THE PRE-ILLNESS MARITAL RELATIONSHIP AS THE CONTEXT FOR WIVES CAREGIVING FOR A HUSBAND WITH ALZHEIMER DISEASE

by

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Abstract

Wives caregiving for husbands with Alzheimer disease (AD) pursue the caregiving role within the context of their pre-illness marital relationships. A relationship-oriented approach to understanding informal family caregiving from the wives' perspective of their experience caregiving for their husbands with AD offers a new perspective to enable nurses to identify the caregiver's individual support needs. The purpose of this qualitative inquiry was to contribute to our knowledge of family caregiving by offering an understanding of the influence of the marriage relationship from the perspective of wives caregiving for husbands with AD. This research also endeavored to increase nursing knowledge regarding the wives' experience caregiving for husbands with AD within the context of marriage. This qualitative study is a secondary analysis of Dr. JoAnn Perry's (1995) PhD dissertation data. The secondary research method was guided by the principles of grounded theory and operated within the interpretive research tradition of symbolic interactionism. Symbolic interactionism framed the analysis to promote understanding of the influence of the wives' pre-illness marital context. The findings of this study revealed that the nature of the pre-illness marital relationship for wives caregiving for husbands with AD was formed by the wives' interpretation of their husbands' behaviour and the meaning they assign to it and their understanding of their interactions as a married couple. The nature of the pre-illness marital relationship influenced the wives' ability to (1) access internal support from the marriage experience, and (2) preserve a sense of couplehood within the caregiving experience. The concept of connection
emerged as an important experience within the marital-caregiving relationship in the following two ways. First, connecting with the person describes the process by which the wives enacted their desire to preserve a sense of couplehood. Secondly, the marital connection appeared to be the wives' link to internal support from the past marital relationship experience. Connecting with the past was one way that wives could enrich their caregiver-care-receiver relationship and experience gratification from the wife-caregiver role. Further investigation is required to confirm the marriage context as an influence within spousal caregiving. The author's interpretation of the wives' narratives in this secondary analysis offers one understanding of the wives' marital-caregiving experience for husbands with AD. This research outlines implications for nursing practice, education, and research.
# Table of Contents

Table of Contents ........................................................................................................... iv

List of Tables ..................................................................................................................... viii

List of Figures .................................................................................................................... ix

Acknowledgements ........................................................................................................... x

Dedication .......................................................................................................................... xi

CHAPTER ONE: INTRODUCTION ..................................................................................... 1

  Background to the Problem ......................................................................................... 1

  Senior Population and Chronic Illness ..................................................................... 1

  Health Care Delivery ................................................................................................. 3

  Caregiver Support and Wife Caregivers .................................................................. 6

  Marriage and Caregiving ......................................................................................... 8


  Research Question ..................................................................................................... 14

CHAPTER TWO: A REVIEW OF THE MARITAL-CAREGIVING LITERATURE ............... 15

  Marriage and Informal Caregiving ........................................................................... 16

  Definition of family .................................................................................................. 16

  Definition of marriage. ............................................................................................ 19

  Marriage as a family subsystem ............................................................................. 20

  The Marital Relationship in Caregiving .................................................................. 22

  Communication ........................................................................................................ 23

  Companionship ........................................................................................................ 25

  Commitment .............................................................................................................. 29

  Affection .................................................................................................................... 35

  The Pre-Illness Marital Relationship in Caregiving .................................................. 38
Accessing the Past Marital Relationship ........................................................................................................... 116
Nursing Practice ......................................................................................................................................................... 123
Nursing Education ...................................................................................................................................................... 128
Nursing Research ....................................................................................................................................................... 130
Summary ................................................................................................................................................................. 134
References ................................................................................................................................................................. 137
Appendix A: Consent for Primary and Secondary Studies ......................................................................................... 147
List of Tables

Table 1: Fit Between the Primary and Secondary Research Studies ............... 55
Table 2: Demographic Information .............................................................. 67
List of Figures

Figure 1: The influence of the wife's interpretation and understanding of the pre-illness marital relationship in caregiving for a husband with AD ......... 69
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Dedication

I would like to dedicate this thesis to:

My husband Ken - You carried me through this intellectual and emotional experience, while providing for our family, raising one, then two very energetic boys, and working on your own graduate work. I truly would not have completed this work without you. Thank you for encouraging me to take the time to be the student I needed to be.

My big boy Thomas - All of three, for your encouraging words over the past several months, such as, “Do good work Mommy” and “That’s okay Mommy”. I hope to offer you the same unconditional support you so easily gave me in all of the endeavours you wish to pursue.

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My Mom – Words cannot express all that you have done for me. You have supported me in several different ways throughout this process, as you have throughout my entire life. I will never be able to repay you for all that you have done for me but I will always try to offer my children the same support that you have offered me.

My Dad – For always believing in me. When the demands in my life weighed heavily, you always knew what to say to help me focus on the outcome of a continued effort.
CHAPTER ONE: INTRODUCTION

Background to the Problem

Over the past several years, there has been a marked increase in the incidence of informal caregiving for a family member with a chronic illness, and the literature suggests that the demand for family caregivers will continue to rise (McAllister & Hollander, 1994; Canada, 1997). The consequence of this increase is important because the Canadian health care system presently relies on families to care for a large portion of the chronically ill older adult population. The reasons contributing to this reliance include the changes to the delivery of health care, the desire for older adults to age at home, and the competitive demands for health care funds.

Senior Population and Chronic Illness

The recent motivation to study issues faced by seniors and to prepare appropriate health care imperatives at the federal and provincial levels in Canada is largely based on the forecasted increase in the senior population. According to statistical projections, the population aged 65 years and older will represent 16% of all Canadians in 2016 and 22% to 25% in 2041, approximately 9 to 11 million people (Statistics Canada, 1994). According to 1996 census data, this cohort currently represents 12% of the Canadian population, approximately 3.4 million people (Statistics Canada, 1994; Statistics Canada, 1997). Statistics confirm that the number of Canadian seniors with chronic and debilitating diseases who are cared for at home is rising (McAllister & Hollander, 1994; Canada, 1997). The literature also identifies a proportionate increase in the incidence of chronic
illness as people age (Statistics Canada, 1994). At the same time, a growing number of chronically ill seniors are being cared for at home and the provision of non-technical care is largely dependent on available family support (Fast & Frederick, 1999; McAllister & Hollander, 1994; Canada, 1997). These trends suggest that the need for family caregivers will increase over the next 30 years. Factors contributing to this prediction include a large portion of the Canadian population achieving old age, even shorter hospital stays, and in time, better home care options being developed (Hill, Forbes, Berthelot, Lindsay & McDowell, 1996; King, Collins & Liken, 1995; Statistics Canada, 1994; Statistics Canada, 1993; Wilkins & Park, 1996; Worcester & Hedrick, 1997). The rise in the chronically ill senior population has tremendous implications for family caregivers.

Alzheimer disease (AD), a form of dementia, is a chronic illness that is marked by the progressive decline in both cognitive and functional abilities. According to the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV) (1994), AD is characterized by memory impairment (criteria A1) and other impairments (criteria A2) such as, aphasia, a deterioration of language functioning, apraxia, an impairment in motor functioning, agnosia, an inability to recognize or identify objects, and disturbances in executive functioning, an inability to think abstractly and to plan, initiate, sequence, monitor, and stop complex behavior. In order to establish a positive diagnosis, the above criteria must be severe enough to preclude social and occupational functioning and represent a decline from previous functioning
(criteria B). The cognitive decline is progressive and the diagnosis of AD is only given when all other conditions are ruled out.

While people with AD are often cared for within institutional settings, there is research acknowledging that many individuals are cared for at home by family members. Based on the Canadian population in 1991, Hill et al (1996) reported that a quarter of a million (252,600) elderly Canadians were afflicted with dementia. They found that only half of these individuals lived in institutions. The authors further noted that the number of seniors with dementia could triple by the year 2031. Despite current efforts in biomedical and psychosocial research, advancements in treatments are occurring slowly. It appears that AD and dementia will remain a serious health concern for some time. Parallel to this is the need for family members willing to provide informal care.

Health Care Delivery

The restructuring of health care in Canada also has implications for family caregivers. The emergence of long-term care policy in the late 1980's was based on the adoption of “an ideology of shared responsibility” designed by the provinces to reduce the cost of existing health care services by sharing more of the caregiving responsibility for chronically ill people with the public sector (Guberman, 1999, p. 19). Guberman's perspective identifies two major criticisms with respect to this plan. First, by 'sharing' responsibility with families, government assumes that family members are the most desired and best providers of care. Secondly, health officials failed to consult with families
regarding their perspective on the effectiveness of existing support programs and on their long-term care needs.

It appears that the motive behind the change in delivery was to ease the economic burden of the existing care structure, rather than support chronically ill people in the community. Fast and Frederick (1999) provide research evidence to support that the provision of care for older adults by family members in the community is economically sound for the Canadian government. Reporting on a 1996 sample of Canadian caregivers, the researchers calculated that the unpaid caregiving work performed by 2.1 million family caregivers in Canada was equivalent to the work of 275, 905 formal caregivers (based on janitors, cleaners, taxi drivers/chauffeurs, administration and service management workers and nursing aides/orderlies), with a replacement cost estimated between $5.1 to $5.7 billion dollars (p. 4-5). Evidently, these costs were absorbed by the caregiving families. With reports of limited and in some cases non-existing funding for community programs to support family caregivers, the Canadian government's ideology of shared responsibility is perhaps more of a transfer of responsibility to Canadian families (British Columbia, 1999). There is a need for more research reporting on Canadian samples of caregivers and their experience providing care to chronically ill family members within the current care system.

In BC, the Continuing Care system perceived the shift in service delivery to be in the best interest of the health of the chronically ill population to which they provided nursing and home care services. With a transfer of money from the acute care sector to the community to support the increasing need for service,
the plan appeared to be feasible. To date, because of competing health care demands, the transfer of funds has not materialized and acute care issues continue to receive the attention (British Columbia, 1999).

Most recently, the Ministry of Health and Ministry Responsible for Seniors developed a strategic direction plan for BC, with Continuing Care and Home Care being one of six areas requiring immediate federal funding to relieve the burden on the province’s health care system. It is expected that $108 million dollars is necessary to expand the Continuing Care system. The federal government is calling for new and innovative approaches to service delivery to improve the system (Farnworth, 2000). Yet, community services report a lack of available start-up funding for the development of innovative programs because of the preference of local health authorities to remain with established programs that already receive ongoing funding (British Columbia, 1999).

In sum, a number of studies have been undertaken to explore ways to decrease the financial costs of health care on the government. The recommendations from these studies have effectively shifted the burden of care from government to institutions and families. In response to these studies, critics suggest that the government’s motive behind change is to alleviate the burden long-term care patients place on the health care system, rather than improve services for families in the community. This perspective does not provide any direction for family caregivers within the home relevant to their immediate service needs. According to the Steering Committee of the Review of Continuing Care services in British Columbia (1999), "... British Columbians need to be clear
about what they want the Continuing Care system to provide, in order that the system makes the most of its funding" (p. 15). It is therefore timely that researchers facilitate the identification process for family caregivers by exploring what they deem important in their experience. Caregivers will not feel adequately supported unless the providers of health care seek out their opinions regarding the needs and services they feel are important to help them deliver good care to their family members.

**Caregiver Support and Wife Caregivers**

Because of the ongoing lack of appropriate support, family caregivers are found to experience burnout early in the caregiving experience (Fast & Frederick, 1999) and to develop health problems or exacerbate pre-existing health conditions (British Columbia, 1999). The expressed dissatisfaction of family caregivers is found within reports and research exploring service utilization. Caregivers most commonly report dissatisfaction regarding the type, quality and accessibility of services, one example being respite services, such as day programs (Guberman, 1999; Perry & Bontinen, 2001; British Columbia; Strang & Haughey, 1998). Family caregivers also report difficulty accessing information regarding available community support options (Guberman; British Columbia), managing financial responsibilities, meeting family caregiving and employment commitments (Guberman), and dealing with the stress, burden and isolation often associated with managing the tasks of caregiving (Wright, 1993).

The challenges facing caregiving families have received political attention through working groups like the National Forum on Health (1997), studies such
as the Canadian Study of Health and Aging (1994) and reports such as Guberman’s (1999) work outlining new policy for caregiving research. Yet, the current direction of the health care system places more responsibility on Canadian families to care for the aging population without offering adequate funding and supportive strategies (Fast & Frederick, 1999; British Columbia, 1999).

Despite financial and social barriers, such as lack of government funding for caregivers (British Columbia, 1999; British Columbia, 2000), shrinking personal support networks (Wright, 1991; Wright, 1993) and inappropriate and irrelevant relief services (Strang & Haughey, 1998), patients continue to be discharged into the care of family members. Of all informal caregivers, older wives typically care for their husbands and women provide more personal care than any other group (Anderson & Sabatelli, 1999; Burke, Lindsay, McDowell & Hill, 1997; Cranswick, 1997). Reporting on a national US based sample, Stone, Cafferata and Sangl (1987) found that wives provide care most often to their partners with AD or a related dementia. Caring for a memory-impaired spouse is somewhat different from caregiving for a spouse with a physical illness. Although there is a growing recognition that research is needed to explore the expressed needs of the younger onset AD population, the disease is most often associated with the older adult. Memory-impaired spouses are unable to participate in decisions regarding their care needs and the combination of cognitive and physical decline in the older adult results in an emotionally intensive and physically laborious role for the caregiver (Guberman, 1999). AD caregiving is
stressful and intensive not only for the increasing responsibility in personal care due to the progressive nature of the disease but also for the experience of loss of the person once so familiar to the caregiver. In addition, people with dementia become unable to maintain reciprocal relationships with their family members, and that is a tremendous source of stress for both the caregiver and the person with dementia (Clarke & Watson, 1991). Often, older adult spouse caregivers are also dealing with their own disease related health challenges (Guberman). The statistical literature also projects an increase in the number of wives caring for their partners with chronic illness at home because of the increased life expectancy of women over men (Moore, Rosenberg & McGuinness, 1997; Wilkins & Park, 1996). The prevalence of wife caregiving warrants an approach to caregiving research that explores their individual experiences and support needs.

**Marriage and Caregiving**

Thompson and Pitts (1992) claim that most of the marriage literature can be divided into three sections: (1) marital therapies, (2) marriage and health outcomes, and (3) marriage across the life span. Upon review of the marriage literature, their opinion accurately describes the focus of marriage researchers. The research literature on marital therapies, although interesting, will not be discussed, as it does not pertain to the wife's caregiving experience. The discussion will focus on marriage and health and the long-term marriage as it applies to older couples, followed by a review of the marriage and caregiving literature and its contribution to the current understanding of spousal caregiving.
There is a small body of research exploring the relationship between marriage and health. Most of the marriage and health literature concerned with older adults tends to focus on the negative impact of marriage on health. Several research studies link the long-term marital relationship to the incidence of depression among spouses later in life (Edwards, Nazroo & Brown, 1998; Herman, 1994; Knop, Bergman-Evans & McCabe, 1998; Tower & Kasl, 1996; Williamson & Schulz, 1990). More recently, the marital relationship has been explored for associated positive health outcomes. Schone and Weinick (1998) have found marriage to influence the involvement of elderly couples in illness preventive behaviour. Ren’s (1997) study, reporting on a national sample of married individuals, found that the quality of a marriage influenced an individual’s perception of personal health.

The study of marriage and the older adult is largely focused on marital satisfaction in later life. Despite a reported increase in marital satisfaction among older couples when compared to marital satisfaction in the child rearing years, later life is not necessarily the most satisfying time of the marriage. A decline in physical and mental health and a decrease in income because of retirement are cited as reason interfering with renewed marital satisfaction (Kaslow & Hammerschmidt, 1992; Rice, 1999; Weishaus & Field, 1988).

Most of the marital caregiving research is based on the investigation of the negative health outcomes associated with providing care. The spouse caregiver’s declining physical health (Review of Continuing Care Services in BC, 1999) and experience of depression, (Edwards, Nazroo & Brown, 1998; Herman, 1994;
Knop, Bergman-Evans & McCabe, 1998; Kramer, 1993; Tower & Kasl, 1996; Williamson & Schulz, 1990) stress and burden (Pruchno & Resch, 1989; Spaid & Barusch, 1994) have all received attention within the caregiving research.

Burden and stress are the most commonly studied concepts within the caregiving literature. Abel (1990) reviewed the literature on informal care for the disabled elderly and found it to describe the emotional stress caregivers experience and the physical tasks they perform. Abel claims that stress and burden identified as tasks are easily quantifiable, and in turn, have contributed to the narrow caregiving research focus. The author recognizes the information gained through quantitative investigations of caregiving from a burden and stress-coping orientation, but also identifies the limitations a task and stress focus places on understanding the caregiver's total experience. Abel does not disqualify the caregiver's experience of burden and stress or the labour intensive work of caregiving; however, she stresses the importance of diversifying our thinking in terms of the caregiver's experience. She argues a qualitative approach for caregiving research to uncover new areas for policy research, find positive aspects in caregiving, and develop an accurate understanding of the relationship between caregivers and care receivers.

Thompson and Pitts (1992) expand upon Abel's (1990) comments based on their research program on stroke patients, chronic illness, and relationships. The authors discuss three methodological problems repeatedly found in studies reporting on the effects of chronic illness on the marital relationship. First, they deem that questionnaires and interview methods with correlational designs are
frequently used in this area making it impossible to determine cause and effect between relationship factors and changes in health status. The authors suggest using longitudinal studies to measure the changes to relationship concepts over time. Second, many concepts in this area lack clear definitions such that various interpretations lead to low generalizability with respect to study findings. Lastly, reliability and validity of the measurement tools used to assess concepts have not been tested in some cases, leaving data open to interpretation. The authors comment on one final and related point in terms of the limits to the interpretation of studies. When the research focus surrounds one outcome measure, as we have seen with burden and stress in caregiving research, other indicators of the caregiver's experience can be missed. The lack of research acknowledging the complex world of the caregiver and her experience providing care supports the exploration of concepts to extend the current conceptualization of informal caregiving.

The caregiving literature provides direction for the study of marriage and caregiving. Thompson and Pitts (1992) recommend studying both the effects of long-term illness on the marital relationship and the effects of the marital relationship or spousal characteristics on the care of the person with the illness.

Over the past decade, a small number of caregiver studies have found the pre-illness marital relationship to influence some aspect of caregiving. Among these findings, the pre-illness relationship is an indicator of the caregiver's ability to seek respite, experience less stress and cope more successfully (Morgan & Laing, 1991; Kuhlman, Wilson, Hutchinson & Wallhagen, 1991; Strang &
Haughey, 1998; Wright, 1991). The authors recommend further study into the nature and quality of the prior marital relationship as it applies to the caregiving experience.

Gubrium (1995), a sociologist, recommends a new direction for caregiving research. The new direction stresses a critical assessment of caregiving grounded in the many experiences of caregivers and care recipients. The author believes that caregiving research has become so large and contradictory that it does not accurately describe the experience of caregivers and care recipients and is no longer moving toward new discoveries. Gubrium suggests that researchers revisit basic questions such as, "How does [caregiving] relate to the way everyday life is practiced in relation to it?" (p. 268-269). This assertion is central to the development of this thesis. It is essential to capture what spouse caregivers believe to be important in their experience before investigating possible relationships between concepts. Unearthing alternative concepts important to caregiving that focus on the caregiver’s well being is timely. In accordance with Gubrium’s (1995) perspective, this study will contribute to caregiving by offering an understanding of the marriage relationship from the perspective of wives caring for their husbands with AD.

Calls for a relationship-oriented approach to caregiving research have been documented in the caregiving literature (Keady, 1996; Clarke & Watson, 1991). Informal caregivers are challenged by a personal relationship history that influences the decisions they make regarding the care they provide to their chronically ill family members. With spouses, the marriage and family relationship
history can pose significant emotional, social and financial challenges to providing quality care. Pre-illness relationships characterized by conflict are found to have a negative impact on the informal caregiver’s ability to cope with care demands, provide care wholeheartedly and experience satisfaction from caregiving (Morgan & Laing, 1991; Kuhlman et al, 1991; Strang & Haughey, 1998; Wright, 1991). Wives require support services pertinent to their individual needs, some of which are shaped historically and contextually by the nature of their family and marital relationships. Relationship-oriented research is therefore needed to guide service delivery for wives providing informal caregiving. This thesis will attempt to provide such research.

Perry’s (1995) PhD Dissertation Research

This thesis is a secondary analysis of Dr. JoAnn Perry’s PhD dissertation research data. The primary purpose of Perry’s (1995) grounded theory dissertation research study was to understand the process of becoming and being a caregiver to a husband with AD. From this research, Perry developed the substantive theory of Family Know-How as Interpretive Caring.

The data collection process consisted of in-depth interviews, participant observation, and a pencil and paper instrument to collect and organize demographic data and act as a resource guide during the interview process.

From the collection, analysis, and interpretation of data from 20 wife caregivers emerged the theory Family Know-How as Interpretive Caring. Interpretive caring is a cyclical process composed of five major concepts: (1) seeing the signs, (2) picking up the slack, (3) increasing awareness, (4) changing
roles, and (5) adjusting identities and making daily life work. A new cycle begins with a behaviour change in the husband with AD or the caregiving wife, while the number of cycles experienced varies from dyad to dyad. Perry (1995) considers caregiving within the context of the family and her findings support exploring the concepts of marriage important to wives in caregiving.

Research Question

The specific research question directing this inquiry is: *What marriage and family concepts can be identified in women's descriptions of their experience caring for their husbands with AD?* This question is explored through a secondary qualitative analysis of Perry's (1995) existing data set.
CHAPTER TWO: A REVIEW OF THE MARITAL-CAREGIVING LITERATURE

The marriage experience of caregivers has not been a key area of study within the caregiving literature. A literature search within the Cumulative Index to Nursing and Allied Health Literature (CINAHL) database spanning the years 1969 to 2001 revealed 10 research articles and one book chapter that combined "marriage", "caregiving" and "spouses" or "wives". Of this literature, three articles studied marriage and nursing home placement, four articles explored marriage and the older couple, two articles examined long-term marriages, one article studied marriage and the selection of a caregiver, and one book chapter discussed marriage and chronic illness. The addition of "Alzheimer disease" to this search resulted in one article and one book that specifically looked at marriage and caregiving to a spouse with AD. Similar searches attempted in psychology, social work and family and women's studies databases identified many of the same research articles. Additional searches were conducted by combining relationship concepts cited within the identified caregiving literature.

The following is a critical review of the literature contributing to the conceptualization of marriage within caregiving. To help justify the investigation of caregiving in the context of the marital system, the review begins by defining marriage within a family system perspective. It is then followed by an exploration of the state of knowledge regarding marriage concepts. The chapter concludes with a review of the pre-illness marital relationship literature. The overall purpose of this review is to discuss the literature in relation to wife caregivers and AD.
caregiving, and to demonstrate the importance of studying the previously expressed research question with this population of interest.

Marriage and Informal Caregiving

The study of marriage and the marital relationship in caregiving can be conducted within the larger body of family caregiving research (Anderson & Sabatelli, 1999; Whitechurch & Constantine, 1993). This thesis will explore caregiving within a marriage context. This section will discuss the literature contributing to the family and marriage perspective within the present study.

Definition of family. Anderson and Sabatelli (1999) authored a text designed for classroom use describing family interaction, dynamics and function based on a family-systems, multigenerational and developmental framework and the developments in the field of family studies. The authors begin by explaining the difficulties associated with defining the concept of family. They claim the main problem to be the inaccurate image of the family grounded within traditional social values surrounding the ideal family. Today, there is diversity in family form and function, yet the less than 'ideal' family circumstance is still ignored or stigmatized because it shatters society's idealistic and unrealistic perception of family. In most family situations, the older adult caregiver's values and beliefs regarding the concept of family would be perceived as traditional or conventional. This knowledge can provide insight into the wife's commitment to providing care for her husband with AD. Still, it is important to understand that the concept of family changes over time when anticipating the values and beliefs of the members of a population in which we are providing care. Lastly, it is important to
consider a husband and a wife as a family form when designing an approach to caring for the caregiving-care-receiving dyad.

Eshleman and Wilson (1995) co-author a Canadian text which describes the family within Canada. They make similar arguments to those of Anderson and Sabatelli (1999) in defining the family as a social institution and a social system. Eshleman and Wilson assert that considering the family according to any one set standard neglects the culturally, sexually and economically diverse reality in family form and family relationships.

In considering the above arguments, Rice's (1999) definition of family, grounded in marriage and family research, is borrowed with minor modifications for this study as it is written to support and include the many family forms in existence today. Family is defined as:

Any group of persons united by the ties of marriage, blood, or adoption, or any sexually expressive relationship, in which (1) the adults cooperate financially for their mutual support and care of the children, (2) the people are committed to one another in an intimate, interpersonal relationship, and/or, (3) the members see their identity as importantly attached to the group with an identity of its own (p. 4).

In section one of the definition of family, Rice's reference to children does not discount couples without children, as evidenced by the inclusive nature of the definition when considered as a whole. This definition also permits the understanding of the older adult couple as a family system. Although the second section of the definition does not make allowance for marriages that continue to
exist in the absence of a commitment between the partners, Rice's understanding of the makeup of the family is not conditional on meeting all three components of the definition.

Rosenblatt and Fischer (1993) in their chapter on qualitative family research within Boss, Doherty, LaRossa, Schumm and Steinmentz', Sourcebook of Family Theories and Methods explain that regardless of how family might be defined, the three basic assumptions common to all forms of qualitative family research are:

1) the focus of the research is always on the family and never on the individual;

2) the meaning people share by form of action, communication, thought and feeling regarding their experience with the family is important data, and;

3) the interpretation of what families communicate regarding their members and their perceptions of themselves within the family are key to understanding the complexity that exists within the family experience. The interpretations of these complex processes are the foundation for the development of theoretical constructs that demonstrate an understanding of the family experience.

In accordance with the above three assumptions, this study will consider the wives’ descriptions of their perspective regarding the marital relationship experience with their husbands within the family system. The marital dyad is a
family form and will be considered according to the basic family assumptions to gain insight into the marital-caregiving relationship.

In an introductory editorial to the journal publication, *Qualitative Health Research*, Gubrium (1995) describes three directions for caregiving research. The purpose of new caregiving research foci are “to discover new meanings and fruitful understandings” as current models of caregiving over-simplify the complex processes of caregiving and the relationships within (p. 267). Gubrium claims that a study of concepts important to caregiving is in order, and progress made by:

1) understanding the term caregiving itself;
2) capturing the experiences of the *actual* caregivers, and knowing when we can say a relationship *is* caring or caregiving, and;
3) developing models that capture the diverse historical, cultural and social backgrounds of the people and from the people who provide the care.

The aim of this research project is to contribute to the broad goal of conceptual clarity for caregiving research. This thesis will offer insight into the marriage perceptions of a specific population by studying the wife's caregiving experience within the context of marriage.

**Definition of marriage.** The union of two individuals through marriage is one family form and a family subsystem (Anderson & Sabatelli, 1999). A description of marriage as a family subsystem and the importance of conceptualizing marriage from this perspective is found in the following section.
The National Advisory Council on Aging (1994) provides an eloquent and inclusive description of marriage. The council asserts that marriage offers individuals a unique opportunity to invest their emotional, spiritual and physical self, and that economic and social responsibilities contribute to the complexity and challenge of maintaining a healthy marital relationship.

In the most optimal life situations, commitment to developing the marital relationship is confounded by competing demands in the couple's life. The initiation of caregiving by a wife to her partner with AD is undoubtedly a change or disruption to the marital relationship as it stood before illness. Continuing to foster the marital relationship within the context of caregiving can be an onerous goal for the caregiver-care recipient dyad. Exploring this experience is important to the developing conceptualization of caregiving.

**Marriage as a family subsystem.** Family system theory is based on the general system theory (GST) and is appropriately used to understand family processes. GST is based on three core assumptions:

1) systems can unify science (similar behaviour patterns are seen whether the form is electronic, human or neurological);

2) systems are understood as a whole which is greater than the sum of its parts and;

3) human systems are self-reflexive (human systems are able to examine and monitor their own behaviour and that of others) (Whitechurch & Constantine, 1993).
Family system theory provides a theoretical framework for the investigation of marriage within this thesis. Viewing marriage as a subsystem within the family provides a clear frame of reference for an otherwise challenging and eclectic concept that has undergone extensive change over several decades (Anderson & Sabatelli, 1999; Whitechurch & Constantine, 1993).

Whitechurch and Constantine (1993) summarize three topic areas effectively addressed by family system research. The family system approach to research is most effective when questions are developed to:

1) understand family processes by looking at the transactions among family members;

2) understand the relationship of family systems to other systems, and;

3) understand how systems change.

This study will address all three questions, particularly how the marriage and caregiving relationships influence one another, and the changes wives describe to the marital subsystem with the addition of family caregiving.

Whitechurch and Constantine (1993) provide a thorough analysis of the limitations inherent within a system theory perspective. They explain that critics claim that system theory is too broad, that it is unable to explain relationships between concepts, and that it is better described as a perspective than a theory. However, the authors contend that these same arguments support the flexible nature of the theory and its application to the family. They also report that some feminist scholars believe that certain concepts of the family GST perpetuate the
power imbalance because of patriarchal practices experienced by groups such as women and children by subscribing to a hierarchy to organize systems and delegating power to some systems and not to others. Whitechurch and Constantine also claim that system theory allows an interpretation that responsibility for negative experiences within a family are shared equally among all members. The authors assert that careful use and a complete and thorough understanding of the principles and assumptions of the theory are necessary when research is conducted to test and support family system theory. This thesis will not test the tenets of family system theory. However, this research subscribes to the idea that the family is a system best understood by its relationship with other systems. Family system theory supports the assumption that the nature and quality of the marriage relationship (marital subsystem) influences a wife’s (individual subsystem) experience providing care to her husband (individual subsystem).

The Marital Relationship in Caregiving

Wright’s post-doctoral research is pivotal to our understanding of what is currently known regarding the impact of AD on the marital relationship. Her study (1993) combined qualitative and quantitative measures to compare the marital relationship of 17 ‘well-spouses’ and 30 ‘AD afflicted spouses’ to provide knowledge of how married couples deal with marital issues while in caregiving situations. For the study, Wright considered five marital issues based on a marital adjustment scale. Household responsibility, tension, companionship, affection
and sexuality, and her own addition of commitment to the spouse form the basis of her investigations.

A review of spousal caregiving research found four of the above concepts generating much of the research. Commitment, (Horowitz & Shindelman, 1983; Motenko, 1989; Stanley & Markman, 1992; Wright, 1991; Wright, 1993), communication, (Cartensen, Graff, Levenson & Gottman, 1996; Herman, 1994; Thompson & Pitts, 1992; Wright, 1991; Wright, 1993), companionship, and (Cartensen et al; Motenko; Schone & Weinick, 1998; Spaid & Barusch, 1994; Thompson & Pitts; Tower & Kasl, 1996) affection (Biegel, Sales & Schultz, 1991; Horowitz & Shindelman; Morgan & Laing, 1991; Wright, 1998) are four frequently cited marital characteristics investigated in spousal caregiving relationships. These four concepts are described in the following review.

Communication. Marriage partners communicate for several reasons, from exchanging basic information like the assignment of tasks, to determining the boundaries of the relationship (Anderson & Sabatelli, 1999). Communication between spouses is found to be important to marital satisfaction in later life (Herman, 1994). The inability or lost desire to communicate feelings and express ideas is detrimental to marital stability (Rice, 1999). In AD caregiving, the care receiving spouse's cognitive decline includes communication impairment, and is cited as a source of frustration for the caregiver (Motenko, 1989).

Herman (1994) surveyed 168 married persons over the age of 55 years regarding marital satisfaction in later life. A marriage questionnaire and marriage scale completed by the elderly sample identified no significant difference in the
satisfaction of married elderly according to age-associated factors. When married elderly did report marital dissatisfaction, Herman found the three main sources to be communication, time spent together and sexual relations. The author did not discuss the particular aspects of communication investigated within the study, attributing difficulty in generalizing the findings to understand this concept in other married elderly cohorts, such as older spousal caregiver-care recipient dyads. However, the reported link between marital dissatisfaction and communication in married elderly remains significant and raises questions of its importance in spousal caregiving relationships where the care receiver’s ability to communicate is challenged by AD or dementia.

The power of communication in marriage is represented within Wright’s (1993) research. She asserts that the ability to effectively communicate curtails the negative feelings that arise from not being heard, as long as the partner is equally willing to communicate. Wright discovered that the well couples in her sample dealt with tension by expressing their feelings to their spouse, while the AD couples coped through self-control and displacing emotions. The AD couples controlled themselves by holding back their need for discussion and walking away to avoid terrible arguments. Furthermore, the AD spouses’ diminished ability to communicate required the caregiving spouses to provide simple directives to avoid exacerbating their partners’ confused state and triggering agitation. Wright’s findings elicit empathy for caregivers who decide not to express feelings to their partners, such as their experience of anger and resentment, when the source of those feelings is the spouses’ disease process.
For many caregivers, guilt overrides the need to express negative feelings to the care-receiving partner even when that partner is maintained as sole confidant (Thompson & Pitts, 1992). It would appear that fostering marital satisfaction through communication in later life is a challenge for wives and their husbands with AD.

The literature reports a link between communication and companionship. Thompson and Pitts (1992) explain that in many marriages, the spouse is named as confidant and is the only source to which feelings, emotions, ideas, and desires are communicated. They claim that this relationship is especially difficult when the spouse becomes caregiver to a partner who can no longer fulfill that role. In addition, Wright (1993) found that the AD spouses' lost ability to communicate restricted the couples' social activities and strained previous social relationships. For these reasons, seeking support outside of the marital-caregiving relationship can be difficult for the caregiver.

**Companionship.** A companion or confidant can be chosen outside of the marital relationship, but in terms of successful marriages, it is most often the spouse (Rice, 1999). In their study reporting on marital closeness, gender and depression in older couples, Tower and Kasl (1996) define marriage partners as confidants, privileged to some of the most intimate information about one another that is often shared with no other. Reporting on a sample of 317 older married couples, the authors found husbands more likely than wives to identify the spouse as confidant. Wives who did not report their husbands as confidants tended to seek out other people, whereas husbands generally did not. However,
40% of both husbands and wives identified their spouse as a source of emotional support (p. 121). Depressive symptoms were lower for husbands and higher for wives when the spouse was reported as both confidant and a source of emotional support. These results identify a relationship between gender and marital closeness in older adults and imply that wives may experience mental health challenges when they identify their husbands as a confidant and a source of emotional support. The study of marriage partners as confidants when caregiving occurs is important to the development of a more complete understanding of the caregiver's experience. In an earlier study of caregiving wives and husbands, Pruchno and Resch (1989) found that lacking a confidant more strongly correlated to the wife's experience of burden than the husband's.

In Wright's (1993) study, companionship was assigned importance in the marriage relationship by the AD couples and the well couples. The AD couples reported a loss of mutually satisfying companionship and the caregiving spouses specifically described a need to reach out to others for support. This finding is particularly important in understanding the support needs of spouse caregivers because much of their support network is lost to the nature of the illness.

Cartensen et al (1996) comment that losing a long time marital companion affects coping resources and socialization. Wright's (1993) study highlights the caregiver's perspective in which the nature of AD hastens the loss of social opportunity and social support from the spouse, family, and friends. The cognitive and physical changes in spouses with AD affect their ability to provide emotional support to the caregiver while the social experiences the couple shared in the
past become infrequent. Over time, as the disease progresses, the changes can ultimately deplete the caregivers' emotional support network. Wright found that both the spouse caregiver and spouse with AD reported a lost ability to rely on their partners for emotional support. From their research experience into chronic illness and caregiving, Thompson and Pitts (1992) have found that caregivers of partners with AD lose spousal support, even though the care-receiving spouse is still living.

Some authors discuss a relationship between marital closeness and the quality of the caregiving experience. Motenko (1989) studied the caregiving experience of 50 wives caring for husbands with AD. Motenko found that wives reporting a change in marital closeness since illness also reported more frustration with caregiving. The relationship between change in closeness and caregiver frustration was found regardless of whether wives noted an increase or decrease in marital closeness. Spaid and Barusch (1994) investigated the closeness of the marital relationship as a predictor of burden in 131 elderly spouse caregivers. In Spaid and Barusch's study, 70% of the caregivers were wives and 51% of the care receivers had a primary diagnosis of dementia. The authors report that closeness of the couple was the most important predictor of caregiver burden once all co-variates (coping ability of caregiver, memory and behaviour problems of care receiver and caregiver age, sex, health, frequency of emotionally supportive and aversive social contact) were regressed on caregiver burden. The authors discuss the inability to determine causal relationship between burden and closeness as a limitation to the study because it was
measured at the time of the study as opposed to before the initiation of caregiving. Further investigation into emotional closeness in marriage and caregiving is warranted.

The marriage literature supports the relationship between the presence of a marital partner and lower morbidity. Schone and Weinick (1998) found older married couples more likely to engage in preventive health behaviour than their widowed counterparts. The findings link marital status to health promotion behaviour without considering the nature or quality of the couple's marital relationship.

Ren (1997) investigated the impact of marriage status and quality of marital and cohabiting relationships on global health perception. Reporting on a National survey sample of 12,274 adults, the author used logistic regressions to estimate the effect of family conditions, that is, marital status (married, separated, divorced, widowed, cohabiting and never-married) and quality of marital and cohabiting relationships (overall rating of relationship as happily married or not happily married, fairness in housework, means of communicating disagreements between spouses/partners – verbal and physical, and prediction of the future of the relationship), control variables, (individual-level profiles, ethnicity and SES and community-level characteristics) and social support networks (perceived financial support, emotional support and participation in social or group activities) to the odds of reporting good health versus poor health to measure global health perception. Of particular interest in this review, Ren found separated and divorced individuals more likely to report poor health when compared with
married individuals. In addition, married and cohabiting individuals rating their overall relationship as unhappy were more likely to report poor health than those reporting happy relationships. Overall, Ren asserts that the health of individuals is dependent on marital status and the quality of the marriage.

The importance of Ren’s (1997) argument in caregiving is exemplified in Kramer’s (1993) work. Specific to the marital-caregiving relationship, Kramer explored the marital history and the quality of the prior marital relationship in 72 wives caregiving for husbands with probable AD. Her findings suggest that a weak marital relationship before the onset of caregiving is associated with increased depression, decreased quality of life, and decreased satisfaction from caregiving for caregivers.

The caregiving literature investigating the influence of marital quality on health has focused largely on the effects of the dissolution of marriage on health. There is a growing interest in understanding the quality of the marriage relationship. Questions persist regarding this relationship and building on previous work is essential to forming an understanding of the past and present marital relationship in caregiving.

**Commitment.** In her text, Rice (1999) describes commitment as a threefold concept involving the self, the couple, and the relationship. Commitment is demonstrated by a willingness to improve and change to be a good partner, by the couple’s promise of love and fidelity throughout the marital life span and by building and supporting the relationship, the marriage, and the family. A lack of commitment between marital partners to foster the relationship
and be a source of support for one another foreshadows the eventual breakdown of the marriage.

Horowitz and Shindelman (1983) designed a study to explore the family caregivers’ commitment to providing care. This study sampled 203 caregivers of frail elderly using qualitative and quantitative measures of affection and reciprocity. The sample was comprised of adult children (65%), spouses (9%) and other relatives (26%) of the older person. The sample of caregivers participated in an in-depth structured interview and completed a questionnaire schedule that included open-ended questions, fixed-choice questions, and scales. The authors measured reliability and validity of the schedule questions. From the interview data, family obligation emerged as the major factor motivating caregiving. Family obligation was not formally defined in the study. Rather, the authors included samples of the caregivers’ responses to the question, “Why do you provide the help that you do?” that collectively describe familial obligation. Adult children reasoned their caregiver role according to family values that subscribe to the provision of care for family members. Spouses and adult children described the provision of care as a duty or obligation rather than a choice.

Horowitz and Shindelman (1983) found that family obligation (58%) to care was the most frequently cited reason for caregiving with affection (51%) a close second from all respondents. Reciprocity (17%) was the third most frequent response for caregivers excluding spouses. The authors did not examine reciprocity in spouses, limiting part of the findings to children and other relatives.
The authors claimed that spouses experience reciprocal obligations differently than other relatives, but do not discuss the nature of the differences in the study. The authors also examined the degree to which affection and reciprocity influenced the caregiving experience. Although the concept of reciprocity provides a meaningful contribution to our understanding of caregiving, the results from this study concerning reciprocity will not be discussed because the spouses' responses were not considered. The authors' understanding of reciprocity does not pertain to the spouse caregivers in their study, limiting the present discussion to the spouse caregivers' affective relationship. According to their analysis of the affective relationship, the authors explain that providing care can bring the emotional relationship closer, but at the same time make daily caregiving interactions less enjoyable than pre-illness interactions. The authors found that spouses most often reported close affective ties prior to caregiving and less often in the current caregiving situation when compared to adult children and other relations. Horowitz and Shindelman conclude that the spouse's marital relationship endures the greatest strain from continued caregiving. The study findings acknowledge family obligation, affection, and reciprocity as three factors forming a family member's commitment to caregiving.

Stanley and Markman (1992) present research evaluating the Commitment Inventory (CI) and offer researchers a more informative understanding of commitment. The authors present a model for investigating relationship commitment by dividing commitment into two related construct domains, personal dedication and constraint commitment. Stanley and Markman
developed the CI to measure the six dimensions reflecting each domain. Personal dedication is defined as "the desire of an individual to maintain or improve the quality of his or her relationship for the joint benefit of the participants...and to improve it, to sacrifice for it, to invest in it, to link personal goals to it, and to seek the partner's welfare, not simply one's own" (p. 595). While, constraint commitment refers to, "the forces that constrain individuals to maintain relationships regardless of their personal dedication to them...arise from internal or external pressures, and they favor relationship stability by making termination of a relationship more economically, socially, personally or psychologically costly" (p. 595-596). The CI proved to be a reliable and valid measure of relationship commitment. The authors ask that researchers distinguish between the two domains of commitment and conduct future commitment studies that incorporate the CI measure to help test its usefulness in clinical applications. Investigating relationship commitment in spouse caregivers could provide a meaningful understanding of commitment in the marriage relationship. Seeking the perspective of wives who are caregivers in later life marriages can provide information regarding marital commitment at a time when earlier familial and marital constraints are lifted and the anticipated opportunity to focus on the marriage is lost due to illness.

In support of Stanley and Markman's cost argument, Perry (1996) found that several wife caregivers held a socio-cultural belief that divorce was not common practice in their generation and that they married, "for better or for worse" (p. 92). Although the nature of their marital relationship changed for many
of the wife caregivers, their belief continued to support their commitment to caregiving.

Motenko (1989) studied the experience of frustration and gratification in wives caregiving to husbands with AD. Motenko’s study is seminal to our understanding of commitment and obligation in spousal caregiving. The author found that wives who provided care through love and to return their husbands’ past attention viewed caregiving as a continuation of the marital relationship. Importantly, continuity of the marital relationship was associated with the wife’s experience of high gratification from caregiving. Motenko described caregiving by obligation or duty as a break in the continuity of the marriage. It was found that caring for a spouse out of responsibility rather than love lead to greater frustration in caregiving. The author asserts that it is difficult to maintain a meaningful marriage relationship when the ill spouse is “...needing their wife as a child needs their mother” (p. 171).

Wright (1993) also investigated the spouse caregivers’ commitment to providing care. The author asked the well couples and AD couples three questions measuring their commitment to the present and future marital relationship. The author first endeavored to determine whether the well couples and AD couples were committed to the spouse or committed to the marriage as an institution. The questions were also designed to measure commitment in the past, indicating the beginning of the marriage, and in the present. Overall, Wright found that the well couples and AD couples were committed to their spouses, with some reporting commitment to both the spouse and marriage as an
institution. The AD afflicted partners described the highest levels of commitment to the spouse both in the past and in the present. The well couples reported reasonably high commitment to the spouse at the beginning of the marriage that increased over time. In contrast, the caregiving spouses' level of commitment to their AD spouses was similar to that of well couples in the beginning of the marriage but did not increase over time. Wright explains that one might have expected the AD spouses to indicate a higher commitment to the marriage as an institution in the caregiving situation. However, Wright's interpretation found that the spouse caregivers maintained their commitment to their spouses as valued individuals despite the progressive cognitive decline of AD.

Secondly, Wright (1993) elicited the responses of both couples regarding their commitment to the future of their marriage. The author found that spouse caregivers reported a low commitment to the future of the marriage even though they valued their ill spouse and characterized their prior relationship as positive. Upon further investigation, Wright found low commitment associated with the caregiver's poor physical health and depressed mood. The author explains that the anticipation of ill health limited the caregiver's ability to commit to a future that included providing care to the AD afflicted spouse.

The importance of relationship commitment is in need of further investigation within spousal caregiving. It appears that wives may experience greater negative consequences when perceiving caregiving as an obligation to uphold the marriage commitment rather than a commitment to their loved one and their relationship. There is a need for research replicating Motenko's (1989)
study that specifically explores the difference between caring out of a love commitment and caring out of obligation. The consequences of past and current attempts to foster the marriage commitment and the associated effect on caregiving would contribute important information to the developing conceptualization of spousal caregiving.

**Affection.** Affection is a realistic expectation of a relationship, emerging at the time of courtship and developing throughout the marriage. In addition, affection encourages closeness among couples and helps strengthen marital bonds (Rice, 1999).

Wright (1998) conducted a longitudinal study to investigate the responses of AD couples and well couples to measures of affection and sexuality. Wright found both groups reporting similar levels of affection at Time 1. Time 1 was a retrospective measure of affection that was prior to illness for AD couples and five years before retirement for well couples. At Time 2, the first home interview, the expressions of affection had declined significantly for the AD couples, and results comparing the AD couples to the well couples were not significant. Two years later (Time 3), the author set out to test the remaining participants regarding their perception of affection and sexuality. At this time, Wright categorized the AD couples by living arrangement, for the care recipient spouses had been placed in nursing homes. The caregiving spouses who placed their partners in nursing homes were found to experience a dramatic increase in frequency of affection for their spouse. In contrast, the level of affection for both the AD couples at home and the well couples had not changed over time. Wright
proposes that relief from stress by nursing home placement is partly responsible for a caregiver's ability to experience renewed affection for the ill spouse.

Earlier research by Horowitz and Shindelman (1983) offers a different perspective regarding the importance of the affective relationship. The authors found the affective relationship significant when dependency on one spouse increased for the purpose of care. They determined a positive correlation between past and current affection and a family member's commitment to continue providing care to the ill member. The link between a positive marital relationship and caregiving relationship is supported in the literature. When couples experience a close prior relationship characterized by affection, caregiving is performed with less resentment, anger, and ambivalence (Biegel, Sales & Schultz, 1991; Morgan & Laing, 1991).

Unlike Horowitz and Shindelman's study, Wright (1998) did not consider the nature of the prior relationship among the sample. An understanding of the pre-illness marital relationship of the caregivers who placed their spouses in nursing care would provide a more complete picture of their experience and motivation behind placement. In addition, the level of cognitive and physical decline experienced by the AD afflicted spouse was not assessed at Time 3. Assessment at Time 3 might offer additional information regarding the spouse caregiver's experience providing care to his or her partner with AD. Wright's study does not investigate the reasons associated with placing the AD spouse in formal care, but does report that the caregivers experience an increased level of affection after placement. Wright reports that past affection was high (Time 1),
current affection was low (Time 2) and affection increased after placement for spouse caregivers (Time 3). Horowitz and Shindelman (1983) assert that past affection may influence one's commitment to continue providing care, while Wright (1998) maintains that placement may bring back the caregivers' ability to express that affection.

In Wright's (1998) concluding remarks, she acknowledges that the measure of affection may not have adequately captured the emotional bond between spouses demonstrating relatively stable levels of affection and that measures of affection like, trustworthiness, comfortableness, and helpfulness could tender other explanations for the results and should be assessed in future studies. Wright encourages health professionals to positively reinforce expressions of affection by caregivers toward their spouses. She claims that affection is one way to connect with the past regardless of the relationship before nursing home placement. The author does not define whether the prior relationship was the caregiving relationship before nursing home placement or the marital-caregiving relationship before nursing home placement. The quality of the relationship before illness and the level of affection within the caregiving relationship require further study to clarify the caregiver's experience of affection.

In their summary, Horowitz and Shindelman (1983) identify caregiving to occur within a historical context. They determine that each member of the caregiver-care receiver dyad enter the caregiving relationship influenced by a past relationship that will either facilitate or hinder the caregiver's efforts. This perspective recognizes historical experiences like the nature and quality of the
marital relationship and marital interactions throughout the couples' life span and its influence on the present day experience of providing care to one's spouse. The nature and quality of the marriage relationship prior to caregiving should be considered in the investigation of affection and spousal caregiving.

The literature suggests that affection evolves over the course of the couple's marriage relationship and is tested within several contextual experiences and relationships like caregiving. The next section discusses literature contributing to the development of the pre-illness marital relationship in spousal caregiving.

The Pre-Illness Marital Relationship in Caregiving

Investigation into the pre-illness marital relationship and spousal caregiving is a relatively new area of caregiving research. Keady (1996) described the literature reporting on the early experiences of dementia, the impact of dementia caregiving on the caregiver and the services created in response to support demands. A review of qualitative studies between 1980 to mid-1990 found little research exploring the marital relationship between the caregiver and the person with dementia. Keady suggests that health professionals inquire into the nature and quality of the relationship when assessing caregiver needs. More recently, commenting from a psychology background, Caufield, Moye and Travis (1999) caution health practitioners not to ignore the quality of the marital relationship of patients in long-term marriages.

Kuhlman et al (1991) reviewed the literature on family caregiving for people with AD between 1979 and 1990. Pertinent to caregiving and the
influence of relationships, the authors found studies frequently identifying wives and daughters as caregivers to the person with AD. They also identified caregiving to occur within the past and present relationship. The authors concluded by asking researchers to channel their efforts toward describing caregiving within various contexts such as the pre-illness marital relationship.

Quality of the pre-illness marital relationship. Strang and Haughey's (1998) recent and powerful caregiving research imparts significant knowledge regarding the pre-illness marital relationship. They described how 10 family caregivers, including eight wives, one husband and one son, experienced respite. The authors collected data by interview method and used grounded theory techniques to guide data analysis. The pre-illness relationship appeared as a factor influencing the caregiver's ability to have a respite experience. The nature of the marital relationship was found to influence the caregiver's ability to seek respite and "...get out of their caregiver world" (p. 231).

Personality factors and role expectations over the course of the marriage also described the caregivers' experience. How issues and dispositions were dealt with in the past provided insight into the wife's caregiving experience. Caregivers who had relationships characterized by conflict and lack of resolution described an inability to forget past insults and assume the caregiving role wholeheartedly (Strang & Haughey, 1998).

A Canadian study by Morgan and Laing (1991) explored the spouses' experience of caregiving in the first six months following their partners' diagnosis of AD. The sample consisted of nine spouses of newly diagnosed AD patients
who were interviewed between two and seven times. The authors found that the caregivers could be placed into two groups; the grief group, those dealing with loss of a familiar relationship, and the role strain group, those coping with the increasing responsibilities of caregiving. Morgan and Laing found that the couple’s pre-illness marital history factored into the decision to assign study participants to either the grief group or the role strain group.

Members of the grief group coped more successfully, experienced less distressed, had knowledge seeking behaviours, considered support services, were empathic, and had pre-illness relationships characterized by life long friendships and closeness. In contrast, members of the role strain group were overwhelmed by caregiving responsibilities, had prior relationships characterized by conflict, power, and lack of intimacy, felt ambivalent about caregiving and attempted to cope by a process of "hanging on" (Morgan & Laing, 1991).

In both caregiving groups, subjective and objective burden were experienced. Subjective burden is the emotional link to one’s perception of burden and is most resistive to existing coping strategies and interventions designed to help caregivers. Clearly, the role strain group held negative perceptions regarding their caregiving responsibilities and indicated higher subjective burden than the grief group (Morgan & Laing, 1991). In an earlier study of burden, Robinson (1990) found that caregivers describing past marital adjustment reported significantly lower subjective burden.

The authors discuss the need for a future research initiative focusing on the development of strategies for subjective burden management where the
couple’s past relationship plays a significant role in the caregiver’s emotional (subjective) response to the caregiving situation (Morgan & Laing, 1991; Robinson, 1990).

**Emotional closeness.** A lack of closeness between the caregiver and the person with AD stemming from their prior relationship is associated with increased caregiver distress (Morgan & Laing, 1991; Williamson & Schultz, 1990). In contrast, marital quality and emotional closeness between husbands and wives are conducive to successful caregiver care-receiver relationships (Horowitz & Shindleman, 1983; Kramer, 1993).

Prucho and Resch (1989) conducted a study of 315 husbands and wives caregiving to their spouse with AD or dementia. Using question and scale methods, the authors compared eight variables: (1) level of caregiver depression, (2) caregiver burden, (3) severity of care receiver’s impairment, (4) presence of a confidant, (5) caregiver age, (6) caregiver health status, (7) caregiver tasks, and (8) the extent of the caregiver’s emotional investment into the marriage relationship between husband and wife caregivers. Wife caregivers were found to be more depressed and burdened than their male counterparts. They found that wives who did not feel emotionally invested in the marital relationship experienced greater burden and depression than husbands in the caregiver role. Husbands were found to be highly invested in the marriage relationship and provided care to reciprocate the past.

In contrast to the above findings, Tower and Kasl (1996) more recently uncovered negative implications associated with emotionally close relationships
and gender in caregiving. The authors asked husband and wife caregivers to identify a person they considered a confidant and a person they considered a source of emotional support. The authors found that caregiving husbands experienced an increase in depressive symptoms when they reported an emotionally close relationship with their wives but did not consider their wives as confidants or vice versa. However, the husbands describing a lack of emotional closeness in the marriage relationship and a lack of a confidant or an emotionally close marriage relationship and wife as confidant also reported a decrease in depressive symptoms. The authors propose that husbands may experience depressive symptoms if they acknowledge their wives as confidants but are unable to access them as a source of emotional support or vice versa.

Williamson and Schultz (1990) studied the responses of family caregivers to scale questions that measured relationship quality, relationship orientation, depression and burden at Time 1 (n=170) and Time 2 (n=151). The authors focused on the responses obtained at Time 2 because they produced slightly stronger results. They found that women caregivers reporting a lack of prior relationship closeness to the care receiver experienced more burden and resentment than those with close relationships. The authors also examined the relationship between communal orientation and relationship quality. A person high in communal orientation is concerned about the needs of others, feels responsible for meeting those needs, believes people should help each other and experiences less distress by the costs associated with helping another person regardless of the type of helping relationship. The authors found that women low
in communal orientation, had high levels of depression when their prior relationship was close. They suggest that older women may experience higher levels of resentment and depression because they have finally reached a point, late in their lives, that creates opportunities for personal development and independence only to assume yet another caregiving role.

**Enrichment interventions.** Cartwright, Archbold, Stewart and Limandri (1994) conducted a qualitative study of 20 caregiver-care recipient dyads, nine of which had diagnoses of dementia, on the contribution of enrichment interventions to meaning and satisfaction in caregiving. Enrichment was defined as, “the process of endowing caregiving with meaning or pleasure for both caregiver and care recipient” (p. 32). An antecedent factor to enrichment was found to be the quality of the historic and dyadic relationship between the caregiver and care recipient. The enrichment activity was often something the dyad shared in the past, such as music. One of the most significant outcomes of engaging in enrichment was the strengthening of the caregiver-care-recipient relationship (Cartwright et al). This outcome supports Motenko’s (1989) assertion that interventions directed toward strengthening the relationship promote caregiver well-being.

This study found that caregivers could bring meaning to their role by using the enrichment strategy. This finding offers hope to caregiving families, especially those relationships characterized by conflict, who may be able to select an experience from their shared past to provide meaning and reward within the caregiving relationship.
Summary

In sum, the caregiving-care-receiving dyad is acknowledged as a family system. The interactions of that system can be understood by considering the family's values and beliefs. Current definitions of the family are attempting to include all family forms and functions. However, it is difficult to find an all-inclusive representation of every family in existence today. For example, Rice's definition chosen for this study can be interpreted to challenge marriages that are not based on an emotional commitment between the members. Family system theory provides a useful framework for this study because it is based on understanding the family in terms of its relationships with other systems. Family system theory provides an understanding of the wife's caregiving experience according to her appraisal of the couple's interactions in the past and present contexts.

Upholding the marital relationship is a challenge for wife caregivers and their spouses with AD. Within the context of spousal caregiving, characteristics such as commitment, communication, companionship, and affection, known to sustain marriage, can be a source of conflict for the spouses and emphasize the experience of loss. Yet, a marital history characterized by affection, commitment, companionship, and communication is perhaps the foundation from which spousal caregiving interactions occur. These relationship concepts maintain a continued presence in the wife caregiver's experience. However, there are many unanswered questions regarding the influence of these marriage concepts in the wife's experience caring for her husband with AD.
The literature suggests that the nature of the pre-illness marital relationship can influence the wife's experience of gratification and reward in the marital-caregiving role. Furthermore, enrichment experiences may contribute to the wife's ability to reach a level of satisfaction and obtain reward and gratification from the caregiving experience. Investigation into the concepts of marriage important to wives by obtaining their perspective regarding the marriage experience will lead researchers and practitioners toward a more complete understanding of spousal caregiving.
CHAPTER THREE: QUALITATIVE RESEARCH PROCESS

This master's thesis is a secondary analysis of Perry's (1995) dissertation research interview data describing the marriage experience of wife caregivers to husbands with AD. This chapter begins by describing the methodological perspectives of the primary and secondary research studies, followed by an explanation of the methods used to obtain and analyze the data. The research method of secondary retrospective analysis is described in detail and the primary researcher's method of grounded theory is described to satisfy comparability between the two studies. The chapter closes with a discussion of rigor and ethical implications.

Qualitative Research Tradition

The primary research study was conducted by Dr. JoAnn Perry (1995) and is entitled, *A study of women caregiving to husbands who have Alzheimer's disease: Family know-how as a process of interpretive caring* (1995). Perry defines her dissertation research as an interpretive study that follows the tradition of symbolic interactionism. The grounded theory approach best suited the development of Perry's theory, which describes the process of becoming and being a caregiver to a husband who has AD.

This secondary analysis is also an interpretive study. In a chapter discussing constructivist and interpretivist approaches to human inquiry, Schwandt (1994) explains that the goal of interpretivist and constructivist research is to "... understand the complex world of lived experience from the point of view of those who live it" (p. 118). Through this approach, the researcher
provides understanding of the meaning of phenomena in everyday life by interpreting the actor's language and actions while interacting within a specific social context. Furthermore, the interpretive research tradition recognizes the interpretive processes of the researcher in all aspects of the study (Lowenberg, 1993). This research set out to understand marriage and family from the perspective of wives caregiving for husbands with AD and was dependent on the researcher's ability to interpret the wives' descriptions of their marriage and family relationships.

Thorne (1994) argues that a secondary analysis is an approach that can be studied within an inductive, interpretive analytic tradition. Although secondary analysis is a qualitative research approach, Thorne maintains that it does not have an established research tradition, guiding principles, or evaluation criteria from which to conduct proper research. Therefore, a secondary analysis can be considered within other interpretive approaches such as grounded theory, phenomenology and ethnography (Thorne). In congruence with Perry's (1995) primary study, grounded theory methodology was the most appropriate methodological approach for the secondary investigation.

Perry's (1995) dissertation incorporated the interpretive research tradition of symbolic interactionism. Symbolic interactionism is described as "... a frame of reference for understanding how humans, in concert with one another, create symbolic worlds and how these worlds, in turn, shape human behavior" (LaRossa & Reitzes, 1993, p. 136). This perspective maintains that individuals and their behaviour are understood within a social context (Hutchinson, 1993). Symbolic
interactionism framed the analysis of the wife caregiver interviews conducted by the secondary researcher while seeking an understanding of the marital context in caregiving. Understanding how context such as marriage influences spousal caregiving assigns meaning to the experience (Lowenberg, 1993; Schwandt, 1994). Hinds, Chaves and Cypess (1992) argue the importance of context and claim that “. . . the intent of health care professionals is to understand human beings and to help create conditions that promote health and meaningful life experiences” (p. 61). The research explored the wife’s caregiving experience by considering their marriage relationship. The intent is to disseminate this information to nurses who work closely with wife caregivers in the community and acute care settings. It is the assumption of this thesis that informed nurses can help caregiving wives find meaning in caring for their husbands with AD through validation and consideration of their experience.

Secondary Analysis

A secondary study is the analysis of a problem from data collected for a study with a different purpose. The purpose of this secondary analysis is to explore the ways that women’s experiences in marriage influence their experiences caring for their husbands with AD. The secondary researcher can address the data with the same question, a different question, a different unit of analysis or by applying a different method of analysis (Hinds, Vogel & Clarke-Steffen, 1997; Lobo, 1986; McArt & McDougal, 1985; Woods, 1988; Szabo & Strang, 1997). This methodology is further explained by the emergence of new
insights by considering new questions (Thorne, 1994; Jacobson, Hamilton & Galloway, 1993). The present researcher conducted a retrospective analysis of an existing data set, pursuing an idea that was raised but not thoroughly explored within the primary research study (Thorne). The following section describes the application of secondary analysis to this research study.

Advantages

Nurse researchers are becoming more accepting of the value of secondary analysis as a method in qualitative research. This acceptance is driven by the researcher's ability to explore rich data previously collected to extend ideas that may have originated within the primary research study, to expand nursing knowledge with the emergence of new thoughts and insights, and to bring data to a new level of understanding. There are opposing views regarding the level of experience held by the researcher conducting a secondary analysis. Thorne (1994) presented several theoretical considerations, such as the fit between the primary and secondary research questions and the implications of methodological changes in her article describing secondary analysis in qualitative nursing research. Thorne maintains that attending to those considerations may require the skills of an advanced level researcher. In contrast, McArt and McDougal (1985) believe the economic arguments of cost and timesavings make secondary analysis a useful method for both student researchers and experienced researchers. Several researchers agree that the practical advantages of time and cost savings logically support the maximization of existing databases (Lobo, 1986; McArt & McDougal, 1985; Szabo & Strang,
1997; Thorne). For this study, two reasons supported the selection of the secondary analysis method. First, the richness of the data offered the secondary researcher the opportunity to follow through on an idea that originated with the primary researcher's work that was also compatible with the secondary researcher's interests. Secondly, using the existing data set allowed the secondary researcher to focus more time on the analysis.

Limitations

Researchers face general methodological challenges and specific data set challenges when working with a secondary data set in qualitative research (Hinds et al, 1997). These challenges are discussed along with strategies to overcome the limitations inherent within this methodology.

Methodological Issues

Hinds et al (1997) identify two main methodological challenges to consider when conducting a secondary analysis. First, Hinds et al establish that the "... data generated by individual qualitative methods are amenable to a secondary analysis" (p. 411). Secondly, the authors ascertain that researchers consider the "... extent to which the research purpose of the secondary analysis [differs] from that of the primary study without invalidating the effort and the findings [of the primary study] " (p. 411). The first methodological challenge is addressed by ensuring the fit between the two studies. The primary researcher used grounded theory methodology where sample selection was part of the process of analysis. Therefore, data collected by the primary investigator was not always available to the secondary researcher. Hinds et al caution secondary researchers to consider
the nature of missing data. In discussion with the primary researcher, telephone interviews at Time 3 were not transcribed if the nature of the interview did not contain information about the wife caregiver's experience with the process of caring. Perry (1995) considered all aspects of the wife caregiver's direct experience with caregiving and would not have excluded a woman's description of the marriage relationship from the data set. To address the second challenge, the authors suggest that: (1) the new phenomena of study is consistently addressed within the data, (2) the study question be closely related to the primary phenomena of interest, and (3) the concepts in the secondary study are openly explored. The second methodological challenge is addressed by the secondary researcher in the following three ways. First, the secondary researcher reviewed five transcripts for marital relationship data and confirmed the presence of the wife caregiver's descriptions of the marriage experience with the primary investigator. Second, the secondary researcher compared the congruence of the study questions. The idea for the secondary research question originated within Perry's dissertation. Perry found that the marital relationship appeared to be a significant concept in caregiving, but had not thoroughly explored this theme within her study. This gave the secondary researcher the opportunity to study a question in an area of interest related to marriage, family, and caregiving. Third, the analysis focused in on the participants' descriptions of marriage and family, but allowed further definition of these concepts and additional concepts to come from the data itself.
Data Set Challenges

Access, accuracy and interpretability of the data describe some of the
data set challenges of conducting a secondary analysis (Hinds et al, 1997).

Access. The computer disks and original transcripts were obtained from
the primary researcher. Access to the primary researcher was secured to answer
the secondary researcher's questions regarding the study context, missing data,
ideas, biases, and assumptions. Additionally, field notes, memos and cassette
tapes were available to facilitate the study's progress or enlarge the student
researcher's perspective.

Access to the actual cassette tapes can be useful to the secondary
researcher in terms of capturing the environmental context and the respondent's
emotion and tone of voice (Szabo & Strang, 1997). Without listening to the
participants, some authors assume that "the secondary researcher might not
anticipate reacting to or being affected by the data" (Hinds et al, 1997, p. 414).
However, a pilot analysis conducted by the secondary researcher, which
included five of the wife caregiver transcripts to ensure that the phenomena of
study was consistently addressed, elicited a surprising amount of emotion which
required the researcher to begin journaling to acknowledge personal values and
beliefs. Therefore, the secondary researcher did not require further
documentation from the primary researcher and maintained the journal
throughout the analysis.

The primary research method was grounded theory. This method is
characteristically defined as the simultaneous collection and analysis of data to
test hypotheses that ends only when saturation of the categories, themes, or ideas is achieved. The method's purpose is to develop theory grounded in the data (Strauss & Corbin, 1990). Therefore, as ideas appear, data collection develops with a new purpose where criteria are selected and tested and the outcome of the interview becomes structured in comparison to earlier dialogue dedicated to broad exploration. This was a limitation for this secondary study because the sample was drawn from the data set as opposed to speaking with actual participants. However, the aim of the primary study was broad enough to surface rich data that included ample descriptions of the marital relationship. The secondary researcher's ability to pursue an idea presented within the wife's description of her marriage experience by asking additional questions remains a limitation of this study.

Accuracy. Accuracy, such as completion of the data sets, is important for the secondary researcher. Upon review of the code books, missing interviews were found. The benefit of having access to the primary investigator was reinforced as she explained that occasionally telephone interviews at time three were not transcribed because they did not contain any information regarding the wife's caregiving experience. In addition, not all participants were interviewed four times. Toward the end, some participants in the primary study were interviewed for the purpose of testing hypotheses and confirming ideas.

Interpretability. Clearly, lack of involvement with the primary study places the secondary researcher at risk for "...drawing invalid conclusions that arise from misinterpretation of findings" (Jacobson et al, 1993, p. 484). The primary
researcher followed the secondary study’s progression closely as the chair member of the student researcher’s thesis committee. Perry’s feedback and continued commitment to overseeing the research study provided the student with valuable insight regarding the context of the original study and factors that influenced the original study’s outcome. The lack of control over the conception of the data set remains a limitation for this secondary study (Jacobson et al).

**Fit of Question**

The fit between the primary data set and the secondary research question was determined in order to pursue the study. First, the primary and secondary research questions were compared to ensure that the data represented the second question and method. In the secondary study, the question asked of the data was raised by the primary researcher but never fully explored. Secondly, the secondary researcher evaluated similarity within the general atmosphere of the studies. In the primary study, the wives were interviewed regarding their experience of becoming and being caregivers to their husbands with AD. The secondary study followed closely in that the wife caregiver interviews were analyzed for descriptions of the marriage relationship (see Table 1).
Table 1:

Fit Between the Primary and Secondary Research Studies

<table>
<thead>
<tr>
<th>Study</th>
<th>Study Aim/Question</th>
<th>Methodology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary</td>
<td>To describe the process of becoming and being a caregiver to a husband with AD.</td>
<td>Grounded Theory</td>
</tr>
<tr>
<td>Secondary</td>
<td>To explore marriage concepts described by wives caring for their husbands with AD</td>
<td>Retrospective Analysis</td>
</tr>
</tbody>
</table>

Research Method

Data Collection

The data collection procedures of the primary and secondary study were examined for compatibility. In the secondary study, the management of data demanded attention because of the high volume that originated from the primary and secondary study and the potential for confusion between the two studies. The aim of the secondary study allowed the researcher to focus on specific ideas within the data that did not require undertaking an analysis of the entire code book. The secondary researcher focused on the wives’ descriptions of their marriage experience rather than their entire journey providing care to their spouse. The primary researcher’s disks containing all of the interview data were obtained and two copies, a working copy and a backup copy, were made by the secondary researcher. The ability to read unmarked interviews removed the risk of mistaking the primary researcher’s ideas for the secondary researcher’s own. The primary researcher was available to the secondary researcher to ensure that confusion did not arise between the two studies.
Data Analysis

For this study, "the coding and analysis procedures occur[ed] simultaneously in a manner that [was] flexible and nonlinear allowing the focus to shift if needed and end[ed] when there [was] theoretic saturation" (Szabo & Strang, 1997, p. 69). The secondary study followed the interpretive research tradition of forming an understanding of marriage and family through real life perspectives (Lowenberg, 1993) and used coding strategies similar to those found in grounded theory. It is important to acknowledge that a limitation of the present author's study is that insight into the marriage relationship and the husband's behaviour was grounded within the wife's interpretation of her husband's behaviour and the meaning she assigned to it based on her understanding of their marital history. The wife caregiver's understanding of her husband's behaviour and her interpretation of their interactions as a couple throughout the marriage experience was obtained from data analysis and provided a meaningful understanding of the impact of marriage on caregiving. However, because it is the wife's understanding of her own experience, the findings should be applied to other caregiving relationships with due caution for they may not represent the experience of other family caregivers.

The researcher had access to the primary investigator's transcribed data. In addition, the primary researcher agreed that personal journals, memos and cassette tapes could be accessed by the secondary researcher should it prove necessary. At study outset, it was determined that approaching the interviews without a predetermined sample size would optimize the search for relationship
data and eventually achieve saturation of emerging categories. The secondary researcher analyzed 25 in-depth interviews that considered the experience of 16 wife caregivers to reach saturation of the categories and themes.

A line-by-line approach to data analysis was conducted to extract major themes and ideas. The analysis entailed searching for a specific word, sentence, or paragraph addressing the marriage relationship more than the caregiving role. From there, the major ideas were defined and the interviews were explored to identify the presence of the particular ideas within the data set. The major themes and ideas were clustered and grouped into categories. This process continued until saturation was achieved for all of the categories. At the same time, the researcher carried out an analysis that involved searching for four specific words. The following four marriage concepts were included in the inquiry: communication, companionship, commitment, and affection. The four marriage concepts were chosen because they were prevalent within the existing body of marital-caregiving research. They were sought to identify whether or not the wives acknowledged the involvement and importance of the four concepts within their marital-caregiving experience. Although the literature review conducted by the researcher was the initial entry into the data, the presence of the concepts was not as important as whether or not the wives described the concepts as appropriate and relevant to the challenges they encountered in caregiving. Although all of the results of this analysis are important to the wife's experience caregiving for her husband with AD, only the findings that describe the influence
of the wives' appraisal of their marriage experience on the caregiving experience will be described in this thesis.

Sample

The primary study sample consisted of 20 wife caregivers for husbands with AD interviewed up to four times over a six-month period. The sample was obtained from three sites: an AD support group, an AD diagnostic clinic, and an outreach program affiliated with a United States university. The interviews took place within the participants' own homes, situated in the Northwestern United-States (Perry, 1995).

In the secondary study, interviews were selected using the find option located within the edit option on the toolbar of the Microsoft Word 97 computer software to identify words that offered the researcher entry into the data. The initial list of letters included (a) mar, (b) rel, (c) close, (d) couple, (e) partner, (d) love, (e) commit, (f) affect, (g) comp and (h) comm. For example, searching the letters mar would include all words beginning with mar, such as marriage, married and marital. This strategy helped the present author acquire initial entry into the sections of the transcripts that included the wives' description of their perspective regarding the marital relationship. These letters were chosen because they captured the words that were reflective of the wives' relationships. The words were selected according to the review of the marriage and caregiving research and the initial pilot analysis that included five wife caregiver interviews. During the secondary study analysis, other words were found to be significant relationship descriptors for the wives and were found within several of the initial
few interviews. The words and letters included (a) divorce, (b) diff, (c) stranger, (d) lack, (e) guilt, (f) past, (g) then, (h) at that time, (i) present, (j) current, (k) now, (l) famил and, (m) social. These words were added to the search strategy for the analysis of the wife caregiver interviews.

The researcher was comfortable with the recurrence of themes upon completion of the analysis of interview 19. However, the researcher analyzed six additional interviews to confirm the existence of the emergent patterns for a sample that included 16 wife caregivers and 25 interviews.

Rigor

The desired outcome of the secondary study is the same as that of the primary research - to contribute to the development of knowledge in the area of caregiving. With that said, trustworthiness of the research process is crucial. There are four issues of rigor paired with four tests of rigor to consider: auditability (consistency), confirmability (neutrality), credibility (truth value) and fittingness (applicability) (Szabo & Strang, 1997; Sandelowski, 1986). The aforementioned issues are addressed and the strategies incorporated to uphold rigor within the secondary qualitative study are described in the following sections.

Auditability. An audit trail, which is a systematic and detailed recording of the research process, acknowledges the issue of auditability (Szabo & Strang, 1997). The purpose of organizing the data, the researcher’s interpretations and the findings is to ensure that another researcher would arrive at the same or a similar conclusion when handed that information (Sandelowski, 1986). The
secondary researcher acknowledged auditability by keeping a personal journal, theme and colour coding the interviews and maintaining methodological memos.

**Confirmability.** A journal recorded the researcher’s personal biases, thoughts, and feelings. This allowed the researcher the opportunity to reflect on the research process and personal interpretations that were subject to bias. In accord with the interpretive research tradition, the researcher’s interpretive processes at this phase of the research process provided insight into the meaning of the marriage relationship to wife caregivers of husbands with AD (Lowenberg, 1993; Schwandt, 1994). Journal writing and code notes were the means by which the researcher met the requirement of auditability. Journaling also maintained neutrality and acknowledged the issue of confirmability.

It is clear that findings in qualitative research are based on the researcher’s interpretation of the participant’s experience. Therefore, there is a potential for the secondary study to exaggerate the effect of the researcher’s bias from the primary study (Thorne, 1994). However, this was also acknowledged by the secondary researcher through reflective journal writing. Furthermore, in terms of qualitative research, the benefit of becoming involved with the actual subjects, or in this case the accounts of the subjects, outweighs this limitation (Sandelowski, 1986).

Confirmability was also achieved by linking the categories with actual quotes from the data set within the analysis and the discussion of the interpretation of the interview data. This helped to ensure that the findings were actually originating from within the data set itself (Szabo & Strang, 1997).
Credibility and Fittingness. Credibility and fittingness were achieved by validating the research findings with the primary researcher and thesis committee members. The research participants were not available to confirm or refute findings as they unfolded, therefore, recognition of the categories and themes as true (truth value) or typical (applicable) experiences of caregiving families came from the committee members who are experienced in the areas of caregiving, family, and gerontological nursing research (Sandelowski, 1986; Szabo & Strang, 1997).

Ethical Considerations

As with all research, a secondary researcher is presented with ethical research challenges. In this section, two key issues are discussed, participant consent and primary researcher approval.

Informed Participant Consent

In the main study, the primary researcher informed the participants of the possibility of further analysis of the interview data when obtaining original consent. It is advisable that researchers obtain consent for a secondary analysis when beginning the primary study (McArt & McDougal, 1985; Szabo & Strang, 1997). This study adheres to ethical standards as the primary researcher obtained consent in anticipation of future research. Obtaining consent from the primary research participants at this time would be difficult, time consuming and potentially unsuccessful. The next chapter presents the secondary researcher's interpretation of the data. Several of the quotations include the names of the wives and their family members. Confidentiality of the data was maintained by
using the same pseudonyms assigned to the participants and members of the participants' family within the original research study.

Primary Researcher Approval

The primary researcher offered the student researcher the opportunity to use her data set for the purpose of secondary analysis. Based on the secondary researcher's interest in family, marriage, and caregiving, a question was formulated from an idea that originated within the primary study but was never fully explored. The ethics review committee at the University of British Columbia approved the pursuit of this secondary study.

Conclusion

This chapter discussed the methodological perspective of the research study, described the research method of secondary analysis guided by grounded theory and detailed the progression of the secondary analysis. Data collection and analysis procedures were described and the strategies for achieving methodological rigor were discussed. This secondary analysis was established as an ethically sound study. The next chapter reveals the categories and themes that emerged from the data set by focusing on the wives' descriptions of their marriage, family, and caregiving relationships.
CHAPTER FOUR: INTERPRETATION OF THE INTERVIEW DATA

The analysis of wife caregiver data was conducted to answer the research question: *What marriage and family concepts can be identified in women's descriptions of their experience caring for their husbands with AD?* The outcome of the analysis was an understanding of the marriage experience of women caregiving for husbands with AD. In addition, the analysis identified congruency between the marital concepts investigated within the current body of marital-caregiving research and the wives' descriptions of the challenges they faced in the marital-caregiving experience.

The concept of connection was identified as one process emanating from the marriage experience by which the wives established meaning within their caregiving experience. Connection surfaced as one way in which the marriage experience, identified by the wives' interpretation of their husbands' behaviour and their interactions as a couple, affected the wives' caregiving experience. It is important to clarify that the concept of connection emerged from the wife caregiver data. Most recent literature reviews confirm that the concept of connection has not been explored within the family caregiving research.

This chapter will focus on the wives' interpretations of the influence of the marriage experience on their caregiving experience. The wife caregiver's marital-caregiving experience was captured by the following three categories: (1) the pre-illness marital relationship, (2) the caregiver's desire to preserve a sense of couplehood and experience connecting as a couple in the caregiving relationship, and (3) the caregiver's ability to access the past marital relationship
and connect with the past for support. The chapter begins by describing the participants, followed by a description of the categories. Verbatim quotations from the caregiver interviews were included to validate the categories.

The Participants

This section will describe the sample of caregivers that participated in the primary study, followed by a description of the caregivers were included in the secondary study.

Primary Study

In the primary study, the researcher selected caregivers based on the following six criteria: a wife caregiver, over 60 years old, lived at home with spouse with AD, had primary care responsibilities for husband, spoke and understood English and provided informed consent. The wives ranged in age from 57 to 82 years with a mean age of 76.3 years (SD 5.61). Their husbands with AD ranged in age from 59 to 84 years with a mean age of 78 (SD 6.34). The average length of marriage was 45 years (SD 9.26). All of the wife caregivers graduated from high school and two had attended graduate school. Seventeen wives were Caucasian and three were African American. The length of time the women had been caregiving for their husbands was between 2 and 20 years (Perry, 1995).

The sample characteristics, with the exception of the wives' level of education, were reasonably similar to those found within the overall caregiving population. Each of the wives in this sample had achieved a high school diploma while two had also completed graduate level education. The wives' educational
achievements represent a higher level of education than obtained by older adult wife caregivers in the larger population.

In Perry's (1995) study, 20 wives were interviewed between one and four times. Fifteen wives participated in four interviews, four wives participated in one or two interview(s) and one wife, widowed from her husband who had AD, was considered a key informant and asked to comment on preliminary findings.

Secondary Study

Twenty-five interviews that included 16 of the wife caregivers from the main study were analyzed for the secondary study of a possible 54 interviews that included 18 caregivers. Caregiver number two and caregiver number 13 were excluded from the primary sample. The secondary researcher found that both of the interviews were very difficult to follow and that the wives focused on discussing their husbands' disease process and the tasks associated with caregiving, such as, assisting with activities of daily living (ADL), rather than their marriage experience. The secondary analysis focused primarily on interviews one and two, which described the experience of being a caregiver to a husband with AD. In the original study, the third interview was conducted via telephone, and the primary purpose of interview four was to test the emergent theory. Interview three and four were analyzed in the secondary study if the caregiver continued to share examples of her marriage relationship. Of the 16 caregivers, 13 wives characterized their marriage as a very positive experience, two characterized their marriage as a negative experience, and one did not regard her marriage or her husband's behaviour as chiefly positive.
Demographic Information for the Secondary Study

In the secondary study, all of the participants were wives caregiving for their husbands with AD. Based on a sample of 16 wife caregivers, the age range for the wives was from 57 to 82 years of age with a mean of 71 (SD 7.09). Their husbands' ranged in age from 59 to 84 years of age with a mean of 75 (SD 7.25). The average length of marriage was 44 years (SD 9.50). All of the wife caregivers had attended high school and two completed graduate education. In the present sample, 15 of the caregivers were Caucasian and one was African American. The length of time the wives were caring for their husbands with AD was between 2 and 20 years with a mean of 8 years (SD 5.01) (see Table 2).

In Perry's (1995) study, burden was part of the wives' experience providing care to their husbands with AD. However, the sections of the wife caregiver interviews that were analyzed for the secondary study did not include a heavy focus on the wives' experience of burden, rather, the women tended to focus on their marriage relationship and their understanding of their husband's behaviour, past and present, and how those factors influenced the marital-caregiving experience. It was not the intent of this study to capture the wives' experience of burden. Overall, it remains that the wife caregivers in this sample are representative of wives caregiving for their husbands with AD within the larger population.
Table 2

Demographic Information

<table>
<thead>
<tr>
<th>Caregiver Number</th>
<th>Age</th>
<th>Race</th>
<th>Years Married</th>
<th>Education Level</th>
<th>Spouses Age</th>
<th>Number of Years with AD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>74</td>
<td>C</td>
<td>51</td>
<td>4</td>
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<td>AfAm</td>
<td>33</td>
<td>4</td>
<td>64</td>
<td>3</td>
</tr>
</tbody>
</table>

Note. Race: C = Caucasian, AfAm = African American

Education Level: 1 = no schooling, 2 = elementary, 3 = some high school, 4 = high school graduate, 5 = post high school college or training, 6 = college graduate, 7 = graduate or professional school. Adapted from Perry, J. (1996). A study of women caregiving to husbands who have Alzheimer's disease: Family know-how as a process of interpretive caring. Unpublished doctoral dissertation, University of Washington, Washington. Adapted with permission.
The Marital-Caregiving Experience of Women Caregiving for Husbands with AD

The following description provides an understanding of the influence of the wife's interpretation and understanding of the pre-illness marital relationship in caregiving for a husband with AD. To illustrate this idea and clarify understanding, a schematic representation is found in Figure 1. The researcher acquired a sense of the pre-illness marital relationship from the women's descriptions of the nature of their husband's behaviour and their interactions as a couple throughout their marriage. The wife's interpretation of her husband's behaviour and the meaning she assigned to it and her understanding of their interactions as a married couple formed the nature of the pre-illness marital relationship. The wife's understanding of her husband's behaviour also provided insight into her perception regarding her husband's behaviour in illness.

The wife's interpretation of the nature of her husband's behaviour and the meaning she assigned to it in concert with her understanding of the nature of their pre-illness marital interactions dominated the caregiver's ability to access the past as a source of support and strength and the caregiver's desire to preserve a sense of couplehood as she persisted in her caring efforts.

The pre-illness marriage relationship emerged as an important source of support for women caregiving for husbands with AD. Each of the wives in this sample acknowledged that the quality of the pre-illness marriage experience contributed to her ability to access internal support from the relationship she and
Figure 1: The influence of the wife's interpretation of her husband's behaviour and her understanding of the pre-illness marital relationship in caregiving for her husband with AD.
her husband nurtured over the course of their marriage. For the wives, the idea of connecting with their husbands as a married couple was also important in preserving a sense of couplehood in the caregiving experience. Furthermore, locating the caregiving experience within the context of the marriage influenced the wives' experience providing care for their husbands with AD. For the wife caregivers in the present study, the nature of the marriage history appeared to influence the quality of the spousal caregiving experience.

The Pre-Illness Marital Relationship

The pre-illness marital relationship category included the wife’s description of her interpretation of the nature of her husband’s behaviour and her understanding of the nature of their past interactions as a married couple. For most of the caregivers, the marriage relationship was described as a positive experience. The caregivers spoke of being “very close” to their partners and characterized their marriages with descriptors such as “a great life” and a “partnership”. For two caregivers, the marriage relationship had always been a challenge and their husbands’ past and present behaviour created friction between the couple, while one caregiver presented a mixed description of her understanding of her husband and their marriage. At some point in the interview, each of the women placed the caregiving experience within the context of their marriage by describing the effect of caregiving and the losses associated with AD on their marriage relationship. The caregivers describing positive marital experiences also turned to the past marriage relationship for strength in caregiving by focusing on the positive moments in their relationship and the
wonderful outcomes of their marriage, such as the early years, traveling, raising their children and preparing their home together. Some of the caregivers also shared their conscious attempts to provide their husbands with experiences that fostered their interactions as a couple. For wives describing an unsatisfying marriage relationship and a husband they could not “relate to very well”, reading the marriage relationship into the caregiving experience fostered resentment and guilt.

The wives' interpretation of their husbands' behaviour and the meaning they assigned to it and of their interactions as a couple were important and recurring themes in the wives' descriptions of their pre-illness marital relationship. The nature of the pre-illness marital relationship was important in shaping the wives' caregiving experience.

For many of the caregivers, their appraisal of the care recipients' personal characteristics affected their perception of their spouses' challenging behaviour in illness. Most of the wives shared the essence of their husbands' character by describing their spouses' influence on marital, family, and social relationships. One wife provided insight into her understanding of her husband's behaviour by sharing examples that demonstrated a considerate and caring nature. Consider the following:

We started out dancing ... And the first five years of our marriage we danced every week ... And then we had two lovely children, and he was just wonderful with them. And he was a real helpmate. We never divided
chores. He always helped cook, he always helped ... He took care of the kids. He insisted that I go out.

For wives, there is a link between their interpretation of their husbands' behaviour and the meaning they assign to it and the nature of their interactions as a couple throughout the marriage. Together, these concepts form a historical context that is likely to influence the wives' appraisal of the caregiving experience. Generally, when marital relations were viewed as harmonious the wives' characterizations of their husbands were positive and intended to present their most endearing qualities. Several took great care identifying their husbands as good men and highlighting wonderful moments in their marriage. For example, one caregiver fondly recounts the early years of marriage with her husband.

Oh, yes...very close. Never went, one never went anywhere that the other one didn't go...And it was mutual in everything. We never had any big, fat arguments about who was handling what, and who was spending what, and things like that. But he was always very considerate...we could discuss everything.

In contrast to the positive image captured above, the following characterization is from one wife caregiver who described her husband as “verbally abusive” and “emotionally unavailable” to her and their children. She had difficulty expressing the nature of his feelings for her in response to the interviewer's question, “Did you feel for a while that you were well-loved?” She seemed to stumble over the following response:
I think he, and I think in a way he, uh, you know, in as far as he could he
did, uh, he was fond of me. But I think he, I know now he's, he's limited in
his capacity, you know, to do that. I know this from my own experience,
and I know it from talking with Bryan, his son, who never felt like his dad
was ever there for him either.

This caregiver provided further insight into her interpretation of her
husband's behaviour represented by the following example illustrating the
relationship that he established with his children.

I think that's true with his relationship with, with his boys. They, the boys
used to come over to the house, and I'd be out in the kitchen and come in
the living room and instead of them, you know, kind of talking and
interacting with each other, there'd just be dead silence. They'd all be
reading something. And then the first thing one of them would come out to
the kitchen to talk, and I thought what's wrong here, you know. There's no,
nothing going on. And when he did talk with them, it was like he would be
either giving them directions or competing with them, like, well, you know,
I did such and such, and they'd bring up a subject and, well, you know the
great ... all the great things he did instead of listening to them and trying to
be supportive or interested in what they were doing. Of course their
relationship with him was terrible.

The wives' interpretation of their husbands' behaviour and their
interactions as a couple over the course of the marriage shaped the wives'
interpretation of the behavioral changes experienced by their husbands as a
result of the cognitive decline in AD. Several wives described emotional reactions
to their husbands’ challenging behaviour. Yet, on an intellectual level, they still
perceived this behaviour to be an outcome of illness rather than their husbands’
innate character. The following example demonstrates a wife’s frustration, but
also her understanding of the disease process.

And then, so sometimes I was hollering at him [laughs] You're going to
find, find some other way to get to church if you don't do it, get this done
right, because I'm in, we're in a hurry now. And then I apologize because
it's not his fault.

Conversely, two wives held firm beliefs that their husbands’ challenging
behavior in illness was an exacerbation or extension of their spouses’ negative
character over the course of their marriage. The following examples demonstrate
how the wives read their husbands’ past character into the difficult behavior they
demonstrated in illness. In both examples, the wives believed their husbands’
were reacting with intent to a situation or an idea. The types of situations were
already familiar to the wives who experienced similar reactions over the course of
their marriages. Based on a difficult history, these reactions continued to cause
friction between the couples. In the first example, the caregiver explained how
the disease intensified her husband’s challenging behavior.

I think in a much more subtle way. I mean ... very passive, aggressive, of
course.... I think he, I think he's always been resistant in a way. I think he
resents me in a way. He resents, uh, my getting the upper hand.... He
wants to control, and of course I want to control what's going on. So I think
it's a kind of an impasse thing that's, that's, uh, I suppose if I didn't care so much whether he took a shower or whether he got ready, why he might just not spend so much time doing it.... It's, it's, uh, just balkiness, you know, in my estimation. And then I think, well, I suppose this is, you can blame it on Alzheimer's, but I think this is basic. I think it's always been sort of a resistance to things that I wanted him to do. He's, uh, he doesn't want me to get the upper hand [laughs].

In this next example, the wife caregiver explained how she distinguished between her husband's deliberate expressions of negative character and those truly indicative of illness.

No, see, I think, sometimes I think he's doing it deliberately.... When it's the disease, you know, like we were over town, and he was confused as to the stores, where the stores are. That I know is the disease. That's not deliberate because he's genuine lost.... I was gone longer than he thought I should be. So he came in looking for me, couldn't find me. In the meantime, Tony and I had come out of the store while he was going down the other side. And when he came out of the store, he was terrified. You could see the terror because Tony mentioned to me, she said, grandma, she says, grandpa's so scared. Grandpa's scared. So she could see it in his face too. And that I knew was not deliberate.... But when he sits and asks me about did he change the oil or I'm sitting here with the mail on my lap reading it, and he'll ask me if he went and got the mail. That you know is deliberate.... Because I had my attention on the mail, not on him. As
long as I sit next to him here, he's perfectly happy. If I get up and go to do some housework, then he follows me and annoys me. Any little thing he can think of to annoy me because I haven't, I'm not giving him his attention, what he feels should be total attention. Or Tina will come home from a date and she'll sit there and tell me about what occurred, and then he will interrupt us with questions that aren't even pertaining to what she's talking about because I'm giving her my attention, not him.

She described being able to use prior knowledge of her husband to identify whether or not his actions were deliberate. In the past, she interpreted his constant interruptions as an attention-seeking behaviour conducted to refocus her attention onto him. In her words, "I've been able to figure out, when he's doing it deliberately, because he did that in the past. You kind of catch on to that one."

This wife also associated the "annoying" behaviour, such as "repeating" and "constantly interrupting" to her understanding of her husband's past behaviour and attributed his vulnerability, such as the expression of fear, to the disease. For most caregivers, the "annoying" types of behaviour were most difficult to deal with, whether their husbands' past character had been positive or negative. Still, the wife's perception that her husband's oppositional behaviour was a deliberate attempt to exhaust her resolve had a significant impact on her experience caregiving.

Each of the wife caregivers, despite the nature of their understanding of their husbands' behaviour and their marriage found some way to distinguish
between behaviour exhibited in illness and behaviour exhibited in the past. However, the women differed in their perception of where to make that distinction. The wives of husbands they characterized as intrinsically good-natured seemed to report a sharper contrast between their husbands' past character and the disease related behaviour. Wives who interpreted their husbands' challenging behaviour as part of the disease process were able to see the "man behind the illness." Some of the wives described how the essence of their husbands' natural character still came through despite the confusion they experienced from the disease. The following wife shared personal insight into the illness associated behaviour changes experienced by her husband.

He, he is still heart. He still has that really sweet, you know, caring personality.... He's still very much, he's very feeling. His feelings are all there. He's very caring and, and just terribly confused. And it's, uh, if he didn't feel so worried and anxious about things you know, the problems would be so much easier to handle.

She also attempted to make sense of her husband's anxious behaviour by searching their shared past for a possible explanation. In doing so, she related his anxiety and worry to his past dedication to protect her.

He, uh, seems to worry a lot about doing something that might hurt me. And if, you know, if I'm upset, then he used to take care of me, and it's just really sad to hear him, how he'll take care of me. He's not going to let anything hurt me [laughs], you know.
In contrast, wives' describing their husbands' intrinsic self with descriptors such as "verbally abusive", "deceptive" or "emotionally unavailable" placed the illness behavior within the context of the marriage and were more likely to see the illness as the man.

But it's just that our personal relationship has certainly not been what, what I hear some of the other people talking about, and I, I, in a way I suppose I'm kind of envious of the fact that they have had these good relationships even when now they can see their, their spouse as, uh, someone with a disease rather than someone that's just gotten more and more unbearable to, you know, to deal with.

The wives' interpretation of the impact of the caregiving experience on the marital relationship was another recurring idea emerging from the interviews. Although most caregivers' revealed feeling "frustrated", "angry", and "overwhelmed" with their care receiving spouses, the disease, and the caregiving role, many expressed that they continued to share their lives with their spouses. One caregiver exclaimed, "I don't want to give up the good moments", communicating a mutual purpose for continued caregiving. And another caregiver described that her husband's physical presence alone offered a sense of "security" at night in their home. This traditional view of the husband as protector remained for this caregiver and provided her with comfort in knowing her husband was still there, despite his inability to respond with intent to her needs. Several caregivers saw the caregiving experience as an extension of their
marital relationship and continued to view their spouses as their marriage partner. The following wife caregiver captured this idea best:

That's not really reality for me, oh fine, I will just place this person and I will go and do whatever. It doesn't even sound good to me...but I'm living a life...a marriage. See, that's the difference.

One wife caregiver explained that her husband's inability to communicate was one factor negating the opportunity to resolve past marital issues. She also expressed a feeling of entrapment within her marriage and described that ending the relationship now that her husband was ill would elicit too much guilt.

You know, we had a big thing about this [husband's insincerity and resistance] long ago, and I should have taken some action right then when I was aware of it.

And also:

I can look back when he's at his most trying moments, and say, gosh, why didn't I have the guts to divorce him before he had this diagnosis. Now I feel too guilty if I, if I did that at this point. So I've got to, and I've got to make the best of it.

Several wives described how the illness altered their retirement plans while others saw themselves back in the role of a mother. One wife described how caregiving hindered her ability to become more independent and enjoy her 60's, now that she found herself once again in the "mothering" role. This same woman also saw the illness as a lost opportunity to rediscover her marriage relationship with her husband.
I looked forward to having a husband that [I] could travel with, and you know, spend my golden years with as a husband, protector type. Now I'm back in the mother [role].

Although it was not often the focus of discussion, it is important to include that, a small number of wives perceived that a difference would exist between caring for one's husband from the context of a positive marital experience and from a negative marital experience. The following wife caregiver offered her perspective based on her own experience of a satisfying pre-illness marital relationship.

It must have a lot to do with that, the type of relationship you had before, too. Whether you're able to give the kind of care that they need. I think that if you didn't have a good relationship to begin with, it would be twice as hard because they're, they go through so many stages and so many different phases that it's hard. It's hard to deal with. I mean you've got a lot of anger a lot of times, and a lot of sadness, and I think if you didn't have a good relationship, you'd just say the heck with it...they're just so, he's so vulnerable. I mean, you just want to hold him sometimes because it's just so hard to, to think of somebody going through that, and especially somebody that you love.

Wives describing their marriages with positive descriptors such as, "a good life" or "a great love" had little difficulty articulating exactly why they were carrying out the caregiver role. For most, it was clearly a commitment to their marriage, but more importantly, a commitment to their spouses. The following
caregiver’s description of her husband provided the rationale behind her commitment to provide care.

And everybody loves him. He has never, as far as I know, ever said anything bad about anybody. Everybody loves him, neighbors. I think everybody calls him papa. And all of our children and grandchildren, they think he’s the most wonderful man in the world. And that’s why, that’s why I want to keep care of him.

As previously described, wives caregiving for their husbands from the context of a negative marital experience interpreted the challenging behaviour exhibited in illness as an extension of their spouses’ negative self. These caregivers communicated that they continued to provide care because they had no alternative options. One wife explained that her husband would “fight [her] all the way to the nursing home.” She further explains:

Well, I just said I asked for it. I married him, and I didn’t divorce him at the time before the diagnosis, so I lost on two scores there... so, I guess I have to make sense of taking care of him now.

In this next example, one caregiver described adhering to the marital commitment she made to her husband. In her situation, societal pressure and her own values and religious beliefs assigned her personally responsible for her husband’s care.

He’s a person that I live with. Share the same bed... So I think maybe in my case there’s a difference in, in the caregiving. Because I’m taking care
of a person I feel I have to...Because he’s my husband. And it was a commitment I made. So I’m bound by that commitment.

Caregiver’s Desire to Preserve a Sense of Couplehood

This category is described by the caregiver’s desire to preserve a sense of couplehood and foster the marriage experience within caregiving. For this study, the term couplehood captured the wife’s portrayal of how she and her husband existed as a marital dyad. The caregivers often expressed their marriage relationship before illness as a “partnership” where “one never did anything without the other”. As the disease progressed, the caregivers were required to take on responsibilities they once shared in the past in addition to providing physical care for their husbands. As the wives saw their partnership dissolving, the nature of being a couple inevitably changed for them. Their husbands’ cognitive, emotional, and physical changes in addition to the shift in responsibility challenged the wives’ idea of connecting as a couple. In the first example, the caregiver shared her devastation at the number of relationship losses in the following way.

[crying] You lose your best friend, you lose your helpmate, you lose your lover, you lose your husband. I don't know, you lose everything. I don't even like to think about that. I don't even like to think about the loss because it's overwhelming.

She also described how quickly their “extremely close relationship” was dissolving and attributed this loss to a lack of interaction in a way that fostered the marital relationship.
And so I feel myself slipping, and we've always had an extremely close relationship, and I feel myself slipping in that relationship.

Another wife offered a further perspective on caregiving to a spouse by describing the changing experience of couplehood in the following way:

Oh, at first he was loving ... he wanted to go out .... wanted to be with you all the time.... It was a loving relationship, and it was sort of a fun relationship. But now it isn’t that kind of relationship. It’s a mother, protector relationship which ... the love angle is completely different. You do things because you want him to be as comfortable as possible, but there’s no feeling of the same love ideal that you had before.

For another caregiver, placing her husband in the position of a child with the behaviour of a child helped her cope with the caregiving experience.

As long as I can place him in that child position because he does act like a child so much, it’s easier to cope with because then I’m not losing a husband. Mentally I’m not losing that husband, lover relationship.... I can accept his behavior easier ... it’s the disease.

The wives discussed a variety of relationship changes since illness onset. For many caregivers, “sleeping apart”, “lost communication” and constrained social relationships were particularly symbolic of the loss of the marriage relationship. Several caregivers also described a loss of marital intimacy that previously came from feeling close and comforting one another. One wife shared her dilemma in sleeping apart from her husband. For this caregiver, it appeared
that the change in sleeping arrangement indicated a significant change in their
interactions as a married couple.

We even have to sleep apart because I can't sleep. He sleeps well
because he's medicated, but I don't sleep at all. So we had to sleep apart.

So I guess each day is just a little...further inching away.

She also described how well they communicated in the past and how much she
missed that experience now that he was no longer capable of following a
conversation. Her words illustrate that there must have been a natural and
comfortable ease in their communication as a couple.

He was always kind and willing to communicate. I mean, we never had
any problems with no communication. Uh, I think that's the hardest thing
for me now is because there's no communication at all. Uh, like I said we
always did everything together.

The caregivers also spoke of how they altered themselves because of the
changing experience of being a couple. Several expressed having to become
more independent, but saw the change as a positive experience. Two caregivers
communicated a realization that they needed to take care of their own selves,
now that they had become solely responsible for living their life. Many wives also
talked about having to change their ideals about growing old with their husband
and accepting the loss of retirement plans. The following caregiver account
illustrates the impact of this change in the relationship as she speaks of having,
now, to take care of her own self in terms of developing social relationships.
He's the social person...I'm not. And he was the one that always drew me out and drew me into the, you know, uh, relationships with an awful lot of our friends...so I'm sort of on my own now...but I don't reach out very well.

**Connection**

There were many examples within the caregiver interviews supporting the idea that continuing to connect with the care recipient was important for wife caregivers. For most wives, feeling connected to their husbands and their marriage helped them *preserve a sense of couplehood* in the current caregiving experience. The following section describes connection as an important marriage concept in spousal caregiving. The idea of connection was discussed by most wives at some point in the interview. The examples focus on how the wives labeled and interpreted the experience of connecting with their husbands. The idea of connection surfaced in two slightly different ways that were both related to the couple. The first manner described connecting with the *person*, while the second manner was explained by the wives' descriptions of how the couple connected in their *marriage*. Both ideas provided meaning for the wives' caregiving experience.

**Connecting with the person.** Connecting with the person is essential to the experience of connecting in the caregiving relationship. This experience is formed by the wife's desire or will to continue connecting as a couple. This desire, informed by the wife's interpretation and understanding of the nature of the past marital relationship influences her ability to preserve a sense of couplehood.
Many wives described "fleeting" moments in which their husbands seemed to break through their persistent cognitive fog. The wives identified this breakthrough as connecting with their husbands through words, gestures or actions that resembled their appraisal of their spouses' past self, or "true" nature. Breaking through was most often a rewarding experience for the wives and helpful in sustaining the caregiving experience. These moments of clarity and purpose allowed many wives to see their husbands as they always were, whether that moment was a facial expression or a "purposeful" action. As one wife caregiver witnessed, "we were coming from the bathroom, and he just let go of my hand and went over and straightened it [picture on wall] (laughs). Put it the way it's supposed to be." One wife described a brief awareness in her husband, relating his experience of energy and openness one evening to walking on the beach earlier that day. She found that "he was much more open" and "seemed to be talking again." The belief that they had exchanged a meaningful conversation that was linked to an activity they shared was very important to the caregiver. She also commented on the change in frequency with which he shared his sense of humor. His "one-liners" were particularly characteristic of his nature, yet, expressions of his humour were becoming "more and more infrequent." Another caregiver described making a connection with her husband in this way, "so basically, you think this isn't Wes, but then he'll smile or laugh at something and you think, oh, there's, he is still in there. That is still him." For this caregiver, her husband's smile signified the presence of his "true" self. Another caregiver
emotionally described how precious the experience of connecting with her husband was now that it occurred so rarely:

This [moments where she sees Ralph as she understood him to be in the past] is a special time that jangles. Where Ralph used to be aware of what was outside of him [crying], of the mountain, of the boats, of the birds, of all of it, he's closing down. He's kind of like making a warm nest for himself and comfortable in, within himself.

The wife's experience connecting with her husband was often a moment that took her by surprise, when a part of him she knew so well presented itself once again. In response to a question inquiring into the changes in the person the care recipient had been, one caregiver described how he had become "withdrawn". She then described "one odd thing" that happened, in which her husband initiated a logical conversation with a friend. She expressed surprise at seeing her husband's engagement and sociability in the following way.

He told Vaughn exactly what happened in the t.v. program he'd watched the night before, which did really surprise me that he could recall something that had happened in great detail. I mean, and he connected them. I mean, it wasn't something out of left field.... it was connected with what they were talking about....Yes, I, I think it makes me realize that there's something still there, that he is recalling.

And another wife caregiver commented on how meaningful it was for her to witness her husband responding to an activity they had shared. Connecting with him as an interactive partner fostered their relationship as a couple.
And just here a couple of weeks ago at church we were, we sang a real, real familiar song.... And he just started whistling ... it was just heartbreaking because it had been so long since he, he'd even said anything or made any, any, uh, response that it was just wonderful ... that he was still able to respond that way.

The next caregiver provided an example of how she began to encourage their interactions as a couple to preserve a sense of their marriage and their experience as a couple to help decrease her husband's agitation.

I've started dancing with him to the music, you know, for a while when I think he's feeling, you know, and that, that helps [agitation]. . . it's something that I can do with him, and there's not so many things any more, you know, that where we can interact.

The marital connection. The concept of connection was also discussed by the wives in terms of their past marital relationship. The wives' interpretation of the nature of the pre-illness marital relationship influenced their ability to connect with the past for support in the marital-caregiving role. Accessing the past marital relationship was one process by which wives could obtain internal support to maintain the wife-caregiver role. For some caregivers, the marital connection that existed between the couple was lost forever. For example, one caregiver stated she was already "alone now", despite her husband's physical presence. While other wives nurtured what little remained of the marriage relationship.

I know him better than anybody else...so I can [be a caregiver to her husband]...it's kind of a purpose too...it gives you a sense of
purpose...you know you're not alone. You have him to take care of. And so he's, he's essentially there even though he's not maybe mentally there. He's there, a person to love and take care of. Whereas if he, if he weren't there, then he's just completely gone, and that purpose would be gone too. So it's kind of a fulfillment in a way, a self-fulfillment for me. You're still married, and you still have him there to love. It's just a different kind of love, I guess.

It appeared to be very difficult for some wives to uphold the marital connection when their spouses were unable to interact and reciprocate appropriate feelings. One wife described her husband as more of a “stranger” now and sensed that he was no longer interested in the couple relationship. She clearly remembered the first time he did not recognize her and stated “it shocked me”. She also described their marriage relationship in the past tense, as though they no longer existed as a couple. Consider the following:

And everybody thinking we were such an ideal couple, and that we always had so much fun together, dance together and so forth.

In contrast, several other caregiving wives described experiencing positive and meaningful expressions of marriage within the current caregiving relationship. One wife exclaimed, “people do not realize that when you give a hug ... you get one back”. In response to a question inquiring into what parts of the wife’s relationship experience remained, she described her perception of the “cuddles” she exchanged with her husband.
He’s still a real good snuggler [laughs].... I keep telling him he’s the best cuddler in the whole world. [laughter] We have lots of hugs.... He really expresses, you know, that he really cares and he loves me.

The following caregiver described that the nature of their marriage relationship was present in the caregiving experience and provided her with the will to care for him at home.

Yes, I want to be with him. I want to take care of him. I don’t want anything happening to him. I don’t think anybody can take care of him like I can...Because we’re close. We’re so close. We’ve always been close. I just feel like, well, I’m part of him and he’s part of me. He’s wonderful, You can see, everybody loves him and everybody probably thinks I’m an old bag.

The next example describes a wife’s hesitance to express strong emotion regarding her husband’s rare expression of “true” self.

Once in a while those doors will open [her husband’s “true” self], and he’s okay...I feel good that he was able to do it, but two minutes later it’s gone...it’s hard to enjoy those few moments because they are so fleeting.

For some wives, the caregiving relationship was perceived as a natural extension of their marriage. They often demonstrated a continued investment in their marriage by fostering their interactions as a couple within the limits of their husbands’ capability. In addition, many expressed a continued commitment to their husbands as their marriage partners. As one wife caregiver explained, "He’s still my husband, and I love him, you know, like he was my husband." Another
wife acknowledged that the ease with which she continued to see her husband's true self was not the experience of all wives.

There's a real strong connection there yet...That I feel a lot of the time...I hear and read that personalities change, and it does not seem to me that his has. The same person. It's just that he can't interact, you know, very much.

The following caregiver champions the idea of connecting as a couple in her description of a situation in which she reminded her husband of their shared idea of marriage.

He said, how come you won’t let me drive. I don't see why you would do that to me. And then I, and I tried to explain that we’re in it together, and what happens to him really happens to me. It’s a, you know, it’s the two of us going along. It’s not pulling apart.

Accessing the Past Marital Relationship

Accessing the past marital relationship is the category described by the wife caregiver's ability to look to the pre-illness marital relationship for support in pursuing the spousal caregiving role. Acquiring support for the past was a viable option for caregivers describing mutually satisfying marriage relationships. The caregivers reflected on their past marital relationship for guidance in caregiving. For one caregiver, providing physical comfort was important in preserving her husband's self-esteem and was clearly compatible with expressions of affection in the past. Despite discouraging advice from others, she felt secure in her approach and continued to care for him in that same manner.
And I think just, uh, just being able to hug him or touch him, you know. A lot of times, or one of the kids said one time to me quit touching him all the time, mother. Leave him alone. I said no. If I, if I were sick, I'd want somebody to touch me, and, and I think just the closeness of two people is, is a comfort. I know it would be for me, and so I just treat him like I'd want to be treated, I think. And he was always real affectionate...if it was me that was sick.

Another caregiver described an inability to look to her past marriage experience for support in the present caregiving situation. The caregiver's interpretation of her husband's behaviour and the meaning she assigned to it and their interactions in the past denied her support from their prior relationship. She was clearly aware of her inability to enlist motivational support and strength from the relationship she had with her husband over the course of their marriage. She demonstrated her insight in the following way, "I'm not looking for something that, you know, that I didn't, wasn't ever there in the first place." For this caregiver, reflecting on her understanding of the past marital relationship and her husband's past behaviour fostered resentment of the caregiving situation. It also represented a lost opportunity to resolve past marital issues because of the cognitive decline that rendered her husband incapable of participating in a discussion that was complex in nature.

When you're first married, you, or I tend to read in a lot of things that I want to be there...and it really wasn't there...but I think there was a period of time before the, the stark reality of the Alzheimer or whatever the
dementia is, that it's never quite been there. And now it's just exaggerated to the point where it's harder to deal with...it's never going to be resolved...I'm never going to get from this relationship what I would from, from a marriage relationship.

In the following example, the caregiver provided an insightful account into why caregiving was such a challenging and negative experience for her by comparing it to the experience of a close friend who also cared for a memory impaired spouse.

The one thing about his, Fred's loss of memory [friend's husband]...he's always, he's never been irritable. He's always been a nice person. He's always been easy to get along with. And you can tell. You know, he still is. And I think, oh, wouldn't that be nice to have somebody like that. You know, he's pleasant to Howard [caregiver's husband]. He's pleasant to everybody. He's just, it's sort of, in a way, it's a little painful for me because I realize what I've never had, you know, in a sense. And, and just the, you know, the stark contrast of somebody who also has lost something. Gosh, what, you know, if he didn't have that loss, he's still good, you know. He's still what's easy to take care of. So it's, that's what's hard about it for me.

Summary

In this chapter, the study findings were presented according to the researcher's interpretation of the wives' appraisal of their marriage experience and the influence of that relationship on their caregiving experience. The
categories that emerged from the data are linked to the wife’s caregiving experience and a schematic representation is found in Figure 1.

The pre-illness marriage experience, described by the wife’s interpretation of her husband’s innate character and the nature of their interactions as a couple was an important influence of her caregiving experience. The nature of the pre-illness marital relationship as described by wife caregivers did not create a less challenging caregiving experience and certainly did not revoke their experience of a deep and personal loss. Rather, it appeared that the nature of the pre-illness marital relationship provided a context for the wives’ caregiving experience. For some caregivers, the nature of their history meant continuing to foster the marriage relationship. In viewing caregiving as an extension of the marriage experience, some wives were able to rise above their tragic losses and establish meaning in the caregiving experience by remembering and preserving their perception of the man and the relationship they had shared in the past. In many of the caregiving relationships, the marriage experience was the wife’s connection to her husband as he once was. Connecting was the process by which wives enacted their desire to preserve a sense of couplehood. Some wives made conscious attempts to foster the marriage experience in caregiving by continuing to interact with their husbands as a married couple. Connecting with the past was also important in determining the nature of the wives’ caregiving experience.

In addition, the wives’ interpretation of their marital interactions influenced their reason for assuming the caregiving role. The caregivers describing their
marriage and husbands in a positive light identified a selfless will or desire to care for their husbands, while the two caregivers describing negative marital histories and the one caregiver claiming a mixed experience saw caregiving as the ultimate test of their marital vow. Framing caregiving within the marriage experience gave most wives the language to communicate and validate this role for themselves and to others.

The ability to acquire support from the past was another factor influencing the caregiver’s experience. This category was described as the wives’ attempt to derive support from their past existence as a married couple. Their perception of the past they shared with their husbands was influential in fostering or hindering their caregiving experience.
CHAPTER FIVE: DISCUSSION AND IMPLICATIONS FOR NURSING PRACTICE, EDUCATION AND RESEARCH

The findings of this study suggest that the pre-illness marital relationship is formed by the wife’s interpretation of her husband’s behaviour and the meaning she assigned to it and her understanding of their interactions as a married couple. The pre-illness marital relationship influenced both the wife’s ability to connect with the past and the nature of those connections. The nature of the connections, based on relationship history, influenced the wife’s ability to access the past relationship for support in the caregiving role. Wives who characterized their pre-illness marital relationship as positive attempted to continue existing as a married couple throughout the caregiving experience by preserving a sense of couplehood. These wives perceived that connecting with their husband was a mutually beneficial experience. The caring actions performed by the wife to foster a sense of couplehood in the caregiving experience provided her with opportunity to develop meaning and experience gratification in her role as wife caregiver.

The following chapter will discuss this interpretation as it relates to the existing body of marital-caregiving literature. The discussion is followed by a presentation of the importance of understanding the wife’s caregiving experience from a relationship perspective in nursing practice, education, and research. A summary of the study findings will conclude the chapter.

Pre-Illness Marital Relationship: A Central Process

In the current study, the wife caregiver’s appraisal of her pre-illness marital relationship surfaced as the central process by which the marriage experience
shaped the wife's caregiving experience. The present study supports the small body of spousal caregiving research to date that links the pre-illness marital relationship to specific caregiving outcomes. Robinson (1990) associates the pre-illness relationship to the wife caregiver's experience of burden, measured both by the amount of disruption and change in the caregiver's life and by the caregiver's emotional reactions to caregiving. While a later study by Kramer (1993) offered a further perspective in finding that the pre-illness marital relationship influenced the caregiving experience by predicting the wife caregiver's level of depression and quality of life, both of which influenced her overall experience of satisfaction with caregiving. More recently, the importance of the marriage relationship was supported by Strang and Haughey's (1998) qualitative study that found the pre-illness relationship to be a factor influencing the wife caregiver's ability to experience respite. The authors claim that respite was one way that the family caregivers could alleviate the burden of caregiving. They identified that the dyad's relationship was a factor that determined their ability to "get out of the caregiver world" to experience respite (p. 231). Similarly, the current study highlights the importance of the nature of the past relationship in understanding the wife's experience caregiving to her husband with AD. In this study, a positive pre-illness marital relationship influenced the wife's experience of gratification and meaning in caregiving.

This study responds to the current demand for research that is dedicated toward achieving a thorough understanding of the caregiver's actual experience—an experience that is largely influenced by the nature and quality of the pre-
illness relationship with the care recipient. This study also responds to recent calls for a relationship-oriented approach to caregiving research. Several authors advise a research approach that explores caregiving within the context of the caregiver and care-recipient's relationship to extend the presently narrow conceptualization of caregiving (Clarke & Watson, 1991; Gubrium, 1995; Keady, 1996; Thompson & Pitts, 1992).

Components of the Pre-Illness Marital Relationship: Husband's Behaviour and Marital Interactions

A most important finding within the current study was the wives' identification of the tenets of the pre-illness marriage relationship important to their caregiving experience. In effect, this finding addresses a gap in the caregiving literature concerning the identification of the pre-illness relationship as a factor influencing caregiving without defining the particular aspects of the relationship important to the caregiving experience. This study offers the wives' perspective regarding the aspects of their marriage relationship important to the caregiving experience. Understanding the marriage experience through the wives' interpretation of their relationship with their husbands is congruent with the basic assumptions of qualitative family research, given that the family experience can be uncovered by understanding the relationships that exist between the members (Rosenblatt & Fischer, 1993).

The pre-illness marital relationship category was described by the wives' interpretation of (1) their husbands' behaviour and the meaning they assigned to it and (2) their interactions as a couple in the past. This key finding supports and
extends the recent work of Strang and Haughey (1998) regarding the influence of
the pre-illness relationship in caregiving to the caregiver's ability to achieve a
respite experience. Strang and Haughey's present a similar idea using the
terminology - personality-based factors - in caregiving when discussing the family
caregivers' temperament. Strang and Haughey found that the family caregivers'
temperament throughout the marriage relationship was one component that
influenced their ability to achieve a respite experience and receive support. The
present study captured the wives' interpretation of their husbands' behaviour
throughout the course of their marriage, offering an understanding of the
influence of the care recipients' characteristics in the caregiving experience. In
addition to gaining insight into the wives' interpretation of their husbands'
behaviour, wives would at times share their response to their spouses'
temperament in the past marriage relationship and the present marital-caregiving
relationship. This provided the present researcher with a beginning
understanding of the influence of the wives' own character on the caregiving
experience. However, the wives focused on their understanding of their
husbands' behaviour and the challenges of providing care to a husband with AD,
rather than on their own behaviour in the interviews. Therefore, understanding
the wives' perception of their own behaviour as an influence within the marriage
and caregiving experience can further the current understanding of spousal
caregiving and would be a valuable pursuit for future caregiving studies.
Wife’s Interpretation of Her Husband’s Behaviour in Illness

An additional and considerable finding with respect to the wife’s interpretation of her husband’s past character was how it shaped her perspective of his illness. While the wife’s perception of a mutually satisfying marriage experience positively influenced her ability to see the man (her husband) behind the illness, a conflicted and negative marriage experience made it likely that she would see the illness as the man (her husband). This has implications for the quality of care she is capable of providing her husband and supports a similar finding presented in Morgan and Laing’s (1991) study of burden from the spouse caregiver’s perspective. The present study’s interpretation also responds to Thompson and Pitts (1992) appeal to caregiving researchers to investigate the impact of spousal characteristics on the care recipients’ quality of care. The current study identified the care recipients’ past behaviour as an influencing factor in the wives’ perception of their husband’s illness behaviour and their experience in the caregiving role.

The wives describing negative pre-illness marital relationships had difficulty differentiating between their husbands’ behaviour in illness and their perception of their husbands’ pre-existing character. The care receiving husbands’ frustration, anger, and “annoying” behaviour were interpreted to exist within their innate character, while the confusion they experienced was attributed to dementia. Despite the wives’ knowledge of the process of AD and the associated cognitive changes, they continued to perceive that their husbands’ behaviour was intentionally conducted to disregard their wives’ emotional needs.
While the current findings suggest that the care recipients' past behaviour appeared to shape their wives' perception of their husbands' illness behaviour, further research is needed to also identify the care recipients' appraisal of the marriage relationship. Naturally, consideration of the phase of illness would be required in selecting cognitively impaired care recipients for qualitative interviews. Qualitative research based on narrative inquiry can provide helpful information.

Wife's Perspective of the Influence of Caregiving on Marriage: Extension of Marriage or Lost Opportunity?

The current study's assumption that a loving and nurturing pre-illness marital relationship would yield a desire to extend that nature into the caregiving relationship was validated by the wives who identified their marriage as a positive experience. For some wives, despite their husbands' inability to provide purposeful interaction, the marriage continued because of their spouses' physical presence. The findings suggest that it was the wives' memory of the marriage experience that influenced the dyad's caregiving relationship. Even though wives' relating a negative marital relationship were not well represented in the present study's sample, their perception regarding the influence of caregiving on their marriage experience remains important. One of the most salient findings described by these wives was their understanding of caregiving to impede their ability to resolve longstanding problems existing in their marriage.

Several wives, from both positive and negative marital experiences, also described losing the opportunity to focus on their own personal development in
later life, now that they were providing care to their partner. Williamson and
Schultz (1990) found that caregivers in their study experienced higher levels of
resentment and depression because they had assumed that later life would offer
an opportunity to focus on their own personal needs. The authors’ findings may
account, in part, for those wives in the present study who experienced
resentment of the caregiving role. It appeared that the wives’ communication
regarding their belief that their husbands were purposefully disregarding their
emotional needs may stem from their negative pre-illness relationships. In
contrast, the majority of wives who experienced positive marital relationships
suppressed later life desires and altered their expectation of the marriage
relationship. In contrast to the resentment found in the Williamson and Schultz
study, the wives in the present study often expressed sadness for their loss and
sometimes guilt for communicating a continued longing for the marriage and the
husband of the past. Additionally, despite the lost opportunity to focus on their
own needs, some wives communicated that they still experienced personal
growth that came from learning to manage their lives independently of their
husbands.

It is worthy to note that a small number of wives communicated awareness
that a difference would exist in the wife caregiver’s experience providing care for
her husband, based on the history of the marital relationship. One of the wives,
describing a negative marital history, articulated how her perception of caregiving
for her husband would be different had their marriage been a positive
experience. The power of the marriage influence remained evident in the
caregiver's disclosure of her own unwillingness to rise above the marriage experience in her caregiving, despite acknowledging that the resentment and anger experienced was a product of the prior marital relationship. Insights provided by participants in the current study affirm Strang and Haughey's (1998) claim that wife caregivers with marital histories that are characterized by conflict have difficulty adopting the caregiving role wholeheartedly.

**Commitment: Is Caregiving Motivated by Love or Obligation?**

In the present study, wives described their commitment to care for their partner to evolve from two different sources: (a) out of love for their partner and (b) out of an obligation to fulfill the marital vow. Most of the wives with positive past marital relationships provided care out of love. An ongoing investment in the marriage relationship characterized their commitment to provide care. For the wives expressing negative marital histories, personal and societal constraints were the driving forces behind caregiving. The findings of the present study support Stanley and Markman's (1992) classification of commitment as either (a) a personal dedication or (b) a constraint commitment. The wives in the current study communicating negative past marital histories were found to provide care out of constraint, and felt compelled to maintain the relationship in the absence of possible alternatives. In contrast, most of the wives with positive relationships were considered to provide care out of a personal dedication for their husbands. The wives' commitment to provide care out of a personal dedication for their husbands and their marriage was clearly represented in their comments regarding their continued investment in the marriage relationship and their desire
to provide for their husbands' emotional and physical well-being. In light of Stanley and Markman's conceptualization of commitment, a question posed to identify whether or not a spouse caregiver can experience a change in the perception of his or her commitment toward the marriage, especially one that was characterized by conflict, may expand the current understanding of the marital-caregiving experience. Perhaps caregiving can offer an otherwise unharmonious relationship a new purpose and a potential for developing meaning. There is a need for nursing research dedicated toward furthering our understanding of the wife's experience of commitment to the marriage relationship when her partner is unable to reciprocate that same level of commitment.

The wife caregiver's commitment to provide care for her husband with AD has implications for long-term care. The prior relationship is identified as a factor influencing the decision to place one's family member in a nursing home (Wright, 1993). Furthermore, Strang and Haughey (1998) found that wives describing a negative marital history were least likely to benefit from a formal respite service, largely because their husbands' refused to attend and had been controlling in the past relationship. Without opportunities for periods of relief, a formal care service such as a nursing home may be the only reasonable solution for these wives.

Preserving a Sense of Couplehood

In the current study, preserving a sense of couplehood emerged as a unique and important aspect of the wife caregiver's approach to caregiving for her husband with AD. Preserving a sense of couplehood was described by the
wife’s desire or will to promote the pre-illness marriage relationship within the caregiving experience in the presence of her husband’s cognitive decline and diminished ability to contribute to their marital partnership. From the wives narratives, preserving a sense of couplehood in the present study can be conceptualized in two ways: (1) by the wives perceiving a need to interact as couple, and (2) by their ability to both connect with their spouse and marriage and to promote interaction as a couple. Wright (1993) found that spouse caregivers reported losing a confidant in their spouse with AD. Similarly, the wives in the present study described that the dyad’s altered ability to communicate exacerbated their feelings of loss. However, participants in the present study noted that their inability to maintain the marriage as it had always been did not prevent them from retaining a sense of what they had previously experienced, such as closeness.

The category, preserving a sense of couplehood, complements Perry and O’Connor’s (in press) recent study conceptualizing personhood within the spousal caregiving-care-receiving relationship. In their study, personhood was described by (1) the spouse caregiver’s effort to maintain the memory-impaired partners’ sense of self, and (2) the spouse caregiver’s effort to preserve their marriage identities. The findings of this study expand upon the idea presented in Perry and O’Connor’s second operationalization of personhood – preserving their marriage identities. In the current study, fostering a sense of couplehood was formed by the wife’s acknowledgement of the loss of the marriage relationship and fueled by her desire to preserve a continued existence as a married couple.
For most wives, caregiving was perceived as a natural continuance of their marriage. Many wives considering caregiving as a natural progression of the marriage experience communicated an acceptance of the change to their family system. Others identified the change as an overt disruption to their marriage and challenged the new direction by making positive decisions about how they would interact with their husbands' in order to further the marriage experience.

This study found that the wives who characterized their pre-illness marital relationship as positive were most likely to interact with their husbands in ways that fostered the marriage relationship within the caregiving experience. Fostering a sense of couplehood was one way that wives nurtured closeness after being consumed by the tasks associated with the wife caregiving role. Fostering interactions as a couple provided a sense of purpose and meaning in caregiving and gratification in the wife caregiver role. This finding extends Motenko's (1989) study of wives caregiving for husbands' with AD, where the wives' perception of a change in the couple's closeness correlated with lower gratification from caregiving. In accordance with Motenko's study, fostering a sense of couplehood captured the wives' response to the perceived change in closeness of the couple.

Perry and O'Connor's (in press) qualitative exploration of personhood challenges the notion that caregiving is a unilateral process. In the present study, the wives' appraisal of the benefit received by their husbands through fostering their interactions as a couple provides support for their claim. One wife described the collective benefit as physiological for her husband by decreasing the
physiological manifestations of his agitation and psychological for herself by fostering a sense of emotional closeness.

**Connection.** The concept of connection, also an important finding in the current study, was identified as the mechanism by which the wife caregivers' operationalized the notion of fostering a continued sense of their status as a couple within the caregiving relationship. The present study affirms Wright's (1998) finding that affection is one way to connect with the past. The wives who expressed affection with hugs and touch also described a sustained sense of marital closeness. This discovery also supports the work of Cartwright, Archbold, Steward and Limandri (1992) regarding enrichment interventions, a method by which caregivers can foster meaningful relationships through activities that promote closeness with family members with dementia.

Spaid and Barusch's (1994) study also acknowledges the importance of closeness in the marital-caregiving relationship. The authors found that closeness of the married couple was the primary predictor of burden in caregiving. The closer the caregiver felt to the care receiver, the lower the experience of burden from caregiving. In addition, more effective coping also led to fewer burdens from caregiving. The authors measured closeness at the time of the study and consequently did not capture the pre-illness relationship. The interpretation of the wives' narratives in the present study found the pre-illness marital relationship to be a possible influence in the wives' desire to promote closeness in the caregiving relationship and extends Spaid and Barusch's
findings regarding closeness and burden. In their study, the wives’ experience of

closeness was communicated to positively influence the caregiving experience.

The nursing literature is beginning to generate research dedicated toward
understanding the concept of connection in the aging and chronically ill
population. Connection, most often represented by the term connectedness or
inter-connectedness, has been previously explored within the nursing literature
as an antecedent, a critical attribute and an outcome of other major concepts
such as *spiritual perspective*, (Haase, Britt, Coward, Leidy & Penn, 1992) *hope*,
(Bays, 2001; Haase et al, 1992; Herth, 1993; Leidy & Haase, 1999) *acceptance*,
and (Haase et al) *self-transcendence* (Haase et al). Connectedness is
infrequently defined or explored in detail; however, Haase et al describe the
experience of connectedness as a “significant, shared, and meaningful
relationship with another person, a spiritual being, nature, or an aspect of one’s
inner self” (p. 146). In addition, studies are only beginning to identify
connectedness as a concept in its own right. Connectedness is therefore in need
of clarification for nursing research and practice.

The related relationship literature also classifies connectedness as family
connectedness, spiritual connectedness, and social connectedness. Becvar
(1997) describes connectedness as a principle of family and couple therapy in
her article discussing a tentative theory of soul healing in the family. Becvar
perceives soul healing as the evolution or the growth of the family toward
wholeness. There are five basic assumptions and five guiding principles from
which to operate when adopting a soul healing approach to the family. The first
principle is acknowledging connectedness. Acknowledging connectedness is to acknowledge a sense of interdependence with the family. Becvar expresses that the connection we feel with our family is a model of what is possible in all of our relationships. The notion of family connectedness or the connection we feel with our family, such as unconditional love, has implications for spouses' caregiving for a partner with AD. In the present study Becvar's interpretation of family connectedness and the experience of unconditional love, elucidates the wife's commitment to provide care out of love for her spouse in the absence of obvious mutual benefit. For the wives in the current study, the goodness and strength of their husbands' past character informed their ability to provide care out of love in the present.

The research literature has established a relationship between the concept of hope and connectedness. Two concept analyses were reviewed and both found connectedness to be a critical attribute of hope (Bays, 2001; Benzin & Saveman, 1998). Benzin and Saveman explored the concept of hope for nursing research and practice. Their analysis revealed inter-connectedness as one defining attribute of hope. The authors found that a person's experience of hope could include the self and/or others. However, there were no further descriptions of inter-connectedness within the concept analysis. According to the cases (model, borderline, related, and contrary) presented by the authors, the present researcher assumed that mention of the person of interest's relationship with another person referred to his or her experience of inter-connectedness. According to the authors' concept analysis of hope, the nature and influence of
inter-connectedness within nursing practice remains unclear. The elusiveness of the concept of connection warrants further investigation. Researchers need to clarify the importance of understanding connection or connectedness by identifying its usefulness in nursing practice. To begin identifying strategies to incorporate into nursing practice, researchers can assist practitioners by conceptually clarifying connection or connectedness as an attribute describing other concepts and as a concept for nursing in its own right.

As noted above, there do not yet appear to be any studies exploring connectedness within the AD or dementia caregiving relationship. However, a small body of related nursing studies explore the importance of understanding connectedness within nursing research and practice. A study by Leidy and Haase (1999) offers an understanding of connectedness from the perspective of patients with chronic obstructive pulmonary disease (COPD). Leidy and Haase performed a naturalistic qualitative study that described the meaning of functional performance from the patients' perspective with COPD. For patients with COPD, preserving their personal integrity was important and the qualities most salient to integrity were a sense of effectiveness, or “being able”, and of connectedness, or “being with”. Family members were most often the objects of connectedness for the patients with COPD. The past relationship was not overtly acknowledged in the study because preserving integrity was found to occur within the present day-to-day experience. However, the patients’ past was important in maintaining effectiveness by sharing what they were previously able to do, while connectedness with family members was based, in part, on relationship history.
For the patients with COPD, being able to reciprocate the help they received from others and/or provide altruistic assistance was important to preserving integrity. As the disease progressed, patients described learning new ways to reciprocate the assistance they received from family and friends.

Preserving integrity is a similar concept to both couplehood and connection. These concepts are understood by the patient, or caregiver in the present study, to be important for preserving quality in the life experience. However, in the present study, the wife caregiver is alone in her effort to preserve a sense of couplehood and experience a continued and meaningful marital connection with her partner with AD. Personal rewards, such as gratification and meaning in the caregiving experience, appeared to be an outcome of the wife's effort to foster the marriage experience. However, further research is necessary to understanding the complex nature of preserving an experience for a partner over a period of time in which the partner is unable to reciprocate meaningful interaction.

A second example of nursing research utilizing the concept of connection is Bays' (2001) recent exploration of the concept of hope in nursing according to Roger's Science of Unitary Human Beings. From the older adults description of hope after a stroke, Bays captured their patterns of hope and the factors associated with their patterns of hope. Connectedness emanated as a pattern of hope, while family and spiritual connectedness were specified as factors associated with hope patterning. Family and spiritual connectedness provided the stroke survivors with a sense of encouragement, support, and belonging. The
participants acquired support by connecting with family and through religious faith in their current situation. Interestingly, the stroke survivors communicated an intense concern for caregiver burden. Bays cautioned nurses to provide ongoing assessment regarding the delicate balance between connectedness of the caregiver-care-recipient dyad and the caregiver's experience of burden. This finding is important for wives caregiving for husbands with dementia where the care recipient is often unaware of the caregiver's experience of burden. Nurses must consider the wife's experience and develop strategies with her to help her maintain a balance between caring for her partner and experiencing relief from the caregiving experience.

In Bays' study (2001), faith was identified as a major theme of hope. Faith was perceived as an inner strength when the participants described hope within the context of being connected with God. Bays did not interpret the same meaning for family connectedness. Perhaps the opportunity for mutual connectedness with their partner in the present did not require the same level of personal reflection integral to connecting with a higher power. Interestingly, in the present study, wives connecting with their husbands with AD derived strength and internal support in the caregiving relationship by reflecting on the past marital relationship. The wives compensated for their husbands' inability to contribute to the emotional relationship by reflecting to a time when their husbands were cognitively able to offer support and strength.

Letvak's (1997) phenomenological study is a third example of nursing research exploring the concept of connection. Letvak inquired into the relational
experiences of rural elderly women living alone. The women were found to describe themselves within the context of their relationships with other people. The women with good relationships talked about the strong bond they had with their children. Disconnection emerged as an important factor in the women's experience of dissatisfaction with their lives, rather than the frequency of contact with family. Letvak found that part of the women's experience supported the work of Miller (1988) who described disconnection as an adult's experience of a lack of mutually responsive and mutually enhancing relationships. In the context of wives caregiving for husbands with AD, disconnection may account for part of the dissatisfaction some of the wives experienced in their marriage relationship and consequently in caregiving. At the same time, the wives describing good prior relationships derived internal support by connecting with their husbands with AD. The husbands with AD did not overtly reciprocate expressions of closeness, but the wives' memory of closeness in the past marriage experience filled that void in the present caregiving experience.

A final example of nursing research is Herth's (1993) examination of hope in frail older adults. Herth described interconnectedness with self, others, nature, and/or the world as one of eight hope-fostering strategies for frail older adults residing in the community and long-term care settings. Interconnectedness was the meaningful link between themselves and others that fostered hope. The meaningful link or interconnectedness was represented by the establishment of a caring reciprocal relationship. The frail older adults' opportunity to share a part of their lives involved the formation of a real sense of connection with others. Herth
explains that “older adults need to feel that they are in a real relationship – one where they give as well as receive.” (p. 153). The wife caregivers in the present study did experience a connection with their partners, despite their partners’ inability to reciprocate or “give and receive”. It is important that nurses explore the reciprocal nature of relationships and define what it truly means when considering various contexts such as caregiving and the family. Herth suggests that nurses in the community and acute care settings have a responsibility in fostering caring reciprocal relationships and the experience of hope with frail older adults. Swift (1994) extends Herth’s (1993) suggestion that nurses connect with patients to foster a meaningful and reciprocal relationship by conceptualizing caring as the action by which nurses can connect with their patients. The present study found that several wife caregivers fostered meaning in the marital-caregiving experience by integrating opportunities for the dyad to connect as a couple into the tasks they performed as wife caregivers for their memory-impaired husbands.

In their discussion, Haase et al (1992) establish that the concept of connectedness requires further clarification to unveil the extent of its meaning within nursing research and practice. For example, a prevalent finding within the reviewed literature was the reciprocal nature of connectedness. The findings of this study suggest that the experience of connectedness can occur in a relationship that is not currently reciprocal in nature but founded on a history of relationship reciprocity, such as the caregiver’s experience connecting with her husband with AD based on her relationship memories.
Haase and colleagues (1992) present a very important and interesting understanding of connectedness and relationships. The authors understood connectedness to be more than a person's link to social support. Rather, the experience of connecting could come from within where we draw support from the rich experiences we share with others or one's inner self. The present study affirms this conceptualization of connectedness, in that the wives were able to turn within themselves, access the past marriage experience, and draw support and strength in the caregiving role.

In sum, the interpretation of the present study suggests that wives who attempt to connect with their husbands as marital partners describe better adjustment to the caregiving role. By virtue of their memories, wives can instill a greater sense of meaning in their caregiving experience by connecting with their husbands as marital partners. Research oriented toward understanding the concept of connection is devoid within the AD caregiving literature. The findings of this study offer an understanding of connection from the description of the wives caregiving experience. The wives describing a positive marital experience commented on their ability to connect with their husbands in marriage through their pre-illness marriage experience. For these wives, the caregiving experience remained challenging but still yielded reward and gratification. In contrast, wives who described a negative marriage experience and a husband with a difficult character were unable to connect with a past that offered support in the caregiving experience. For example, one wife did not recognize her marriage relationship as a source of support because she did not perceive her marriage
relationship as a source of support in the past. Because the sample of wives describing negative marriage relationships was small, this finding is limited to their particular experience and merits further exploration. The importance of connecting with the past in the spousal caregiving-care-receiving relationship warrants further investigation directed toward understanding the outcome(s) of being invested in the marriage relationship when the partner can no longer reciprocate.

Accessing the Past Marital Relationship

There is a growing body of research exploring the influence of the pre-illness marital relationship within the caregiving experience. To date, few researchers have reported on the pre-illness relationship in relation to the support it can offer caregivers. This study found that most of the wife caregivers describing positive marital histories acquired personal support from their appraisal of that past.

The wife's interpretation of her husband's behaviour and the meaning she assigned to it and her understanding of their marital interactions were components of the pre-illness marriage relationship that influenced (1) the wife's desire to sustain the marriage relationship within caregiving and (2) the wife's ability to turn to her past relationship for motivational support. The latter finding recognizes the interpersonal support needs of the caregiver and supports Robinson's (1990) research, which identifies the pre-illness relationship to be a predictor of the wife caregiver’s experience of subjective burden. The results of Robinson’s study indicate that wives who report better adjustment in their past
marriage experience lower subjective burden, desire less support, and require less direct guidance in caregiving. In light of these findings, Robinson posited that close marital relationships might offer the caregiver a form of "intimate support" (p. 199). The findings of the present study affirms Robinson's claim. Similarly, Morgan and Laing (1991) found that the quality of the previous spousal relationship determined the caregiver's ability to cope with the caregiving experience within the first six months of the initial diagnosis of AD. In their study, the grief experienced by spouse caregivers mourning the loss of a close and loving relationship transcended the challenges of caregiving. For these caregivers "a close prior relationship meant that caregiving was performed with less anger, resentment and ambivalence" (p. 384). In addition, the caregivers experienced more gratification in the caregiving role than those caregivers who experienced marriages characterized by conflict.

The present study found that the pre-illness relationship was a mechanism by which the caregiver could access personal support from her memory of the past to pursue the caregiving role. This finding is congruent with Strang and Haughey's (1998) study of family caregiving that uncovered a link between the nature of the pre-illness marital relationship and the family caregiver's ability to "get out of the caregiver world" to experience respite (p. 231). The authors found that marriages based on a history of "mutual respect for the individual identity of the other" facilitated the caregiver's ability to consider his/her own needs without feeling guilty and resenting the care receiver (p. 238). In sum, the present study compliments the work of Strang and Haughey in that the wife caregivers...
describing a positive marriage experience drew support from the pre-illness relationship in making decisions about their personal needs and the physical and emotional needs of their spouse with AD.

There exists research designed to understand the motivation behind a caregivers’ commitment to continue caregiving despite the challenges associated with the disease process (Morgan & Laing, 1991; Motenko, 1989). This study describes the pre-illness marital relationship as one area that can offer wives support. The wives characterizing their marriage history as positive also communicated an ability to draw motivational support from the past to pursue the caregiver role. In contrast, the wives who interpreted their past marital relationship as negative also indicated that the act of reflecting on their marriage relationship and their husbands’ behaviour fostered resentment of the caregiving role and reinforced the “pain” they experienced in their marriage. These wives perceived that caregiving and their husbands’ disease process hindered the opportunity for marital reconciliation at this point in their lives. Furthermore, one wife’s narrative described an unwillingness to accept the past and reconcile her resentment because the marriage experience was just too distressing. Similarly, Strang and Haughey (1998) found that conflicted pre-illness marital relationships lead to the wives’ inability to forget past insults and assume the caregiving role wholeheartedly. In sum, this study found that wives with positive marriage histories perceived the pre-illness relationship to be a source of support.

Guided by the resiliency model of family stress, adjustment, and adaptation, Kramer (1993a) conceptualized the quality of the prior relationship as
a vulnerability factor affecting the wife caregiver’s personal and family resources. For the wives in the present study, the pre-illness relationship could be identified as both a vulnerability factor, in accordance with Kramer’s conceptualization of the pre-illness relationship, and a personal resource. The wives, who characterized their marriages as a positive experience, viewed the pre-illness relationship as offering support in the role of wife caregiver. However, wives reporting conflicted pre-illness marital relationships described negative caregiving experiences. In this situation, the pre-illness relationship could be perceived as a vulnerability factor influencing the caregiver’s ability to obtain support. Kramer’s study linked the pre-illness marital relationship to negative caregiver health outcomes, decreased caregiver satisfaction, and a lower quality of life. In the current study, the wife caregivers reporting positive marital histories identified that the relationship they nurtured with their spouses offered support in the caregiving role. Therefore, this finding proposes that the memory of the prior marital relationship could be considered as both a personal or internal resource for wife caregivers’ describing positive marriage experiences and a vulnerability factor for wife caregivers’ describing negative marriage experiences.

Kramer’s (1993a) interpretation of the pre-illness relationship as a vulnerability factor is based on a family stress model. However, later, in her discussion, Kramer contemplates the importance of the pre-illness relationship and the caregiver’s base of support. The present study suggests that the pre-illness marriage relationship can be interpreted as a factor in the wife caregiver’s base of support. The wives were found to access the past for strength and
support by drawing on their memory of the marriage relationship. The findings of this study also support Cartwright et al.'s (1994) work involving enrichment interventions as a method by which meaning can be instilled into the caregiver’s experience. Enrichment is defined as “the process of endowing caregiving with meaning or pleasure for both caregiver and care recipient” (p. 32).

In the present study, when wives incorporated dancing, music, gardening and other meaningful activities shared in the past into the care they provided to their husbands with AD, they derived meaning from the caregiver role while soothing agitation and other challenging behaviour experienced by the care recipient. Enrichment interventions are one mechanism by which the wife can bring meaning to the marriage relationship within the caregiving experience. In sum, describing aspects of caregiving that identify the role as meaningful to the caregiver offer health care professionals a much different approach to support the needs of the caregiver than that described within the current caregiving research orientation of burden and stress.

As noted above, the pre-illness marital relationship may be a personal resource for wife caregivers. This is of particular importance given Thompson and Pitts' (1992) comment that perceiving the spouse as one’s confidant becomes difficult when the partner receiving care can no longer fulfill that role. In addition, Wright (1993) found that previous relationships often become strained, depleting the caregiver's social support network. Both authors ascertain that wife caregivers' are often required to cope with the demands of caregiving on their own. The current findings affirm those presented above regarding the wife's
experience of the loss of personal and social support. However, the wives’ narratives revealed that the pre-illness relationship, perceived within a positive frame, could become an internal resource for the caregivers in their role. When wives perceived their past as a source of personal support, the pre-illness marital relationship could be identified as a factor sustaining their caregiving experience.

In addition, Tower and Kasl’s (1996) findings also imply that there may be negative mental health consequences when older adult wives identify their husbands as confidants and a source of emotional support. In the present study, the wives perceiving their husbands as a confidant and a source of emotional support yielded support from the marital-caregiving relationship. Although the qualitative study did not actively investigate possible levels of depression experienced by the wives, many wives described that on an emotional level they had "good days and bad days" and "ups and downs". The wives, who accessed support from the pre-illness marital relationship, conveyed feeling less troubled by the caregiving role than wives who could not turn to the past for support. For these wives, being able to draw support from the past placed them in a better position to provide care for their husband than the wives relating negative marital histories and resentment in their current experience. The findings of the current study do not dispute that a loss of confidant within the marriage relationship and a lack of confidant outside of the marriage relationship can have negative implications for the wife caregiver.

Thompson and Pitts (1992) and Wright (1993) report that caregivers lose social support from their spouses because they are no longer able to reciprocate
by way of purposeful interactions. Yet, the wives in the present study acquired personal and motivational support by focusing on how their husbands contributed meaning to their lives in the past and by fostering a sense of closeness with their husbands in the present.

The findings of this study show that wives with positive marital histories can turn to the past for support in the present, and places the caregiving experience within the context of the marriage. The positive caregiving outcomes derived by the wife caregivers who acquire support from the past marriage experience affirm Cartwright et al’s claim that enrichment interventions can help caregivers find meaning in their experience.

The present study also supports that caregiving can occur within a historical context. A positive pre-illness relationship can offer a rewarding caregiving experience, especially when coupled with the wife’s interpretation of caregiving as a natural progression of the marriage relationship. However, the need for research exploring the influence of the multiple roles of the pre-illness relationship to caregiving outcomes is important in the continuing effort to understand the wife caregiver’s experience. This sentiment is echoed by Horowitz & Shindelman (1983) who found that the affective relationship was important in bringing the emotional relationship closer in family caregiving. The authors recommend that when caregivers try to maintain bonds of affection, health care professionals should support them because of the opportunity for a more meaningful experience that can bring closeness to the caregiving relationship.
Nursing Practice

It is important that nurses in all practice contexts consider the influence of family relationships in family caregiving. Consideration of contextual factors like the caregiver and care-receiver's pre-illness relationship during assessment of the family's needs is crucial to the health of both the spouse caregiver and care-receiver. Nurses should not assume that the presence of the patient's spouse automatically identifies the spouse as the most appropriate informal caregiver. The influence of the nature and quality of the dyad's relationship in the past and present contexts should be a priority assessment for nurses before discharging a patient into the care of that family member. It is also important for community health nurses to consider the family's relationship history when planning for the family's needs within the home. The same advisory can be extended to all health practitioners who encounter families, often in crisis, to offer assistance in arranging for the patient's care at home. Caufield, Moye and Travis (1999) recently provided the same cautionary note to mental health professionals.

People with dementia and AD often enter the acute care system for treatment of co-existing illnesses or for an emergency admission when the caregiver is no longer able to cope with the member at home. In this situation, it is important that acute care nurses and community health care nurses effectively communicate to ease the patient and caregiver's transition from the hospital back to the home. In this regard, discharge planning should begin immediately upon the patient's admission so that appropriate resources are in place before the patient returns home. Considering the current workload of the acute care nurse,
clinical resource nurses and case managers are regaining popularity on medical units and they can be utilized as a support in planning discharge. In addition, a focus on discharge planning from the beginning will allow the nurses in both health care delivery settings to communicate any developments regarding the patients psychosocial or physical care or relay important information regarding the caregiver and care-receiver that transpired during hospital admission in a timely manner.

Families are often ill-prepared to assume the in-home care of a member with dementia or AD in terms of coping with the patient's behaviour changes, providing physical care, preparing a safe environment for the patient, and knowing who to access in the community for caregiving support. The family or spouse caregiver requires a comprehensive discharge plan that includes education regarding the disease and resources in the community. The caregiver should also be able to negotiate a course of action when a crisis occurs or when the family's needs change. Anticipatory preparation of this nature can prevent unnecessary hospital admissions. Family caregivers require support for the specialized care they provide to their family member within the home. As health care professionals, we must shift our thinking and recognize the home as the health care delivery setting for the person with dementia.

Knowledge of the family's relationship is a key element in determining the family's care options. Nurses can help caregivers by exploring all of the available care options for their member with AD. When pre-illness relationships were highly conflicted, it is reasonable to offer nursing home placement as an option
that might best meet the care needs of the person with AD and their family. In the present study, wives who were not invested in the marriage relationship expressed higher levels of emotional difficulty in the caregiving role and a lack of emotional investment in the caregiving role. This lack of emotional investment was based on marital relationship history. Nurses have a counseling role or a responsibility to help arrange for related professional counseling for the caregiver who may benefit from sessions geared toward overcoming past grievances that will help her provide good care to her family member.

In the present study, when caregiving was perceived by wives as a natural progression of the marriage experience, the past relationship tended to be characterized as positive. In this situation, nurses may consider discussing the value of enrichment interventions in bringing meaning to the caregiving role. Enrichment is described in Cartwright et al’s (1994) research study as “the process of endowing caregiving with meaning or pleasure for both caregiver and care recipient” (p. 32). In the present study, hugging and dancing could be perceived as enrichment interventions. Hugging was a method of expressing affection in the past and dancing was an activity shared by the couple in the pre-illness relationship. These interventions were particularly effective in bringing meaning to the wife caregivers who communicated good pre-illness marriages but tended to focus on the losses associated with both their husbands' cognitive decline and their full-time caregiving role.

For wives describing a negative pre-illness relationship, considering the caregiving experience as a natural extension of their marriage hindered the
caregiving experience. Though more research in needed, one may question the therapeutic value of enrichment interventions for caregivers expressing negative past experiences. Although enrichment is an excellent way to provide meaning and satisfaction within a caregiving relationship, nurses must assess the wife’s interpretation and understanding of her past marital relationship before encouraging her to connect with her husband by implementing interventions that are based on positive moments and experiences shared by the couple in the past. In the current study, the wives who expressed conflicted marital relationships did not describe positive marital relationship moments in the past from which they could draw support in the caregiving role.

In the present study, the wives’ were also the experts on their husbands’ care needs within the home. Because wives do express a commitment to caring for their husbands with AD, the nurse can best serve the wives’ needs by offering them a supportive presence. Wives require support in caring for their partners. Nurses can support wives by offering a therapeutic environment in which information is provided so that wives make their own decisions based on knowledge. Nurses can also validate the caregiver in her ability to make good decisions regarding her husband’s care. Determining a plan of care with the wife may increase the likelihood of meeting her expressed needs. This is clearly important, as many services available to caregivers today are not effective in meeting their support needs.

In the same way that many of the wives were able to see glimpses of their husbands’ “true” nature, we, as professional caregivers, must also see past the
patient's illness and connect with the patient's past to enhance our own experience in caring for those who are cognitively impaired. When nurses are driven to provide holistic care, their patient's past becomes increasingly important. When a cognitively impaired patient's behaviour is perceived as a threat to the nurse's physical and emotional well-being, knowledge of the patient's past character can help the nurse retain compassion and a willingness to provide care. For example, sharing the cognitively impaired person's past character with the community(ies) in which the person is a member can foster social and family connectedness. This intervention might be most effective in the earlier phases of the disease process for the patient to benefit as much as possible from the experience; however, the nurse can determine appropriateness of the intervention at any point in the disease process by assessing the patient's level of interaction. Families and nursing staff can collaborate to foster a sense of connectedness between themselves and the person for whom they provide care. For example, staff and families can plan a specific day in which the patients with dementia are celebrated for who they will always be in the minds of their families. This would foster connectedness between staff, patients and families, bringing meaning and pleasure in their caregiving.

In addition, this experience would be a very effective way to validate wives in deciding to schedule respite for their own personal support needs or in placing their husbands in the long-term care of professional caregivers. It is important for caregivers that their family members also benefit from the respite experience (Perry & Bontinen, 2001). Enrichment interventions can provide an opportunity
for nurses to refresh themselves and sustain their caring efforts when providing care to patients who are no longer able to interact. It is current thinking that nurses who derive meaning from their work may experience a lower risk of burnout and are less likely to convey a sense of purposelessness in describing the value of their caregiving. Sharing the person with dementia with the community can offer family and staff the opportunity to connect with the patient and may also offer a meaningful experience for the person with dementia.

**Nursing Education**

The findings of the present wife-caregiver study stress the importance of understanding the family relationship. The present study also highlights the importance of family nursing curriculum in undergraduate nursing education. Teaching nurses to identify family concepts and recognize the influence of relationships is important in developing their understanding regarding the family experience in various contexts.

In light of the nursing shortage, baccalaureate nursing education has become increasingly important, as new graduates assume complex roles before they have had the time to gain confidence in practice. Nurse educators are already challenged with the task of presenting a very large curriculum within a condensed period of four years. In addition, students choosing nursing as a second degree can often complete the program in less than half that time. Still, students must be prepared to enter the workforce with an introductory understanding of the importance of the family in nursing. A detailed understanding of family concepts, such as the pre-illness relationship in wife
Caregiving, may be more effectively presented in graduate level advanced practice education where the student's expressed population of interest is the older adult. Furthermore, it is important that nurses practicing in all contexts begin to consider gerontological nursing as a specialty and that more educational institutions offer specialized programs to increase access for nurses interested in understanding the older adult population. Additionally, health care institutions must begin to recognize the nurses in specialized programs that receive less attention, like gerontology, and compensate the practicing nurses for their efforts according to the same standards set for nurses in other specialty programs.

There are several specialty programs offered to nursing employees of acute care institutions in an academic setting at the expense of the institution. Although long-term care nurses are described as valued members within the institutional setting, the same opportunity for expert training is not offered to employees with an expressed interest in the older adult. This attitude diminishes the value of the nurse and of the older adult patient.

When offering an educational experience to nurses interested in providing care to older adults, it is important to teach nurses how to encourage meaningful interactions between the caregiver and the care recipient. Nurses must demonstrate awareness of the complexities of caregiving and respect that communicating about the past relationship can be an emotionally sensitive and deeply private topic of discussion for the caregiver. One approach to teaching nursing students how to communicate with wife caregivers regarding their past is through a combined effort of nurses in education and practice. Nurses must be
able to ask appropriate questions regarding the wife caregiver's marriage experience to avoid inadvertently contributing to her experience of resentment in caregiving. Teaching nurses how to help wife caregivers connect with their husbands by mapping their memories can encourage the wife's ability to access personal support in the role of wife caregiver.

Nursing Research

The interpretation of the wives' narratives in the present study identifies the pre-illness marital relationship as an important factor influencing the wife's experience caregiving for her husband with AD. Although the strategies that nurses incorporate into the care they provide family caregivers are intended to offer support, wives still have difficulty acquiring an experience of relief from caregiving.

The current study offers a very important understanding of the wife's caregiving experience by looking at her pre-illness relationship. The wife's ability to access personal support from her past marital relationship is a considerable finding. However, there is a need for further research designed to understand the potential link between the nature of the pre-illness marital relationship and the wife's ability to acquire personal support from the past before firm conclusions can be drawn. A related point is that nursing requires a solid and representative understanding of what forms the pre-illness relationship. The wives in the current study defined their pre-illness marital relationship according to their appraisal of their husbands' past character and their marital interactions. In order to develop our understanding of what forms the pre-illness relationship, many questions
need to be answered. How would another researcher perceive the influence of the pre-illness relationship for wives? What other factors form the wives' understanding of their marriage experience, and how do those factors impact their caregiving experience? Do those factors hinder or sustain the caregiving experience? Do wives, caregiving for husbands with AD, conceptualize the influence of their marriage experience in the same way across cultural, socio-economical and educational backgrounds? Answering the aforementioned questions using qualitative methodology would help clarify the importance of the pre-illness marital relationship. Quantitative measurements of the pre-illness marital relationship are designed to understand the marriage experience as good or bad, happy or unhappy and positive or negative. These measures provide excellent introductory information regarding the wife’s perspective of her marriage experience, however, a qualitative interpretive approach is necessary to venture beyond a surface-level understanding and uncover the meaning behind the wife caregiver’s rating of her marriage experience.

Relationship oriented research is necessary to guide service delivery, as caregiver service support needs can be based on relationship history. Researchers must direct their family caregiving inquiries toward understanding the historical and contextual components of the experience so that health care professionals can tailor a support program specific to the caregiver's needs. For example, a caregiver’s individualized support program might include both the nurse sharing strategies to sustain a meaningful relationship with the person with AD, and providing education regarding community service organizations that
offer various respite options. For a caregiver unable to overcome a negative past relationship with the care recipient, exploring alternative options to caregiving such as nursing home placement may be the most appropriate and supportive action the nurse can provide the family.

There is a small body of research studies, reviews and anecdotal literature highlighting the importance of including assessment data regarding the quality of the patient’s or client’s marital history for health practitioners (Cauffield, Moye & Travis, 1999; Edward et al, 1998; Keady, 1996; Kuhlman et al, 1991). However, the reports generally do not outline how to approach patients and clients to collect information on such a complex topic involving family relationship history. For example, Edwards, Nazroo and Brown (1998) investigated marital support, onset of depression, and gender following a shared and threatening life event in married couples. However, they did not include any comment regarding the significance of their findings for health care practitioners. Caregiving research directed toward uncovering appropriate assessment and intervention strategies is essential for nurses to effectively support family caregivers in the community. Cauffield et al’s (1999) clinical application article is an example of research informing practice. The authors note that a multidisciplinary team approach is important when asking elderly clients or patients to talk about their marital history, and that a psychologist may be more skilled in broaching an area that has potential for conflict. In sum, researchers must consider the marriage relationship as a factor influencing the family caregiver’s experience, and
appreciate that relationship-focused research is an important new direction for understanding family caregiving.

The present study explored the wife caregiver's appraisal of her pre-illness marital relationship as a factor influencing her caregiving experience. Understanding the caregiver's perspective regarding her effort to foster marital interaction in caregiving was a considerable finding. In addition to the nurse providing interventions to benefit the marital dyad, it would also be helpful to understand the care receiver's perspective regarding his or her appraisal of the marriage experience. This would provide an additional understanding of the effect of interventions aimed toward bringing meaning to the caregiving experience. Accessing the care receiver's perspective regarding the marriage experience through qualitative interview may be possible. In addition, obtaining the care recipient's reaction to enrichment interventions by way of participant observation would bring about understanding of their experience. For example, a researcher can train registered nurses working in long-term care facilities to collect information during an intervention designed to foster a caring and meaningful relationship with the care recipient.

In order to develop our understanding of the wife caregiver's decision making process regarding the placement of her spouse with AD into long-term care, research designed to explore the possible association between the pre-illness marital relationship and institutionalization of the care receiving partner is necessary. Answering this question was beyond the scope of this study. However, the wives describing positive marital histories were clear on their
personal commitment to caring for their partner with AD, whereas the wives describing a negative marital experience were providing care out of obligation. These wives might benefit from an exploration of options with a nurse who can remain unbiased and non-judgmental when the caregiver shares a lack of desire to care for her spouse.

Summary

The experience of caregiving needs to be explored as caregivers continue to suffer from strain and health care professionals search for options to help ease the relentless struggle that accompanies the caregiving role. It is clear that caregiving is a difficult role to undertake, however, this on its own does not necessarily intend that researchers focus on the negative outcomes of caregiving when conducting their studies. Searching for the positive outcomes of the caregiving experience and focusing on the caregiver and the care receiver's strengths and coping abilities impart an invaluable understanding of the potential of the caregiving experience. Often, studies dilute the positive contributions and powerful influence of the pre-illness marital relationship.

The current qualitative inquiry provides significant contributions to the family caregiving literature by offering an understanding of the influence of the marriage relationship from the perspective of wives caregiving for husbands with AD. The present research shows that wives' caregiving for husbands with AD pursue the caregiving role within the context of the pre-illness marital relationship. This study reveals that the nature of the pre-illness marital relationship for wives caregiving for husbands with AD is formed by the wives'
interpretation of their husbands' behaviour and the meaning they assigned to it and their understanding of their interactions as a married couple. The nature of the pre-illness marital relationship influences the wives' ability to (1) access internal support from the marriage experience, and (2) preserve a sense of couplehood within the caregiving experience. The present research also identifies the concept of connection as an important experience within the marital-caregiving relationship. Connection is important, first, because connecting with the person describes the process by which wives enact their desire to preserve a sense of couplehood. Second, the marital connection appears to be the wives' link to internal support from the past marital relationship experience. Connecting with the past is one way that wives can enrich their caregiver-care-receiver relationship and experience gratification from the wife-caregiver role.

Clearly, wife caregivers experience a number of challenges in providing continued care to their husbands with AD. What they seek are ways to deal with their husbands' behaviour and the care they provide at a point where their internal resources are taxed and no longer effective while caring for their loved one. An understanding of the dynamics of the family relationship, in terms of the interactions between the caregiver and care receiver, is essential for the nurse to understand the caregiver's concerns and to identify with the caregiver interventions designed to help achieve gratification and reward in the caregiving experience. The wife caregiver can benefit from the nurse's encouragement
regarding the expression of affection within the caregiving relationship with her husband to help foster the caregiver's experience of emotional closeness.
References


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Appendix A: Consent for Primary and Secondary Studies
TELLING THE CAREGIVER STORY: AN EXPLORATORY INTERVENTION STUDY OF WOMEN WHO TAKE CARE OF SPOUSES WITH ALZHEIMER’S DISEASE

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Purpose and Benefits

The purpose of this study is to describe the experience of caregiving, as well as to describe how talking about the experience can be used to help make daily caregiving easier. The anticipated benefits to those who participate include: increased understanding and insight into the experience, a plan of care for the spouse with AD that combines family knowledge and nursing knowledge. The results of the study will be placed in the University of Washington Library, and will be published in national journals. The information will be used to help nurses and other health care professionals learn to assist others in similar situations.

Procedures

Participation in this study involves four interviews. At least three of these interviews will be conducted in your home, or a place that is convenient for you. One of the interviews can be conducted either over the phone, or in person. The first interview will last approximately two hours. I will ask you to tell me in your own words all about what caregiving is like for you. This will include questions about how your husband is different and how he is the same despite his illness. For example, some wives say that their husband even looks different, because his facial expression has changed, while other women report that their husband still has many of his same mannerisms, even though his Alzheimer’s disease is advanced. This will take an hour or an hour and a half. I will also ask you to complete a questionnaire that asks specific questions about your relationship before the illness began, your beliefs about caregiving and your own level of wellness. It takes approximately twenty or thirty minutes to complete the questionnaires. Our second interview will be seven to ten days later and take approximately 45 minutes. At this time you and I will organize a plan of care, based on all the things we talked about at the first interview. Sometimes talking about the way that the person with Alzheimer’s used to be can be raise ideas about ways to approach care. The third interview will be a time to check in to see if the plan is making things any easier, or if we need to try something different. This may take anywhere from 15 to 45 minutes. The fourth interview will be six weeks later, and will take one hour. At this time I will ask you to describe what caregiving is like now, and what you think has happened over the time we have been meeting. I will ask you to complete the questionnaires regarding your relationship before the illness.
began, your beliefs about caregiving and your own level of wellness for a second time. You may refuse to answer any question, at any time during any interview. All the interviews, including the phone call will be tape recorded, so that I can pay attention to what you are saying, rather than writing down your responses. All the tapes will be destroyed after they have been transcribed. The transcribed data, free from any identifying information, will be kept indefinitely.

Risk, Stress or Discomfort

The risk involved in participating in this study relates to your experience of distressing emotions when talking about someone who is important to you. I will be sensitive to this during the interviews, and not probe into any area that you indicate you do not wish to discuss.

Other Information

All the information you provide will be confidential, and seen only by my faculty advisors and myself. The only exception would be incidents of elder abuse that you might report and risks of imminent harm to others or to yourself. The only place that your name will appear is on this consent form, and on a code list that will be on file in my computer. The consent form will be filed separately from your responses. The code list will be destroyed when the research is completed, but the interview data and the questionnaire data will be kept indefinitely. You may refuse to participate or withdraw from the study at any time without penalty or loss of benefits to which you or your husband are otherwise entitled.

_________________________  __________________________
Signature of Investigator     Date

PARTICIPANT’S STATEMENT

The study described above has been explained to me. I voluntarily consent to participate. I have had an opportunity to ask questions. I understand that future questions I may have about the research or about my rights as a subject will be answered by Ms. Perry.

_________________________  __________________________
Signature of Participant     Date

Copies to: Study participant and investigator’s file