements about what stress is not (Selye, 1974).

♦ “Stress is not merely nervous tension” (Selye, 1974, p. 30).
♦ Stress is not always the non-specific result of damage, but can be a pleasant experience without causing harm. “Damaging or unpleasant stress is distress” (Selye, 1974, p. 31).
Stress is not something to be avoided, or as previously noted, cannot be avoided. The energy it expends is necessary to resist aggression and to adapt to the constant changes in life.

However, it was noted that complete freedom from stress is death (Selye, 1974). Lazarus (1993) discusses psychological stress and refers to anger, anxiety, guilt, shame, sadness, envy, jealousy and disgust, as the stress emotions are the result of conflict. He feels that the emotions are much better predictors about how people are adapting to various encounters in life, (e.g., anxiety rather than anger, or aggression rather than guilt), and shows a person’s reactions to particular situations, rather than just knowing that the person is under stress. In reference to caregivers of patients with Alzheimer’s disease, it would be beneficial to them if education and support could be designed around aggression, depression, anxiety, or whatever emotions are exhibited as a result of the stress that they endure. Lazarus finds it more rewarding to analyze each emotion on its own merit, due to its uniqueness, therefore providing us with the potential to better understand people and their situations. In the case of caring for a patient with AD, the caregiver has to be very patient and not argue with the patient, as this could result in increased agitation and aggression towards the caregiver.

In comparing the works of Sigmund Freud and Hans Selye, David Fernandez concludes that there is a common base in relation to stress (Fernandez, 1983). He notes that whereas Selye was able to discover the original event that triggers the disturbance of the homeostasis, Freud limited his research to the study of the psychic aspect of the behavioural response, in particular to the sexual response in humans. He also agrees with Selye (1974) in concluding that stressors in the environment trigger all biologic responses
including physiologic ones, and with Lazarus (1993) that stressors trigger psychological responses. He refers to the physiologic response as consisting of the Local Adaptation Syndrome (LAS) and the General Adaptation Syndrome (GAS) outlined earlier by Selye (1983). Fernandez also defines stress as “the non-specific response of the body to any demand” (p. 227). Instinct (psychological stress) is always associated with Freud, however, he regrets that much of his work was ignored or misinterpreted by other researchers.

An example of the interconnectedness of social, psychological, and physical levels, which at times result in stress for both the patient and the caregiver can be seen in caring for someone with Alzheimer’s disease as the disease progresses. As the patient becomes physically, and psychologically dependent on the caregiver, they both become more socially isolated due to the patient’s lack of social skills, and embarrassment to the caregiver as a result of these (e.g. a patient eating with her hands and continually spilling food on herself in a public restaurant). The caregiver also becomes, socially isolated from his friends and at times family, resulting in psychological deprivation and a lack of normal conversation and personal free time. Physical stress results from the tremendous work that is involved in providing care for his wife as she becomes more dependent on him. He also becomes psychologically and physically stressed as he assumes more and more responsibility in the home. The caregiver stress process consists of four domains: the background and context of stress; the stressors; the mediators of stress, and the outcomes or manifestations of stress (Pearlin, Mullan, Semple, & Skaff, 1990). In order to understand all of these domains, in a study on “Cargiving and the stress process” they
categorized the stress in caring for a patient with Alzheimer’s disease, into primary and secondary stressors.

**Primary stressors:** Three indicators are classified as primary stressors for caregivers of persons with AD. Miller and Cafasso (1992) also agree that the first indicator relates to the AD person’s cognitive status. The worse the memory, the increased level of stress for the caregiver, as there is a greater need for cuing, reminding, and even compensating for the memory impairment. The second indicator of primary caregiver stress relates to the behavioural problems exhibited by the person with AD. This requires the caregiver to provide surveillance of the person due to wandering, maintaining more control, and assuming more and more responsibility for that person as the disease advances. “The level of vigilance that must be maintained and the ‘damage control’ that must be exercised to ensure that the patient harms neither himself nor others constitute, from all indications, a formidable stressor” (Pearlin et al., 1990, p. 587). The third indicator of a primary stressor is the increased dependency of the impaired person on the caregiver for a number of activities, and the extent of each activity. This includes activities of daily living such as personal hygiene, and instrumental activities of daily living such as preparing a meal or using the telephone, etc.

**Secondary stressors:** This consists of role strains and intrapsychic strains. Several factors outside the caregiving role can result in secondary stressors and role strain. Such factors involve the caregiver’s relationship with other family members and their perception of the degree of the illness, the care required, and recognition given to the caregiver for such an important role. Other factors resulting in role strain relate to the caregiver’s occupation if employed outside of the home, economic strains, and finally the
constraints of social and recreational activities as the care giving responsibilities escalate. Intrapsychic strains result from damage to the caregiver’s self-concept as a result of the difficulties in the caregiving role, and can be manifested by symptoms of depression.

"The relentless and progressively expanding demands of care giving, together with ensuing secondary role strains, are capable of diminishing positive elements of self; this in turn, leaves people increasingly vulnerable to stress outcomes" (Pearlin et al., 1990, p.588).

Family Caregiving Systems

Many studies have tried to explore the effect of caregiving by family members for their loved ones. Keith (1995) cited studies done by Horowitz (1985), and others, and concluded that there are several beliefs about the family caregiving system. Although it is ideal to have family members share the caring, Horowitz (1985) thought that was the exception; however, later studies identified the need for further research of the family caregiver system as opposed to just exploring the “primary caregiver” (Horowitz 1992). In a study exploring the divisions of caregiving labour, Keith (1995) concluded that there are three types of caregiving systems: the primary caregiver, the partnership, and the team. In identifying these systems, she mentioned the importance of the size of the family and the gender of the members of the family available for caregiving.

Primary caregiving model: The primary caregiving model identifies one person as the caregiver. Most often, caregiving is provided by one person, however, this model provides the opportunity for caregiving by several members, one at a time, with no specific length of time (Keith 1995). In caring for cognitively impaired persons, this model will be effective in providing relief for each caregiver, if the primary caregiver’s
position is shared among family members, and not done solely by one person. Many spouses or daughters more than sons seem to be allotted this role.

**Partnership caregiving model:** Keith (1995) describes this model of caregiving as being performed by two persons, usually two daughters or one daughter and one son. These persons contribute equally to the care of the ill person. They also hold equal authority and responsibility in making and implementing decisions in caring for the ill person. Additional family members may be involved, but to a lesser degree.

**Team caregiving model:** Caregiving is a team effort, with each family member providing care in an organized, planned manner. Many families formulate a schedule for its members in relation to time, chores, and responsibilities. Each member knows exactly what is required and expected of each other. These teams are comprised of three or more family members, but according to studies done by Keith (1995), can consist of all females or a combination of male and female (Appendix Q).

**Gender Differences in Caregiving**

Spiriopulos et al., (1999), noted that there is a need to explore gender differences in caregiving, as very little is known about the experiences of men as caregivers. An earlier study by Harris (1993) referred to male caregivers as the misunderstood caregiver. However, Mathew, Mattocks, and Slatt (1990) did explore the roles of men in caring for relatives with dementia, and found that there were differences in the type of caregiving provided by the men they studied. They also noted that education regarding activities such as bathing, feeding, and dressing a female is needed, as these chores are relatively new to many men. These chores are, however, quite natural to female caregivers. In a study done by Chappell and Kuehne (1996) examining the
congruence in spouse-spouse caregiving relationships, it was noted that although there were positive affective tones in the husband and wife caregiver, the husband caregiver reported a more positive affect congruency in caring for his wife. They further mentioned that although their sample was small (296 spouses), few husbands expressed negative sentiment, whereas a third of wife caregivers expressed negative affect. They concluded that this result was possibly due to men’s perceived choice but women’s obligation to take on caregiving, as they are socialized to be.

Miller and Cafasso (1992) in a study applied meta-analysis to the results of 14 descriptive studies of gender differences in caregiving (mean sample size 200); they noted that among spouse caregivers, approximately 67% of caregivers were women and 33% men. Although they noted no significant gender differences in functional impairment of the frail care recipient, total caregiver involvement in care, or in money management tasks, they discovered that female caregivers were more likely to carry out personal and household tasks and are more likely to report greater burden. They concluded that further research is required into gender differences in caregiving.

Support Groups and Respite

The type of support to be discussed relates to community support or support given by other than family members to caregivers. Smith, Fernengel, Holcroft, Gerald, and Marien (1994) in an analysis of the impact of social support and health outcome, talk about quantitative, qualitative, and functional social supports. Although it is the belief that social support enhances an individual’s health, their meta-analysis results indicated only a small association between the two at the time of the study (Smith et al.,). This summary will focus on qualitative social support, as this is defined as relationships,
interactions, and a perception of belonging, emotional bonding and attachment of caregivers (Smith et al.,). Support groups are formed by professionals to provide education and support or by caregivers and persons experiencing the same issues and diseases, to provide education or support for its members. “Support groups provide a sense of empowerment and comfort for the caregiver, and these types of groups serve as an arena for the exploration of issues related to the caregiver experience” (Raybuck, 1995, p. 26). She also suggested that support groups for caregivers and persons with AD are a rich area for future intervention and outcome studies for health care professionals. A 3-year randomized clinical trial testing the effectiveness of an interdisciplinary psycho-educational family group intervention, in dealing with the perception of disruptive behaviour in persons with dementia, concluded that following a 7 week, 2-hour training session that included education, family support, and skills training, there was a reduction in the caregivers’ negative reaction to disruptive behaviours. This in this turn helped to reduce caregiver burden (Raybuck, 1995).

There are many perceptions of support groups for caregivers or persons with AD; however, many researchers noted that these groups provide a feeling of belonging for their members, therefore decreasing feelings of isolation and helplessness. They also help members to increase coping skills in dealing with difficult situations and working through the grieving process prior to and after their loved one’s death (Raybuck, 1995; Shadday-Haarhoff, 1992). Online support groups are becoming popular, as they provide an arena for sharing experiences anonymously. A support group for persons diagnosed with early AD is available at the Alzheimer Society in Hamilton. Many of these persons are still fairly active in society.
Respite

Respite is described as temporary relief time for the caregiver from caregiving (Deimling, 1991). There are several types of respite available in various countries and cities, including Hamilton/Wentworth, Ontario: in-home care, adult day programs, overnight respite, and scheduled respite in designated retirement and long-term care facilities. This period of time can be scheduled for 1 to 5 hours a day, one or more days a week, or from one week to a maximum of 28 days, as provided by facilities. Feinberg and Kelly (1995) outline the qualities or purposes of respite as being flexible, a choice for caregivers, and controlled by the caregivers of the cognitively impaired or terminally ill persons. Deimling (1991), engaged in a project about the Time Off Promotes Strength (TOPS) program in the U.S. where 223 families involved in the program in the first 2 years, were assessed. Seventy-eight of those families was in the program for the required 4-month period and agreed to complete two interviews. They reported that although respite may reduce depression, stabilize caregiver strain in families of declining AD patients, and reduce health problems and family relationship strain in families caring for stable AD patients, there was no significant reduction in caregiver strain.

In spite of this report, they identified areas in which families and caregivers benefit. Respite provides greater personal freedom for social, recreational, or employment activities, reduction in interpersonal tension or strain among family members, time for taking care of their own health needs, and time to catch up on sleep lost during caregiving. It is also seen as a way of delaying or preventing institutional placement that results from caregiver burnout (Deimling, 1991).
CHAPTER THREE: RESEARCH METHODOLOGY

Introduction

In this chapter, the following areas are discussed: an introduction to the pilot study, including the research methodology, methodological limitations, clinical assumptions, the selection of respondents, instrumentation, the process of data collection, methodological assumptions, and analysis of the pilot study. The outline of the current study follows a similar format: introduction to the study, research methodology, methodological limitations, clinical assumptions, respondents selection, selection criteria, instrumentation, the process of data collection, the open-ended questions used in data collection, and the methodological assumptions. As previously mentioned, there has been a lot of literature on caregivers; however, very little is available on male caregivers (Spiropoulos, et al., 1999). Results of the pilot study done in 1998, and lack of information in the literature, made it more apparent that additional research is needed in this area. The participants in the pilot study seemed to identify some issues experienced in their caregiving roles, which are unique to male caregivers and, more precisely, husbands as caregivers. However, some research has shown that there is little difference in the experiences between male and female caregivers (Miller & Cafasso, 1992; Spiropoulos et al., 1999). They also agree with Rose-Rego et al., (1998) that female caregivers seem to be more emotional and express their distress more often than male caregivers, but that they also adjust more readily to the role because of their nurturing nature.
PILOT STUDY

This Pilot study was conducted in the fall of 1998, involving 3 male spousal caregivers. Two of these men's wives were still being cared for at home, while the other's wife was already institutionalized due to the impact of his deteriorating health, resulting in his inability to care for her at home. This supports the finding of Monahan (1995) that the well being of the caregiver is one of the deciding factors influencing the decision to institutionalize the demented person. The information gathered provided insight into issues encountered by the 2 husbands providing direct caring to their wives in their homes, and indirect care by the other husband.

Research Methodology

This was a qualitative, research study. The design selected for this research is identified as s descriptive survey. The survey method was identified as being most appropriate because it possesses three major characteristics. These are:

(a) Information was collected from a group of people in order to describe some aspects or characteristics (such as abilities, opinions, attitudes, beliefs, and/or knowledge) of the population of which that group is a part;

(b) The main way in which the information was collected was through asking questions. The answers to these questions by the members of the group constitute the data of the study;

(c) Information was collected from a sample rather than from every member of the population (Fraenkle & Wallen, 1990)

This method also provides the researcher with the opportunity for face-to-face interaction with the respondents, observing their emotions and body language while
obtaining firsthand information. In comparing qualitative researchers to quantitative researchers, some critics noted that qualitative researchers tend to observe what others miss, listen when others talk, and have the opportunity to ask questions which others may miss or to clarify information received (Glesne & Peshkin, 1992). The qualitative researcher must, however, be aware that this type of research is very time consuming, and must therefore be patient during the data collection period of the study. To collect the required data, the researcher must be aware that the participants may also provide what may seem to be irrelevant information to the researcher, but important to be conveyed or expressed by the participants. Glesne and Peshkin agree with this by making the following statement: “Qualitative researchers must be able to tolerate, and perhaps even to enjoy, ambiguity in their pursuit of complexity” (p. ii). They further referred to qualitative researchers as being good listeners, observers, and seekers for clarification of information received. However, they advise that although it is difficult at times to remain focused, the researcher must try to avoid being caught up in the emotional aspects of the interview.

**Methodological Limitations**

Qualitative, like quantitative, research has its own limitations. One of the main limitations to the study is in arranging a suitable time to interview the participants. Although some of their wives are still being cared for at home, some may or may not be attending a day program, and therefore may be present at the interview if appropriate care for them is not available. It will, however, be easier to schedule an appointment with the participants whose wives are attending a program, but for those who may be present, one can assume that there may be interruptions. If there are interruptions, rescheduling of
another session or a phone call may be necessary to complete the interview. The researcher must also be flexible, anticipating a possible cancellation and rescheduling of interviews on the day or at the time appointed, depending on the type of day that the patient and her caregiver are experiencing. AD has many stages, and depending on the stage, the patient can exhibit unpredictable behaviors like verbal and physical aggression and mood swings at times, which determines the type of day for both the patient and the caregiver.

Triangulation (see glossary) is a method of data collection utilized in qualitative research, as it provides the researcher with the opportunity to collect data by several methods (Neuman, 1997). Reliability will be difficult to prove however, one can believe that all accounts have some validity to whatever they claim, and although the experiences may have common themes, each is unique in its own way. Wolcott (1994) noted that the qualitative researcher's equivalent for validity is in understanding the data provided, and the ability to make the experience intelligible, by applying concepts and categories.

Qualitative research lends to a certain amount of anxiety in the interviewer when arranging interviews with persons that one is not familiar with during the interview, and an uncertainty of proper interpretation of the information received. AD is a very sensitive and emotional subject; therefore, although the interviewer may be familiar with the prognosis of the disease, emotions must be kept under control during the interview, as this can have an impact on the process (Glesne & Peshkin, 1992). These issues can add to the limitations in the study.

Clinical Assumptions

- Alzheimer's disease affects more and more people in Canada, therefore impacting on the lives of caregivers (Appendix Q).
Knowledge about the disease process and its prognosis can provide caregivers with a better understanding of the various issues relating to the disease (Gendron, Poitras, Dastoor, & Perodeau, 1996; Monahan, 1995; Raybuck, 1995, Appendix A).

Knowledge of support services and utilization of the appropriate ones can assist healthy male caregivers to care for their wives with AD at home.

Limitations of the Study

The study provided information about the experiences of only 10 men caring for their spouses with Alzheimer’s disease in their homes, and is not a good representation of all men in this situation. Although further research is needed into the effects of AD on various cultures, it will, however, give health service providers an insight into some of the issues encountered by men in this situation. The interview time and the type of day that the participant and his spouse are having influenced the information given, as experienced with one of the couples interviewed. On a good day, the participant may be more composed and less emotional, providing the information in a more positive fashion. However, on a bad day, the same participant may be less patient and more emotional, resulting in a more realistic picture of the burden that is experienced. Some or all of the symptoms of AD may also be exhibited by the person with AD, impacting on the type of relationship between the wife (the patient) and her husband (the caregiver) (see Appendix B for the signs of AD). One also has to acknowledge that in many cultures it is very difficult for men to show their emotions, as this may be interpreted as a sign of failure or weakness and their inability to cope with their wives illness.

The participant’s knowledge about AD before and after his encounter with it could influence his ability to comprehend and cope with the complexity and the demands that the situation has imposed on him. AD affects people of all educational levels, caregivers, and patients; therefore, the participants in the study were selected by
educational knowledge. The participant's educational level may also be a determining factor about how well he may be able to cope, his ability to problem-solve, and insight into his own needs.

Scheduling the interviews with the participants may or may not be difficult, for although their wives are still being cared for at home, some of them may or may not be attending a day program. It is easier to schedule appointments with the participants whose wives are attending a program, but for the wives who may be present, there may be interruptions, resulting in rescheduling another session if not completed. The researcher must also be flexible, anticipating a possible cancellation and rescheduling of interviews on the day or at the time appointed, depending on the type of day that the patient and her caregiver are experiencing. AD has many stages, depending on the stage, the patient can exhibit unpredictable behaviors, like verbal and physical aggression, at times, and mood swings which result in good and bad days for both the patient and the caregiver.

"Perfect reliability and validity are virtually impossible to achieve" (Neuman, 1997, p. 138). Therefore, reliability and validity are difficult to achieve in a qualitative study as one cannot control the sources, and no two stories are identical but may identify similar issues. Therefore, one has to believe that all accounts have some validity to whatever they claim, and although the experiences may have common themes, each is unique in its own way. Wolcott (1994) noted that the qualitative researcher's equivalent for validity is understanding and the ability to make the experience intelligible by applying concepts and category.

Qualitative research lends to a certain amount of anxiety in the interviewer when arranging interviews with persons that one is not familiar with, during the interview, and an uncertainty of proper interpretation of the information received. AD is a very sensitive and emotional subject; therefore, although the interviewer may be familiar with the topic, emotions must be kept under control during the interview as this can have an
impact on the process (Glesne & Peshkin, 1992). These issues can add to the limitations in the study.

**Selection of Respondents**

The Executive Director of the Alzheimer’s Society was initially contacted by phone to arrange a meeting at her convenience. Prior affiliation with the society was advantageous in that knowledge of the program structure, and some of the activities offered were already known. At our first meeting, much of the necessary introduction was curtailed, as the Executive Director already was affiliated with my professional involvement. The meeting focused on the project proposal, the objectives of the course, and the time required for completion of the course. A tentative date for 2 weeks following this meeting was scheduled for attendance to the support group meeting, pending their approval. The week following our meeting, she informed the group of the study and sought their permission for my attendance at the session the following week.

Observations made during my visit to the session with the support group are outlined in the section that follows. Three men volunteered to participate. Interview appointments were scheduled at a time and place of their choice (at their home or at the Alzheimer society’s office). No follow-up interview or phone call was necessary, although this was an option if it was required. A thank you card was later sent to the members of the support group and the Executive Director.

**Selection Criteria**

- Male spousal caregivers, retired, and whose wives are diagnosed with AD.
- Caregivers involved with community services, such as the Alzheimer Society, CCAC (the Community Care Access Centre), VON (Victorian Order of Nurses), and Day Programs etc.
- Caregivers aged 60 years and older.
- Caregivers living in the Halton/Wentworth region.
- Caregivers attending the support group at the Alzheimer’s society.

Participants from the Caregiver Support Group at the Alzheimer’s Society in Hamilton were selected for the pilot study. This was a sample of convenience due to time constraints. Information was obtained from male caregivers other than the ones being cared for in my area at the Health for Older Adult Program (Geriatrics) at St. Joseph’s Community Health Centre. This helped me to determine if there were similarities in their experiences in caring for wives with AD.

**Instrumentation**

Audio taped interview with open-ended questions was conducted.

**The Process of Data Collection**

- A written consent was obtained from the respondents regarding taping the interview. This method of data collection provided me the opportunity for a more interactive process. Permission was also received from the participants for a repeat interview or phone call for the clarification of information, if necessary.
- The interview consisted of open-ended questions and provided an opportunity for voluntary information and conversation.
- Attendance at a support group meeting as a participant observer and to take notes, at the Alzheimer’s society for both male and female caregivers.
The Interview

Open-ended questions similar to those in the thesis study were asked (Appendix E).

In addition to these questions, other unscheduled ones were asked at times as directed by the participant in conversation. Comments were also made and clarification sought for some answers provided during the interview.

Participant Observer

Attendance at the combined male and female caregiver support group meeting on October 21, 1998 from 1000 hrs to 1200 hrs was very insightful. Upon my arrival, an introduction to the group and confirmation of my intent were done. The members of the group were thanked for allowing me to attend the session. There were 20 members present, 17 women and 3 men, along with a coordinator facilitating the session for the first hour. I was informed that there are actually 11 men attending that group, but that those absent were either ill or attending to urgent situations. The first half hour of the session provided members with the time to share difficult issues encountered over the past week and the coping skills used to deal with these issues. The second half of the hour was used for education, provided by the coordinator on that day, but can also be provided by a guest speaker. The group meeting concluded with a time of socialization, with everyone, including the volunteers and the persons with Alzheimer’s disease.

Observations

Two of the men sat together, while the other sat at one end of the group, which was formed in a semicircle. The group’s atmosphere was very relaxed, with two of the men being very vocal and entertaining. All of the members, including the men, shared
both difficult and pleasant experiences encountered in caring for their loved ones. They also shared interventions that were effective and ineffective, in support of each other. This sharing provides information and helpful tips regarding effective and ineffective coping mechanisms in assisting each other in their role as caregivers. This interaction I found to be unusual, as it did not support the literature, which identified combined groups as being intimidating for men (Marks, 1993).

The setting provided by the Alzheimer’s Society made it possible for the caregivers to attend the group meetings while volunteers cared for their relatives in an adjoining area with a kitchen and a recreation room. This provided the volunteers with easy access to the family members and to professional assistance if needed. They engaged the patients in activities such as baking, painting, music, and games. During the social time, everyone seemed to know each other’s relatives and interacted with them in a family, type fashion.

Interviews with the 3 Male Caregivers

A meeting was arranged with each of the 3 men who consented to be participants in the study at a time and place convenient to them. The wives of these men were at different stages of the disease, however, although their stories were different, similar experiences seemed to emerge, as they assumed more responsibility as caregivers. The following is a description of the setting for each interview.

Mr. M was the first person to be interviewed. This was done at his dining room table in his apartment that he previously shared with his wife in Dundas. One of his daughters, who lived in the same building, is very supportive to him. Mr. M’s wife was already institutionalized at that time, and according to his account, she seemed to be
demonstrating symptoms of a person in the middle stage of the disease, who could be cared for at home (see Appendix C for the stages of A.D). However, due to his failing health, it was very difficult for him to care for her, even with maximum support from community agencies and family members. The characteristic of this caregiver supported research done by Monahan (1995) in which he identified the caregiver’s ill health as being one of the determining factors for the institutionalization of the demented person. The interview lasted for approximately one hour and a half, which was much longer than I had intended. Mr. M seemed to reminisce a lot, showing pictures of his wife and family, while demonstrating pleasure in telling stories of incidents in his life. He became emotional at times though, when commenting on his loneliness and the difficulty in understanding his wife’s illness, especially at times whenever she has a good day. His apartment was maintained with the help of his children and a home support person who assisted him with his hygiene and light housekeeping. He was an overweight man, who seemed to experience some shortness of breath when walking around the apartment and even when speaking at times, requiring him to take frequent rest periods. He, however, seemed quite pleased when commenting on the excellent care that his wife was receiving in the institution and the privilege of visiting as often as he wishes. The interview ended with his volunteering his time for future studies.

Mr. L was the second participant to be interviewed. This took place at his home with his wife present, in the west end of Hamilton, and lasted for one hour. She exhibited signs of someone in the early stages of the disease (Appendix C), as she was able to sit quietly for an extended period of time in the same room with us, looking at television. She seemed to be in a pleasant mood that afternoon and smile, a lot during our encounter
and during parts of the program that she had been looking at on the television. She also answered simple questions appropriately in short sentences, as she demonstrated much difficulty in completing a sentence due to her memory impairment. Both Mr. and Mrs. L looked physically healthy, with Mr. L looking a bit younger than his wife was. The atmosphere during the session was quite relaxed as we sat comfortably in the bright, well-furnished living room. The neighbourhood was also very quiet, as there was very little traffic. The volume of the television was low, and Mr. L explained that his wife prefers to look at the pictures as she finds the conversations confusing, resulting in her becoming anxious at times. Mr. L seemed quite composed initially, but once relaxed, was very emotional at times, for which he continually apologized. I assured him that as a clinician I have had much experience in dealing with sensitive issues, and no apology was necessary. On a few occasions, he tried to include his wife in the conversation, but she just mumbled at times or smiled. The interview ended with a pleasant goodbye from both of them.

Mr. W was the third participant in the study. He and his wife were seen at the Alzheimer’s Society following the support group meeting. This location was chosen because he thought that some uninterrupted time for the interview could be provided. During the first half-hour of the interview, Mrs. W had her lunch with other patients and was supervised by a staff member. The interview took place in one of the staff’s offices, a few doors from the luncheon area. The office provided a soothing atmosphere, adequately lit, painted in a baby blue colour, and decorated with a few flowering plants. Mr. W seemed quite comfortable during the first part of the interview, and became tearful at times when sharing certain sensitive issues. However, due to her demanding
behaviour, short attention span, and her need to be with him, calling him “Daddy”, the staff member was forced to interrupt us by bringing her to him. We tried to continue, and included her at times, but eventually concluded the interview after 15 minutes as she became agitated and very repetitive, requiring constant reassurance from him. Mrs. W could be classified as being in the late-middle stage to the early-late stage of the disease (see Appendix C). Although she is being cared for at home, she required a lot of assistance with activities of daily living, like washing and dressing herself, and at times even required being fed. Both she and her husband appeared to be in good physical health. His good health, knowledge of the illness, utilization of community and family support helped him to cope, thus delaying her institutionalization. He did admit to being short tempered with her at times, but stated that he quickly realizes that her behaviour is part of the disease and not of her own conscious doing. At the time of the study, Mrs. W attended a day program on a daily basis. This provided her husband with respite or free time to attend to everyday issues. However, he took advantage of the opportunity to have coffee with her and others (caregivers and their spouses) when he dropped her off at the centre.

**Methodological Assumptions**

This study employed triangulation to effect methodological rigour. In this case, triangulation was made by:

(a) Responses gathered in the taped interviews

(b) Researcher observation as participant-observer

(c) Validation of data retrieved with Program Coordinators
This method was perceived to be the best way of gaining insight into several components of the caregiver's experience. However, validity of the experience is difficult to prove but depended on the researcher's interpretation of the data collected and the assumption that the information provided during the taped interviews is correct and the experiences lived. This method also provided the researcher with the opportunity to have a face-to-face interaction with the participants, observing their emotions and body language while obtaining firsthand information. Prior knowledge of the disease process of Alzheimer's disease and its impact on the patients and their caregivers was an asset and provided the researcher with the ability to ask appropriate questions to obtain the desired outcome. Consequently, the researcher was also able to cope with the patient's behaviour and the emotional occurrences by the participant during the interviews, by providing support for both while still remaining focused.

Analysis

The data collected was transcribed and the themes were identified according to the information provided. This was also a first attempt at conducting a research study with no definite approach to identifying the themes, however, analysis was guide by the answers to the questions.

**Identified Themes**

1: Psychological

- Denial, anger, confusion and frustration are feelings identified by the participants.
- Seeking assistance.
- Acceptance of the disease.

2: Social
Family and friends

- Support groups such as the Alzheimer Disease Caregiver Support Groups, and the Hamilton Victorian Order of Nurses' (VON) Caregiver Support Program.
- Other community resources such as the Community Care Access Centre (CCAC), the VON Day Program, the Health for Older adult Programs and others.

The information obtained during the interviews as these men described their situations seemed similar to the stages of the caregiver bereavement described in stage 1 during caregiving (Appendix Q). Jones and Martinson (1992) refer to coping with the disease as a bereavement experience. Knowledge of the grieving process, response of patients and caregivers to the diagnosis in my clinical practice, and responses of the participants of this pilot study resulted in the formulation of the above themes. Many caregivers relate Alzheimer's disease to a death sentence for their loved ones and refer to it as a long and tedious task that is taking control of their lives. Some researchers describe it as the most common form of incurable or irreversible dementia, while others refer to it as a pervasive, debilitating disorder that destroys the affected person's capacity for self-care (Wuest et al., 1994), (see Appendix B for the signs and symptoms of AD).

The themes chosen in the analysis were quite accurate in categorizing the information obtained as they seem to correspond with those identified in the literature; however, the information gathered identified the need to revise the purpose of this study, not only for information gathering but to devise strategies to better meet the needs of the male caregivers in our society. An additional and appropriate theme would be to explore how these male caregivers are dealing with "the stranger" in their partner's body. "The
stranger" is a term used by many caregivers in acknowledging the loss of the person they once knew and having to deal with and care for a stranger as a result of the disease.

The information gathered provided insight into issues encountered by all 3 caregivers; however, they were a small sample of male caregivers in the community. Although one of the men was not performing direct care to his wife as she was already institutionalized, he identified similar issues as the others and seemed as stressed as the ones providing direct care to their wives in their homes. The information obtained was valuable in that it identified the need for subsequent studies, that these studies be more focused on specific issues such as how caregivers could learn about and access the appropriate services available, how they could be encouraged to become involved in support groups, and how care providers could improve the services available to assist caregivers and patients.
THE THESIS STUDY: INTRODUCTION

In an article on Eldercare in Canada, our ability to care for the rapidly increasing ailing senior population was questioned (Fredrick & Fast 1999). They also stated: “At the same time that demand for caregiving is increasing, the supply of informal caregivers is diminishing” (P.26.). The pilot study outlined previously in this chapter also identified the need for further research regarding the experiences of male spousal caregivers in caring for their wives with AD. It was also noted that a lot of care is required in caring for someone with AD, as this person eventually becomes totally dependent on the caregiver as they deteriorate, cognitively initially, then physically. Care also must be provided for the caregivers as they become more and more stressed in their role. Many researchers noted the negative impact on caregivers’ physical and emotional health in caring for loved ones with AD, especially if the caring is done in isolation (Corbeil, Quayhagen, & Quayhagen, 1999; Fredrick and Fast, 1999; Patterson et al., 1999, Wackerbarth, 1999).

Research Methodology, Methodological Limitation, Clinical Assumptions and Methodological Assumptions are already described earlier in this chapter. Modification made to the selection of respondents and the selection criteria are outlined in the following sections.

Selection of Respondents

The proposal for this study met with the approval of the Ethics Committees of Brock University, and St. Joseph’s Hospital and McMaster University, (see Appendix O, and P). Participants in the study were from the Health for Older Adult Program (HOAP) at St. Joseph’s Centre for Ambulatory Health Services, the Alzheimer’s Society Caregiver Support Group, the Victorian Order of Nurses (VON) Caregiver Support
Program in Hamilton, and the VON Caregiver Support Group in the Halton area. The VON Day Program and the St. Joseph’s Villa Day Program were also contacted; however, caregivers did not meet the criteria for this study. An initial letter was sent to each agency involved, seeking participants and informing them of the study (see Appendix G).

**Selection Criteria**

- Ten male spousal caregivers, retired, and whose wives are diagnosed with AD.
- Respondents caring for their wives at home.
- Respondents should be involved with one or more community services, such as: The Alzheimer Society, CCAC, VON, Day programs or other Geriatric programs.
- Caregivers aged 60 years and older.
- Caregivers living in the Halton/Wentworth region.
- Caregivers should be involved in a support group.

The sample size of 10 men was selected because the researcher wanted to expand the sample size used in the pilot study. This sample size was easily managed to stay within the time frame allotted for the completion of this degree, and to provide an opportunity to explore the experiences of more men. It was necessary to revise the selection criteria used in the Pilot study for this study, to receive data from participants providing hands-on care, and dealing with the same disease. This was achieved by focusing on men providing care for their wives with AD, in the home. Although the Pilot study explored the experiences of three male caregivers, one of the caregiver’s wives was already relocated to a nursing home, resulting in a slightly different experience at the end
of his interview. Although their experiences were quite different, they were very interesting and set the stage for more focused studies.

Instrumentation

Audio taped interviews were conducted. This method of data collection was quite successful with the pilot study and provided the opportunity for a more interactive session. Permission was also received from the participants, if required, for a repeat interview or phone call for the clarification of information; however, this was not necessary.

The process used in conducting the study

A second letter regarding the study, copies of the research approval from St. Joseph’s Hospital Ethics Committee and Brock University, and the researcher’s Proposal were taken to the agencies, at a second meeting with them. The letter also requested permission for the researcher to attend the support group meetings and the obtaining of consents from volunteers for the study, by staff at the agencies (Appendix H). This study was conducted during the Fall 2000 to February 2001. Permission was obtained for the researcher to attend two co-ed support group meetings and a support group for patients in the early stages of the disease at the Alzheimer Society in Hamilton. Several appointments were made with various agencies, including the VON program in the Halton region, which is located in Oakville. This resulted in the attendance at a co-ed Caregiver Support Group meeting in Burlington (Halton area). The male Caregiver Support Group originally held at the Alzheimer’s Society is no longer in existence. A brief description of the study was provided and a request for male
volunteers made at that time. Copies of the approvals from both ethics committees were presented to each of the agencies/careproviders contacted.

- A written consent was obtained from each respondent by the staff involved (Appendix F). A letter of appreciation for their involvement in the study was given to the participants by the staff following receiving the participant’s written consent (Appendix I). In this letter, they were advised that they were under no obligation to answer any questions to which they were uncomfortable, and that they had the option to withdraw from the study at anytime, with no penalty or impact on the services available to them.

- Interviews were scheduled at a time and location most suitable to the respondents.

- Questions were open-ended, providing an opportunity for voluntary information and conversation (Appendix E).

- Six of the interviews were conducted at the participant’s home with four of their wives present, one at a day program, and the other sleeping. Two interviews were conducted at the Alzheimer’s Society and two in the Health for Older Adult Program.

- A final letter of appreciation will be sent to the agencies and the participants in the study following completion of my thesis (Appendix L).

   Interview

   A list of 18 open-ended questions guided the interview.

   i: Could you tell me when you first noticed that something was “not right” with your wife?

   ii: What was your reaction when you were told that your wife was suffering from Alzheimer’s Disease?
iii: How and when did you inform other family members and friends about your wife's illness?

iv: Could you describe to me what it feels like to be assuming more and more responsibilities as your wife becomes more dependent on you?

v: Would you tell me about the type of person that your wife was prior to her illness?

vi: What was your role in the marriage prior to your wife's illness?

vii: Could you describe to me what you consider a good day for yourself and your wife?

viii: What is classified as a bad day?

ix: How has your own health been since you are caring for your wife?

x: Could you tell me what is the most important thing that you are missing in your relationship with her now?

xi: I would like you to tell me about the things that are most frustrating to you in caring for your wife.

xii: How do you cope with your frustrations?

xiii: At what point in your situation did you seek outside assistance?

xiv: Could you tell me what made you accept the help that was offered?

xv: In what ways are support groups helpful to you?

xvi: What are the frustrations, if any, that you are encountering with them?

xvii: Could you provide me with some suggestions that will help us to improve the services available to patients and caregivers coping with Alzheimer's disease?

xviii: What do you find most helpful in assisting you to care for your wife?

In addition to these questions as guidelines, other unscheduled ones were asked, comments made, and clarification sought as the interview progressed.
The following chapter provides the results from the study.

Statement of the Problem

This study investigated the experiences of 10 men who provide care for their wives with AD in their homes: The lived experience and the men’s perception of Support Groups. Within this context, the study investigated the following foci:

- Learning to live without conversation, intimacy and independence
- Grieving the loss of the marital relationship
- Compensation for spousal deficits

Data retrieved were used to:

(ii) identify areas in which agencies may enhance existing services;
(ii) formulate a strategy to enable caregivers to maximize the use of resources
(iii) formulate a teaching plan to assist caregivers in dealing with the diagnosis, understanding the progression of the disease, and to be able to cope with the presenting behaviors in maintaining a high quality of care in the home (Appendix N).
CHAPTER FOUR: RESULTS OF THE STUDY

Introduction

This chapter provides the results from the study, discusses the observations made during the visits to four Support Group meetings, analysis of the information obtained during the interviews, suggestions for service providers, and recommendations for future research. Observations made during the visits to the groups will be discussed in regard to the number of people present, number of male members, seating of the members, participation of group members, format of the group activities, the atmosphere in the group, professional involvement, care for the person with AD while caregivers attend the group, and the topics discussed in the group.

The meetings were attended without the researcher’s knowledge of the names of prospective participants. This was instrumental in helping to avoid any biases towards any of the group members. Visits to the support groups were made between mid-October 2000 and January 26, 2001, and were scheduled upon approval from the group members. Three groups were visited at the Alzheimer Society in Hamilton and one at St. Raphael’s church in Burlington. Following the meetings, participants voluntarily consented in writing to be involved in the study. The researcher was not involved in obtaining any of the consents. It must be noted that although the original intent was to obtain participants actively involved in attending a Support Group, the desired number of participants for the study was difficult to obtain. Participants involved in the VON Caregiver Support Program were then selected as they met the criteria by being involved with one or more community services, including a support program. Some of the men registered in the support program were considering joining a support group.
Data Collected from Attending the Support Group Meetings

The first group visited consisted of male and female caregivers. This support group meeting is usually held every Wednesday morning, from 1000hrs to 1200hrs at the Alzheimer Society in Hamilton, and consists of 50 enrolled members. The persons with AD are entertained or monitored by volunteers in a kitchen/sitting room adjoining the meeting room. This provides easy access to the caregiver should their relative become agitated and difficult to manage. A health professional is always available for consultation with the volunteers. The volunteers engage the persons with AD in activities such as baking, tending plants, or chatting, while the caregivers attend the group meeting. On the day of the visit, 11 caregivers attended, 3 of who were men. It was explained that the group consisted of more men, but many were unable to attend for various reasons but were interested in participating in the study. Two of the men sat close to each other, while the other, a very entertaining person, sat among the women. The group was formed in a circular fashion, with everyone participating in the group discussion. On this particular day, there was no formal education by the professional, who only stayed for the first half of the session. The group members seemed very comfortable with each other, as they had been meeting for several months and had an established relationship. The members of this group were either of retirement age or had taken an early retirement to become a full-time caregiver. There were no first-time members in the group on that day. They shared a lot of effective and ineffective coping skills used in caring for their loved ones. Some of the members in the group were spouses, while others were daughters. Two of the others attending had already relocated their loved ones to a nursing home, but felt that they still needed the support for themselves, while supporting other members who
were still providing care in the home. The three male caregivers were spouses. It was very interesting to observe the body language, comments, even the sharing of depressed moments, and at times the laughter among the members. Many stated that humour is very necessary in maintaining a certain degree of "sanity," as the caring can become very stressful and depressing at times. The group members also planned their next monthly dinner, which many seem to look forward to attending. Many of these caregivers utilized the services of the VON caregiver support program in arranging care for their loved ones at a reduced cost, to attend various social activities. Two of the men attending consented to participate in the study.

The second caregiver support group meeting was also held at the Alzheimer Society. This is held monthly on the last Tuesday night of each month. Fifteen members were present at this meeting on this particular night; however there are 50 registered members. Attendance to the group meetings fluctuates; however, this group meets throughout the summer also. This group seemed to consist of many employed caregivers who are unable to attend group meetings during the day. There were no male spousal caregivers at this meeting; however, sons-in-laws (3) and sons (1) attended alone or with their wives. The other members were female spouses and daughters as caregivers. This was an interesting group, as most of their relatives are already in nursing homes; however, many of the issues discussed related to the stress experienced during the visits to their relatives. Many members expressed guilt in placing their relatives, while others shared particular incidents when they were called during the night to go back to the nursing home to assist in calming their relatives. The coordinator, a health professional, was also caring for his mother who was diagnosed with AD. The few relatives with AD
not already placed were being babysat at home while the caregiver attended the meeting. The atmosphere was very relaxed, with everyone sitting in a semicircle, participating in the sharing and discussion of issues encountered in their roles. Tips relating to the management of legal issues were shared, as many seemed to have had difficulty obtaining Power of Attorney for their relatives. Although some members were fairly new to the group, there were no first visits, and many had previously attended formal educational sessions provided by the Alzheimer Society. One of the sons-in-law provided information about a support group website, which he invited members, including the researcher, to view. None of the members present met the criteria for the study. However, this was an opportunity to learn and observe the functioning of the group and the interaction of its members.

On December 5, 2000, the caregiver support group held at St. Raphael’s church in Burlington was visited. This group consisted of retired persons with an average age group around late 60s to 70s. Four male spousal caregivers attended this meeting, three of whose wives were already in nursing homes. The other members were female spousal caregivers, with one woman visiting for the first time. There were 10 members, one professional, and a volunteer present. This meeting is usually held on the first Tuesday of each month from 1300 hours to 1500 hours at that location for the Halton region. The atmosphere here was also quite informal as the other groups, and each member wore a nametag. Following an introduction of the new member and the researcher, all of the members, except the new person, were actively involved in the meeting, which on that day consisted of finalizing the plans for a bus trip the following day. This trip included some of the relatives with AD who were still able to socialize. Following the break, there
was a short educational session given by the professional present, on the stages of Alzheimer Disease. This was followed by a lot of sharing, laughter, and even sadness, as everyone provided an update on their relatives’ condition. The new lady was invited to participate, but became very emotional and tearful. Members were very sympathetic and understanding, providing written and verbal advice. She related to everyone that her husband was recently diagnosed and that she found it very difficult to envision many of the difficulties that members were discussing. They were also recently retired and moved to the city. The four men in the group sat near to each other, with three of them being more actively involved in the discussion than the other one. The relatives not already in a nursing home were attending day programs at various locations. One male caregiver from this group agreed to participate in the study.

On January 26, 2001, the last group was attended, mainly to explain the study to a group of four men who brought their wives to the monthly patient support group meeting held on the third Friday of each month. This support group was formed for persons who are newly diagnosed with AD and are still fairly high functioning. Some are still quite involved in community activities, such as advocating for persons with AD, and one was still functioning quite well in her family business. Although the group consists of eight registered members, (persons diagnosed with an early diagnosis of AD) three women and one man attended the group meeting at the Alzheimer Society on this particular day. This is an open group and is facilitated by a health professional, providing education for the members and an opportunity for them to socialize. The spouses of the persons from the support group for the persons diagnosed with early AD, provide support for each other in a very informal way, by having coffee together away from the building at times
or staying in the adjoining room to where their spouses attended their meeting. The spouse of the man who had AD, did not stay, however, the husbands of the three women did. As the researcher was scheduled to visit, these men decided to stay at the Alzheimer Society that morning, instead of going for coffee. During the visit, they discussed their wives' illness with one of them stating that he was still not convinced that his wife had Alzheimer's disease. Two of these men consented to participate in the study following the meeting. Two of these men had previously attended larger caregiver support groups, but were overwhelmed with the degree of caring that others were providing to their relatives.

The members of these groups seem to function as a family and maintain some form of communication between meetings. Someone in the group always has an update on members absent from meetings. They seem to pair up or maintain contact according to geographic location or according to similarity with the issues/stage of the disease that they are dealing with. Groups contacted were the Alzheimer Society, the VON Day Program and Caregiver Support Programs, St. Joseph's Community and Ambulatory Health Services in Hamilton, St. Joseph's Villa Day Program in Dundas, and the Halton VON Program, Oakville.

Identified Themes from data collected with samples of answers

The revisions made to the themes identified in the data analysis of the pilot study facilitated a better description of the data collection for this study. This related to changing the themes "Psychological and Social" and incorporating information relating to psychological and social issues within the themes identified. These themes relate to: compensating for spousal deficits, learning to live without conversation, intimacy and
independence, and grieving the loss of the marital relationship. They were developed following the analysis of the rich data collected from the stories that the participants told during the interviews, and correspond with various ones mentioned in the literature. Spiriopoulos et al (1999) mentioned five major themes that emerged from their participants’ stories, relating to: loss, caregiver burden, coping methods, quality of previous relationship, and effects of AD (p, 79). In reference to dealing with the issues relating to AD and other terminal illness such as cancer, some researchers refer to these diseases as a death sentence and coping with them as a bereavement experience (Jones and Martinson, 1992).

Samples of questions and answers relating to the themes

It is difficult to related each theme to a particular question, as the answers provided seemed to be an expression at times, of the caregivers’ frustrations in dealing with their wives’ illness, and are encompassed in various questions. The themes were, however, identified from the several answers provided and not necessarily relating to a particular question. For example, some answers included compensating for spousal deficits and the loss of independence. The following provides a sample of questions asked and few answers provided, in relation to the various themes.

1: Compensating for spousal deficits

**Question:** Could you describe to me what it feels like for you to be assuming more and more responsibility?

**Answer:** She couldn’t do the things she used to, so I accepted the position of full-time caregiver.

**Answer:** It is closing in on me, I have less free time to think, you don’t have a life of
your own (losing independence).

2: Learning to live without conversation, intimacy and independence

Question: Could you tell me what is the most important thing that you are missing in your relationship with your wife?

Answer: We don’t carry on many conversations.

Answer: It’s while we have time during the day we can have a good relationship and laugh about things, they are not the same. You try to be kind and understanding but you know that you are dealing with an upset mind.

Answer: Freedom to do something what you want.

3: Grieving the loss of the marital relationship

Question: What was your role in the marriage prior to your wife’s illness?

Answer: I was the provider, and my wife looked after the house and family

Answer: I worked and her life was at home

The following chapter discusses the analysis of the information obtained from the interviews in more detail, in the context of the themes identified. Following the analysis, the data was used to identify areas by which agencies may enhance existing services, define a teaching strategy to enable caregivers to access and maximize the existing services, and formulate a teaching plan to educate caregivers in dealing with the diagnosis and in maintaining a high quality of care in the home. The outcome of the data collected from this study will also provide recommendations for community service providers, identify areas of the study supporting the literature, a period of reflection, and will conclude by providing suggestions for future studies in this area.
CHAPTER FIVE: DATA ANALYSIS

This chapter will provide a more detailed analysis of the data collected, in the identified themes mentioned in the previous chapter.

1: **Compensating for spousal deficits**

One has to first note a change or deficit or as the first question states: “something was not right” in another person’s level of functioning, before taking the opportunity to compensate for anything. In this study, 4 of the men stated that they noticed that something was wrong with their wives, for 6 years, 1 said, 6-7 years, another 5 years. The other men, admitted to having noticed a change in their wives for 1-3 years, some of whose wives were newly diagnosed with AD. In some cases, due to the deteriorating health or death of the caregivers, other family or friends are not aware of their spouses’ illness. For example, the caregivers whose wife has had AD for 5 years only sought assistance 2 months prior to this study, to relieve some of the frustrations. One, whose wife has had it for 6 years, was encouraged to use the available services to provide respite for him in helping to relieve some of his frustrations. Yet another, whose wife has had AD for 6 years, was unable to recall when he sought assistance, however he is receiving services from personal support workers and belongs to the VON caregiver support program. The wives of these 3 men could be classified as being in the middle stage of AD, which can last from 2 to 10 years and is classified as being a difficult period for caregivers as the daily care becomes more demanding and stressful (Appendix C).

Accepting the diagnosis of AD would mean admitting to deficits in the level of their wives’ functioning. Although 1 of the men compensates for his wife’s deficits at times, he felt that this was not related to AD, and did not accept this as a diagnosis. For
example he stated: “She does her own shopping, although I also shop along with her; I have my own list with most things that I think we need.” This particular man, however, still associates himself with the Alzheimer’s society and transports his wife to her support group meetings for persons diagnosed as being in the early stages of the disease (Appendix C). This is not an unusual behaviour for caregivers, as AD is not easily identifiable at times, as patients present with a variety of symptoms, which at times may be related to depression. However, as the disease progresses, the caregiver observes that the person is losing many basic skills. Three of the caregivers had previous encounters with relatives of friends suffering from Dementia, and therefore “saw it coming” or “had an idea” of what the symptoms were.

Caring for someone with AD requires adjustment for the caregivers in several areas of their lives, as their wives deteriorate, and as they assume more and more responsibilities. 6 of the men in the study seemed to have assumed more and more responsibilities fairly well, with 4 experiencing some difficulty, although they seem to manage eventually. Some comments from those who saw this as an expected outcome as the disease progressed stated: “The transition was easy, as I did a lot prior to her illness, but the one big thing is the laundry;” “She couldn’t do the things she used to do, so I accepted the position as full-time caregiver;” “It was not much of a change as others, for I always done quite a bit of the housework;” “I just coast along, I manage everything, I just manage;” and another: “You expect that it is coming, so I ask the help of my daughters, over the phone.” Comments from the more stressed caregivers were: “It is closing in on me, I have less free time to think, you don’t have a life of your own;” and “I find it affects my nerves, no question about that.” One man voiced his frustration about
having to compensate for his wife, and the disbelief of other family members when they visited, as she seemed to function normally and joked about her deficits when her children visited. He stated: "She would put on such a good show, so when the children visit they would say: 'Dad, Mom is fine,' but they are not living with her."

One caregiver had difficulty expressing his feelings openly, as his wife continually interrupted and seemed to be getting angry. This was not an unusual situation, as the researcher had expected to encounter interruptions, as many of the wives were present at the time of the interviews. A reschedule of this interview was offered, but both wanted it continued at that time.

Some areas of adjusting or compensating for their wives' deficits also involved shopping for their personal clothing, providing personal care such as bathing, dressing, choosing their daily outfits, making the meals, and doing all of the household chores, including shopping and maintenance of the home. Duties involved performing the ones previously carried out by their wives, and a continuation of the caregivers' previous duties. When having to shop for personal items such as underwear, assistance by the sale's clerk is very valuable to the men, as one man stated: "The ladies in the store help me with her shopping, and I learn".

Frustration and confusion, however, seem to arise in coping with their wives' deteriorating short-term memory and confusion, and the need to constantly provide reminders or cuing. This is demonstrated by her constantly losing things, not being able to find them, requiring the caregiver's vigilant supervision and assistance in always locating his wife's misplaced items. One caregiver referred to this constant losing and finding things as wasting time, and very frustrating as he stated; "I am frustrated by so
many things that... Yesterday she lost her wallet and she was really worked up about it, you know, all the cards and that. I think that it is the wasting time and doing nothing constructive, that bothers me.” (Appendix B).

All of the caregivers seemed to compensate for their wives' deficits. Nine of them had no issues with their wives being incontinent of urine or stool, as they were still able control these urges until reaching the toilet, however, one man did. Frustration, due to increased burden and caregiver stress were identified by this man in referring to the urinary and stool incontinence, as he stated: “Many days start well, but changes when she does her business on the floor.” This is also referred to as anger provoking, as at times. As a result of the confusion and disorientation in his wife, she is at times, incontinent of stool and urine, anywhere in the house, including on the bathroom floor instead of in the toilet. Loss of bladder and bowel control, are symptoms exhibited by persons in the late stage of AD (appendix C). When these occur, it presents additional financial strain for the caregiver, as appropriate clothing (diapers) have to be purchased.

Maintaining any form of independence in the person with AD is very important especially for those in the earlier stages of the disease. During the first and second stages, the person may still possess skills in simple tasks, with direction and cuing to perform them (Appendix C). However, in the late stage, these skills are absent and the person requires 24-hour care (Appendix C). Some caregivers can overcompensate as early as in the first stage and this results in more harm than good. One of the men confirmed this by stating: “I think if I try to help too much, it frustrates her and frustrates me, so sometimes I just let things.” However, in trying to compensate for his wife’s inability to care for herself, one of the men found it very frustrating, and realized that he needed some
assistance and education in dealing with this issue. In acknowledging this he stated: "It started to get too much because I couldn’t wash her, and the odour and smell, I couldn’t. So, I thought that professionals have a way of handling it, and I figure I would learn something." One man even blamed himself for his wife having a "bad day" by stating: "You know, any bad day is my fault. There are days when I don’t feel good because of medication. I don’t see how I can blame her for that. It just spoils my day."

2: Learning to live without conversation, intimacy and independence

Learning to live with many deficits seems to be an ongoing process in dealing with AD, and living without conversation was identified as one of the great losses. Comments such as: "I don’t like that we are missing a lot. We don’t carry on many conversation." "If we get into heavy discussion, we start to natter at one another, not name calling. Before the pill not only was she argumentative, but she was aggressive."

"When her mind is completely blocked, and I can’t reach her, can’t talk to her. When her mind is blocked, she just shoots down all your suggestions to cope, as fast as you try."

Conversation and intimacy seem to go hand in hand, for if one has to engage in conversation or intimacy, one has to devote the time and attention to the other person. Frustration seems to be identified by many caregivers in dealing with these deficits in their wives. One man was even concerned that his wife’s heart was not strong enough for her activity. He stated: "It is like when I get her up after lunch, she would not sit to rest, she would not sit down. She would keep pacing the floor and start sweating, and that bothers me, as I think that it is involving the heart or something."

Avoiding arguments or confrontation results in a lack of conversation and intimacy. As early as the first stage, the person with AD starts to experiences word-find.
difficulty, which causes frustration in their partner (Appendix C). Combined with this is the increased forgetfulness and confusion. In trying to cope and enjoy the few intimate moments, one man stated: “It’s while we have times during the day, we can have a good relationship and laugh about things. They are not the same. You try to be kind and understanding but you know that you are dealing with an upset mind.” Caregivers find it more effective to avoid conversation or intimacy for fear of initiating an aggressive episode. One man stated: “When she is agitated she is more withdrawn, and I say it is when she had a restless night. That would be a day when I would not expect too much out of her. That would be a stay-at-home day.”

Conversation is achieved by these men associating with others outside of the home, or when family or friends visit. They however, ensure that their wives are cared for while they are not with them. Few comments in dealing with the frustration incurred were: “Sometimes I have to walk away, I can’t take some things;” “I try to forget it. I get out to the super market almost every day for just a short time. Curling once or twice per week for a short time;” “I take full advantage of the help that I am getting form the agency, so that I can get out and enjoy other associations and feel confident that she is being looked after and enjoying her time.”

Lack of independence or personal space was identified as an infringement on the lives of nine of the men. One man stated that he helped with the cooking among other things. The other nine were as some stated: “Bringing in the money, and doing the heavy house hold duties;” “Doing the finances and taking care of the bills;” “Somewhat traditional, I practiced Law and other things and she was the stay-at-home wife;” “I was the provider, and my wife looked after the house and family.” One can gather from these
comments, that these men were very independent and in control of their lives and had specific roles as the breadwinners. Although retired, many had activities outside of the home, and committing to the care of their wives with AD has impacted on their independence, as they now have to devote most of their time to her care and schedule.

In regards to the loss of freedom and independence, lack of personal space is also an issue and causes frustrations in caregivers. Lack of personal space was identified by one of the men as he stated: “Something that is building up now more recently is the fact that she follows me around, she does not actually follow me around, but she is there. Mostly you have to work around her” This is not an unusual behaviour, as his wife deteriorates, she finds that he is the only person whom she trusts or feels safe with. This is until she is unable to recognize him as her husband, and then it will be even more devastating for him. Another man stated: “When you are shaving or having a shower, she wants to be looked after, you are trying to make breakfast... You don’t even have time to properly wake up. Well, I got someone and she got shook up because she did not want the girl dressing her.” Another man found it difficult to lose the authority of delegating work instead of now doing it himself and stated: “Well, I don’t think I had a choice. I cannot do everything and I am used to in my past employment, delegate.”

Another man referred to assuming more and more responsibility as frustrating and a loss of independence, while another referred to the inability to get back to bed for few more hours, as being frustrating for him. When asked about the thing missed most in the relationship, one man stated: “Freedom to do what you want.” It is quite obvious that these men are very caring, however, they are a group that also needs to be cared for.

Some comments in relation to the loss of independence and a cry for help were: “It is
closing in on me, I have less free time to think, you don’t have a life of your own;” “It’s frustrating, and the loss of independence.” AD also is seen as impacting on the health of the caregiver, and one caregiver stated; “I find it affects my nerves, no question about that.” Situational education relates to the caregiver’s adjustment to the changes in his wife, learning from the daily events as she increasingly becomes dependent on him. Making her needs a priority is a big adjustment for many men as they learn to lose their independence. As one caregiver stated: “It is just a loss of your freedom. It is like having a 6 months baby that you got to constantly be attentive to. She can’t even answer the phone.” Most of the caregivers stated that they had to learn to live without conversation, intimacy, and going out and enjoying themselves.

Interventions such as education or respite help the frustrated caregiver to cope with the increased caregiver burden or stress, however, some caregivers seem to utilize effective coping skills learned through trial and error and are at times less frustrated.

3: Grieving the loss of the marital relationship

Anticipatory grief noted in the theory on bereavement, is a process that each of these caregivers are experiencing. These husbands are grieving the various losses of their marriage relationships, while their wives are still alive, but not functioning in the same capacity as the companion that they once knew. Dempsey and Baago (1998) agree with this process and quote Rando, (1984) in describing anticipatory grief as “a psychological response in a person who is becoming more and more aware, not only of his loved one’s impending death, but of the associated losses of past, present, and future” (p.87)

Grieving for these men, seem to have started with the diagnosis of AD, and even prior, as many of them recognized that “something was wrong” with their wives. Denial,
belief/disbelief, anger, confusion, and frustration seem to be feelings identified by these caregivers throughout the care giving process. Prior to their illness, and receiving a confirmed diagnosis of AD, many of the wives were described as very friendly, easy going, quiet, and not outspoken. Comments by three of the men as they reflected with great pride in their wives’ previous personality were: “A strong person and a great lady, who spoke excellent grammar and taught grade school;” “A very out-going girl who was very much in sports like golf;” “She was a good nurse and liked to travel, we were not socials nor joiners.”

In receiving a diagnosis such as AD, caregivers seem to react in various ways, which are similar to the stages of the grieving process identified by Kubler-Ross (1974). This is not unusual, as many see the diagnosis of AD as a death sentence. Denial is the first stage of the grieving process and acts as a buffer after unexpected shocking news. It allows people to collect themselves, and with time, utilize appropriate methods of coping with the disease. Denial was identified as a reaction to the diagnosis of AD by some of the caregivers and family members. One of the caregivers continued to be in denial of his wife’s illness, at the time of the interview, stating: “I do not believe it, so I don’t have that emotional baggage.” Changes in their wives’ personality result in losses in the marital relationship, as the men are at times uncertain of the mood of their wives

Aggressive behaviour, at times replaces their wives’ original character as they deteriorate. As one man stated: “Before the pill (medication prescribed by the physician for the aggression), not only was she argumentative, but she was aggressive; she opposed everything I say. I don’t mind the job of being full-time caregiver. What I do mind is not being accepted.” The many changes cause a lot of confusion for the husband, and
discord at times in their relationship. One caregiver stated: “In the past weeks, she now opposes everything I say... If I say ‘Black’ she says, ‘White;’ Maybe I am over protective.” Caregiver frustrations also occur with changes in their wives’ sleeping habits, their wives’ uncooperativeness, as a result of them becoming more and more disoriented. This increases the caregiver burden and a change in the caregiver’s sleeping pattern also. Many persons with AD are however, pleasantly confused and do not exhibit the aggressive behaviours as others; therefore care giving seems less stressful.

Lack of knowledge and experience of AD resulted in one of the caregivers admitting to being in denial initially, and resulted in his not seeking advice about his wife’s behaviour, but instead, related it to other causes. For example he stated: “I would ask her different things and you weren’t getting the right answer. She was answering, but as if she was not hearing you properly. Once I asked her to bring me a pencil and she brought me a can opener instead. I guess that I was in denial.” Disbelief can be a form of denial used by some people also in dealing with a diagnosis such as AD. One of the caregivers said that his children did not believe it and thought that their mother was faking it with him. Although nine of the caregivers seemed to accept the diagnosis of AD eventually; words such as disappointed, devastating, didn’t like it, were words used to describe their initial reaction. One stated: “I guess I accepted the fact, didn’t like it, but realized that I had a job to do.” Another said that he was not told until the third visit to the doctor and following several investigational tests. Hope is always something that helps many caregivers in their belief that the person being cared for has the determination and strength to endure the illness and look forward to the future with some form of positive expectation. Unfortunately, current knowledge about AD does not give the
patient or the caregiver this option, as it is termed an incurable disease with an unfavourable prognosis (Ryden, 1998).

When asked about the most important thing that is missing in the relationship with their wives, going out seems to be one of the activities mentioned. Statements such as: “Just the fact that we can’t go out and enjoy many of the things that we used to, as she is very reluctant;” “We are not as close as we were now. We used to discuss things, which we cannot now;” “We used to love going to the races, going to Las Vagus. I kind of missed the travelling;” That we can’t go out and enjoy ourselves the way we used to, and you know it’s not going to happen.” Caregivers find it difficult and frustrating at times to plan events due to the unpredictable behaviours of their wives and are required to take things one day at a time. Good days and bad days are defined by the mood of their wives upon awaking in the mornings, or in some cases, whenever they get up, which could be around noon. Initially, many caregivers found it difficult to deal with the changes in their wives’ personality prior to the diagnosis of AD, as they had no knowledge of the disease process. Although one stated that he and his wife cuddle at nights, he denied any sex. Humour was identified by some of the caregivers as a strategy learnt in dealing with the various chores that they have to perform, and felt that without this, they would be unable to cope. One caregiver stated: “I spent the first half of my life taking my wife’s pants off, now I am spending the other half putting it on.” Another, whose wife is not as advanced, stated: “I have to learn to ride with it.”

The men’s perception of Support Groups

Seven of the participants belonged to and attended support group meetings, while the others were involved with the VON Caregiver Support Program. Support groups are
formed by professionals to provide education and support or by caregivers experiencing the same issues, to provide education or support for its members (Raybuck, 1995). Five of the participants attended formal support groups formed by professionals, while 2 others attended an informal support group formed by men comparing notes about their wives whom they had brought to their support group meeting. One of these men, and two others who did not participate in the study but were present at the researcher’s visit to the group, shared their experiences when they attended the formal support group meetings. One of the men who participated in the study had attended a group meeting three times before discontinuing his attendance. He found it very depressing listening to the experiences of some of the other caregivers, as his wife was in the early stages of the disease and he was not experiencing these difficulties as yet. His comment was: “They basically talked about people who are in the class six and seven category, “ (Late stage, Appendix C).

The other men found the support group meetings to be very educational, helpful, and supportive. Some comments were: “I learn whatever I can and they help me out;” “Well, it is good to rub shoulders with people. You can talk about your personal experiences. The frankness cannot be expressed anywhere else but in a group with people who are walking in the same shoes that you are, and they are very compassionate people because they need compassion.” Another man stated: “I find them very, very helpful. Each one has a chance to talk about their family member, and you learn a lot from that. You learn from other people about how they handle things, and what to expect along the line. There is a lot of sharing with other people who have something in common with you.” Raybuck (1995) agrees with these comments, as she stated: “Support groups
provide a sense of empowerment and comfort for the caregiver, and these types of groups serve as an arena for the exploration of issues related to the caregiver experience” (p. 26).

Other Community Resources utilized

The 3 men who were receiving support, education, and services through the VON Support Program found the weekly or monthly visits from the VON nurse very helpful and educational. One man stated: “The nurse comes once per month, checks our blood pressure, talks to us and checks things.” Another stated: “Very helpful. The nurse is nice, comforting to have someone to talk to and check on me, more than my wife.” Many of the caregivers belonging to this program eventually join the VON support group, as their family members attend the VON Day Program as the disease progresses.

Other community resources involve services such as the CCAC (the Community Care Access Centre), which provides Personal Support Workers (PSW) services to assist the caregivers with light household chores, while providing personal care for their wives. This service is provided at a maximum of 40 hours per month, and 60 in some cases. Caregivers belonging to the VON Caregiver Support Program have the privilege of purchasing additional relief hours in blocks of 4 or more hours at a reduced cost of $5 per hour. The most recent service provided by this program involves recreational activities in the home at a cost of $2 per hour for a minimum of 2 hours. The VON Caregiver Support Program is not presently available in the Halton area, as one of the participants in that area noted. Only one of the wives with AD attended a day program; however, one of the caregivers also receives supplementary income to purchase housekeeping services from Veteran Affairs, as the PSW is not contracted to provide regular housekeeping duties. Others receive assistance from families and friends.
Suggestions for Use of the Data Retrieved

Identify Strategies by which Agencies May Enhance Existing Services

Most of the caregivers were very pleased with the services provided; however, two of them voiced their concerns about the attitude and education of some of the Personal Support Workers (PSW) in relation to dealing with persons with dementia. In exploring the programs offered for these PSWs, it was noted that information relating to dementia is included in the curriculum. However, this may need to be covered in a more extensive manner as the prevalence of this disease increases and patients become more difficult to manage at home. Consistency with the same PSW or Nurse is vital to the provision of efficient patient-centred care. This helps to alleviate some caregiver stress and agitation in the patient as the patient and the caregiver become more acquainted with the worker. This helps to build trust and foster a good working relationship between the parties involved. The caregiver develops confidence in the service provider, and as well the service provider becomes quite knowledgeable about the likes and dislikes of both the patient and the caregiver in providing the care required.

Following the suggestion of one of the caregivers for an anonymous call-in service, it was determined that this service already exists; however, it is recommended that the information about this service be made more readily available to the members of the community. It is fairly new and is located in Mississauga and available to everyone in Ontario.

In regard to the support groups, two of the men identified the need for support groups to be structured to provide education and support for caregivers experiencing issues in the same stage of the disease. For example: A support group for the caregivers

...
of newly diagnosed patients, one for those in the middle stage, and those who are in the late stage or even have been relocated to a long-term care facility (LTCF). They voiced their frustration and an overwhelmed feeling in attending the general support group meetings. They apparently heard issues relating to aggression, incontinence, long-term placement, and other difficulties that they were not experiencing or ready to address. They preferred to be in a group with others experiencing the same or similar issues as theirs.

The VON Caregiver Support Program seemed to be unique to Hamilton and is not available to caregivers in the Halton area, as identified by one of the caregivers. As this is a very vital program to caregivers, this could be a service that needs exploring for the Halton area.

**Suggestion for Educating Informal and Formal Caregivers**

**Educational Needs**

Educating oneself is an ongoing process, and especially in caring for someone with unpredictable behaviours such as those exhibited by persons with AD. Learning to cope with the frustrations and various issues encountered through the stages of the disease is very vital to effective caregiving. One caregiver stated: “I guess that I have read just about everything that I can get my hands on in relation to AD, and I know that things are going to happen, so I try to console myself.” Researchers such as Aneshensel et al., (1995) refer to caregiving as the unexpected career, as no one seems to plan to be ill or plan to be diagnosed with a cognitively debilitating disease such as AD. However, once diagnosed, caregivers and families find themselves in an irreversible situation as their loved ones lose their abilities and become more and more dependent on them.
The caregivers attending support groups stated that they value the formal and informal education received. Formal education relating to the nature, stages, and progress of the disease were provided by the professional facilitating the support group meetings and through a series of lectures offered by the Alzheimer Society. Informal education was in the form of experience sharing among the members of the group. Caregivers also stated that they learned by trial and error and developed their own coping strategies. One of the caregivers stated that he learned about services offered by the Alzheimer society following recognition by the provincial office of a donation that he had made. This resulted in his contacting the society in his area for further information, including a schedule for the support group meetings, which he and his wife found to be very helpful.

The caregivers involved with the VON Caregiver Support Program attributed their education to the weekly or monthly visits to their homes by the Psycho-Geriatric Nurse. Some of them, however, attended educational sessions offered by the VON program and learned through trial and error and by talking with other caregivers and friends informally. Although most of them had heard about AD, an in-depth knowledge was required to actually cope with the issues presented by the disease. Many of the men had to learn to provide personal care, learn to dress their wives, and do the shopping for their clothing, including her underwear. Cooking, shopping, and doing the laundry was chores that many of the men learned to master. Some received support and guidance from friends and family; however, Personal Support Workers play a vital role in assisting others in their roles.

In order for family and friends to provide support and assistance to caregivers coping with AD, they also need to be educated about the disease. Many of the caregivers
bridged this gap by supplying family members with written information about the disease; however, some of the children remained in denial and are of little support, especially to one of the caregivers interviewed. Actually, one of the caregivers who did not believe that his wife has AD was being supported and educated by his daughter, who is a nurse, about the progression of the disease. Other family members attended formal educational sessions to learn more about the disease. This was confirmed by one of the caregivers, who stated: “Our daughters went and took the 12-week program.”

Although some caregivers still hope for a cure for the disease by utilizing the use of herbs and vitamins, education regarding medication usage is very important, as well as coping strategies. Caregivers need to be educated that drugs such as Aricept and Exelon are not cures for the disease; however, it is claimed that they slow the process. Other antipsychotic drugs provide temporary symptomatic relief from some behaviour, such as hallucinations and aggression. Therefore, caregivers must be educated to access respite services to maintain their health and well-being.

**Suggested topics for Education**

- Educate caregivers about the pathology of the disease
- Educate caregivers about the services available in the community
- Referring them to the appropriate services, e.g. the Alzheimer Society, the Community Care Access Centre, The VON Caregiver Support Program and the Adult Day Program, Seniors Activation Maintenance Program, other Day programs, the Stay Well Program in HOAP, and other issues-related program, such as the Continence Program, DARTS, Meals on Wheels, and much more.
- Providing written information for patients and caregivers coping with dementia.
Educating staff in the Emergencies / Urgent Care areas of St. Joseph's Healthcare Services about the services provided by HOAP.

The ultimate goal is for them to be able to identify seniors requiring a more in-depth assessment, and referring them to HOAP for this assessment. It is hoped that this will help to decrease the frequency of visits to the Emergency department, as many issues relating to their health would be addressed in HOAP. Many of these seniors may have some cognitive impairment, and staff is not currently trained to recognize and assess these issues.

Two such programs are already functioning at the Sunnybrook and Women's College Health Sciences Centre, and the North York General Hospital. St. Joseph's Hospital in Hamilton provides assessment for seniors coming to the Emergency department on a consultative basis; however, this is not an established program.

Information has been obtained from Sunnybrook and a call placed to North York. A formal proposal will be submitted to administration at ST.JCAHS once the required information is obtained; however, this undertaking has already been discussed with the Program Manager for the Centre. This venture is supported by an article in the Toronto Star, identifying the need for Geriatric teams in emergency departments (Henderson, 2000).

A proposed teaching plan to educate caregivers was formulated initially as a component of a combined dementia/mood disorder venture; however, due to the impact of unplanned issues, this did not materialize (Appendix T). Instead, the Alzheimer Society in Hamilton has been contacted about exploring the feasibility of organizing a Dementia Caregiver Support Group in the east end of Hamilton in collaboration with
them. This support group in the East End of Hamilton started to meet in January 200, on the four Tuesdays of each month, from 7-9 pm at St. Joseph’s Centre for Ambulatory Health Services. This arena will provide an opportunity to provide education to the members of the group in assisting them to care for their loved ones diagnosed with dementia.

This proposed teaching plan however, is different to the Alzheimer series offered at various locations around the city. This will be a closed, focus group of ten caregivers, all members starting the session at the same time. This provides more control of the material covered and closer monitoring of the caregivers attending. The Alzheimer Society offers an open-group model, with caregivers attending the sessions that are of most interest to them. There is no control of who receives what material and when they received it. The closed group also provides an opportunity for participants to bond, share and discuss issues, and being a small group, provide an opportunity for everyone to be heard. Similar educational topics covered by the Alzheimer Society will be covered, but with an opportunity to address specific situations relating to the members of the group.

**Supporting the Literature**

This study has confirmed the assumption that husbands can adjust to the role of a caregiver; however, it requires a lot of adjustment and knowledge. Although men are not seen in the traditional sense as caregivers, Swanson’s mid-range theory of caring is supported by Ryden (1998) in defining caring as a nurturing way that one person relates to another to whom they feel a sense of commitment and responsibility (Swanson 1991). The participants in the study portrayed this type of caring by compensating for their wives’ deficits, by slowly assuming more and more responsibilities as their wives lose
their ability to perform their usual tasks, including self-care. They also learned to live without conversation, intimacy and independence, while grieving the loss of the wife they once had. Instead, they are now caring for a person who is unable to maintain a meaningful, marital relationship with them.

In a comparative study of male and female caregivers, Rose-Rego et al., (1998) noted there was no difference in perceived well-being of wives and husbands caring for persons with AD. The results of this study also support the literature noting that men are acquiring new skills through increasing involvement in caring for spouses and aging parents with terminal illnesses, such as AD (Mackie, 1995). Education about the disease was identified as being vital to assist them in caring for their wives in their homes. Support in the form of in-house education, community services, and attendance to support group meetings seems to be very instrumental for most of them in helping to cope with the issues presented by AD.

Coping with the losses in the various stages of the disease identified by many of the participants, supports the stages of death and dying noted by Kubler-Ross (1974) in her identified stages of the grieving process. However, the participant, who continued to deny that his wife has AD, is still in the denial stage. The patient diagnosed with AD may not experience all of the stages depending on how rapid his/her cognitive status declines; however, the caregiver will (Kubler-Ross 1974).

This study should be viewed as a precursor to future studies relating not just to husbands as caregivers, but also to men in general. Valuable information could also be obtained by exploring the experiences of sons as caregivers for their mothers or sisters with AD. It is interesting that the Alzheimer Society has a functioning support group for
persons who are newly diagnosed with the disease, as the experiences or thoughts of these persons could be very valuable as they continue to function in society at a high level. Valuable information could be obtained by closely monitoring these persons as they continue to function effectively in society and the measures used in trying to delay the symptoms of the disease. In attending the various support groups, it was determined that many of their current members have already relocated their loved ones to a long-term care facility. However, they attend to provide support to others, and for personal support in coping with the decision that they have made. They also experience issues such as guilt or sadness in visiting their loved ones. This cohort (men and women) would be an interesting group for future studies.

**Reflection**

In reflecting on the process of this study, the experience was a very valuable educational venture. However, it would have been wonderful to be able to conduct a larger study that would be a better representation of the male caregivers in the society. It, however, identified the need to provide private interviewing sessions due to the interruptions experienced with one of the wives. That caregiver’s experience was unique, in that he also suffered from many physical disabilities. In an update, both he and his wife have now been relocated. He is now residing at a retirement home adjoining the nursing home in which his wife resides. In regard to the questions used during the interviews, they could have focused more on the caregivers’ feelings and the interventions used in caring for themselves.

**Conclusion**

This study has identified the need for ongoing research into the experiences of all caregivers coping with the issues of Alzheimer’s disease, and ongoing evaluation of the
adequacy of the services provided. Healthcare providers at both the macro and micro levels need to be adequately equipped and prepared for the impact of the issues presented by our aging society. As noted in a previous chapter, 1 in 13 persons over the age of 65 has AD and related dementias, which will impact heavily on health care dollars in Canada (Alzheimer Canada, 2000; Ostbye & Crosse, 1994). It is very encouraging to know that many agencies and academic institutions are preparing future care providers with the education and skills required in caring for our senior population. As noted in surveys done by Health Canada (1993), service providers must provide support, education, and adequate service in assisting the growing number of male caregivers in their role. Special note must be made about the growing number of male spousal caregivers (see Appendix Q).
References


Office of Gerontological Studies


Appendix A

What is Alzheimer’s disease?

Alzheimer’s disease, as mentioned previously, is the most common form of incurable or irreversible dementia, and is further described by many health care providers as a very pervasive, debilitating disorder that destroys the affected person’s capacity for self-care (Wuest, et al., 1994). The average life expectancy of the AD patient following diagnosis is about 10 to 11 years, during which time almost all of the patients experience psychiatric symptoms and exhibit behavioral disturbances (Kumar, Durai, and Jobe, 1998). As a Nurse Clinician, these behavioral disturbances are the most difficult part of care giving that I have encountered, and require providing ongoing education to caregivers in the home and in long term care facilities (LTCF). AD was discovered by a German neurologist, Dr. Alois Alzheimer, in 1906, when he studied the behaviors of a 51-year-old mentally ill woman in the asylum where he worked. Following her death, he conducted an extensive autopsy to learn about the changes that occurred in her brain. This disease is often called senility, and accounts for 64% of all dementias. It can strike at any age, but the people most affected are over age 65 (Alzheimer Society Canada 1999). DSM-IV (Diagnostic and Statistical Manual of Mental Disorders, 1995), describes two features of AD as being early and late onset. Early onset is a term used to describe those who are age 65 or under and diagnosed with the disease. Late onset occurs in persons over 65 years of age. Alzheimer Society Canada (1999) agrees with these two features, but classified them as Sporadic, which can strike adults at any age but usually occurs after age 65. Another classification identified by the Society is FAD (familial autosomal dominant Alzheimer disease), which runs in families.
Alzheimer’s disease gradually destroys vital nerve cells in the brain, and this is not a normal part of aging. It consists of a set of symptoms that include loss of memory, judgment and reasoning, and changes in mood and behavior. Patterson et al, (1999) stated: “AD is characterized by gradual onset, continuing decline of memory and at least 1 additional cognitive domain, not explained by other neurologic or systemic disorders. The most common cause of dementia in Canada, AD accounts for about 60% of cases” (p. S3). Various patterns of deficits are seen, but deficits with memory are the most common, followed by aphasia, apraxia, and agnosia after several years (see Appendix N for Diagnostic criteria DSM-IV).
Appendix B

Signs of Alzheimer’s disease:

This is a checklist by Alzheimer Society Canada (1999) in the Practice guidelines for the treatment of patients with AD and other Dementias of late life.

♦ Memory loss that affects day-to-day functions. This memory loss initially affects recent events or is known as “short-term” memory loss. Normally, people occasionally forget appointments but remember them later. The Alzheimer patient forgets things more often, and does not remember them later, or does not even remember being told anything. Speaking from experience, instructions have to be repeated often, need to be written, or given to the caregiver. Following a home safety assessment by our Occupational therapist, or Nurses, signs are posted in the home of the persons with AD to facilitate safe functioning and to relieve some of the caregiver stress by avoiding constant repetitiveness which can cause frustration for both the patient and caregiver.

♦ Difficulty performing familiar tasks: Many people get distracted from time to time, but remember what they were doing. Many caregivers complain that the person with AD is unable to do chores that they previously mastered, such as not putting the correct ingredient in a cake, or forgetting how to cook. These people are at risk for causing fires, getting lost when driving, and even forgetting how to drive in a safe manner. Many, prior to diagnosis, have had accidents with burnt pots or burnt holes in articles of clothing or other possessions.
Problems with language: Many caregivers initially complain that the person with AD does not speak as much as before, or confabulates, or even uses the wrong words when speaking. This person also experiences word-finding difficulty, and becomes more and more frustrated when unable to express him/herself. This at times leads to the person becoming more and more isolated, and even staying in bed a lot.

Disorientation of time and place: It is normal for one to forget the date or the location of a certain place; however, they remember later. The person with AD even gets lost in their neighborhood and at times in the home. Unfamiliar surroundings also create a lot of anxiety and frustration for that person.

Poor or decreased judgment: Dressing inappropriately is a common area of poor judgment with the AD person, (e.g., wearing a winter coat in the summer, or going out in the snow and cold with house slippers and a nightgown). One of my patients enjoyed trying to eat frozen foods straight from the freezer. Allowing strangers into their homes or spending large amounts of money in a short space of time on inappropriate things are other problems.

Problems with abstract thinking: Understanding or remembering things like balancing a checkbook, accessing help in an emergency situation, or even recognizing an emergency is often difficult or absent with AD. Celebrating a birthday or other festivities bear no meaning to that person.

Misplacing things: Many of us misplace things, but an AD person puts things in inappropriate places and then accuses others of taking them. They may also put something like an iron in the fridge, or money in the freezer, as one of my patients did.
Changes in personality: People's personalities can change with age, but a person with AD can change dramatically. Their mood fluctuates, frequently without warning. Many caregivers complain of the unpredictability of the person with AD. They can become very confused, withdrawn, change from a meticulous person to wearing the same clothes for days if no one helps them to change them, and even refusing personal hygiene. Hallucination and paranoia are also behaviors exhibited by some AD patients.

Loss of initiative: People complain of being tired of housework and other activities, but regain their interest. The person with AD has no interest in his/her surroundings and requires prompting or cuing to become involved. Many of them are easily influenced at times, agreeing to be led around by the hand. Others become verbally and physically aggressive if invited to participate in activities.
Appendix C


EARLY STAGE: This stage can last for 2 to 4 years, with the person showing mild forgetfulness, and having difficulty learning new things and following directions. Word finding and the proper use of grammar are two areas of communication difficulties experienced in this stage. Many people recognise that something is wrong, but react differently to the situation. Some remain in activities, trying to compensate or cope with their deficits (e.g., many use notes as reminders). Others withdraw, isolating themselves, and become depressed. Areas affected in all stages are: mental abilities, moods and emotions, behaviours and physical abilities.

MIDDLE STAGE: This stage can last from 2 to 10 years, with further decline in the mental and physical abilities. There is increased forgetfulness, with a loss of memory about personal history, inability to recognize friends and family, and may even be disoriented to time and place. The person will require assistance with daily tasks, including personal care. Personality changes will continue to occur, and the person may become confused, anxious, suspicious, or apprehensive. In this stage, the AD person becomes restless and paces or wanders. There may also be a demonstration of repetitive, disruptive, or threatening behaviour, or to the extreme, become more passive or withdrawn. This stage can be a difficult one for formal and informal caregivers, as the daily care becomes more demanding and stressful.

LATE STAGE: This stage usually lasts from 1 to 3 years, with the AD person's inability to remember, communicate, or care for self, therefore requiring 24-hour-a-day care. The person eventually becomes bedridden and loses control of bladder.
and bowel. Weight loss results from difficulty eating or even swallowing. Death also often results from pneumonia.

**THE GLOBAL DETERIORATION SCALE (GDS):** The Global Deterioration Scale or Reisberg Scale.

This scale is divided into seven stages, and is used by some health care providers.

These stages are:

- no cognitive decline
- very mild cognitive decline
- mild cognitive decline
- moderate cognitive decline
- moderately severe cognitively decline
- severe cognitive decline
- very severe cognitive decline
Appendix D

DSM – IV (1995): Diagnostic criteria for Dementia of the Alzheimer’s type

A: The development of multiple cognitive deficits manifested by both

(1) memory impairment (impaired ability to learn new information or to recall previously learned information)

(2) one (or more) of the following cognitive disturbances

(i) aphasia (language disturbance)

(ii) apraxia (impaired ability to carry out motor activities despite intact motor function)

(iii) agnosia (failure to recognize or identify objects despite intact sensory function)

(iv) disturbance in executive functioning (i.e., planning, organizing, sequencing, abstracting)

B: The cognitive deficits in criteria A1 and A2 each cause significant impairment in social or occupational functioning and represent a significant decline from a previous level of functioning.

C: The course is characterized by gradual onset and continuing cognitive decline.

D: The cognitive deficits in criteria A1 and A2 are not due to any of the following:

(i) other central nervous system condition that cause progressive deficits in memory and cognition (e.g., cerebrovascular disease, Parkinson’s disease, brain tumor, subdural hematoma, normal-pressure hydrocephalus)

(iv) systemic conditions that are known to cause dementia (e.g., hypothyroidism, vitamin B12 or folic acid deficiency, HIV infection etc.)
(iii) substance -induced conditions

E: The deficits do not occur exclusively during the course of a delirium.

F: The disturbance is not better accounted for by another Axis I disorder (e.g., Major depressive disorder, Schizophrenia).
Appendix E

Questions for the Interview

i: Could you tell me when you first noticed that something was “not right” with your wife?

ii: What was your reaction when you were told that your wife was suffering from Alzheimer’s disease?

iii: How and when did you inform other family members and friends about your wife’s illness?

iv: Could you describe to me what it feels like for you to be assuming more and more responsibilities as your wife become more dependent on you?

v: Would you tell me about the type of person that your wife was prior to her illness?

vi: What was your role in the marriage prior to your wife’s illness?

vii: Could you describe to me what you consider a good day for yourself and your wife?

viii: What was classified as a bad day?

ix: How has your own health been since you are caring for your wife?

x: Could you tell me what is the most important thing that you are missing in your relationship with her now?

xi: I would like you to tell me about the things that are most frustrating to you in caring for your wife.

xii: How do you cope with your frustrations?

xiii: At what point in your situation did you seek outside assistance?

xiv: Could you tell me what made you accept the help that was offered?

xv: In what ways are support groups helpful to you?
xvi: What are the frustrations, if any, that you are encountering with them?

xvii: Could you provide me with some suggestions that will help us to improve the services available to patients and caregivers coping with Alzheimer’s disease?

xviii: What do you find most helpful in assisting you to care for your wife?
Appendix F

BROCK UNIVERSITY DEPARTMENT OF EDUCATION
Informed Consent Form

Title of Study: “Gaining insight into the experiences of Male Spousal Caregivers, in caring for their wives with Alzheimer’s Disease, in their homes”

Researcher: Gloria Charles, Master of Education, Student
Professor and Thesis Advisor: Dr. Richard Bond, PhD.

Name of Participant: (Please print)

I understand that this study in which I have volunteered to be in, will involve a taped interview and a follow up phone call if needed. I also understand that prior to this, the researcher would be attending a support group meeting to which I am a part of, upon approval by the group members.

I understand that her purpose for attending the support group meeting is to observe everyone’s participation in the group, and to answer any questions that anyone may have in relations to her professional / academic background and the study.

I understand that prior to the group meeting, the researcher will be unaware of the names of those men volunteering to be in the study.

I understand that the interview will be scheduled at a time convenient to me, and preferably at my home. This interview will involve 18 questions in a conversation with the interviewer, in sharing my experiences in caring for my wife with Alzheimer’s disease, in my home.

I understand that I can refuse to answer any questions in any part of this study.

I understand that my taking part in this study is voluntary and that I may withdraw from the study at anytime and for any reason without a penalty.

I understand that there will be no payment for my participation.

I understand that all personal data will be kept strictly confidential and that all information will be coded so that my name is not associated with my answers. I understand that the results of the study could be published and shared for the benefit of others, and may help care providers improve the services available to other male caregivers in a similar situation.

Participant Signature ________________________________ Date ____________________

Witness: ________________________________ Date ____________________
This study has been approved by the Brock Research Ethics Board File # 99-320, and by St. Joseph’s Hospital Research Ethics Board, File # 00-1854.

Please contact Gloria Charles at 573-2591 or Dr. Richard Bond at (905) 688-5550, with any questions or concerns. Data collected could be available during the spring of 2001.

Thank you for your help! Please take one copy of this form with you for further reference.

Procedure of this study was fully explained to the above volunteer.
Appendix G

Copy of the first letter to the Agencies

TO:

FROM: Gloria Charles, Graduate Student- Master of Ed. Brock University

RE: Research project: Gaining insight into the experiences of male spousal caregivers, caring for their wives with Alzheimer’s Disease, in their homes

DATE:

I am a student in the Master of Education Program at Brock University, and seeking participants for a study to fulfill the requirements of my Thesis.

The purpose of the study is to explore the experiences of male spousal caregivers, caring for their wives with Alzheimer’s disease in their homes. It will also obtain information on the services utilized by them in assisting them in their role. Details of the study could be discussed at your convenience.

I am hoping to commence the study Fall 2000, pending approval by the Ethics Committees at St. Joseph’s Hospital and Brock University.

I am seeking male volunteers for the study, but prior to obtaining participants, I would like to be a participant observer at one of your support group meetings, upon approval from you and the members of the group. I would like to observe the interaction of the group members, and to answer any questions if requested by you or any of the group members, about me or about the study.

Please do not hesitate to contact me by phone. H: 573-2591, or W: 522-1155 ext. 8750. Email: heartr10@yahoo.com

Looking forward to hearing from you soon.

Gloria Charles
Appendix H

Copy of second letter to the Agencies

TO:

FROM:  Gloria Charles, Graduate Student- Master of Ed. Brock University

RE:  Research project: Gaining insight into the experiences of male spousal caregivers, caring for their wives with Alzheimer’s Disease, in their homes

DATE:

Enclosed are copies of the approval for my research from St. Joseph’s Hospital Ethics Committee, and Brock University, along with my Proposal, for your viewing.

Could you also please arrange for a convenient time in September 2000, that I could attend the support group meeting? I would also appreciate you providing me with a list of the names of the participants and their phone numbers, following the meeting or sometime later. I do not wish to know who the volunteers are, prior to the meeting.

It is recommended that I not be involved in obtaining the consent, therefore, I have enclosed copies of the consent form that I would appreciate you obtaining the signatures of the men volunteering to be in the study. I will provide each of them with a copy of the consent at the time of the interviews, which I am hoping to commence in October 2000.

Please also hand to each of them, a copy of the letter to the participants.

I can be reached preferable at H: 573-2591, or at W: 522-1155 ext. 8750, for any questions. My email is: heartr10@yahoo.com

Thank you.

Gloria Charles
Appendix I

Copy of the First Letter to the Participants

TO: Participants in the study

FROM: Gloria Charles, Graduate Student- Master of Ed. Brock University

RE: Research project: Gaining insight into the experiences of male spousal caregivers, caring for their wives with Alzheimer’s Disease, in their homes

DATE:

Thank you for consenting to participate in the study. I would contact you in the next week or two, to arrange for a suitable time and place for a taped-interview. At that time, you will receive a copy of the signed consent.

The purpose of the study is to explore the experiences of male spousal caregivers, caring for their wives with Alzheimer’s disease, in their homes. It will also obtain information on the services utilized by them in assisting them in their role. Details of the study could be discussed at your convenience.

You will be under no obligations to answer any questions to which you are uncomfortable with. Also, should you at anytime need to withdraw from the study, there will be no penalty, or impact on the services available to you. However, I would request that you notify me as soon as possible of your withdrawal, at: 573-2591.

I am hoping to commence the study Sept. 2000, pending approval by the Ethics Committees at St. Joseph’s Hospital and Brock University.

The results of the study can be available for your viewing upon request, when the project is completed.

Looking forward to speaking with you.

Gloria Charles
## Appendix J

### Watson's Carative Factors

<table>
<thead>
<tr>
<th>Carative Factor</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Formation of a humanistic-Altruistic system of values</td>
<td>This carative factor provides the basis for human caring and includes the humanistic values of kindness, empathy, and love.</td>
</tr>
<tr>
<td>Nurturing faith and hope</td>
<td>Patients' beliefs are encouraged to promote health and assist them to reach their full potential.</td>
</tr>
<tr>
<td>Cultivation of sensitivity to one's self and others</td>
<td>Developing sensitivity in &quot;something or someone beyond his or herself&quot; (Watson, 1989, p. 228) begins with the exploration of the nurse's self and feelings.</td>
</tr>
<tr>
<td>Development of a helping-trusting human relationship</td>
<td>Transpersonal caring relationships, bound by a moral ideal for human dignity, involve congruence, empathy, non-possessive warmth, and effective communication.</td>
</tr>
<tr>
<td>Promotion and acceptance of the expression of positive and negative feelings</td>
<td>The sharing of feelings are risk-taking, in the human caring, process. Promoting acceptance of feelings enhances honesty and depth of relationships.</td>
</tr>
<tr>
<td>Use of carative problem-solving caring process</td>
<td>Creative problem-solving provides a focus for planning nursing care.</td>
</tr>
<tr>
<td>Promotion of transpersonal teaching-learning</td>
<td>This carative factor refers to health teaching/learning with the nurse and patient as co-participants in a caring process. The nurse must assess the learner's perceptions, feelings, concerns, and understanding.</td>
</tr>
<tr>
<td>Provision of supportive, protective or corrective mental, physical, sociocultural, and spiritual environment</td>
<td>Enhancement of self-concept occurs through a holistic health-healing environment.</td>
</tr>
<tr>
<td>Assistance with gratification of human needs</td>
<td>Needs gratification refers to facilitating patients' growth and development, reducing stress, and promoting well-being.</td>
</tr>
</tbody>
</table>
Allowance for existential-phenomenological-spiritual forces

This provides a philosophical way of understanding the personal meaning and experiences related to living, problems, life, and death.

Adopted from Piccinato, and Rosenbaum, (1997). These 10 carative factors are portrayed in the day-to-day human caring in which the caregiver, professional or family caregiver, needs to promote the health of the patient, while maintaining his or her own health, in a holistic manner.
Appendix K

Caregiving System

<table>
<thead>
<tr>
<th>Size and Gender</th>
<th>Caregiving System</th>
</tr>
</thead>
<tbody>
<tr>
<td>Solo offspring</td>
<td></td>
</tr>
<tr>
<td>F</td>
<td>Primary</td>
</tr>
<tr>
<td>F</td>
<td>Primary</td>
</tr>
<tr>
<td>F</td>
<td>Primary</td>
</tr>
<tr>
<td>F</td>
<td>Primary</td>
</tr>
<tr>
<td>F</td>
<td>Primary</td>
</tr>
<tr>
<td>F</td>
<td>Primary</td>
</tr>
<tr>
<td>M</td>
<td>Primary</td>
</tr>
<tr>
<td>M</td>
<td>Primary</td>
</tr>
<tr>
<td>M</td>
<td>Primary</td>
</tr>
<tr>
<td>M</td>
<td>Primary</td>
</tr>
<tr>
<td>Two offspring</td>
<td></td>
</tr>
<tr>
<td>FM</td>
<td>Primary</td>
</tr>
<tr>
<td>FM</td>
<td>Primary</td>
</tr>
<tr>
<td>FM</td>
<td>Primary</td>
</tr>
<tr>
<td>FM</td>
<td>Primary</td>
</tr>
<tr>
<td>FM</td>
<td>Primary</td>
</tr>
<tr>
<td>IM</td>
<td>Primary</td>
</tr>
<tr>
<td>IM</td>
<td>Primary</td>
</tr>
<tr>
<td>IM</td>
<td>Primary</td>
</tr>
<tr>
<td>MIM</td>
<td>Primary</td>
</tr>
<tr>
<td>MIM</td>
<td>Primary</td>
</tr>
<tr>
<td>MIM</td>
<td>Primary</td>
</tr>
<tr>
<td>MIM</td>
<td>Primary</td>
</tr>
<tr>
<td>MIM</td>
<td>Primary</td>
</tr>
<tr>
<td>MIM</td>
<td>Primary</td>
</tr>
<tr>
<td>Three or more</td>
<td>Partnership</td>
</tr>
<tr>
<td>FTF</td>
<td>Partnership</td>
</tr>
<tr>
<td>FTFM</td>
<td>Primary</td>
</tr>
<tr>
<td>FTFM</td>
<td>Primary</td>
</tr>
<tr>
<td>FTFM</td>
<td>Primary</td>
</tr>
<tr>
<td>FTFM</td>
<td>Primary</td>
</tr>
<tr>
<td>FTFM</td>
<td>Primary</td>
</tr>
<tr>
<td>FTFM</td>
<td>Primary</td>
</tr>
<tr>
<td>(O)MM</td>
<td>Primary</td>
</tr>
<tr>
<td>(O)MM</td>
<td>Primary</td>
</tr>
<tr>
<td>(O)MM</td>
<td>Primary</td>
</tr>
<tr>
<td>(O)MM</td>
<td>Primary</td>
</tr>
<tr>
<td>(O)MM</td>
<td>Primary</td>
</tr>
<tr>
<td>(O)MM</td>
<td>Primary</td>
</tr>
<tr>
<td>(O)MM</td>
<td>Primary</td>
</tr>
<tr>
<td>(O)MM</td>
<td>Primary</td>
</tr>
<tr>
<td>(O)MM</td>
<td>Primary</td>
</tr>
<tr>
<td>(O)MM</td>
<td>Primary</td>
</tr>
<tr>
<td>(O)TM</td>
<td>Partnership</td>
</tr>
<tr>
<td>(O)TM</td>
<td>Primary</td>
</tr>
<tr>
<td>(O)TM</td>
<td>Primary</td>
</tr>
<tr>
<td>(O)TM</td>
<td>Primary</td>
</tr>
<tr>
<td>(O)TM</td>
<td>Primary</td>
</tr>
<tr>
<td>(O)TM</td>
<td>Primary</td>
</tr>
<tr>
<td>(O)TM</td>
<td>Primary</td>
</tr>
<tr>
<td>(O)TM</td>
<td>Primary</td>
</tr>
<tr>
<td>(O)TM</td>
<td>Primary</td>
</tr>
<tr>
<td>FTTM</td>
<td>Team</td>
</tr>
</tbody>
</table>

Adopted from Keith (1995). “F” (female) & “M” (male). This table provides a composition and caregiving system of families with an elderly, cognitively disabled mother. In their study, ten families had one and ten had two offspring, however the third had three or more offspring. Although the male caregivers are sons, this study supports the fact that the role of men is changing, from the traditional dominant female role to an almost equal role for female and male as caregivers.
Appendix L

Copy of final letter to the Agencies / Participants

TO:

FROM: Gloria Charles, Graduate Student- Master of Ed. Brock University

RE: Research project: Gaining insight into the experiences of male spousal caregivers, caring for their wives with Alzheimer’s Disease, in their homes.

DATE:

Thank you for your participation in the study relating to “Exploring the Experiences of Male Spousal Caregivers caring for their wives with Alzheimer’s Disease at home”.

Your co-operation was greatly appreciated, and it was both a great learning experience and a pleasure working with you.

I apologize for any inconveniences caused.

I have completed the study and a summary of the results can be available for your viewing, upon request by phoning me at 573-2591 or email: heartr10@yahoo.com

Sincerely yours

Gloria Charles
Appendix M

Maslow’s Hierarchy of needs

Primary Needs

♦ **Physiological**: Survival needs. Examples: Food, drink, health.

♦ **Safety**: Physical and emotional security. Such as clothing, shelter, protection against attack.

♦ **Affection needs**: Affection and the need to belong. Examples: Family units, other small groups such as support groups.

♦ **Esteem needs**: For self-respect, for accomplishment, for achievement. The achievement must be recognized and appreciated by someone else.

♦ **Self-fulfilment needs**: To utilize one’s potential to the maximum working with and for one’s fellow beings.

Adopted from Wlodkowski (1985).
Appendix N

St. Joseph's Centre for Ambulatory Health Services
Health for Older Adult Program (HOAP)
Educational sessions at HOAP

Objectives:
- To provide education to Caregivers/family members about dementia, and coping with issues relating to the disease
- That caregivers will be knowledgeable about the community services available, and the process of accessing these services

Rationale: At the end of the sessions, caregivers will have a better understanding of dementia and its related issues. They will also gain knowledge about effective coping strategies in the management of behaviours relating to the disease.

Target Population: Caregivers/family members of persons with dementia.

Group format: A closed group of approximately 10 caregivers. Four 2 hour sessions, with ½ hour as a joint session with caregivers of patients with a mood disorder and depression, for education on effective coping.

Proposed date: Winter 2002

Topics for the sessions:

Week 1: Introduction to dementia: What do the caregivers already know
Stages of dementia
Prevalence

Week 2: Communicating with persons with dementia
Understanding changes in behaviour (early and advanced stages)

Week 3: Future Planning – legal/financial issues
Community services and the process of accessing these services

Week 4: Care for the caregiver
Coping with issues unique to dementia
Evaluation/Recognition of the attendees
* 5 minutes at the end of each session will be used for feedback
Appendix O

Approval Brock U (2400x1799x2 tiff)

Elliot <gillott@spartan.ac.brocku.ca> wrote:

Brock University
Senate Research Ethics Board
Extensions 3670/4315, Room B311

cc:
M. Rose Kranser, Acting Chair
Senate Research Ethics Board (REB)

To: Dr. Richard Bond, Faculty of Education
Gloria Charles

Date: August 15, 2000

The Brock University Research Ethics Board has reviewed the research proposal:

"The Impact of Alzheimer’s Disease on Male Spousal Caregivers Caring for their Wives with the Disease at Home"

The Research Ethics Board finds that your revised proposal conforms to the Brock University guidelines set out for ethical research.

Accepted as resubmitted.

Please note: Changes or Modifications to this approved research must be reviewed and approved by the committee. Please complete form #5 - Request for Ethics Clearance of a Revision or Modification to an Ongoing application for Ethics Review of Research With Human Participants and submit it to the Chair of the Research Ethics Board.

You can download this form from the Office of Research Services or visit the web site:

http://www.brocku.ca/researchservices/mainethicsformpage.html

LNX/98

Call Elliott - Brock University
Administrative Assistant
Office of Research Services
http://www.brocku.ca/researchservices/
Phone: (905)688-5550, ext. 4315
Fax: (905)688-0740
Email: gillott@spartan.ac.brocku.ca
September 5, 2000

Mrs. Gloria Charles
Geriatrics Program
St. Joseph's Community Health Centre
St. Joseph's Hospital
Hamilton, ON

Dear Mrs. Charles:

RE: R.P. #00-1854: THE IMPACT OF ALZHEIMER'S DISEASE ON MALE SPOUSAL CAREGIVERS, CARING FOR THEIR WIVES WITH THE DISEASE AT HOME

Your project was reviewed by the Research Ethics Board at its meeting of July 31, 2000 and approved with some conditions.

Those conditions have now been met. You have full approval of the project including the revised consent form and revised protocol.

You may proceed with the project. We wish you well in the completion of this research project.

Sincerely yours,

Michael D. Coughlin, PhD
Secretary, Research Ethics Board

MDC:ah
**Table 3.18**

<table>
<thead>
<tr>
<th>Age/Gender of those providing assistance *</th>
<th>Recipient of Assistance **</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Spouse/Partner (%)</td>
</tr>
<tr>
<td>45-64 Males</td>
<td>69</td>
</tr>
<tr>
<td>45-64 Females</td>
<td>40</td>
</tr>
<tr>
<td>65+ Males</td>
<td>66</td>
</tr>
<tr>
<td>65+ Females</td>
<td>32</td>
</tr>
</tbody>
</table>

Adopted from Health Canada (1993). * Assistance provided in the 12 months prior to the survey.

** Multiple answers were accepted.

This table shows a comparison of age and gender of caregivers and recipients, from their survey. One can conclude that more men age 65+ (shaded area) are providing care for their spouse/partner (66%), compared to female 65+ (32%). This supports the results from a Canadian study on Health and Aging (1991), that there are more female cases than male per 1000, suffering from AD, in Canada.

It must also be noted that in the 45-64 age group more men seem to be providing care for their spouse/partner than female caregivers. Therefore educating and supporting these men should be a priority for health service providers.
Adopted from Canadian study of health and aging working group (1994). Community, diagnosed with AD, by age group, in Canada. The largest age group is the 85+. This leaves one to assume that there are either older spouses or relatives caring for their loved one in the community with AD, or that these people are living alone.
This figure shows the percentage of persons 65+ in Institutions, who are suffering from AD, by Region in Canada, 1991. It seems that the Prairies has the highest percentage of persons with AD, living in an institution, compared to the other provinces Ontario and BC seem to have the next highest percentage. This seems to identify a need for proper training and education of staff in these institutions, in the care of these residents.

Adopted from Canadian study of health and aging working group (1994).
This figure shows a graph of the number of cases of Dementia in the 65+ age group, in the Canadian statistics for 1991, and a prediction for the following years. AD is identified as the fastest growing type of dementia, as noted in the graph.
STAGE 1: During Caregiving

**Conditions**
- Diagnosis + Deterioration
- Powerlessness & Loss
- Empty Space Begins
- Process of Detachment

**Strategies**
- Intense caregiving
  - Continue to love and try to communicate
  - Cry a lot
  - Isolate oneself
  - Pray that family member will die

**Consequences**
- Exhaustion
- Depression
- Guilt
- Satisfaction

Adopted from Jones and Martinson (1992).

This figure identifies the Stages of Alzheimer Caregiver Bereavement. Although this is a suggested process of bereavement, many caregivers take longer than others, to go through these stages, and may not necessarily achieve the outcome suggested.
| Age Group | Community | | Institution | | Total |
|-----------|-----------|-----------|-------------|-----------|
|           | Estimated # in 1000's | % | Estimated # in 1000's | % | Estimated # in 1000's | % |
| 65-74     |           |       |                   |       |                       |   |
| Male      | 3.0       | 0.4   | 1.3               | 8.1   | 4.3                    | 0.6 |
| Female    | 11.2      | 1.1   | 3.6               | 16.9  | 14.7                   | 1.4 |
| Total     | 14.1      | 0.8   | 4.9               | 13.1  | 19.0                   | 1.0 |
| 76-84     |           |       |                   |       |                       |   |
| Male      | 14.2      | 3.9   | 7.3               | 26.4  | 21.5                   | 5.5 |
| Female    | 24.5      | 4.6   | 22.5              | 36.0  | 47.0                   | 7.8 |
| Total     | 38.7      | 4.3   | 29.8              | 33.1  | 68.5                   | 6.9 |
| 85 and over |         |       |                   |       |                       |   |
| Male      | 7.7       | 12.1  | 9.2               | 41.7  | 16.9                   | 19.6 |
| Female    | 17.7      | 14.7  | 38.9              | 51.1  | 66.6                   | 28.8 |
| Total     | 25.5      | 13.8  | 48.1              | 49.0  | 73.5                   | 26.0 |
| All Ages (65+) |      |       |                   |       |                       |   |
| Male      | 24.9      | 2.2   | 17.8              | 30.0  | 42.7                   | 3.8 |
| Female    | 63.4      | 3.0   | 66.0              | 39.4  | 118.3                  | 5.8 |
| Total     | 78.3      | 2.7   | 82.8              | 36.7  | 161.0                  | 5.1 |

This figure provides an estimated number of cases of Alzheimer’s disease in the 65+ population, by regions and residential groups, Canada, 1991.
It also shows an estimated number per 1000, of male and female cases per Region, in the community and in institutions. In viewing this figure, it seems that Ontario has a larger number of female cases than male with AD living in the community. One can assume then that men are providing much of the care for some of these women. The total numbers of cases across Canada shows that there are more female cases of AD, than male.
<table>
<thead>
<tr>
<th>Region</th>
<th>Community</th>
<th>Residence</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Estimated # in 1000's</td>
<td>%</td>
<td>Estimated # in 1000's</td>
</tr>
<tr>
<td>Atlantic Provinces</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3.3</td>
<td>3.1</td>
<td>2.0</td>
</tr>
<tr>
<td>Female</td>
<td>6.2</td>
<td>3.9</td>
<td>6.5</td>
</tr>
<tr>
<td>Total</td>
<td>9.5</td>
<td>3.5</td>
<td>7.5</td>
</tr>
<tr>
<td>Quebec</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>8.4</td>
<td>3.4</td>
<td>3.3</td>
</tr>
<tr>
<td>Female</td>
<td>16.2</td>
<td>3.6</td>
<td>14.9</td>
</tr>
<tr>
<td>Total</td>
<td>23.6</td>
<td>3.5</td>
<td>18.2</td>
</tr>
<tr>
<td>Ontario</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3.8</td>
<td>1.0</td>
<td>6.4</td>
</tr>
<tr>
<td>Female</td>
<td>20.4</td>
<td>3.1</td>
<td>23.7</td>
</tr>
<tr>
<td>Total</td>
<td>24.2</td>
<td>2.2</td>
<td>29.1</td>
</tr>
<tr>
<td>Prairies</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>5.3</td>
<td>2.5</td>
<td>4.9</td>
</tr>
<tr>
<td>Female</td>
<td>6.3</td>
<td>2.2</td>
<td>13.8</td>
</tr>
<tr>
<td>Total</td>
<td>11.6</td>
<td>2.3</td>
<td>18.7</td>
</tr>
<tr>
<td>British Columbia</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>4.1</td>
<td>2.6</td>
<td>2.2</td>
</tr>
<tr>
<td>Female</td>
<td>5.3</td>
<td>2.2</td>
<td>7.1</td>
</tr>
<tr>
<td>Total</td>
<td>9.4</td>
<td>2.3</td>
<td>9.3</td>
</tr>
<tr>
<td>All</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>24.9</td>
<td>2.2</td>
<td>17.8</td>
</tr>
<tr>
<td>Female</td>
<td>53.4</td>
<td>3.0</td>
<td>65.0</td>
</tr>
<tr>
<td>Total</td>
<td>78.3</td>
<td>2.7</td>
<td>82.8</td>
</tr>
</tbody>
</table>

Adopted from Canadian study of health and aging working group, (1994).

This picture provides an estimated number of cases of Alzheimer’s disease in the 65+ population by regions and residential groups. It also shows an estimated number per 1000, of male and female cases per region, in the community and in institutions. In viewing this picture, it seems that Ontario has a large number of female cases than male, with AD, living in the community. One can assume then, that men are providing much of the care for some of these women. The total numbers of cases across Canada shows that there are more female cases of AD, than male.
Appendix R

Glossary of Terms

A glossary is presented to give a clearer understanding of terms used in this paper.

Agnosia: loss of the ability to recognize the meaning of stimuli from the various senses (visual, auditory, touch).

Alzheimer’s Disease (AD): AD is a progressive, degenerative, irreversible disease, which gradually destroys vital nerve cells in the brain (Alzheimer’s Society Canada, 1999). Wuest, King Ericson and Noerager Stern (1994) refer to it a type of dementia that is, insidious, pervasive, debilitating disorder that destroys the affected person’s capacity for self-care.

Apraxia: the inability to carry out a learned movement voluntarily or to plan and execute movements when comprehension and motor abilities are intact.

Caregiver support program: This is a program provided by the Victorian Order of Nurses in Hamilton, mainly to provide respite and education for the caregivers of patients suffering from dementia and who are being taken care of in their homes. Components of this program are scheduled visits by a Psychogeriatric Nurse, maybe weekly initially, then monthly. The caregiver also has the opportunity to purchase respite or hours of babysitting at a cost of $5/hour provided by a Personal Support Worker, and this gives the caregiver the opportunity to have some scheduled relief hours as needed. The most recent addition to this program is the services of therapeutic recreation at a cost of $2/hour for patients with dementia and whose caregivers are registered with the program. It is available to other patients, but at a higher cost. Unfortunately, this is service is not available in the Halton area.
Cognitive Decline in Normal Aging: "Intelligence is known to decline with age" (Peterson, 1994, p. 45). This conclusion was based on the results or test scores from three different versions of the Wechsler Adult Intelligence Scale (WAIS). They showed a pattern of decline in intelligence tests across the life span. Researchers try to discount other hypotheses that attribute this general decline to motor slowing, disuse of intellectual functions, or cohort effects (Peterson, 1994). The WAIS is divided into verbal and performance scales. The verbal tests measure one's store of general information and vocabulary, known as "crystallized intelligence" or acquired knowledge. The performance scale taps into the "fluid intelligence," which is the ability to perceive relationships and to manipulate information. Comparing the verbal and performance scales, it was concluded that people maintained their level of crystallized intelligence until about age 70, after which it begins to decline. Fluid intelligence, however, peaks at age 20 and gradually declines, so that at age 60, there is a considerable loss of this ability. This decline makes it difficult for one to diagnose dementia in its early stage. It is recommended that neuro-psychological testing is probably the most sensitive in making a diagnosis of dementia (Peterson).

Cuing: prompting the patients in assisting them to carry out the desired task.

Dementia: cognitive losses that lead to declining function in occupational, social, or day-to-day functioning. These losses are more than the normal aspects of cognitive performance, which deteriorates with age.

Formal caregivers: Formal caregivers are paid caregivers, most of them being professionals.

Geriatrics: health Services for seniors.
**Informal caregivers:** Informal caregivers are unpaid caregivers, who are mostly family members or friends, and who care for loved ones in their homes or in the patient's home.

**Instrumental activities:** activities such as the ability to use a phone, perform multilevel tasks, banking, problem solving, critical thinking, and everyday executive functions.

**Nurse clinician:** A registered nurse with a Bachelor of Science in Nursing, who functions as a Case Manager, providing education and support to patients and their caregivers. The Nurse Clinician also has a good knowledge of the available community agencies/resources and a working relationship with them.

**Homeostasis:** maintenance of a steady, stable state in the body.

**Instinct:** a complex pattern of responses by an organism, supposedly inherited, and independent of any thought process.

**Triangulation:** the use of different types of measures or data collection techniques in order to examine the same variable.

**Alzheimer Society Wandering Registry:** Patients are registered with the society and provided with identification in the form of a bracelet or necklace. This article has the person's name and address or directions to take them to the police, who have a record also of persons registered with the registry.
Appendix S

Data Collected from the Interviews

Question 1: Could you tell me when you first noticed that something was “not right” with your wife?

Answers:

- 3 men answered 6 years
- 1 said 6 to 7 years
- 1 said 5 years
- 1 said 3 years. Some were newly diagnosed
- 2 said 1 year
- 1 said 1½ years
- 1 man said that he never did. He attributed these changes to the epileptic seizures that she has had for most of her life. He further said that he does not believe the diagnosis.

Question 2: What was your reaction when you were told that your wife was suffering from AD?

Answers:

- I found it devastating and sick at heart. It was very disconcerting.
- Oh! I felt awful because I wasn’t aware of what it was all about.
- There was no traumatic reaction, I could see it coming.
- I suspected something of this nature quite a while before that. I guess disappointment is the big thing.
- It made me feel bad and it bothered me.
What can I do in this situation, I accepted the fact, didn’t like it, but realized that I had a job to do, no question about it.

I have a friend who went through it.

I didn’t know what the disease was all about. It is hard to say.

I do not believe it, so I don’t have that emotional baggage.

Well, not much I could do about it. Tough. I really don’t know what I felt. It is hard, especially in my condition, to relate to it.

Question 3: How and when did you inform other family members and friends about your wife’s illness?

Answers:

Well I did not.

My daughter had an idea and I just came right out and told our friends.

My son and his wife were with me when the doctor told us.

They were informed from the first day we were told.

For the first year we did not say anything.

It was a gradual thing as things came up and I had to explain.

Within the week, and they did not believe.

They could see it and I never made a big thing about officially telling them.

I don’t know, I have no idea, but they know.

My son and I spoke with the specialist but he never mentioned AD.

Question 4: Could you describe to me what it feels like for you to be assuming more and more responsibility?

Answers:
She couldn't do the things she used to do, so I accepted the position of full-time Caregiver.

It was not much of a change as others, for I always done quite a bit of the housework.

I am not, I am no more pressed, we pretty well share everything.

You expect that it is coming, so I ask the help of my daughters over the phone, and they sneak in and replace her personal stuff, like her underwear.

It is closing in on me, I have less free time to think, you don't have a life of your own.

The transition was easy, as I did a lot prior to her illness, but the one big thing is the laundry.

I just coast along, I manage everything, I just manage. The ladies in the store help me with her shopping, and I learn.

I find it affects my nerves, no question about that.

It's frustrating, and the loss of independence.

Yes and no. His wife continually interrupted and seemed to be getting angry.

Question 5: Would you tell me about the type of person that your wife was prior to her illness?

Answers:

- A strong-willed person and a great lady, who spoke excellent grammar and taught grade school.
- A very out-going girl who was very much in sports like golf.
Always on the nervous side, never a forward person, always in the background and took care of the housework.

Very quiet, friendly, loved to joke, liked to travel, and just an all-round person.

Very friendly and easy to get along with, you can always count on a smile from her.

Usually really quiet, not outspoken like some.

Always a little quiet in a group of people, would just sit and listen, putting in a comment now and then.

She was a good nurse and she liked to travel, we were not socials nor joiners.

She was very active, loved to do needlepoint, read, and we always did the shopping together.

Unable to ask this question to one person, due to interruptions by his wife.

Question 6: What was your role in the marriage prior to your wife’s illness?

Answers:

Bringing in the money and doing the heavy house hold duties.

Doing the finances and taking care of the bills.

Somewhat traditional, I practiced Law and other things and she was a stay-at-home wife.

Bread earner and handyman.

I was the provider, and my wife looked after the house and family.

I looked after the paperwork and the bills.

I was very much devoted to my job and worked hard at it, being very successful.
I worked and her life was at home.

I helped with cooking the things on top of the stove, and directed her with the things in the oven, as he was experiencing difficulty with bending and mobility.

Question 7: Could you describe to me what you consider a good day for yourself and your wife?

Answers:

♦ No attitude problems like her not wanting me to do anything for her. If she had a good night’s rest, you know that you have a good day. If she was restless during the night, she gets up agitated.

♦ Lots of good days, not bad.

♦ That she would get up by 10 o’clock in the morning. If she would, then we could have breakfast together. Quite often it is lunch.

♦ When we do things together, with friends and our children.

♦ I like a day when I get up, read the paper, get her breakfast, her pills, shower, then she goes for a little rest. Then I would get her up and take her to a drive-through for a burger, then visit my sister and come home.

♦ Oh, I don’t know. Maybe going out for supper, or the show, or to visit friends.

♦ When we don’t get into conflicts. In the past weeks, she now opposes everything I say... If I say ”black” she says ”white.” Maybe I am overprotective.

♦ When we can keep on a friendly conversational basis without her getting mixed up. A good day is when the problems do not get too serious and I can ride along with it and we can have some laughs out of all of this.
• Well, there are more bad days than good days now, and yet at the end of the day you say: "Well, I guess things went well."

• It was not appropriate to ask one of the men this question due to constant interruptions from his wife.

**Question 8:** What was classified as a bad day?

**Answers:**

• I am frustrated by so many things that... Yesterday she lost her wallet and she was really worked up about it, you know, all the cards and that. I think that it is the wasting time and doing nothing constructive that bothers me.

• If we get into heavy discussion we start to natter at one another, but never name-calling. Before the pill not only was she argumentative, but she was aggressive.

• She opposes everything I say. I don’t mind the job of being a full-time caregiver, I don’t mind it. What I do mind is not being accepted.

• If she wakes up and seems out-of-sort. She does not have a bad bone in her body. I can’t describe a bad day.

• When she does her business on the floor and I have to clean up.

• You know, any bad day is my fault. There are days when I don’t feel good because of medication. I don’t see how I can blame her for that. It just spoils my day.

• A bad day is when she does not get up until 12 o’clock, and then she is nervous and really does not want to have breakfast. On a bad day she seems to come around about 4 to 5 o’clock in the afternoon.

• When I can’t get back to bed for another 2 hours.
When she is agitated she is more withdrawn, and I say it is when she had a restless night. That would be a day when I should not expect too much out of her. This would be a stay-at-home day.

It was not appropriate to ask one of the men this question due to constant interruptions from his wife; this was obviously a bad day.

**Question 9:** How has your own health been since you are caring for your wife?

**Answers:**

- Not really. I've been in the hospital twice in the past 3 years, but that had nothing to do with looking after her. I have the odd cold.
- Not too bad. Can't complain.
- Well apart from my arthritis, I had couple of heart attacks, the first one when I was 46 years old and one three years before I retired at 63 years.
- I feel fine.
- I feel healthy. I do everything.
- Well, I have a problem that my heart accelerates up to 170 and there could also be an irregular heartbeat. I was in the hospital about 10 days ago.
- Well, as far as I'm concerned it's ok.
- No, not in a physical way, but maybe I get exhausted.
- I have been getting old faster the last year or 2. I feel good though, and I tire easily and can't keep up. I am 80 you know.
- Although this question was not asked directly, this caregiver was legally blind for 10 years; he stated that he also has Crohns disease and is recently walking with crutches as a result of one of his legs being painful and obviously swollen.
Question 10: Could you tell me what is the most important thing that you are missing in your relationship with her now?

Answers:

- I don’t know that we are missing a lot. We don’t carry on many conversations.
- It’s while we have times during the day we can have a good relationship and laugh about things, they are not the same. You try to be kind and understanding but you know that you are dealing with an upset mind. (conversation)
- I don’t think that we can discuss things on the same level as we were able to do. (conversation)
- Freedom to do something what you want.
- That we can’t go out and enjoy ourselves the way we used to, and you know it’s not going to happen.
- Nothing.
- Just the fact that we can’t go out and enjoy many of the things that we used to, as she is very reluctant.
- We are not as close as we were now. We used to discuss things, which we cannot now. (conversation)
- We use to love going to the races, going to Las Vegas. I kind of missed the traveling
- Unable to ask this question to one person whose wife continually interrupted.

Question 11: I would like you to tell me about the things that are most frustrating to you in caring for your wife.

Answer:
I think if I try to help too much it frustrates her and frustrates me, so sometimes I just let things.

The little things. She does things and then she doesn’t realize it: “She would put on such a good show, so when the children visit they would say: ‘Dad, Mom is fine,’ but they are not living with her.”

How she is not getting up. This time in bed was probably there for the last year.

You see, I don’t care for her. She does her own shopping, although I also shop along with her. I have my own shopping list with most things that I think we need or that I want.

It is like when I get her up after lunch, she would not sit to rest, she would not sit down. She would keep pacing the floor and start sweating, and that bothers me, as I think that it is involving the heart or something. As she sweats, she gets on the red side and that bothers me a lot.

Well, it is the inability for her to make decisions. Once in a while you make the error of sending her for something, and you get the wrong thing coming. You might as well gone and got it yourself to save the whole frustration.

I can’t think about anything else except not listening to me.

Something that is building up now fairly recently is the fact that she follows me around, she does not actually follow me around, but she is there. Mostly you have to work around her.
When her mind is completely blocked, and I can’t reach her, can’t talk to her.

When her mind is blocked, she just shoots down all your suggestions to cope, as fast as you try.

Although this question was not asked, it was obvious that the caregiver was frustrated with the constant interruption of his wife.

**Question 12:** How do you cope with your frustrations?

**Answers:**

- Well, living in a house, you can go out into the back yard and do something outside. Pop up to the neighbour for 5 to 10 minutes, making sure that the door is locked. You have to learn or teach yourself to be patient or you will lose everything. Your whole attitude has to change.

- Well, I buy myself a Mickey and drink it, not to get drunk, and I watch sports or TV.

- I guess that I have read just about everything that I can get my hand on in relation to AD, and I know these things are going to happen, so I try to console myself. I guess I talk myself, I don’t know, out of those frustrations.

- I don’t have any in dealing with her.

- I don’t know myself, but I do, you know. Oh, I watch TV. I always like my sports so I watch what’s on television and get like golf, baseball or something.

- Just don’t send her for things. It just increases your workload. I curl and spend time in my shop.

- Sometimes I have to walk away, I can’t take some things.
I try to forget it. I get out to the supermarket almost every day for just a short time. Curling, once or twice per week for a short time. So, almost pretty well every day, I am out for a short time running errands.

I take full advantage of the help that I am getting from the agency, so that I can get out and enjoy other associations and feel confident that she is being looked after and enjoying her time.

This question was not asked directly; however, it was observed that the caregiver dealt with his frustrations by being quiet, allowing his wife to continually speak.

Question 13: At what point in your situation did you seek outside assistance?

Answers:

- I would say, just after she was diagnosed, Spring'94. I went to the 5-week course, and from there, Jan'96, I started going to the Alzheimer’s support group.

- About a couple months ago, and my daughter and the specialist set it up (wife has had AD for 2 1/2 years).

- Well, I guess that it was just over a year ago when I made a contribution to the Alzheimer’s society, the Toronto one, and received a pamphlet. So I phoned the Alzheimer Society here and the coordinator categorized my wife from the gist of our conversation, and we have been associated with them over a year now (wife has had AD for 3 years).

- While we were still in Toronto, again our daughter felt that my wife should visit the Alzheimer Society there and see a specialist. When we moved, it was decided then maybe, a support group would be a good idea (wife has had symptoms since
1962, however, her driver’s license was revoked in 1997, so there is no definite time of diagnosis provided by the caregiver).

- I would say about 2 months ago (wife has had AD for 5 years).
- I didn’t. Last year I had someone coming in the morning to relieve the frustrating part (wife has had AD for 6 years).
- I don’t know if I sought outside help, or they sought me. I think that it all started with the social worker at the hospital. (wife has had AD for 1 year).
- I really didn’t. I have a fair idea of what is out there. Things were approved for over a year before we got someone. I didn’t want to go to an agency to get someone (wife has had AD for 6-7 years).
- When I could not cope with her disorientation, stumbling and falling as a result of the stroke (wife has had Dementia for 1 year)
- No definite time was established, however, a homemaker visited regularly due to the disability of the caregiver and a nurse to assist in coping with dementia (wife has had AD for 6 years).

Question 14: Could you tell me what made you accept the help that was offered?

Answers:

- It was too much for me.
- I guess it was after reading the brochure, and she agreed to it. (wife attends the support group for persons with AD).
- Well, I really haven’t had any part in any of the decision making on this. She herself has (wife attends the support group for persons with AD)
♦ It started to get too much because I couldn’t wash her, and the odour and smell, I couldn’t. So I thought that professionals have a way of handling it, and I figure I would learn something.

♦ When you are shaving or a shower, she wants to be looked after, you are trying to make breakfast... You don’t even have time to properly wake up. Well, I got someone and she got shook up because she did not want the girl dressing her. The doctor mentioned the support group and from that I learned about the Day program.

♦ Well, I don’t think I had a choice. I cannot do everything and I am used to in my past employment, delegate. I know I cannot, and the housework would be a big problem for me. It wouldn’t get done the way it is now and the way she did it.

♦ Well, I wanted it at that time and I felt that I could do the inside work ok, and I could do the outside work ok, but it was getting to the point that I couldn’t do both.

♦ Well, she couldn’t walk properly. She was unsteady and she had to use the walker, and this means that she couldn’t climb the steps, and when we went in the Mall she couldn’t walk from store to store to store, she had to stop and rest. As the physical got better, the mental got worse.

♦ It would have been tough without the homemaker.

♦ One caregiver preferred to just attend the support group meetings and receive education through his affiliation with the Alzheimer Society.
Question 15: In what ways are support groups helpful, to you?

Answers:

♦ Very helpful. It means that when they are here, I can go out for a coffee, read the paper, and whatever I want to do. The nurse is nice, comforting to have someone to talk to, and checks on me more than my wife.

♦ Well, I have been to three, and I found it very depressing. They basically talk about those people who are in the class six and seven category. She enjoys coming once per month.

♦ To me, I don’t know, because I have just been talking with the men.

♦ I learn whatever I can, and they help me out.

♦ Well, it is good to rub shoulders with people. You can talk about your personal experiences. The frankness cannot be expressed anywhere else but in a group with people who are walking in the same shoes that you are, and they are compassionate people because they need compassion.

♦ Ok, I have the housekeeper coming twice per week, and this program here, and I have the VON comes once per month, and I get in touch with her whenever I have a problem.

♦ The nurse from VON is coming to see me.

♦ Well, it has been very helpful.

♦ I find them very, very helpful. Each one has a chance to talk about their family member, and you learn a lot from that. You learn from other people about how they handle things, what to expect along the line. There is a lot of sharing with other people who have something in common with you.
Very helpful. The nurse comes once per month, checks our blood pressure, talks to us and checks things.

Question 16: What are the frustrations, if any, that you are encountering with them?

Answers:

♦ We used to, but now we have a very reliable woman. The others did very little.

♦ None.

♦ Some of the men are retired, some not, but it depends on how happy the man is in his other jobs.

♦ I don’t think I have any frustrations. They are pretty good. I’m satisfied.

♦ I don’t have any frustrations for I am a good manager. The frustrations could be self-inflicted. If you can’t cope, then you get frustrated.

♦ No, I think that the services provided are really excellent; however, he later complained about the lack of dedication and negative body language of some homemakers.

♦ No, the only thing we have so far is the housekeeper (recently registered with the VON Caregiver support program).

♦ Ah, this all so brand new to me. If anything, I have so many visits. I haven’t had so many in all my life, and so many appointments.

♦ No, as a matter of fact, everything to me is really... I am fortunate to have something like this.

♦ No, direct answer from one person; however it seems as if he was very satisfied with the services that he was receiving.
**Question 17:** Could you provide me with some suggestions that will help us to improve the services available to patients and caregivers coping with Alzheimer’s disease?

**Answers:**

- I think that people should get as much help as possible.
- I would think that when it gets closer to the time, that I would be able to get in contact with somebody that I could have come to the house, for 3 to 4 hours
- I find this hard to answer; however, maybe an information line where people can receive information anonymously
- I think from what I hear, there are services galore and if people really wanted them, I think that there are enough services and things for people if they wanted them.
- In-house Respite (this caregiver does not live in Hamilton and does have access to the Hamilton VON Caregiver program).
- Could we have one person that we can relate to (apparently there was a problem with a different homemaker coming each time, until a regular person was requested).
- I don’t think that I have a lot of advice.
- Others need to know what is available when they suspect or have someone with the disease, and what to do.
- As much information as possible, like the information sessions relating to the disease process, and the behaviours. Things like advice on Power of Attorney, wills, and funeral arrangements were very helpful.
- Not addressed with one caregiver, as questions seem to irritate his wife.
Question 18: What do you find most helpful in assisting you to care for your wife?

Answers:

♦ The homemakers.

♦ I find, to keep her in a good mood.

♦ She cares for herself, but speaking like this…

♦ Oh, I find it helpful with these nurses keeping tabs on her all the time, and I go to my sister’s (in-house respite).

♦ Oh, quality time is the most precious thing.

♦ I think, the housekeeper coming in. The VON nurse gave me a lot of education in a folder and she told me to go on the net.

♦ I don’t know.

♦ I think the practical suggestions and the expertise of the counsellors who come.

♦ The Support Group.

♦ The homemaker (the caregiver) and the nurse (his wife).