CAREGIVER'S EXPERIENCE: PAIN AND ELDERS WITH ALZHEIMER'S

By

Mary J. Waldo

A Dissertation

Presented to

Oregon Health Sciences University

School of Nursing

in partial fulfillment

of the requirements for the degree of

Doctor of Philosophy

October 14, 1996

APPROVED:

[redacted]

Jane Marie Kirschling, RN, DNS, Associate Dean for Graduate Studies
Co-Research Advisor

[redacted]

Beverly Hoeffer, RN, DNSc, FAAN, Professor, School of Nursing
Co-Research Advisor

[redacted]

Sheila Kodadek, RN, PhD, Associate Professor, School of Nursing
Committee Member

Marilee Donovan, RN, PhD, Clinical Specialist, Kaiser Sunnyside Hospital
Committee Member

[redacted]

Kathleen Potempa, RN, DNSc, FAAN, School of Nursing
Dean

Acknowledgment of Financial Support

Alzheimer's Disease Center NIA Grant P30 AG08017

Alzheimer's Research Alliance of Oregon 1995 - 1996

NIH, National Institute of Nursing Research, NRSA, 1F31 NR07040-01A1.
April 1995 - October 1996

Acknowledgments

I would like to express my heartfelt gratitude to those who patiently supported and encouraged me throughout this process.

Dissertation Committee
Jane M. Kirschling, RN, DNS, Co-Chair
Beverly Hoeffer, RN, DNSc, Co-Chair
Sheila Kodadek, RN, PhD
Marilee Donovan, RN, PhD

Oregon Health Sciences University
Patricia Archbold, RN, DNSc
Barbara Stewart, RN, PhD
Dana Tasson, MD
Faculty and Student, Gerontology Research Seminar, School of Nursing
Office of Research Development and Utilization, School of Nursing

Clinicians and Participants
Gordon Campbell, RN, NNP
Berta Derman
Joyce Lear, RN
Aging and Alzheimer's Disease Clinic, OHSU
Dementia Clinic, Veteran's Administration
Lake Oswego Senior Center
Family Caregivers and Care Receivers

Faculty, Staff, & Students, School of Nursing, University of Portland

And most of all to my family. Thanks for believing in me and supporting me every step of the way.
Bruce Waldo
Matt Waldo
Tom Waldo
Warren Waldo

ABSTRACT

Title: Caregiver's Experience: Pain and Elders with Alzheimer's

Author: Mary Waldo

Approved:____
Jane Marie Kirschling, DNS, Associate Dean for Graduate Studies

Chronic pain is a significant problem for many elders with chronic illnesses. The actual prevalence of chronic pain in elders, and in elders with Alzheimer's Disease (AD), is unknown. Further there is a paucity of literature that addresses the experiences of chronic pain in persons with AD and no studies that address the experiences of family caregivers managing the chronic pain of AD elders.

This descriptive study used intensive interviewing and qualitative analysis to describe the experience of 13 family caregivers (mean age: 67.85 years; 84.6% female; 69% wives) managing the chronic pain of elderly persons with AD (mean age: 73.9 years; 76.9% male; 69.2% husbands; 69.2% with arthritis). The major finding of this study was that the experiences of caring for a family member with AD was of paramount importance to caregivers and the experience of the family member's pain became embedded within and overshadowed by the experience of AD. Thus the presence of pain in the care receiver was often not identified or investigated. The paramount concerns typically centered around four areas: behavioral and physical changes of the care receiver, emotional response to caregiving, restriction and isolation, and planning for the future.

Family caregivers developed the knowledge that the elder with AD was experiencing chronic pain in concert with a general understanding of AD and the stages of AD. Pain assessment strategies developed by the family caregiver included listening for verbal complaints, use of probing questions, and behavioral observation. Family caregivers had identified pain cues that indicated when the elder is having pain. This knowledge evolved over many years and was the result of a long-enduring relationship. The stage of AD the care receiver was experiencing influenced which assessment technique was most appropriate. However, pain intervention strategies used throughout the course of AD by family caregivers did not change as the AD progressed. The interventions used by the caregivers were those that they had experience with rather than those that might be effective for the care receiver.

Table of Contents

List of Tables

CHAPTER 1

Introduction

> "Our Alzheimer's patients don't experience pain, but we can talk anyway." (A health care professional's reply when asked how caregivers managed the pain of elderly care receivers with Alzheimer's Disease.)

Chronic pain is a significant problem for many elders with chronic illnesses. The actual prevalence of chronic pain in elders, and in elders with Alzheimer's Disease (AD), is unknown. Further, there is a paucity of literature that addresses the experiences of chronic pain in persons with AD, and no studies that address the experiences of family caregivers managing the chronic pain of AD elders.

Almost 2.4 million persons are afflicted with AD (Beck, Heacock, Rapp, & Shue, 1993). The care of the majority of these elders with AD is provided at home by at least one family member (Rabins, Mace, & Lucas, 1982). Thus, the family is instrumental in maintaining AD elders in the community (Light & Lebowitz, 1989). Caregiving literature has also reported that family caregivers of elders with AD experience many detrimental effects from caregiving (Light & Lebowitz), including increased stress and burden (George & Gwyther, 1986). Little is known, however, about the experiences of a caregiver caring for elders with AD and chronic pain. An understanding of these experiences is required before intervention strategies can be designed to enhance family caregivers' ability to manage chronic pain in elders with AD.

The pain literature does address the effects of chronic pain in adults on their significant others (Block, 1981; Flor, Turk, & Scholz, 1987; Maruta, Osborne, Swanson,

& Halling, 1981; Shanfield, Heiman, Cope, & Jones, 1979). The majority of these studies address the needs of an adult population able to participate actively in the assessment and management of their pain. However, family caregivers and health care professionals cannot rely solely on similar self-reports from elders with AD because of their cognitive deficits.

It was not the purpose of this study to develop a definition of pain appropriate for elders with AD nor to determine if elders with AD were physically capable of experiencing pain. Based on personal clinical experience, this researcher believes that elders with AD do experience pain. This researcher also believes that this pain must be assessed and managed as would the pain in any other population. The overall purpose of this study was to identify, describe, and analyze the experiences of family caregivers managing the chronic pain of elders with AD. This was the first study in a program of research designed to enhance caregiving to older persons with AD through development of assessment and intervention strategies to improve chronic pain management in elders with AD. The specific aims were to:

1. describe how a caregiver develops the knowledge that the elder with AD is experiencing chronic pain,

2. identify intervention strategies used by family caregivers in managing the chronic pain of elders with AD, and

3. analyze how the trajectory of these strategies changed as the status of the care receiver changed over time.

Background

Pain is a phenomenon that has long interested researchers. The literature addressing pain has focused on many aspects, including: (a) the effect of pain on the experiencing person (Cohen-Mansfield & Marx, 1993; Ferrell, Ferrell, Ahn, & Tran, 1994; Kerns, & Turk, 1984); (b) the effects of pain on family members or caregivers (Block & Boyer, 1984; Ferrell, Grant, Chan, Ahn, & Ferrell, 1995; Flor, Turk, & Rudy, 1989; Snelling, 1990); (c) the experience or perception of pain based on age (Ferrell, Ferrell, & Osterweil, 1990; Ferrell, Rhiner, Cohen & Grant, 1991; Gibson, Katz, Corran, Farrell, & Helme, 1994; Harkins & Chapman, 1976; Sorkin, Rudy, Hanlon, Turk, & Stieg, 1990); (d) the experience of pain based on acute and chronic medical conditions (Acute Pain Management Guideline Panel, 1992; Jacox et al., 1994); and (e) pain in children (Eland, 1990; Engel, 1991; Grootenhuis, van der Wel, de Graaf-Nijkerk, & Last, 1996; Schechter, 1995; Villarruel & Denyes, 1991). Of all the published studies on pain, fewer than 1% address pain in elders (Melding, 1991). McCaffery and Beebe (1989) anticipate that the growth of literature on pain in elders will mirror the recent growth of literature addressing pain in children. Selected literature on pain in children can be applied to elders with AD experiencing chronic pain. For example, the ability of children to give accurate self-report of pain is questionable because of their limited cognitive and verbal abilities (Villarruel & Denyes). When the ability to self-report pain is limited or impaired, other relevant data sources must be used. It has been suggested that parents can provide information about their children's pain when the ability to self-report is not present (Eland; Engel).

This study drew from the literature regarding the use of someone other than the person in pain to interpret the experience of pain in persons with AD. Although one could question the use of others for reporting pain, previous work with cancer patients and family caregivers has explored the accuracy of caregivers' assessment of pain in others. Family caregivers of cancer patients either matched the patient's estimates of pain (O'Brien & Francis, 1988) or rated the care receiver's pain significantly higher than the patients rated their own pain (Ferrell, Ferrell, Rhiner, & Grant, 1991; Yeager, Miaskowski, Dibble, & Wallhagen, 1995).

Several studies have attempted to identify the prevalence of pain in specific populations. In long term care populations, studies have indicated the incidence of pain may be as high as 39% to 83% (Ferrell, Ferrell, & Rivera, 1995; Morley, Kraenzie, Bible, & Bundren, 1995; Roy & Thomas, 1986; Wagner, et al., 1996). Ferrell and colleagues indicated that over 70% of elderly long term care residents (37% with some cognitive impairment) reported the presence of pain; approximately one third of these patients were in constant pain (Ferrell et al., 1990). Estimates of the prevalence of pain range from 25% to 70% in community-based elders (Ferrell & Ferrell, 1990; Roy & Thomas, 1987). Crook, Rideout, and Browne (1984) report a 100% increase in the incidence of persistent pain in community informants over age 60 when compared with informants under age 60. They also found that persistent pain (pain that is often troubling to an individual) increased with age, affecting 40% of participants over age 80.

Despite the general information on pain in community-based and institutionalized elders, the actual prevalence of pain in the elderly population as a whole is unknown

(Ferrell et al., 1990). Furthermore, the prevalence of pain in the AD population has yet to be explored.

CHAPTER 2

Review of Literature

General Overview

The most common form of the irreversible dementing illness, Alzheimer's Disease (AD) (Beck et al., 1993), affects approximately 60% of the 4 million persons diagnosed with dementia (Kuhlman, Wilson, Hutchinson, & Wallhagen, 1991). AD is a leading cause of total disability and death for adult Americans (Kuhlman et al.).

The presence of agitation in demented elders is a significant problem for caregivers (Cohen-Mansfield, 1986; Cohen-Mansfield, Marx, & Rosenthal, 1990). Cohen-Mansfield and colleagues (1990) maintain that agitation is manifested by a wide range of inappropriate behaviors (verbal, vocal, or motor) that are not caused by the presence of needs or confusion. They suggest that agitation may result from pain in more cognitively intact elders or may signal cognitive deterioration. A foster caregiver interviewed in the pilot study supported this contention by saying, "I first have to decide if the agitation in my AD residents is because their cognitive status is changing. Once that possibility has been ruled out, my next step is to decide if they're in pain. Sometimes it's very difficult to decide what's causing the agitation."

It is difficult for nurses, as well as other formal and informal caregivers, to determine the cause of agitated behaviors in elders with AD (e.g., pain, declining cognitive status). Family caregivers of elders with AD have had to struggle with the elder's behavior 24 hours a day, 7 days a week. They have had to learn, often times by trial and error, how to manage effectively the elder's pain (Stewart, Archbold, Harvath, &

Nkongho, 1993). This qualitative study was needed so that nurses could gain a better understanding of family caregivers' experiences in caring for elderly persons with AD in chronic pain.

Despite the growing attention given to pain, minimal work has been done with chronic pain in elders with AD and no research was found related to family caregiving for persons with AD and chronic pain. Given this lack of research, a qualitative study was warranted in order to gain a comprehensive picture of the experiences of family caregivers caring for elders with AD and chronic pain. Although no research was found on this topic, the literature was reviewed in related areas to inform the study. The following areas are covered in more detail: (a) the presence of chronic pain in elders, (b) chronic pain in the cognitively impaired, (c) effects of care receiver's pain on family caregivers, and (d) family caregivers of elders with AD experiencing chronic pain.

It is interesting to note that while the review of literature included a 20 year time span conducted through CINAHL, Medline and by hand searches, studies focusing on spouses' response to chronic pain were conducted primarily in the late 1970s to early 1980s. Studies which address pain in demented elders are much more recent chronologically. Appendix A provides a summary of 14 key articles which address the above related areas.

The Presence of Chronic Pain in Elders

Several misconceptions about elders and pain are commonly held by health care professionals (McCaffery & Beebe, 1989). These misconceptions include: pain is a normal part of growing old; pain perceptions decrease with age; lack of pain behaviors indicate lack of, or limited, pain; and, when a known cause for pain is absent, the pain is caused by depression. It has been shown that pain is not a natural outcome of the aging process; the presence of pain in elders necessitates assessment and treatment. Harkins and colleagues (Harkins & Chapman, 1976; Harkins, Price, & Martelli, 1986) did not find significant age-related differences in sensitivity to pain. Sorkin et al. (1990) found no significant differences between young (under age 35) and old (over age 65) chronic pain patients in measures of self-reported activity and in measures of how pain influences their lives. Ferrell et al. (1990) suggest that a lack of pain behaviors does not necessarily indicate a lack of pain, but rather a hesitancy on the part of elders to report pain symptoms. In the case of persons with AD, the ability to self-report may be absent due to their level of impairment.

The literature supports the association of chronic pain in elders with depression (Cohen-Mansfield & Marx, 1993; Parmelee, Katz, & Lawton, 1991), increased health care utilization, malnutrition, sleep disturbances, cognitive dysfunction, decreased socialization, and falls resulting from impaired ambulation and gait disturbances (Ferrell & Ferrell, 1990; Ferrell et al., 1990). Moss, Lawton, and Glicksman (1991) interviewed the closest available person, usually kin, of 200 deceased elders. Using these retrospective reports, they concluded that when illness is associated with pain some aspects of psychological well-being suffer more than others. For example, at 3 months prior to death, pain contributed significantly to depression and decreased happiness of the elder.

Chronic Pain in the Cognitively Impaired

Although we do not know the prevalence of chronic pain in elders with AD, there is no reason to believe that they experience less chronic pain than cognitively intact elders. Few studies were found that addressed chronic pain in elders with AD. Parmelee, Smith, and Katz (1993) used a cross-sectional correlational study design to examine the association between self-reported pain and cognitive impairment. The predominantly female (70%) sample included 758 institutionalized elders (30% urban nursing home, 70% congregate apartments) with a mean age of 83 years. The cognitive status of the participants ranged from no impairment to marked impairment. Physicians or physician assistants rated the participants' health. Other measures included self-reports of pain intensity, number of localized pain complaints, and disability in performance of activities of daily living. These researchers found that pain complaints tend to decrease with increasing cognitive impairment and that cognitive impairment interferes with chronic pain self-reporting. A negative association was present between cognitive impairment and reported pain intensity and number of complaints (after controlling for effects of physical health and functional disability). However, for acute or serious problems such as cardiac or gastrointestinal disorders, no differences were found in the reporting patterns of pain in severely impaired individuals as compared to the mildly impaired or intact participants. These findings argue for focusing this study on chronic rather than acute pain in AD elders.

Parmelee et al. (1993) also assert that "(1) in comparison with cognitively intact persons, impaired individuals are almost equally able to accurately report pain, and (2) their complaints tend to be genuine" (p. 522). Ferrell, Ferrell et al. (1995) support Parmelee and colleagues (1993) findings by reporting that pain assessment in the cognitively impaired nursing home patient is possible by using or modifying existing pain assessment scales to compensate for individual disabilities. The resulting self-ratings of pain are seen to be both reliable and valid.

Even though the pain reports of cognitively impaired elders are usually reliable and valid, it is not known if their pain recall is as reliable (Ferrell, 1995). This indicates that cognitively impaired elders may require more frequent pain assessments than do elders who are cognitively intact.

Since cognitive deficits are correlated with lower reported chronic pain, health care professionals need to consider non-verbal indices of pain to ensure that pain and its causes are identified among AD elders. This is consistent with the work of Hurley and colleagues (Hurley, Volicer, Hanrahan, Houde, & Volicer, 1992), who developed a 9-item behavioral indicator discomfort scale for use with patients with advanced dementia. Care providers rate the person with AD on the presence of: noisy breathing; negative vocalization; content, sad, and frightened facial expression; frown; relaxed and tense body language; and fidgeting. This qualitative study, which builds on the work of Parmelee et al. (1993) and Hurley et al. describes the clues that lead a caregiver to conclude that the elder with AD is experiencing pain. An understanding of these family caregivers' perceptions is essential given that the majority of care for persons with AD occurs in the home.

Effects of Care Receiver's Pain on Family Caregivers

Family members describe an intense physical and psychological burden that results from caring for a cognitively intact person in pain (Ferrell, Taylor, Grant, Fowler, & Corbisiero, 1993). Pain and comfort of family members are frequently identified as a concern of family caregivers (Ferrell, Rhiner, et al, 1991; Ferrell, Taylor, et al., 1993 ; Hinds, 1985; Stetz, 1987). Family caregivers of chronic pain patients report feelings of helplessness (Stetz) and uncertainty when attempting to manage pain of care receivers (Rowat & Knafl, 1985).

Four major themes have been identified regarding family descriptions of pain. These themes are: anatomical descriptions, hidden pain (caregivers perceived the patient as hiding or minimizing pain), family fear and suffering, and overwhelming and/or unendurable pain (Ferrell, Rhiner, et al., 1991). Ferrell, Cohen, Rhiner, and Rozek (1991) found that significant role functions related to pain management exist for family caregivers of persons with cancer. Frustration related to being ineffectual in providing pain relief was apparent, as was the satisfaction derived from successful pain management; caregiving that surrounds the administration of pharmacological and non pharmacological pain interventions is both frustrating and fulfilling. In addition, Ferrell, Rhiner, et al. identified three themes related to the family experience of pain. These themes were identified from responses to the question, "What is it like for you having someone you love with pain?" The themes identified were: helplessness, coping by denying feelings, and a wish for the care receiver's death. Although focused on persons who were cognitively intact and on persons with cancer, the results of these studies speak to the need for interventions to support family caregivers in managing the chronic pain of elders with AD.

Ferrell and colleagues (Ferrell, Cohen, et al., 1991; Ferrell, Rhiner, et al., 1991) developed a preliminary model that demonstrated the caregiver experience of cancer pain in cognitively intact persons. Family caregivers are thought to be influenced by previous pain experiences, cultural influences, relationship to the care receiver, and the meaning of and understanding of pain (Ferrell, Cohen, et al.). This pain experience may then result in caregiver suffering, burden, and emotional responses. Although this model has contributed greatly to the understanding of family caregivers' experiences with pain, the focus of this model has been specific to persons with cancer and may not address the wide range of situations in which caregivers are involved.

This study expanded on the work of Ferrell and colleagues by the extension of research to family caregivers of persons with AD. Family caregivers were asked to identify intervention strategies that they used to manage the chronic pain of AD elders. This knowledge will contribute to nurses' understanding of managing pain in elders with AD.

Family Caregivers of Elders with AD Experiencing Chronic Pain

Limited research was found that specifically focused on the experiences of family caregivers caring for AD elders with chronic pain. However, caregiving literature on AD does inform the study. The first symptom of cognitive impairment noticed by family members is often an increase in difficulty in performing everyday functional activities (Chenoweth & Spencer, 1986). Loss of functional abilities results in increased familial responsibility for the patient's safety and well-being. Functional limitations and cognitive impairments of elderly care receivers prescribe what type and how many caregiving tasks are required by family caregivers (Given & Given, 1991; Neary, 1993; Silliman & Sternberg, 1988). The behavioral and personality problems that often accompany cognitive deterioration contribute to caregiver stress (Anthony-Bergstone, Zarit, & Gatz, 1988; Mort, Gaspar, Pulscher, & Laird, 1993; Zarit, Orr, & Zarit, 1985). Caring for a person with dementia may demand less physical exertion than caring for a person with physical impairments (Mort et al.; Neary). However, the care receiver with dementia may require more supervision resulting in loss of sleep and companionship for the caregiver. This literature demonstrates the difficulties that are inherent when caring for persons with dementia. These difficulties are most likely magnified by the presence of chronic pain.

"Listening to the family is the beginning of any pain management phase" (Caserta, 1989, p. 3). Flor, Turk, and Rudy (1987) also assert that the family should be included in the assessment and treatment of pain patients. In cases of persons with AD, the family is the key component of pain management. Including the family of persons with AD is crucial in order to get a more complete picture of the pain experience. Herr and Mobily (1991) assert that significant others can identify behaviors or changes in function in elderly persons with AD that can then be used as pain indicators. Marzinski (1991) supports this contention in her study of 26 patients on an AD unit. The staff of this unit were able to assess pain behaviors in residents by recognizing verbal and nonverbal clues, and then arranging these cues into a meaningful pattern (Marzinski). The staff knew their patients and quickly acted upon any deviation from normal behavior. Herr and

Mobily's and Marzinski's writings support using others, such as family caregivers, to report on chronic pain in the elder with AD.

Summary

The review of literature supports the need for a qualitative study. Although the literature indicates the detrimental effects of chronic pain on family members and of dementia in family members on caregivers, literature describing the experiences of family caregivers caring for elders with AD who are at a high risk for chronic pain is absent. Nursing research in this area is needed to enhance nurses' understanding of intervention strategies for elders with AD in chronic pain. In addition, research is needed to develop nursing interventions that enhance family caregivers' pain management abilities, thereby decreasing caregiver burden and enhancing the caregiving situation for persons with AD. The National Institute of Nursing Research (NINR) in a 1994 publication on symptom management with acute pain (NINR, 1994), recommended that research was needed on cognitively impaired elderly to identify behavioral indices of their pain. Furthermore, research was needed with family caregivers in order to learn more about their attitudes and knowledge about pain and how these influence pain management (NINR). This study addressed NINR's recommendations.

Descriptions of assessment and intervention strategies for AD elders with chronic pain have implications for policy and program planning. These implications were addressed by the Agency for Health Care Policy and Research (AHCPR) when acute and cancer pain were selected as clinical problems that required practice guidelines (Acute Pain Management Guideline Panel, 1992; Jacox et al., 1994). The AHCPR guidelines address numerous barriers to effective management of cancer pain (Jacox et al.). These barriers include problems related to health care professionals (e.g., inadequate knowledge of pain management and poor assessment of pain), patients (e.g., reluctance to report pain or to take pain medications), and the health care system (e.g., problems of availability of treatment or access to it and low priority given to cancer pain treatment). As the number of family caregivers providing care to AD elders increases, strategies that enhance the caregiving situation will be of great value to caregivers and care receivers. Nurses can play a critical role in establishing partnerships with family caregivers of elders with AD in order to decrease costs, overcome existing barriers, improve care receiver comfort and enhance the caregiving situation by effectively managing chronic pain (Harvath et al., 1994).

CHAPTER 3

Research Design and Methods

This descriptive study used intensive interviewing and qualitative analysis to describe the experience of family caregivers responsible for pain management of elderly persons with AD. Qualitative methodology is not restricted by predetermined lines of inquiry (Patton, 1990), thus it allowed for an in-depth examination of the experiences of family caregivers in caring for elderly persons with AD and chronic pain. Descriptive/exploratory research, the first mode of qualitative inquiry, was used to provide detailed descriptions of the circumstances surrounding the lives of these family caregivers (Artinian, 1988). Intensive interviewing, a qualitative data-gathering technique, was used to determine what is meaningful to family caregivers caring for AD elders with chronic pain. The detailed material resulting from the interviews with family caregivers was used in qualitative analysis.

Intensive Interviews

The goal of intensive interviewing, also known as unstructured interviewing or in-depth interviewing (Lofland & Lofland, 1984; Taylor & Bogdan, 1984), is to 'discover' detailed information about the informant's experiences surrounding a topic or situation (e.g., the experiences of caring for an elderly person with AD and chronic pain) (Lofland & Lofland). In intensive interviewing, the interviewer is the research tool (Taylor & Bogdan). The interviewer begins a conversation with "a real person and engages the interviewee as human being, not a study subject" (Kaufman, 1994, p. 123). Taylor and Bogdan have identified several drawbacks to interviewing. These include incongruities between what the informant says and does in interviews and across different situations, and inaccurate assumptions and misconceptions that occur due to the researcher not being aware of the context in which the informant's language and experiences are based. Because of these drawbacks to interviewing, the importance of intensive interviewing is emphasized. The process of intensive interviewing requires getting to know the family caregivers well enough to understand what they mean, and creating an atmosphere in which they will talk freely about their experiences in managing the chronic pain of an elderly person with AD.

Open-ended interview questions are designed to allow informants to speak freely in their own words about the research topics, problems, or goals the researcher brings to the interview (Kaufman, 1994; Lofland & Lofland, 1984). These questions are assembled in an interview guide that then becomes a check list of topics to be covered rather than a structured set of closed questions. The interview guide for this study was structured to be consistent with the aims of the study (see Appendix B). The guide addressed how a caregiver knew when an elder with AD was experiencing pain and how this knowledge developed over time, what intervention strategies were used by family caregivers in managing the chronic pain of elders with AD, and how intervention strategies used to manage chronic pain changed over time, including what factors influenced this change.

The interview guide allowed the researcher to be flexible in responding to caregiver replies. This format also allowed for data clarification. General questions asking what it is like to be a caregiver for the care receiver were asked first in an attempt to promote the development of researcher-informant rapport. The interview concluded with the questions "If I were to take care of (care receiver) and you taught me about caring for him/her when he/she was in pain, what would you say?", and finally, "What have you gained from being a caregiver for (care receiver)?" These questions were designed in an attempt to end the interview on a positive note with the caregiver reflecting on the positive aspects of being a caregiver.

The interview guide was developed after consideration of personal experiences in caring for persons' with pain. For example, the daughter of an 80-year-old woman with Alzheimer's taught me to question changes in her mother's usual behavior. The daughter had discovered that changes in her mother's behavior, such as increased restlessness and the throwing of objects, often indicated an increase in her mother's arthritic pain. This experience, and others like it, prompted the question "How do you know when (care receiver) is in pain?"

A review of the literature focused on variables influencing the experience of pain also contributed to the development of the interview guide. Ferrell and colleagues' (Ferrell, Cohen, et al., 1991; Ferrell, Rhiner, et al., 1991) preliminary model, depicting the caregiver experience of cancer pain in cognitively intact persons, guided the development of questions like "How did you learn what to do for (care receiver) when he/she is in pain?"

The interview guide was pilot tested with two spouse caregivers. This pilot test highlighted areas that required revision (e.g., caregivers were ready to discuss the care receiver's pain and did not want to discuss their personal previous experiences with pain). The interview guide was revised with the assistance of Dr. Sheila Kodadek, an expert in intensive interviewing. The revised guide was distributed to 10 nurses with community and acute care backgrounds, and to two elderly women for input regarding the language, and the order and clarity of the questions. The interview guide again was revised and tested on two family members of a person with AD who was experiencing chronic pain. The interview guide, and all aspects of this research study, was approved by the Institutional Review Board at Oregon Health Sciences University and the Veteran's Administration Research Services.

Demographic data were gathered to describe the sample. Questions about the duration of AD and pain in the care receiver addressed the aim of describing how the trajectory of the caregiver's pain intervention strategies changed as the status of the care receiver changed over time. Other data, including the relationship of the caregiver to the care receiver, education levels and occupations of both, were asked to further explain how a caregiver developed the ability to determine when the care receiver was in pain.

Sampling Plan

Informants were accessed through the Alzheimer's Disease Center and the Veteran's Administration (VA) Dementia Clinic, both of Portland, Oregon, and through community based referrals (e.g., adult day care and the Alzheimer's Association). Health professionals at the Alzheimer's Disease Center and the VA Dementia Clinic agreed to assist the investigator by arranging access to informants and identifying potential informants with AD and chronic pain or the presence of potentially painful conditions. Purposeful sampling was used to select information-rich cases and to ensure that the sample was representative of family caregivers who provide care to family members with

AD in their home (Patton, 1990).

For the purposes of this study, family caregivers were the primary informants and included adult children or spouses of the care receiver who had been self-identified as the primary caregiver. Elders with AD were identified as those persons over the age of 65 who had a diagnosis of AD. As self-identification of pain was not always possible in these persons, the caregiver confirmed that the care receiver had chronic pain. Chronic pain was defined as pain having a duration greater than 6 months or the presence of a condition that is known to be painful (e.g., degenerative joint disease and osteoarthritis) (Marzinski, 1991). The results of the pilot study refined the process that was used to determine who had AD and chronic pain.

Sample Size and Study Participants

The purpose of this sampling procedure was to obtain as much information as possible about the family caregiver's experiences of pain in the care receiver and the strategies used by family caregivers to manage chronic pain (Lincoln & Guba, 1985). Issues of sample size and use of probability sampling are critical when the purpose of the study is to generalize the findings (Patton, 1990); this is not the purpose of this study. The sample of family caregivers grew as the properties and dimensions of the caregivers' experience emerged. The minimum number of informants, approximately 12, was based on a desire to capture a range of caregiving experiences. Thus, informants included male and female, spousal and adult child, family caregivers, some who were new to the role others who were experienced caregivers, and family caregivers of elders who were early and late in the disease process. Recruitment of informants ended at 13 caregivers, when new information was not being obtained and when the aims of this research were met (see Table 1 for characteristics of the sample).

Table 1
Demographics of Sample

Variable	Caregivers	Care Receivers
Age		
Mean	67.9 years	73.9 years
Gender		
Male	15.4%	76.9%
Female	84.6%	23.1%
Relationship		
Wife	69.2%	15.4%
Husband	15.4%	69.2%
Partner	7.7%	7.7%
Daughter	7.7%	7.7%
Length of Time Providing Care	<8 years	N/A
Education		
High School graduate or below	30.8%	30.8%
Attended College	69.2%	69.2%
Culture/Ethnicity		
Caucasian	92.3%	92.3%
African-American	7.7%	69.2%
Diagnosed Stage of AD (Care Receiver)		
Early		15.4%
Middle		7.7%
Late		23.1%
Unknown		53.8%
Sources of Pain (Care Receiver)*		
Arthritis		69.2%
Rheumatoid Arthritis		15.4%
Shingles		7.6%
Back/chest pain		7.6%
Headache		7.6%
Duration of Pain (Care Receiver)		1 year to "since high school"

* one care receiver reported two sources of pain.

The ages of caregivers ranged from 40 to 81 years; the average age was 67.85 years. There were two male caregivers (15.4%) and 11 female caregivers (84.6%). Nine caregivers (69.2%) were wives, 2 (15.4%) were husbands, 1 was a partner, and 1 was a caregiver (7.7% each). Education of caregivers ranged from 7th grade through achieving a Ph.D.; 69.2% attended college. Twelve caregivers were white (92.3%), 1 caregiver was black (7.7%).

The ages of care receivers ranged from 61 to 87 years, the average age was 73.9 years. Three care receivers were female (23.1%), the remaining 10 were male (76.9%). Twelve care receivers were white (92.3%), 1 was black (7.7%). Education of the care receivers ranged from 4th grade to achievement of enhanced doctoral degrees; 69.2% attended college.

Length of the care receiver's AD ranged from 2 to 10 years; 2 care receivers were in the early stages of AD (15.4%), 1 in the middle stages (7.7%), and 3 in the later stages (23.1%). The stage of AD of the remaining seven care receivers was not known by the caregiver (53.8%). The time since diagnosis of AD ranged from 1 to 9 years. Of the 13 sampled, 10 care receivers had received a diagnosis of probable AD. Two care receivers had a diagnosis of possible AD versus stroke. The diagnosis of the remaining care receiver was less clear. This care receiver may have had haldol or alcohol induced dementia with characteristics of AD. The results discussed in Chapter 4 include the 12 care receivers with a diagnosis of probable or possible AD. The 13th care receiver will be included in the discussion of the results presented in Chapter 5 and used as a comparison case.

Sources of care receiver pain included arthritis (69.2%), rheumatoid arthritis (15.4%), back and chest pain of unknown cause (7.7%), and headache (7.7%). Duration of pain ranged from 1 year to since high school.

Minority and gender representation. Ethnic, racial, socio-economic, educational or religious factors were not used to exclude caregivers or care receivers from this study. In addition, sampling procedures insured that the sample reflected the gender and ethnic diversity of the population seen by both the Alzheimer's Disease Center and the Dementia clinic. In 1993, 869 persons were seen in the two clinics. Ethnic and gender representation of clients were as follows: 63.9% were male and 36.1% female; the mean age of females was 71 years and of males was 70 years; 96.7% of the females were Caucasian and 3.3% were non-Caucasian; and 97.7% of the males were Caucasian and 2.3% were non-Caucasian. Three percent of the females and 55% of the males were seen at the VA Dementia clinic. While the sample included both male and female caregivers, the proportion of female caregivers, 84.6% of the sample, was congruent with the caregiving literature in which females comprise 60% to 80% of the sample (Horowitz, 1985).

Data Collection Procedures

Health care providers identified persons who might fit the inclusion criteria. Caregiver informants were screened to determine if they were the primary family caregiver of a care receiver with AD and chronic pain and were able to speak English. Care receivers were screened to determine if they were over age 65, with a diagnosis of AD, and had experienced chronic pain or a chronic painful condition for 6 months or longer. When potential informants met the initial screening criteria, a telephone call was made to the caregiver by the investigator. During the telephone call, the investigator further explained the study, ascertained the caregiver's willingness to participate in this study, and confirmed that the inclusion criteria had been met. If the informant was willing, an appointment was made for the interview at a time and place which was convenient to the caregiver and which provided some assurance of privacy.

Twenty-six caregiver-care receiver dyads, who potentially met the inclusion criteria, were identified; 19 were from the Alzheimer's Disease Center of Oregon (ADCO), 3 from community-based referrals, and 4 from the VA's Dementia Clinic. Of the 19 caregivers identified initially through ADCO, 15 were called. Saturation of data was reached before the remaining 4 caregivers were contacted. Of the 15 caregivers, 6 were not interviewed; 1 caregiver refused as she had just placed her husband in the nursing home, 1 caregiver was acutely ill, 2 refused due to busyness of schedules, and 2 did not meet the study criteria (1 care receiver was not being cared for at home, and 1 caregiver stated her husband was not experiencing pain).

The 3 community-based referrals were called. Two caregivers declined to participate as their wives were not experiencing pain. Three of the 4 dyads identified through the VA Dementia Clinic were interviewed, the remaining dyad had moved.

Prior to the beginning of the interview, the study was explained to the caregiver. The right of the caregiver to refuse to answer any questions, to stop the interview at any time, or to withdrawal from the study at any time without repercussions was reviewed. In addition, the purpose and goals of the interview were described. The informed consent form (see Appendix C) was reviewed and the caregiver's signature was obtained if he or she agreed to participate in this study.

Risks to informants were minimal and included emotional distress that may have resulted from exploration of the experiences of the caregiver. The investigator observed the caregiver for signs of fatigue or emotional distress and asked the caregiver if he/she wanted to end the interview. Three caregivers exhibited signs of emotional distress. These signs included anger, crying, expressions of hopelessness or helplessness. All 3 caregivers were asked if they wanted to stop the interview, all three declined. The investigator stayed with the caregivers until the caregivers were outwardly calmer and had stated they were okay with the investigator leaving; in one of the three situations a friend came to visit before the investigator left. Two caregivers were called the next day; neither reported adverse effects from the interviews. These occurrences were discussed with faculty advisors within 48 hours; no additional interventions were identified.

In the event the interview was not completed at the end of 90 minutes, the investigator was prepared to ask the caregiver if the interview should be continued or if another appointment to conclude the interview was desired. All interviews were completed within 45 to 90 minutes. At the conclusion of the interview, the investigator went over the purposes of a possible second contact (i.e., clarification of data; exploration of topics brought up by other participants; discussion, explanation, or verification of the conclusions drawn from the data) to be made either by telephone, in person, or by mail.

All interviews were tape recorded. The tape recorded interviews were transcribed and identifying information was removed. Notes were taken during the interview to supplement the recordings. Post-interview summaries were written after the interview was completed. All interviews, transcripts, notes, and analyses were kept strictly confidential and were stored in a locked file cabinet. Only the investigator and dissertation committee members had access to tape recordings and transcripts. All data were assigned code numbers and identified only by code numbers. The audio tapes of the interviews were erased upon completion of this study. The qualitative data management program, Ethnograph, Version 4.0 (Seidel, Friese, & Leonard, 1995), was used to enter and organize the data for analysis.

Method and Structure of Analytic Approach to Data

The goal of data analysis was to develop an understanding of the people being studied (Taylor & Bogdan, 1984). Analysis was an ongoing process and occurred throughout data collection. The dissertation committee actively participated in reviewing the data and the ongoing analysis.

Aim 1 and 2: Analytic Approach. The data were read and reread in an attempt to identify themes and concepts within the data that spoke to the first two aims (Taylor & Bogdan, 1984). A log containing memos was used during this process of discovery to record the development and interpretation of codes, categories, and definitions. All data were coded and sorted into coding categories. A code book containing all codes and accompanying operational definitions was kept. Each piece of data in a category was examined for fit with that category; categories were revised as new relationships or interpretations were discovered, or as new codes and categories were added. Any data remaining after sorting were re-examined.

Aim 3: Analytic Approach. After coded segments were extracted from the data and summarized, the third aim was addressed through a data display. Miles and Huberman (1994) maintain that valid qualitative analysis requires focused displays that permit a viewing of systematically arranged data. This display of data allows for detection of comparisons and differences within and among data sets, the discovery of patterns, themes, and trends, and the direct use of the results thus improving the credibility of conclusions. A time ordered data display matrix (see Appendix D) was used to discover how the trajectory of pain intervention strategies used by the family caregiver changed as the status of the care receiver changed over time. The columns were organized sequentially by progression of AD, the rows were cases in arbitrary order. Examples of pain intervention strategies that occurred in that case at that time period were entered in each cell. The strategies were accompanied by a descriptor indicating the kind of intervention used (e.g., medication, distraction, and physical means). Scanning rows showed the total range of pain intervention strategies used by specific caregivers; scanning columns showed interventions used for different stages of the progression of AD. This analysis relied on retrospective data, a limitation of the study.

Trustworthiness

The four critera for determining trustworthiness of the data, as described by Lincoln and Guba (1985), were met by use of several strategies throughout this study. The criteria of credibility, transferability, dependability, and confirmability were addressed as described below.

Credibility. The interviews were analyzed by the investigator as well as three members of the dissertation committee. All exceptions to the resulting analysis were identified during meetings with the committee members, and were subsequently analyzed. Regular meetings and communication between the investigator and the dissertation committee were used for exploration of emotions and peer debriefing, refinement of research processes, and review of the methodology.

Transferability. Data collected through purposive sampling and intensive interviews provided thick descriptions of the caregiver's experiences in caring for an elderly person with AD experiencing chronic pain. Through the presentation of the findings, readers should be able to decide if the results of this study are applicable to their situation (Lincoln & Guba, 1985).

Caregivers sampled in this study included wives, husbands, a partner and a daughter of elderly family members with AD who were experiencing chronic pain. The sample of caregivers and care receivers was heterogeneous with respect to the stage of AD, understanding of AD, source of pain, and the means used to assess the pain of the care receiver, as well as educational levels and employment backgrounds. Descriptions of the caregiver's experiences from these multiple perspectives enhance the transferability of the data.

Dependability. The research findings are deemed to be dependable if they can be repeated (Lincoln & Guba, 1985). To ensure dependability of the findings, an audit trail was established through maintenance of raw data, data reduction and data reconstruction products, process notes, and instrument development information. An inquiry audit also was conducted by a faculty member with expertise in qualitative methodology.

Confirmability. Confirmability of the data in this study was addressed by peer debriefing with the dissertation committee. This was done to identify investigator biases and analytical weaknesses, to clarify interpretations, and to stimulate thinking.

CHAPTER 4

Results

The overall purpose of this study was to identify, describe, and analyze the experiences of family caregivers managing the chronic pain of elders with AD. The specific aims were to:

1. describe how a family caregiver develops the knowledge that the elder with AD is experiencing chronic pain,

2. identify intervention strategies used by family caregivers in managing the chronic pain of elders with AD, and

3. analyze how the trajectory of these strategies changed as the status of the care receiver changed over time.

Family caregivers have identified pain as being a major concern of caregiving. Ferrell, Cohen, et al. (1991) developed a preliminary model illustrating family caregivers' experience of the cancer pain of cognitively intact care receivers. The pain experience is central to this model. A caregiver's perception of a care receiver's pain is colored by the caregiver's prior pain experience, cultural influences, the caregiver-care receiver relationship, the caregiver's understanding of the pain, and the meaning that the pain had to the caregiver. The pain experience elicits feelings of caregiver burden, suffering and other associated emotions.

The work of Ferrell and her colleagues has contributed greatly to this researcher's understanding of family caregivers' experiences with pain. In addition, Ferrell, Cohen, et al.'s model (1991) was instrumental in the development of the interview guide used in the current study. However, the pain experience of family members of cognitively intact cancer patients appears to be significantly different than the experience of caregivers of elders with AD who also have chronic pain. Ferrell, Cohen, et al.'s caregivers used their family member's cancer pain, and the changing levels of that pain, as an indicator of the extent of the disease; increased pain was linked to the progression of cancer and the eventual death of the care receiver. Caregivers either welcomed the approach of the care receiver's death as an end to pain or avoided the approach of death by questioning the pain that accompanied the progression of cancer. In contrast, the major finding of this study was that the experiences of caring for a family member with AD was of paramount importance to caregivers and the experience of the family member's pain became embedded within and overshadowed by the experience of AD.

This unexpected finding influenced the direction of the study, guided the analysis of the results, and directed the development of this chapter. The remainder of this chapter will be divided into three sections: (a) paramount concerns of family caregivers, (b) how a family caregiver developed the knowledge that the elder with AD was experiencing chronic pain, and (c) pain intervention strategies used by family caregivers. Refer to Table 2 for a summary of caregivers. The names of caregivers have been changed to protect their anonymity.

Table 2

Caregivers , Relationship to Care Receivers, and Stages of AD/Source of Pain

Pseudonym of Caregiver (CG)	Relationship to care receiver (CR)	Stage of AD and source of pain*
Joshua	Husband	Early, arthritis
Ruth	Wife	Early, arthritis
Mary	Partner	Late, arthritis
Eve	Wife	Early, arthritis
Sarah	Wife	Late, arthritis
Rebekah	Wife	unknown, back and chest pain
Naomi	Daughter	Middle, arthritis
Hannah	Wife	Late, arthritis
Martha	Wife	Middle, chronic headaches
Elizabeth	Wife	Late, rheumatoid arthritis
Abraham	Husband	Early, rheumatoid arthritis
Abigail	Wife	Middle AD versus stroke, arthritis
Ester	Wife	Early AD versus stroke, arthritis

* When caregivers did not know the stage of the care receiver's AD, the investigator placed the care receivers into stages based on family caregiver description of the behaviors of the elder. The investigator used Reisberg's Global Deterioration Scale (1984) to place these six care receivers into early, middle, or late stage of AD.

The Paramount Concern: Caregiving for Elders with AD and Chronic Pain

Each family caregiver was contacted by telephone to arrange the interview. They again were called to confirm the appointment the day before or the morning of the interview. With each contact, an explanation of the study was provided by the researcher, including reading and discussion of the consent form which was signed prior to the start of the interview. Even knowing explicitly that the study's focus was on the pain of the care receiver, family caregivers focused on their experiences of caring for a family member with AD.

That the significance of the AD experience to the family caregiver overshadowed concern about the care receiver's pain was apparent from the start of each encounter. During the walk from the front door to the area where the interview would take place, caregivers would start to talk about the diagnosis of AD or behaviors of their family member that were of concern.

The discussion of the caregiver's experiences of caring for a family member with AD continued to take precedence throughout the interview. This was especially clear from the responses to one of the final questions of the interview: If you could teach me something about caring for someone with chronic pain and Alzheimer's, what would you tell me? Caregivers consistently talked about the AD and not about the pain:

> You really have to be very, very patient.... Just somebody had to do it and I knew it had to be me, but it is frustrating at times, and another frustration is you don't always know whether you are reaching the person... It is so easy to overload. I mean, you can't give too many commands or give her too much information, because it just totally overloads the circuits and she becomes totally confused... And it is hard for me because she was probably one of the most gifted people that I have ever known and to see

> that kind of drift away, that is kind of hard...But I think the main thing is you just got to have the gift of the patience of Job. You have got to remember things are not going to be like they used to be. (Abraham)

Probes were used throughout the interview to elicit and clarify information from the family caregivers. It was anticipated that the initial probes, which were general in nature (e.g., "What's a usual day like for you", "What's it like being a caregiver", "Tell me about your family member before the AD started"), would draw out comments about pain, since that was the specified purpose of the study. However, the participants' responses to these probes regarding the caregiving process typically centered around four areas: behavioral and physical changes of the care receiver, emotional response to caregiving, restriction and isolation, and planning for the future. Each of these areas is discussed below.

Physical and Behavioral Changes of the Care Receiver

A major finding of this study was that the behavioral and physical changes of the care receiver which occurred with AD were of great importance to the caregiver. Incontinence was a significant issue for the majority of family caregivers of care receivers in middle or late stage AD. The incontinence had changed how daily activities were planned, interrupted the sleep of the caregiver, and influenced future plans.

> ...And I got him up and in bed and then the next time he had to urinate, why he woke me up. I kind of scolded him and he woke me up and went back and waded through urine in the bathroom, but we have tile linoleum in there and I put old towels down, just in case, and so I found that and that is a lot of extra work, but thank the Lord, it could be worse, it could have come out here in the other room. (Hannah)

The other physical concern that was described by family caregivers was that of falling. One care receiver with middle stage AD already had fallen and suffered a fractured hip. Another care receiver, in the late stage of AD, had fallen three times, escaping injuries other than bruising. This caregiver worried about her husband's next fall:

> I had him for a walk and I took him around the field and walked through the park. He fell in the park and he was real alarmed. I said "Just sit there for a minute, you are not hurt, you are fine. Just sit there for a minute and gather yourself together and I will help you up." And he did. He had this kind of wild look on his face and thought I am down and I will never get up, but I let him sit there. ... but the next time he fell, he had to step down from the kitchen into the garage and it is a cement floor. He fell and was all black and blue, but he didn't complain about that at all and I watched him.... He could stumble and fall anytime. (Hannah)

The majority of family caregivers identified several changes in the care receiver's personality or behavior that had occurred since the onset of the AD. Caregivers reminisced about who the care receiver used to be and compared this image to current behaviors.

> He was a very bright man. He read a lot. Well, when we moved here, we sold 2500 books. He read constantly. He was a newspaper editor, he was (the editor of a news column), very vocal, very interested in politics and it all changed. He will watch the news, once in a while ask a question, but if there is a commercial, he has forgotten what he saw just before, so it is very confusing. (Eve)

Several behavioral changes of the care receivers were described by the family caregivers. The inability of the care receiver to dress appropriately was of concern to many of the caregivers.

> Well, we usually get up about 7:00. I have to help him dress now, because

> he might come out in my clothes. I used to put his undershirt, underwear, top shirt, pants, shoes and socks in front of the bed and he would come out all dressed. Can't do that anymore. He came out with my girdle on the other day because I let him try...I don't let him tie his shoes anymore, because he ties them in such tight knots that I can't get them out. (Hannah)

Other behavioral changes of the care receiver included shadowing of caregivers (i.e., following the family caregiver around the home), and unexpectedly hitting out at or becoming agitated with the caregiver. More than half of the caregivers were concerned about the care receiver wandering off and getting lost.

> I have a caretaker that comes in for three hours one afternoon a week, and while she was here, and she kind of dusts so that he thinks she is the cleaning lady, she went to the bathroom and he disappeared and three hours later he was across the highway at a restaurant calling. I am sure somebody helped him...So I take my bath late at night when he is in bed. (Eve)

Emotional Response to Caregiving

Emotions surrounding their experiences frequently came to the surface as family caregivers recounted the incidents that lead up to the diagnosis of AD or talked about the current caregiving situation. Caregivers described their circumstances as being hectic, frustrating, and lonely. Several caregivers cried openly as they talked; three reported they were being treated for depression. Most stated caregiving was hard and required patience, gentleness, and self-control.

> It (caregiving) is hard, but I know it has to be done, you know? It makes me nervous and it makes me uptight and then there are times, you know, when he almost seems normal. Of course, he don't think there is anything wrong with him... Sometimes it gets really hard... I try to keep control of myself, because I know he is sick. He is not in any right state of mind that he has been. But, it is hard, because you realize you haven't got the person you married. (Ruth)

Family caregivers of elders in early to middle stages of AD also appeared to struggle with restricting activities they thought were no longer appropriate for their care receiver. If the care receiver was still driving, caregivers grappled with knowing when and how to stop their family members from getting behind the wheel of a car. Others were considering the amount of supervision the person with AD required for everyday activities such as walking to town, working outside or going to the store.

> I am really concerned about a lot of the things she wants to do and thinks she can do; I am not sure she should be trying it. But, now she has gone down to (the corner store). I think I might join her. (Joshua)

For most of these caregivers, AD meant change in their long-term relationship. A daughter believed that she and her mother (middle stages AD) had traded places and found herself saying to her mother what her mother used to say to her. Two wives, one caring for a husband with early stage AD and one with late stage AD, talked about how the man they married was not the person they were living with now. Others discussed how their relationship had changed with the progression of AD:

> I don't feel as loving as I would like to be, I mean in hugging, holding, that type of thing, physical... You put up a wall between you and that person, because if you don't you will lose it.....You are not quite sure what you are going to lose, but that strength, that stamina, that whatever it takes for you to be a caregiver may go out the window. (Sarah)

Sense of Isolation and Restriction with Caregiving

Most family caregivers described a sense of isolation and restriction as the AD progressed. In the early stages of AD, the caregiver and care receiver were still able to enjoy their usual activities. As the AD progressed, caregivers reported feeling restricted. The caregiver was uncertain about leaving the elder with AD and the elder also depended on the caregiver for security. As a result, activities family caregivers once did alone were being neglected or performed in the company of the care receiver.

> He is actually fundamentally very good natured and very amenable to what I want to do, but he is constantly there. I can't let him walk alone anymore. I just had surgery on my feet, so I can't walk right now. He walks around the property and I have to stand and watch for him when he goes because he did get lost once... But it is very restricting, because I just can't go anywhere without him. When I go to the store, he goes and sits in the car unless there is something he wants to make sure that I buy...but I guess the thing that is most stressing is the restriction because I used to be able to go out with my daughter. We would be gone all day and I just can't do that anymore. (Abigail)

Family caregivers often reported not only the loss of freedom to leave the home, but the loss of friends that would come into their home. Feelings of isolation were compounded in those who had recently relocated their homes to be closer to families or medical care.

> I think the hardest thing for us to realize when we moved here because we have our two sons here, is that our friends our age don't come to see (my husband). The men who are 80 are a little forgetful. They look at (my husband), visualize themselves that way and are depressed.... We hadn't anticipated that and these are people who love (my husband), but they just can't handle it. (Eve)

Planning for the Future

Family caregivers of elders in all stages of AD were looking toward the future. This planning for the future was not unique to caregivers of elders in a particular stage of AD. Two caregivers were considering renovations to their home that would make it a safer place for the elder with AD (e.g., new locks, new windows, and fewer stairs). A few caregivers had completed the necessary legal arrangements such as power of attorney. Others were considering when they would need help in the home (e.g., when the care receiver became incontinent). Most of the caregivers for the four elders in the late stages of AD had in-home care and had thought about when nursing home placement would be necessary (e.g., when the care receiver became more agitated).

While planning for the future, most caregivers stated they took one day at a time.

> Well, I think the hardest part is, more or less, just worrying day to day... Hoping that he doesn't walk off someday and sometime and get confused and can't find his way home... I hope he doesn't turn violent, that is my biggest concern...Yyou know that is something you don't know. Just have to take each day as it comes and deal with whatever comes up from that day. (Ruth)

After talking about their hardships and concerns, the majority of family caregivers voiced a desire to continue providing the care for their family member and avoid placement in a nursing home. Some of the caregivers felt an obligation to their family member. These caregivers stated their family member was always good to them in the past. Two caregivers said they knew their family member would take care of them if the roles were reversed. Others believed the elderly family member required care and there were no other options to providing that care. A few voiced satisfaction gained from the caregiving role.

> He was always so good to me, willing to do whatever he could.... Well, it is the satisfaction (of caregiving) I think, to me, not so much to him. When I see his response to some of the things I help him with and some of the things he does and everything, it is just that pleasant look on his face and I feel, well, I am doing my share. It's just that's the thank you, because he can't tell you... and we are standing face to face and many times he will reach over and give me a little kiss, not a big smack like he used to... You know when you have deep feelings for somebody and they have been good, you can't be mean to them. You just can't and you know that they don't know, you know, it is hard, but I feel I am strong and I ask the Lord for help every night before I go to bed, keep me healthy so that I can help him, you know, and that is the way it goes. (Hannah)

In summary, the paramount concern of the family caregivers who participated in the study was the care receiver's Alzheimer's Disease (AD) and how it influenced both of their lives. The care receiver's experience of chronic pain was a secondary concern and was not easily brought to the surface during discussion with the caregiver. However, once caregivers voiced their feelings and concerns about the AD, they then were able to focus their thoughts, with direction provided by the interviewer, on the care receiver's pain experience.

> You know he didn't ask for this disease he has got and his own brother died in June and he has Alzheimer's. Just going to have to try to make the best of it I guess.
>
> Investigator: I would like to ask you a few questions about your husband's pain. Now, you said it was his knee. Was there an injury to his knee?
>
> Yah, he said the first injury on his knee when he was in the service. (Ruth)

The remainder of this chapter is organized according to the three aims of the study (see pp. 35 for the aims).

How a Family Caregiver Develops the Knowledge that the Elder with AD is Experiencing Chronic Pain

The ability of the family caregiver to know if the elder with AD was experiencing pain appeared to be related to two areas of caregiver understanding. The first area was the extent of the caregiver's general understanding of AD and stages of AD. The second area focused on how family caregivers assessed the pain of the care receiver. This area included the type of assessment used (verbal complaints, probing questions, and behavioral observation), the caregiver's understanding of both the caregiver and care receiver's past history of pain, and the caregiver and the caregiver - care receiver relationship.

Family Caregiver's General Understanding of Alzheimer's Disease

Caregivers' understanding of AD influenced their ability to link the care receiver's verbal and behavioral indicators to the presence of pain. Within this group of 12 family caregivers there appeared to be three levels of general understanding regarding AD: caregivers with little understanding of AD (5 caregivers), including the 2 caregivers who were caring for an elder with possible AD versus possible stroke; those with moderate understanding (3 caregivers); and those who appeared to have a substantial understanding of AD (4 caregivers). The understanding of AD was defined as the caregiver's general knowledge about the diagnosis, symptoms, course, and stages of the disease, rather than the ability of caregivers to apply the knowledge to specific situations. Table 3 provides a description of the participants according to their general understanding of AD and the stage of the care receiver's AD.

Table 3

Comparison of Caregiver Understanking of AD to the Care Receiver's Stage of AD

	Caregiver Understanding of AD		
	Little	Moderate	Substantial
Stages of AD			
Early Stage	Joshua Ruth Abraham Ester	Eve	
Middle Stage	Abigail		Naomi Martha
Late Stage		Mary Hannah	Sarah Elizabeth

The level of caregiver understanding of AD was based on subjective criteria and was determined by the investigator. The subjective criteria included caregiver appraisal of their own knowledge, caregiver understanding of the basis for the diagnosis of AD, an understanding of the physical and behavioral changes that occur with AD, and an understanding of the care that would be required as the AD progresses.

Little understanding of AD. The caregiver's level of understanding was determined in part by his or her own self-assessment. The investigator ascertained that caregivers had little or no understanding of AD when a definate diagnosis of AD had not been made. In addition, caregivers who did not appear to have an understanding of the physical and behavioral changes that would occur as the care receiver progressed through the disease also were placed in this category. An example of self assessment in a caregiver with little understanding was the caregiver who stated, in answer to the question. “What stage of AD is your wife in?” I really don't know, I don't know that much about the disease, I mean about the prognosis on her. (Joshua)

Moderate understanding of AD. Caregivers who had significant understanding about AD in some areas (e.g., stage, diagnosis, and care required), but had little understanding in other areas (e.g., perceived intentionality of care receiver's behaviors, dependence on on verbal cues with late stage AD elders) were placed in the category of moderate understanding. A caregiver believed her partner, in late stage AD, purposefully didn't swallow when eating. She also focused on the elder's verbal cues to decide how he was feeling. However, the caregiver appeared to understand the diagnosis, staging, and course of AD. This caregiver, and two others, demonstrated a moderate understanding of AD.

> He won't open his mouth for me. Now, he has gotten, for some reason, he refuses to eat for me now. He will eat ice cream for me, but that is all... But, his (aide) cuts it all up in little pieces and kind of gets him to eat it, boy, he just has to coax him to open his mouth for practically every bite. Sometimes he puts it over here and in his cheek and won't swallow it and (the aide) has to push it over and get him to swallow it before he gets another bite. Sometimes I think he is just doing that on purpose. Sometimes I see kind of a little smirk on his face like he is getting away with something. (Mary)

Substantial understanding of AD. Level of understanding also was determined in part by the caregiver is understanding of the course of the AD relative to the level of care that the care receiver required. A wife caregiver had attended several workshops and support groups to find out more about AD. This caregiver, and three others, verbally demonstrated a substantial understanding of AD by her accurate descriptions of what AD is, her understanding of how the AD was diagnosed, what she expected to occur in her husband in relationship to the AD, and the care she is providing now and she expected to have to provide in the future.

> He was diagnosed in December, we got the written diagnosis. I immediately went to the Alzheimer's Association and (his hospital) and they had workshops going... and a support group and anything else I could grab onto that I knew would help me... He was put in the hospital, where I thought, this is my chance. So, we had the cat scans and the EGs and the EKGs and everything else that I could think of done while we were there and ended with the neurologist. (Sarah)

In addition to the caregivers' understanding of AD, their understanding of the staging of AD also influenced their ability to assess and manage the care receiver's pain.

Family Caregiver's Understanding of the Staging of Alzheimer's Disease

An understanding of the staging of AD assisted the caregiver in recognizing what pain cues the care receiver realistically could offer. Of the 12 family caregivers, 6 were aware of the stage of the care receiver's AD as identified by a health care provider. Of the remaining 6, 2 had a diagnosis of possible AD versus stroke; 4 care receivers had a diagnosis of AD, but the caregivers were unaware of the stage of the care receiver's AD. The investigator staged the later 6 care receivers based on a family caregiver description of the behaviors of the elder. The investigator used Reisberg's Global Deterioration Scale (1984) to place these 6 care receivers into early, middle, or late stage of AD.

For the purposes of this study, early stage of AD corresponds to Reisberg's (1984) stages 1, 2, and 3. Clinical characteristics of this stage include forgetting placement of objects, familiar objects or names, short term memory loss, and memory loss which affects social or employment activities. Middle stage of AD corresponds to Reisberg's (1984) stages 4 and 5. Deficits in concentration and knowledge of current events are apparent in this stage. In addition, participants in this stage have difficulty in traveling alone, performing complex tasks, or in appropriately dressing themselves. Stages 6 and 7 of Reisberg's Global Deterioration Scale (1984) coincide with late stage AD for this study. Participants in this stage needed major assistance for their activities of daily living. Verbal abilities are lost and urine incontinence may be occurring. Psychomotor skills such as walking also may be lacking.

Based on caregiver knowledge of the stage of the care receiver's AD and on the staging of AD by the investigator, 5 elders were in the early stages of AD, 3 were in the middle stages of AD, and 4 were in the late stages.

Caregiver understanding of AD and the stage of the care receiver appeared to be related. The majority of caregivers with little understanding of AD were caring for elders in the early stages. A similar number of caregivers with substantial knowledge were caring for elders in middle or late stages of AD. (See Table 3).

In summary, the family caregiver was more accurate in his or her assessment of the care receiver's pain if the method of assessment was appropriate for the stage of AD. Caregivers' understanding of AD also affected their ability to link verbal and behavioral cues to the presence of pain. The cues family caregivers used to assess their care receiver's pain, the caregiver's and care receiver's past history of pain, and the past and current relationship of the caregiver and care receiver will be described below.

Assessment of Pain

Understanding of the stage of AD and the level of general understanding regarding AD appeared to be related to how the caregiver knew the care receiver was having pain. Caregivers demonstrated three methods of assessing the pain of care receivers with AD. The type of pain cues the care receiver provided formed the basis of each method. These methods of assessment were: (a) listening for unsolicited verbal complaints of pain by the care receiver, then interpreting these verbal cues as being meaningful or not; (b) observing behavioral cues that then then interpreted as possibly being pain related, and then asking probing questions of the care receiver to confirm the existence of pain; and (c) looking for and observing behavioral cues that previously had been interpreted as being pain related, and then interpreting those behavioral cues in the absence of verbal confirmation.

Caregivers assessed the presence of pain by listening for verbal complaints of pain from the care receiver. Often these complaints were not solicited by the caregiver, but were made independently by the care receiver. The caregiver would then interpret the complaint of pain as being real or not, and responded accordingly. The caregivers were asked, “How does (the care receiver) act when he or she is having pain or discomfort?”

> No problem, I mean, he will complain about it a little, he will complain about it and take...Now he takes this Ibuprofen and lets it go at that. (Ester)

The use of probing questions occurred when a family caregiver observed behaviors that were thought to be pain related. These caregivers then asked probing questions of the care receiver regarding the presence of pain. These questions included "You look like something hurts. Are you uncomfortable?" The caregivers received a verbal confirmation or denial from the care receiver. The caregivers then compared the observed behavioral cues with the verbal responses of the care receivers.

> It is really hard, like I will see her rubbing her head and I will say "Do you have a headache?" "No"... "Well, why are you rubbing your head?" "Well, it hurts." So, you know, it takes, you have to sort of watch the body language and then keep at it until you find out why they are doing something. (Naomi)

Other caregivers depended on only their observation of behavioral cues to determine if their care receiver was experiencing pain. These behavioral cues were previously identified by the caregiver as being pain related. This assessment was often done in the absence of any verbal cues.

> Right now he is smiling and I guess the reason I tell if he is in pain if he is really just looks despondent or if he takes his arm and tries to hit, I make some kind of conclusion that some of the aggressiveness may be the pain he is feeling. (Elizabeth)

A few caregivers did not use a single method of pain assessment. Instead, these caregivers assessed their care receiver's pain by using a mix of all three methods, often at the same time. They then selected the method that appeared to provide them with the most accurate information at that time. This was done in response to inconsistent cues being provided by the care receiver. The care receiver may have verbally complained of pain but did not present with previously identified behavioral pain cues. Conversely, the care receiver may have exhibited previously identified behavioral pain cues, but denied the presence of pain when questioned by the caregiver. As a result, these caregivers often were not confident in their ability to know when their care receiver was experiencing pain.

> Well, part of the time he laughs when I don't think he is in pain. So, you know, I don't know, he will say, "Well, my knee sure does hurt, my knee sure is bothering me today." Stuff like that, you know. He has got a lot of arthritis in it too. So the only way he is in pain is when he says he is in pain or he will try to straighten his leg out or try to bend it and it will be hurting him, you know and he will laugh and will say it is hurting, you know, and will still laugh... I can tell when he is not in pain, because when he is sitting over there watching television and he is not saying anything and you can tell he is really paying attention to the television, he is not in pain. (Ruth)

Relationship Between Methods of Assessing Pain and Understanding of AD

Table 4 illustrates the relationship between the family caregiver's methods of pain assessment and their understanding of AD. The methods of assessment used by the caregivers to determine the pain of the care receiver with AD appeared to lie on a continuum with verbal complaints at one end, followed by mixing methods of assessment and by use of probing questions, ending with behavioral observations on the opposite end. The stage of AD and the caregiver understanding of AD also fell on a continuum from early to late stage, and from little to substantial understanding of AD. These three continuums appear to be related. As the care receiver became less able to verbally complain of pain, the caregiver's methods of assessing the presence of pain changed from a verbal assessment to a behavioral one. As the caregiver gained in understanding of AD, they were able to determine which pain cues could reasonably be expected depending on the stage of AD their care receiver was experiencing.

Table 4.
Methods of Pain Assessment Compared to Caregiver Understanding of AD and the Care Receiver's Stage of AD

Stage of AD	**Little**	**Moderate**	**Substantial**
Early Stage	Joshua - V Ruth - M Abraham - M Ester - V	Eve - P	
Middle Stage	Abigail - M		Naomi - P Martha - B
Late Stage		Mary - M Hannah - B	Sarah - B Elizabeth - B

Methods of Assessment
V = Verbal complaints
P = Probing questions
B = Behavioral observation
M = Mixed methods of assessment

Verbal complaints and mixed methods of assessment.. All caregivers with little understanding of AD assessed the pain of their care receiver by listening for verbal complaints or by mixing their methods of assessment. The majority of these were caring for elders in the early stage of AD.

> No, I don't think there are (behaviors that are associated with pain), I think she acts pretty much normal with pain. When it is really hurting, why she complains about it. (She says) Oh, I am hurting. Usually what she says is in response to a question that I ask her, "If she is okay?" "If it does hurt?" "How are your Shingles?" Why, she tells me. It is all very reasonable, so I think I take it for what she says... No, no, (nothing that prompts me to ask) just concern on my part. (Joshua)

The following caregiver used mixed assessment methods to assess the care receiver's pain.

> Oh yes, you could tell just by trying to walk, the pained expression on her face, plus verbally she expressed pain, in fact she still does. I mean ...well, now, for instance, if she sits too long, she has to get up and walk a little bit just to kind of shake the hip out and then she will sit back down... Usually I will ask. "How's the hip?" and she will say "Fine", and then if she would sit down here and we would be sitting here for about fifteen minutes, she had to get up three or four times and walk around and kind of...pat the hip, you know, that is the time to go for the pill box. (Abraham)

Probing questions. This method of knowing appeared to be a transitional stage between verbal complaints and behavioral observation. Caregivers of middle and late stage AD utilized this method. In addition, many caregivers who used mixed methods in their pain assessment of elders in early and middle stages of AD often used probing questions.

> I guess just to watch the changes in behavior. That's about the only thing I can do. And I ask him, if he rubs his stomach or something, I say "What is it?" and he starts describing the pain in his side, I took him to see a gastroenterologist and he said it was probably a diverticulitis. And so, other than just questioning him at the time, I don't know what I will do at

> the time when he is not able to tell me. I guess the matter...just as soon as I notice the behavior I will have to take him to see the doctor. (Abigail)

Behavioral observation. The majority of caregivers with substantial knowledge of AD, and a majority of caregivers caring for elders in the late stage of AD used behavioral observation as their primary method of knowing if pain was present.

> Well, I think that I would see it on his face, I think that he might be walking around, he might be following me a lot more. How I discovered his foot was that he was scratching his heel and he took his shoe off and so he was scratching away at it. (Martha)

However, these caregivers also had noted a decline over time in the frequency that care receivers displayed pain behaviors. They wondered if this decline was related to their inability to assess pain because the care receiver could no longer verbally communicate their pain or if the AD decreased the ability of the care receiver to experience pain.

Questioning the Presence or Severity of the Care Receiver's Pain. The majority of caregivers caring for elders in late stage AD questioned if their care receiver was capable of experiencing pain or was experiencing less pain as the AD progressed. These caregivers questioned if the disease progression inhibited the ability of persons to experience pain.

> Yes, we tried different things like Ibuprofen (for his pain), you know different things they had prescribed at (the hospital), but none of it did any good. He was still able to complain at that point. But now, I don't know if it is not hurting anymore, or if he it is just not registering on his brain that he is hurting. I don't know which it is. (Mary)

> It appears to me that he suffers a lot less pain now than when he was not a victim of Alzheimer's, it just appears that way. Now, I don't know if that is because he can't communicate, but you know, he was almost in constant pain before he had Alzheimer's. (Elizabeth)

In summary, there appeared to be a relationship between family caregiver understanding of AD, stage of AD the care receiver was in, and how the family caregiver knew that the elder with AD was experiencing pain. However, the ability of the family caregiver to know when the elder with AD was experiencing pain, and their confidence in the accuracy of that assessment, was also related to the caregiver's understanding of both the caregiver and care receiver's past history of pain, as well as the caregiver and the caregiver - care receiver relationship.

Assessment of Pain: Family Caregiver Understanding of the Care Receiver's History of Pain

The history of the care receiver's pain experience and how the care receiver demonstrated that pain influenced the confidence that the family caregiver had in assessing current pain. Caregiver confidence also was related to the stage of AD. Family caregivers caring for elders in the early stage of AD appeared to be more confident in assessing pain than those caring for elders in the later stages. Several caregivers indicated that the care receiver's past history of pain and demonstration of pain made it difficult for them to know when the care receiver was experiencing pain. One caregiver reported his wife just worked through the pain, that her attitude regarding pain had always been to grin and bear it.

Another caregiver described how her husband had taken care of his pain himself without her help or knowledge. In a third care receiver, pain was used to camouflage other activities such as having a headache when wanting to avoid balancing the checkbook. Other caregivers felt their care receivers in the past had endured their pain without complaining.

> I am not confident (about knowing when he is having discomfort). Because of who he is, he was determined never to complain ... because of his being so stoic when he was in terrible pain, I don't know whether he is keeping that with him now also, you know that same nature of being very quiet about it. (Elizabeth)

Caregivers who found it difficult to know when the care receiver was having pain due to their history and demonstration of pain usually were not confident in their current ability to determine the care receiver's pain. These caregivers voiced doubt regarding their ability to assess pain in their family member with AD. All caregivers who were insecure in their assessment ability cared for elders in the middle or late stages of AD.

> I don't know. I am not sure that I am confident that I am going to discover all of them (behavioral cues to pain). I am going to do the best I can and even if (the doctor) thinks I am a little overprotective I don't care. I mean, when you are a caregiver, you have to do what you have to do. (Martha)

All caregivers caring for elders in the early stages of AD were confident in their ability to know when their family member was experiencing pain regardless of the care receiver's past history and how they demonstrated pain. These caregivers used verbal complaints or verbal responses to questions in assessing the pain of the care receiver.

> (How confident are you in your ability to know when he is having pain?) I think he would say something, because he certainly does know about the pain in that side. He is very open about it. I don't...I think I would know if he had any severe pain. (Abigail)

A few caregivers were fairly confident in their abilities to assess pain; one care receiver was in late stage and one in middle stage AD. Both of these caregivers used random assessment techniques, using both verbal complaints and behavioral observations as indicators of pain. The following caregiver thought he could tell his wife was having pain because her pain behavior (pacing) had not changed over time.

> (How confident are you in your ability to know when your wife is having pain?) Fair. I can tell, I mean, even at night once in a while she will get up. If she gets up in the night and starts to pace, starts to walk a little bit, I know that her pain is bothering her, so we go to the pain killer and it takes about twenty minutes and she is back down and fine. (Abraham)

Assessment of Pain: Family Caregivers Prior Pain Experience

The caregiver's own pain experiences influenced the ability of caregivers to assess pain in cognitively impaired elders. A caregiver, fairly confident in his ability to assess the pain of his wife who was in the middle stages of AD, stated the only pain he had was normal, “growing up” pain. He used a variety of methods to assess his wife's pain. Another caregiver denied ever experiencing pain. This caregiver was not confident in her ability to assess her husband’s pain and questioned if he was experiencing pain during the late stage of AD.

A majority of the family caregivers had experienced acute episodes of pain from surgeries or accidents. The remaining caregivers had and were currently experiencing chronic pain. There were no patterns relating the previous pain experience of the caregiver to their confidence of assessing pain or to how they assessed the pain of their care receiver. However, personal pain experiences have had a few caregivers to believe in and assess the pain of their care receivers. They were able to empathize with their family member and understood why the elder walked or behaved as they did.

> Well, in 1963 I had back surgery, so...when he talks about his back problems, and that is when I say lower back pain, when he comes in holding his back when he has been out raking the yard or pulling weeds, and I have got the sympathy for it all right enough. (Ester)

In other cases the caregiver's history of pain influenced how he or she perceived care receiver's pain. The following caregiver had undergone many surgeries with little remembrance of pain, and she sometimes questioned if her husband was experiencing as much pain as he complained of:

> After my surgery I was in a little pain... I mean it didn't last for no great long time. I did pretty good with all of them... it wasn't like it just hurted for a long time... a lot of times I would be wondering if he was really in pain, but I really believe that he is and I know I have never been in that much pain. You know, I have had kids, but to me that wasn't even that bad. So, I just dealt with it, you know. I don't know. (Rebekah)

There was no clear connection between how the caregiver cared for their children with pain and how they were caring for their elder with pain. This appeared to be due to the differentiation on the caregiver's part between the usual pains associated with growing up (e.g., broken bones, and tonsillectomies) to the pain that occurred with a disease process such as arthritis.

> Pain in the family has always been through athletics and the kids as far as that goes, you know, besides their normal stuff when they are little, you know and athletic pain. (Sarah)

Family caregivers' reactions to their elder's pain were similar in many cases to how they perceived pain while they were growing up. For example, a caregiver remarked that as a child her family didn't talk about pain. However, she was aware that both parents had painful conditions. This caregiver was able to recount a detailed and lengthy history of her parents diagnosis and course, showing insight into the process of AD. However, her remembrances of his pain were superficial, with many gaps. In the past, this caregiver had depended upon verbal complaints of pain to assess the presence and intensity of pain in her partner. At the time of the interview, she used random methods to assess pain, and usually waited for verbal complaints to signify the presence of pain even though the elder was in the late stages of AD and was no longer talking.

Another caregiver recounted how she and her husband, before the AD started, were both determined to not talk about any pain complaints. This occurred after they witnessed the caregiver's mother dealing with her arthritis. This caregiver wondered if her husband did not complain of pain because he was not having any during the late stages of AD, or if he was unable to complain of pain, or if he was just determined not to complain of pain.

> (What did you learn as you were growing up about pain?) I guess the thing that comes to me most about pain and I think one of the things that even influences (my husband) when he got this was my mother... she does have arthritis. She got to the place she had to have a knee replacement and you couldn't be with her 15 minutes before you heard how her knee hurt, her arm hurt and all these physical complaints. Because of these physical complaints, both (husband) and I determined if we had a complaint, we weren't going to talk about it and I noticed the same thing with my sister. (Elizabeth)

In summary, although there were no consistent patterns among the caregivers, in some cases personal pain experiences did influence how the caregivers viewed the pain of their elder. This finding also held true for the caregiver - care receiver relationship and ability of the caregiver to assess the pain of the elder with AD.

Assessment of Pain: Previous and Current Caregiver - Care Receiver Relationship

There did not appear to be a consistent pattern between the closeness of the caregiver - care receiver past and present relationship and the ability of the family caregiver to assess the pain of the elder with AD. Four caregivers had a shorter relationship history with their care receiver than the remaining 11 caregivers. These included a daughter caregiver, a partner of 14 years, a caregiver who was married the second time to the care receiver with a marriage to another person in the gap, and a husband who talked about the two of them leading separate lives. Of these 4 caregivers, 2 were fairly confident in their ability to assess the pain of the elder with AD and 2 were not confident in their ability. The remaining 9 caregivers all reported a close past and present relationship and varied in their report of confidence in assessing the pain of their care receiver.

Although it was not clear that current and past relationships of the caregiver and care receiver influenced how confident family caregivers were in assessing pain or how they assessed the pain of care receivers, family caregivers who reported a long, close history with their care receiver were able to describe in more depth the signs of pain behaviors for which they watched.

> If he walks quite a bit, he does complain...he doesn't complain...he rubs them and he will show me... but he will get up almost every morning and come down the hall, the lower part of his back, both of his hands, rubbing his back. I know that it is what's the matter.. (Elizabeth)

The current relationship also may have influenced the knowledge of the care receiver's pain. One family caregiver had turned over all primary caregiving duties to a paid helper. This family caregiver could not describe behavioral pain indicators in her partner who was in late stage AD. However, the live-in assistant believed he could accurately assess frequent episodes of pain in the care receiver. This assessment was based upon facial signs (grimacing) and body changes (stiffening), as well as occasional moaning on the part of the care receiver.

In conclusion, the ability of the family caregiver to assess the pain of an elderly, cognitively impaired family member appeared to be most closely related to a general understanding of AD and an understanding of the stage of AD. An understanding of the care receiver's past history of pain affected the confidence of family caregivers in accurately assessing the pain of the care receiver. Although the family caregiver's prior pain experiences and the current and past relationship of the caregiver - care receiver in some cases may have been related to reflect how the caregiver knew their family member was in pain, these factors appeared to be of less importance than caregiver understanding of AD.

The third aim of this study (to analyze how the trajectory of these strategies changed as the status of the care receiver changed over time) is included in the next section, which addresses the identification of intervention strategies.

Intervention Strategies used by Family Caregivers in Managing the Chronic Pain of Elders with AD

In contrast to its impact on assessing pain, an understanding of AD and the stage of AD did not seem to modify what pain intervention strategies were used by caregivers.

These family caregivers appeared to utilize several types of intervention strategies in managing the pain of their elder with AD. These strategies included intervention with medication, repositioning the affected area, use of heat, and use of distraction.

Medication was used for pain intervention by almost all family caregivers. Family caregivers of elders in the early stages of AD used either over-the-counter (OTC) medications or no treatment at all. One of these caregivers also used positioning of the painful limb and application of a brace to decrease pain complaints.

> He does have a lot of pain... He will come in and he will sit down over there and he has got to get it in just the right position before it will quit hurting then he will just laugh and he will grit his teeth and he will just laugh and I will say... It seems like when he gets ahold of it and pull it up it relieves the pain... I will say, "Well, pull you knee up." ...He takes two aspirin and one Tylenol four times a day. That is all he takes for pain... He has one of those, just like the football players wear on their knees, those braces, he uses the soft braces... Sometimes he will wear it and sometimes he won't... sometimes he says it helps him and other times he will say this doesn't do a bit of good. (Ruth)

Of the four caregivers of elders in the middle stages of AD, three used a combination of OTC medications and non-pharmacological treatment (heat, distraction, staying close to the care receiver). One of these also administered arthritic medications prescribed by their physician. The remaining caregiver discontinued her husband's

Tylenol because he was no longer exhibiting pain behaviors from his chronic headaches, nor was he exhibiting pain from fractured ribs obtained in a car accident.

> We did put him on Tylenol as the doctor said, so you know when you kick out of Tylenol or any other medicine, sometimes it is a day before the pain really comes back because it is a continuation and I didn't want to keep him on it any longer than we had to, so we went through three episodes of getting off of Tylenol and getting back on, but I think he is over it now. (Martha)

Two caregivers caring for late stage AD elders were using a combination of OTC medications; neither had not used medications for pain prior to this stage. A third caregiver responded to painful behaviors by changing the position of her care receiver. The final caregiver used aspirin and had throughout the course of her husband's AD.

Neither the stage of the care receiver's AD and the level of family caregiver understanding about AD, nor the confidence with which the family caregiver assessed the care receiver's pain appeared to influence which intervention strategies were used. What does appear to influence the intervention strategies was what had been done for the caregiver by others, what the family caregiver had used personally before, or what the care receiver used when they were still self-administering their own pain interventions.

The strategies that family caregivers learned as children or through their own personal experiences were the same strategies that they used with their care receivers. The caregiver who had used very little medication for her pain during her lifetime reported that her husband currently refused any medication for his severe arthritis. A adult daughter remembered her mother going to bed during painful episodes before the AD started. This daughter sent her mother, now in the middle stages of AD, to bed during painful episodes. A wife who received a hot water bottle or menthol salve for her pain during childhood now supplemented her husbands extra-strength Tylenol with hot water bottles and salve, even though she was uncertain if the salve and heat did any good.

Although family caregivers varied in the confidence they felt regarding the assessment of pain, all but two caregivers who attempted to manage the pain of their care receiver were confident that their intervention strategies served to decrease the intensity of the care receiver's pain.

> Fair. I can tell, I mean, even at night once in a while she will get up. If she gets up in the night and starts to pace, starts to walk a little bit, I know that her pain is bothering her, so we go to the pain killer and it takes about twenty minutes and she is back down and fine... It is not as much, oh, what do I want to say antsieness, you know. (Abraham)

One caregiver felt surgery would be the only effective intervention; the other reported her husband had tried several medications for his arthritis and they did not work in the past. This caregiver stated that no medications would help her husband; they used no other intervention strategy for her husband's pain.

Many family caregivers were uncertain of their next step if the current strategies stopped being effective. Five of the 13 caregivers stated if their current treatment for pain did not work, the next step would be to see their health care provider.

> Well, if (caregiver) can't figure it out, I would tell you take him to the doctor. You are trained and I am not, what is going on here? (Martha)

In summary, the family caregivers of this study used a variety of pain intervention strategies to manage the pain in a family member with AD. The intervention strategies were not clearly related to the stage of the care receiver's AD, the level of caregiver understanding about AD, or the confidence in which the caregiver assesses the care receiver's pain. The intervention strategies used were ones with which the family caregivers had experience, either personally or with the care receiver.

Although the majority of family caregivers felt confident about the intervention strategies they used for their care receiver, 2 caregivers caring for elders in the early stages of AD, 2 caring for middle stage AD elders, and 1 caring for a late stage elder reported feelings of discomfort when they knew their family member was experiencing pain.

> (How do you feel when he is in pain) Well, it makes me nervous. I don't want to see him in pain. I just hope his pain don't last very long. (Ruth)
>
> Kind of a helpless feeling... (how do you cope with that?) Give her pills and just sit and wait, you know. (Abraham)

In summary, family caregivers used a variety of interventions to manage the chronic pain of their elder with AD. The stage of the care receiver's AD, the level of family caregiver understanding about AD, and the confidence of the caregiver in accurate pain assessment did not appear to influence the choice of interventions. Caregivers utilized only those pain intervention strategies with which they had previous exposure.

CHAPTER 5

Discussion and Implications

This chapter will present a discussion of the following areas: trustworthiness of the findings, a comparison of findings with previous studies, strengths and limitations of the method, strengths and limitations of the study, implications and recommendations for nursing research and practice, personal reflections, and a summary.

Trustworthiness of the Findings

The overall purpose of this descriptive study was to identify, describe, and analyze the experiences of family caregivers managing the chronic pain of elders with AD. The four criteria for determining trustworthiness of qualitative data, as described by Lincoln and Guba (1985), were met by use of several strategies throughout this study. The criteria of credibility, transferability, dependability, and confirmability were addressed as follows:

All interviews were analyzed by myself and by three members of the dissertation committee. This analysis was an ongoing process and occurred throughout data collection. Initially, the data were read and reread in an attempt to identify a code for each sentence of the interview. As the interviews, analysis and discussion among the four of us continued, these codes became concepts which reflected a more comprehensive understanding of the data in its entirety. The concepts gradually moved into themes, and categories and subsequently were defined. A log containing memos was used during this process of discovery to record the development and interpretation of codes, concepts, categories, and definitions. Each piece of data in a category was examined for fit with the category; categories were revised as new relationships, or interpretations were discovered or new codes and categories were added. Any data remaining after the sorting occurred were re-examined.

After five interviews were completed and initially coded, I identified and defined a list of concepts. These concepts were developed from an understanding of the first five interviews and from the results of Ferrell, Cohen et al.'s study of caregivers and cancer pain patients (1991). This list was used by both Dr. Kodadek and myself to separately re-code the fifth interview; the fifth interview was chosen because I believed the information it contained was comprehensive and reflective of the other interviews. Examination of the re-coding revealed that Dr. Kodadek and I closely agreed on codes and concepts. At this meeting, the category "paramount concerns" was discussed in detail and tentatively defined.

Based on the results of the re-code, the list of concepts was altered; concepts were merged, deleted, or added, and definitions changed as needed. For example, the concept "meaning of care receiver's pain to caregiver" was not supported by the interviews and was deleted. The concept "caregiver's response to care receiver's pain: suffering, emotional, burden" was identified through Ferrell, Cohen, and colleagues (1991) model. These individual responses were not supported by the interviews, and it was changed to "how does the caregiver cope/deal with the care receiver's pain". The same passages in interviews were placed under both the concept "caregiver's awareness of the care receiver's pain" and "caregiver questioning the reality of the care receiver's pain". These were merged into one. New concepts also wereidentified throughout the analysis. These included "relief of pain due to caregiver management, caregiver role in pain management, how the caregiver knew the care receiver was experiencing pain prior to AD, and what was done for the care receiver's pain prior to AD". These concepts were discussed and approved by the dissertation committee and all subsequent interviews were analyzed for fit with or contrast to these concepts.

The results of this study can be transferred to a variety of situations. The sample of caregivers and care receivers was heterogeneous with respect to their relationship, the length of time providing care, the stage of the care receiver's AD, the caregiver's understanding of AD, the care receiver's source of pain, the means used to assess the pain of the care receiver, and the employment backgrounds of both the caregiver and care receiver. The range of educational backgrounds of the caregivers and care receivers was restricted, as the majority had attended college. These multiple perspectives enhance the transferability of the results as does the thick descriptions of the caregiver's experiences in caring for an elderly person with AD experiencing chronic pain.

The maintenance of raw data, the audit trail of data reduction and data reconstruction, process notes, and instrument development information will allow this study to be reproduced and thus is deemed dependable.

The confirmability of the data in this study is less clear. The initial plan was to confirm the results of the study by presenting them to the participating caregivers. After a lapse of an average of 11 months between the initial contact and the present, I called three caregivers to arrange a discussion of the results. These caregivers were chosen because I believed they represented the experiences of the sample of caregivers and they had also expressed interest in the results. One care receiver had died, one care receiver has moved to a long term care facility, and the third final had deteriorated from early stage AD to late stage AD. All three caregivers declined to participate further; As a result, confirmability of this study was addressed through discussion with caregivers other than study participants, who were identified through social contact, and who each had cared for an elderly family member with AD and chronic pain. Although these caregivers confirmed the findings of this study, these discussions were informal and are not reflected in this manuscript.

Confirmability also was addressed through peer debriefing with the dissertation committee. This was done to identify investigator biases and analytical weaknesses, clarify interpretations, and stimulate thinking. For example, a concept I identified and labeled as "inconsistent methods of assessment" was challenged by the dissertation committee. This concept was defined as the caregiver using inconsistent methods of pain assessment due to their lack of understanding and knowledge about the course of AD. Although I tenaciously retained the label through two discussions, the committee requested I take another look and determine if the data actually supported this concept. The data did not. The concept was changed to mixed methods of assessment and reflects the caregiver's ability to respond as needed to varying pain cues offered by the care receiver.

Comparison of Findings to Previous Studies

To the best of my knowledge, there has been no published qualitative study on the experiences of family caregivers managing the chronic pain of elders with AD. As a result, the focus of the comparison of this study to other studies will be based on the following areas: experiences of family caregivers of elders with AD, family caregivers experiences of caring for chronic pain patients, development of caregiver knowledge that the elder with AD is experiencing chronic pain, and intervention strategies used by family caregivers in managing the chronic pain of elders with AD.

Of the 13 participating in this study, 2 care receivers had a diagnosis of possible AD versus stroke. These 2 caregivers will be identified as stroke-related caregivers for the purposes of this discussion. The diagnosis of the remaining care receiver was haldol or alcohol induced dementia with characteristics of AD. This caregiver will be identified as the contrast caregiver for the remainder of this chapter.

Family Caregivers of Elders with AD

The major finding of this study was that the experience of caring for a family member with AD was of greater importance to caregivers than the experience of caring for a family member with AD and chronic pain. The caregivers were concerned about all aspects of the AD experience from the diagnosis to planning for the future.

Several studies have addressed the effect that cognitive impairment in care receivers have on caregivers. For example, Chenoweth and Spencer (1986) described the major problems recounted by family caregivers of elders with AD. These problems included constant supervision, an inability to get away, contributing to feeling isolated, strain on physical or emotional health, wandering and incontinence of care receiver. My findings were similar to the above. The study participants frequently and eloquently described the isolation they felt from family and friends. They no longer were able to leave their home and family, and friends had stopped visiting. However, of the stroke-related caregivers, only one reported feeling isolated (Abigail). This isolation may have been related to the relocation from a supportive community in which she had lived for many years. The contrast caregiver did not identify isolation as being an issue. It was difficult to arrange a time to speak with her due to her many out-of-home commitments.

The majority of caregivers identified incontinence, agitative behaviors, wandering, and falling as being problematic. These caregivers identified many problematic behavioral and physical changes that have occurred in the care receiver. The stroke-related caregivers each identified one change; one identified the change as being problematic. The inability of the care receiver to perform grooming and dressing activities was identified by the contrast caregiver as being a change, but it did not appear to concern her.

Silliman and Sternberg (1988) described the differences in physical demands, time demands, and caregiving burden among caregivers caring for family members with stroke, hip fracture, and dementia. They reported that caregivers of elders with dementia provided less physical assistance, but experienced more demands on their time related to required supervision of their family member than those caring for stroke or hip fracture victims. A higher proportion of caregivers of elders with AD evidenced depression and a bleak outlook for the future. Given and Given (1991) also maintained that caregivers of elders with dementia had their sleep interrupted or decreased, experienced loss of companionship, and performed intense supervisory tasks.

Even though the interview questions for this study were not designed to elicit information about the caregiver's experiences with AD, these participants freely voiced their frustration about the care required and the demands placed on them. The constant supervision required by the care receiver was of concern to many caregivers. The majority of the caregivers in this study reported feelings of depression or were being treated for depression. Some voiced feeling depressed over the future deterioration of their family member and the decisions they would have to make. Again, one of the stroke-related and contrast caregivers reported feelings of depression (Abigail) related to her sense of isolation.

In summary, the related literature supports the findings of this study regarding the detrimental effects of caring for a demented elder on caregivers. This is further supported by the majority of stroke-related and contrast caregivers reporting fewer feelings of isolation, depression and problematic behaviors on the part of the care receiver.

Family Caregiver's Experiences of Caring for Chronic Pain Patients

The chronic pain experience encompasses the entire family, not just the individual who is suffering from the pain. Ahern, Adams, and Follick (1985) described spousal depression and anxiety that were attributed to the chronic pain of their family member. This observation is confirmed by Flor, Turk, and Scholz (1987). Flor et al. reported one-fourth of their sample of 58 spouses and male chronic pain patients showed significant levels of depressed mood. Although the majority of the caregivers in this study reported feelings of depression or were being treated for depression, these feelings of depression were not linked by the caregiver to the presence of the care receiver's pain, but rather to the AD. In this study, questions asking what it is like for the caregiver when the care receiver is experiencing pain elicited emotional responses such as feeling nervous, terrible, frantic, and frustrated. However, these responses appeared to be transient in nature and did not appear to contribute to the caregiver's well being. There were no differences identified in the stroke-related or contrast caregivers.

Ferrell and colleagues have completed several studies which focus on family caregivers of cancer pain patients (Ferrell, Ferrell et al., 1991; Ferrell, Taylor et al., 1993; Ferrell, Rhiner et al., 1991). Ferrell, Johnston-Taylor, Grant, Fowler, and Corbisiera (1993) reported that family caregivers "described the intense physical and psychological burdens of caring for a loved one in pain" (p. 173). Ferrell, Rhiner et al. discovered families of cancer pain patients experience helplessness, and cope by denying feelings and wishing for the care receiver's death. Ferrell, Ferrell et al. maintained that the presence of pain in a family member precipitates physical and psychological disturbances in the caregiver and disrupts normal family relationships.

Physical, psychological, and social disturbances caused by the presence of pain in their care receiver were not described by the caregivers in this study. However, several physical, emotional, and social disturbances caused by the presence of AD were readily identified and described by the caregivers. In addition, strained family relationships were attributed to the presence of AD. These findings reflect the overwhelming effect that AD has on caregivers. These caregivers were attempting to manage the day-to-day problems associated with AD. Often these problems reflected the physical needs (e.g., nutrition, elimination, and rest) and safety needs (e.g., wandering, falling, and agitative behaviors) of the care receiver and caregiver. Because these needs were monumental and immediate, the effect of pain on caregivers was not as apparent. These findings are supported in part by the work of Hinds (1985) and Stetz (1987).

Eighty-three family members of cancer pain patients were interviewed by Hinds (1985) to determine their perceived needs. Many of the participants identified patient suffering, uncertainty about the disease course, and feelings of insecurity about their ability to provide physical care as being psychological stressors. A greater majority of caregivers identified needs associated with the physical care requirements of the care receivers, with understanding of and provision of treatments being a primary concern. Thirty-one percent of these caregivers were found to be coping poorly with respect to physical needs. Although pain and suffering of the care receiver were identified by the caregivers as being of concern, this concern was somewhat overshadowed by the concerns of caring for the disease itself. This is also reflected in Stetz' (1987) work describing nine caregiving demand categories. The predominant caregiving demand was managing the physical care, treatment regimen and imposed changes of the care receiver (e.g., assisting with activities of daily living, coping with the care receiver's physical and emotional changes), which corresponds to the findings in the current study.

In summary, this study neither supports nor refutes the literature's reports of caregiver uncertainty and helplessness in the face of their care receiver's pain. This result may be related to the nature of AD and the overwhelming needs of the care receiver. There were no identified differences between the stroke-related, contrast and AD caregivers.

Development of CG Knowledge that an Elder with AD is Experiencing Pain

Herr and Mobily (1991) recommend that, when assessing pain in cognitively impaired elders, clinicians should make sure that the patient is attentive and understands what is being asked. They advocate the use of non-verbal color tools or an eight-point facial expression scale for use with cognitively impaired elders. These tools have been used successfully with children but have not been evaluated for use with cognitively impaired elders. There is little literature that addresses the assessment of chronic pain in this population. The literature fails to address how family caregivers assess the chronic pain of cognitively impaired elders and how family caregivers learn these assessment techniques.

The caregivers in this study used verbal self-reports of pain, observation followed by probing questions, and behavioral observation to assess the chronic pain of their elderly family member with AD. The literature supports the use of these methods by health care providers when assessing pain in cognitively impaired elders.

Parmelee et al. (1993) used self-reports to assess pain in 758 elderly institutionalized elders with varying degrees of cognitive impairment. All participants were able to provide self-reports in response to questioning. The investigators reported that, although intensity of pain and number of pain complaints had a significant, negative relationship to cognitive impairment, the self-reports of cognitively impaired elders were as valid as those who were cognitively intact. Ferrell, Ferrell, and Rivera (1995) examined the ability of elders to complete several pain scales, including the McGill Pain Questionnaire and 4 of it's subscales, plus 5 uni-dimensional pain scales (i.e., McGill's

Present Pain Intensity Subscale, Visual Analogue, Memorial Pain Card Subscale, Rand Coop chart, and Verbal Scale). They reported that 83% of the participants could complete at least one of the scales, indicating that self-rating pain reports in moderate to severely cognitively impaired elders were reliable and valid. In this study, caregivers assessed the pain of elders with early or middle stage by listening for verbal complaints of pain. These caregivers were confident in their ability to know when their elder was experiencing pain.

Marzinski (1991) described how the nursing staff on an Alzheimer's unit was able to recognize the verbal and non-verbal pain cues exhibited by the cognitively impaired patients. The staff had identified their patient's "normal" behaviors and quickly recognized and intervened when "abnormal" behaviors were presented. The present study is supported by Marzinski's work. Caregivers caring for elders in late stages of AD linked observed behaviors to verbal complaints of pain during the early and middle stages of AD. These behaviors were used as pain cues when the family member could no longer verbally complain of pain.

Hurley et al. (1992) have developed an objective, multidimensional scale for use with non-verbal elders with advanced dementia of the Alzheimer type. This scale includes behavioral indicators for discomfort, including noisy breathing, negative vocalization, change in facial expression, and change in body language. The caregivers in this study have identified several behavioral cues that correspond to items in Hurley's Discomfort Scale (e.g., negative vocalization, changes in facial expression and changes in body language - especially fidgeting). The appropriateness of use of behavioral cues to assess pain in non-verbal elders is thus supported. The use of probing questions or mixed methods of assessment by caregivers of elders with AD is not discussed in the literature. In addition, the relationship of the caregiver understanding of AD and the staging of AD to the ability of the caregiver to assess the pain of their cognitively impaired elder has not been explored.

In summary, all caregivers in this study used verbal self-reports of pain, observation followed by probing questions, or behavioral observation to assess the chronic pain of their elderly family member with AD. The assessment technique chosen appeared to be dependent on the caregiver's understanding of AD and the stage of AD that the care receiver was experiencing. The contrast and a stroke-related caregiver used verbal self-reports of pain as their care receivers were still able to complain of pain.

A few caregivers, including the other stroke-related case, used mixed methods of assessment. As the care receiver alternated between offering verbal or behavioral cues, the caregiver changed his/her method of assessment. These caregivers possessed either little or moderate understanding of AD.

Intervention of Chronic Pain in Cognitively Impaired Elders

There is no identified literature that addresses pain intervention strategies to be used with cognitively impaired elders who are experiencing chronic pain. McCaffery and Beebe (1989) recommend both pharmacological (narcotic and non-narcotic) and non pharmacological interventions for pain. The intervention strategies they recommend do not change with advancing age. However, the authors, as do Jacox et al. (1994), recommend that consideration be made with respect to the physiological changes of aging that influence distribution, metabolism and clearance of drugs.

The intervention strategies utilized by the caregivers in this study for their elders chronic pain included intervention with medication, repositioning the affected area, use of heat, and use of distraction. These strategies did not appear to be based on recommendations for use or on consideration for advancing age. Rather, the choice of strategies was influenced by what had been done for the caregiver by others, what the family caregiver had used personally before, or what the care receiver used when they were still self-administering their own pain interventions. There were no differences among the caregivers related to their use of pain intervention strategies.

In summary, the experiences of caring for a family member with AD were of greater importance to the caregivers of this study than the experiences of caring for a family member with chronic pain. Although previous research has identified the effect that a family member's chronic pain has on other members, that finding was not replicated in this study. Family caregivers do assess and intervene in the chronic pain of their elder with AD, and when questioned, could describe the processes involved. The assessment methods included verbal self-reports, observation followed by probing questions, and behavioral observation. These methods are supported by the literature. However, these studies only address assessment of pain by health care providers, not family caregivers. Intervention strategies used by caregivers in this study included the use of mediation, repositioning, heat and distraction. These strategies were chosen because of previous experiences of the caregivers. No identified studies were found that address how caregiver intervene in the chronic pain of an elderly family member with AD.

Strengths and Limitations of the Method

Taylor and Bogdan (1984) have identified several limitations associated with interviewing. These include incongruities between what the participant says and does in interviews and across different situations and inaccurate assumptions and misconceptions that occur due to the researcher not being aware of the context in which the informant's language and experiences are based. Because of these drawbacks to interviewing, the strength of intensive interviewing is emphasized. Intensive interviewing requires getting to know the family caregivers well enough to understand what they mean and to create an atmosphere in which they will talk freely about their experiences in managing the chronic pain of an elderly person with AD. This was achieved by up to four contacts with the caregiver.

I met several caregivers initially at the clinic where their care receiver was receiving treatment. I explained the purpose of the study, discussed the inclusion criteria and ask if I might call them to arrange an interview. In others, the health care provider made the initial contact, explaining the purpose of my study and asking if the caregiver's name could be provided to me. Thus, in many cases, the telephone call arranging an interview time was the second exposure the majority of caregivers had to me and to this study. The initial telephone call lasted up to thirty minutes. Many caregivers wanted to know about my background and offered many insights into their caregiving situation.

A second telephone call was made to all participants to confirm the appointment. Many caregivers shared at this time changes that had occurred since the first call, areas of caregiving that were of concern to them, and the amount of pain that the care receiver had been experiencing. The atmosphere of the interview was comfortable and relaxed because of the sharing of information that had taken previously taken place.

Strengths and Limitations of the Study

The strength of this study lies in its potential for helping to fill a gap in nursing knowledge. There were no other studies identified which examined the experiences of caregivers caring for elders with AD and chronic pain. In addition, this study captured a range of caregiving experiences that included differing caregiver-care receiver relationships, differing stages of care receiver's AD, differing caregiver understanding of AD, and differing lengths of caregiving activity. This allows for greater potential in readers finding the results applicable to their situation.

The conclusions of this study were limited by the unique sample involved. Many caregivers had expressed a willingness to be involved in a research project in hopes of helping others with AD. For several caregivers, this was not the first or only research study in which they were involved. In addition, the caregivers of this study were highly educated (i.e., education of caregivers ranged from 7th grade through achieving a Ph.D.; 69.2% attended college). This is unusual for this cohort of elders and both limitations may have influenced the results. In addition, all caregivers resided in a metropolitan area and the racial mix of caregivers reflected that of the area (i.e., 12 caregivers were white, 1 caregiver was black). This study did not provide insight into the caregiving experiences of other ethnic and cultural backgrounds (refer to Nkongho & Archbold, 1996, for results of their qualitative study which describes caregiving of elders in African American families).

My distinctions of early, middle and late stage AD for several care receivers and the distinction made between little, moderate and substantial understanding of AD were, based on my understanding of what the caregiver reported. They were not based on an objective, systematic process or by clinical diagnosis. A better tactic would have been to have the current stage of AD spurred by the care receiver's health care provider and a systematic means to determine the caregiver understanding of the AD. Unfortunately, this was beyond the scope of this study and care should be taken when transferring the results to other situations.

Although all care receivers experienced chronic pain or experienced a diagnosed medical condition that usually was accompanied by chronic pain, the actual presence or absence of care receiver pain, and the pain cues assessed by the caregiver were based on a report provided only by the caregiver. These reports were not verified or substantiated by observation. Again, consideration of this limitation must accompany any transferring of results.

A final limitation was that the data were retrospective in nature and depended on the memory of caregivers to explore changes of pain assessment and intervention over time. In addition, I did not attempt to discuss the findings with the participants until all the data was analyzed, a lapse of almost one year for many of the caregivers. In one year, many changes occur in an AD elder which may influence the caregiver's memory and understanding of past events. The results may have been more credible if a caregiver-care receiver dyad was followed from the diagnosis of AD to the final stage of AD. Again, this was beyond the scope of this study, but suggests a direction for future research.

Implications and Recommendations for Nursing Research and Practice

The results of this study have several implications for nursing research and practice. The following recommendations closely follow the identified limitations of the study as addressed above.

Future studies should address a wider range of caregiver demographics, including a mix of racial and ethnic backgrounds, educational and socioeconomic background, and rural and urban settings. This were improve the ability to transfer the salient results to diverse situations.

The stage of AD and the caregiver understanding of AD should be systematically and objectively determined, and collaborated by the care receiver's healthcare provider whenever possible. This would ensure that the findings of caregiver assessment and intervention are indeed related to the stage and understanding of AD.

Future studies could use a triangulation of methods, including interviewing of family and professional caregivers, and observation of behaviors related to the resulting interaction between caregiver and care receiver. In addition, longitudinal studies following a caregiver-care receiver dyad from early stage AD through late stage AD would decrease the dependency on caregiver memory to explore the changes that occur over time. These methods would increase the credibility of the results.

This was the first study in my program of research designed to enhance caregiving to older persons with AD through development of assessment and intervention strategies to improve chronic pain management in elders with AD. Future research plans are to interview health care providers of elders with AD in long-term and acute care facilities to explore how they assess and intervene in the pain in this population. This next study would also address the understanding that health care providers have regarding the presence of pain in the elderly AD population. I would like to interview health care providers and family members of elders with AD to determine if they are using the same pain cues to assess the presence of pain, and how these cues were identified by the health care provider. Several studies need to be performed around the management of pain in elders with AD, including appropriate pharmacological and non-pharmacological interventions. Finally, intervention studies examining the use of pain assessment guidelines and pain intervention protocols should be developed.

The results of this study have important implications for nursing practice. This study suggested that the experience of caring for an elder with AD was of paramount concern to the caregiver and eclipsed the experience of pain. Thus, the presence of pain in the care receiver was often not investigated. This suggests that before nurses can assist the caregiver in assessing and managing the pain of elders with AD, they first need to address the many needs of the caregiver that results from the AD experience. Nurses who are caring for elders with AD, regardless of the reason for the care, will require substantial knowledge regarding the disease and the needs of the caregivers. These nurses may also be at risk for becoming overwhelmed with meeting the day-to-day needs of the client with AD, and may require support and assistance. Nurses should not rule out chronic pain as a cause of behavioral symptoms without further investigation, even though the presence of pain has not been considered by the caregiver.

When assessing for the presence of chronic pain, nurses need to be especially aware of the stage of AD a care receiver is experiencing. The stage of AD influences what pain cues the care receiver is able to exhibit. Understanding of the stages of AD will assist in knowing how elders may or may not be able to respond to pain. The nurse also will need to assess the understanding the caregiver has regarding AD. Caregivers with little, or an erroneous, understanding of AD may negate the presence of chronic pain because of their lack of knowledge regarding which pain cues are expected in relation to the stages of AD.

Family caregivers of elder with AD often have identified pain cues that indicate when the elder is having pain. This knowledge has evolved over many years and may be the result of a long-enduring relationship. When the elder with AD is admitted into a health care facility, the admission procedures should include an interview with the family caregiver. This interview would start with how the care receiver reacted in the presence of pain before the AD started, what cues now indicate the presence of pain and what intervention strategies are used and are effective. This would end with a nursing plan for the assessment and intervention of pain that reflects the knowledge of the caregiver and the nurse.

Nurses working with caregivers of elders with AD need to understand that the interventions used by the caregivers may be those that they have experience with rather than those that might be effective for the care receiver. Nurses can assess the effectiveness of any pain intervention strategies being used and educate the caregiver on alternative strategies appropriate for their elderly family member.

Personal Reflections

The result that impressed me most was not what I found, but what I didn't find. Although Ferrell, Cohen's et al. (1991) model contributed greatly to the construction of the questionnaire, many aspects of that model were not found to be of importance to caregivers of this study (i.e., cultural background of caregiver, and meaning and understanding of pain by the caregiver). Findings I had not expected were the paramount importance of AD over pain, and the use of mixed methods of assessment in response to the care receiver's ability to provide pain cues.

The generosity and willingness of each caregiver to share their limited time and intimate aspects of their lives was very impressive. I was affected by the love they showed toward their family member and their ability to provide such physically and emotionally demanding care, often with little support or guidance. My understanding of AD and of caring for elders with AD has been greatly enhanced by the participation of these 13 caregivers.

The most difficult part of conducting this research was stopping myself from providing assistance and information and not worrying about the caregiver after the interview was done. I found it difficult to separate the roles of being a researcher from being a health care provider.

Summary

This descriptive qualitative study resulted in a description of caregivers caring for elders with AD and chronic pain. A purposive convenience sample of 13 caregivers were interviewed using a interview guide and intensive interviewing techniques. The interviews were transcribed verbatim and analyzed to identify concepts, categories and themes related to the caregiver's experiences. Three major categories were identified and discussed: (a) paramount concerns of family caregivers (behavioral and physical changes of the care receiver, emotional response to caregiving, restriction and isolation, and planning for the future), (b) how a family caregiver developed the knowledge that the elder with AD was experiencing chronic pain (caregiver's general understanding of AD and stages of AD, type of assessment used, the caregiver's understanding of both the caregiver and care receiver's past history of pain, and the caregiver and the caregiver - care receiver relationship), and (c) pain intervention strategies used by family caregivers (medication, repositioning, heat, and distraction).

The results speak to a need for nurses to assist with the caregiver's needs surrounding the AD experience prior to being able to provide specific help, i.e., pain assessment and management. Caregivers of elders with AD have developed ways to assess their elders pain and effective intervention strategies. Nurses should access this information and utilize it in planning and providing the care for this elders with AD.

Literature Citations

Acute Pain Management Guideline Panel. (1992). Acute pain management: Operative or medical procedures and trauma. Clinical practice guideline (AHCPR Pub. No. 92-0032 ed.). Rockville, MD: Agency for Health Care Policy and Research, Public Health Service, U.S. Department of Health and Human Services.

Ahern, D.C., Adams, A.E., & Follick, M.J. (1985). Emotional and marital disturbance in spouses of chronic low back pain patients. The Clinical Journal of Pain, 1, 69-74.

Anthony-Bergstone, C.R., Zarit, S.H., & Gatz, M. (1988). Symptoms of psychological distress among caregivers of dementia patients. Psychology and Aging, 3, 245-248.

Artinian, B.A. (1988). Qualitative modes of inquiry. Western Journal of Nursing Research, 10, 138-149.

Beck, C.K., Heacock, P., Rapp, C.G., & Shue, V. (1993). Cognitive impairment in the elderly. Advances in Clinical Nursing Research, 28, 335-347.

Block, A.R. (1981). An investigation of the response of the spouse to chronic pain behavior. Psychosomatic Medicine, 43, 415-422.

Block, A.R., & Boyer, S.L. (1984). The spouse's adjustment to chronic pain: Cognitive and emotional factors. Social Science Medicine, 19, 1313-1317.

Caserta, J.E. (1989). Listening to families. Home Healthcare Nurse, 7(6), 3.

Chenoweth, B., & Spencer, B. (1986). Dementia: The experience of family caregivers. The Gerontologist, 26, 267-272.

Cohen-Mansfield, J. (1986). Agitated behaviors in the elderly. II. Preliminary results in the cognitively deteriorated. Journal of the American Geriatrics Society, 34, 722-727.

Cohen-Mansfield, J., & Marx, M. (1993). Pain and depression in the nursing home: Corroborating results. Journal of Gerontology, 48(2), P96-P97.

Cohen-Mansfield, J., Marx, M.S., & Rosenthal, A.S. (1990). Dementia and agitation in nursing home residents: How are they related? Psychology and Aging, 5(1), 3-8.

Crook, J., Rideout, E., & Browne, G. (1984). The prevalence of pain complaints in a general population. Pain, 18, 299-314.

Eland, J.M. (1990). Pain in children. Nursing Clinics of North America, 25, 871-884.

Engel, J.M. (1991). Behavioral assessment of chronic headaches in children. Issues in Comprehensive Pediatric Nursing, 14, 267-276.

Ferrell, B.A. (1995). Pain evaluation and management in the nursing home. Annals of Internal Medicine, 123(9), 681-687.

Ferrell, B.R., Cohen, M.Z., Rhiner, M., & Rozek, A. (1991). Pain as a metaphor for illness. Part II: Family caregivers' management of pain. Oncology Nursing Forum, 18, 1315-1321.

Ferrell, B.R., & Ferrell, B.A. (1990). More research needed on geriatric pain management. Provider, 16(73), 31-32.

Ferrell, B.R., Ferrell, B.A., Ahn, C., & Tran, K. (1994). Pain management for elderly patients with cancer at home. Cancer, 74, 2139-2146.

Ferrell, B.A., Ferrell, B.R., & Osterweil, D. (1990). Pain in the nursing home. Journal of the American Geriatrics Society, 38, 409-414.

Ferrell, B.R., Ferrell, B.A., Rhiner, M., & Grant, M. (1991). Family factors influencing cancer pain management. Postgraduate Medical Journal, 67(S2), S64-S69.

Ferrell, B. A., Ferrell, B. R., & Rivera, L. (1995). Pain in cognitively impaired nursing home patients. Journal of Pain and Symptom Management, 10(8), 591-598.

Ferrell, B.R., Grant, M., Chan, J., Ahn, C., & Ferrell, B.A. (1995). The impact of cancer pain education on family caregivers of elderly patients. Oncology Nursing Forum, 22, 1211-1218.

Ferrell, B.R., Johnston-Taylor, E., Grant, M., Fowler, M., & Corbisiera, R.M. (1993). Pain management at home: Struggle, comfort, and mission. Cancer Nursing, 16, 169-178.

Ferrell, B.R., Rhiner, M., Cohen, M.Z., & Grant, M. (1991). Pain as a metaphor for illness. Part I: Impact of cancer pain on family caregivers. Oncology Nursing Forum, 18, 1303-1309.

Ferrell, B.R., Taylor, E.J., Grant, M., Fowler, M., & Corbisiero, R.M. (1993). Pain management at home: Struggle, comfort, and mission. Cancer Nursing, 16, 169-178.

Flor, H., Turk, D.C., & Rudy, T.E. (1989). Relationship of pain impact and significant other reinforcement of pain behaviors: The mediating role of gender, marital status and marital satisfaction. Pain, 38, 45-50.

Flor, H., Turk, D.C., & Rudy, T.E. (1987). Pain and families. II. Assessment and treatment. Pain, 30, 29-45.

Flor, H., Turk, D.C., & Scholz, O.B. (1987). Impact of chronic pain on the spouse: Marital, Emotional, and Physical consequences. Journal of Psychosomatic Research, 31(1), 63-71.

George, L.K., & Gwyther, L.P. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. The Gerontologist, 26, 253-259.

Gibson, S.J., Katz, B., Corran, T.M., Farrell, M.J., & Helme, R.D. (1994). Pain in older persons. Disability and Rehabilitation, 16(3), 127-139.

Given, B.A., & Given, C.W. (1991). Family caregiving for the elderly. In J.J. Fitzpatrick, R.L. Taunton, & A.K. Jacox (Eds.). Annual Review of Nursing Research (Vol. 9) (pp. 77-101). New York: Springer.

Grootenhuis, M.A., van der Wel, M., de Graaf-Nijkerk, J., & Last, B.F. (1996). Exploration of a self-protective strategy in pediatric oncology staff. Medical and Pediatric Oncology, 27(1), 40-47.

Harkins, S.W., & Chapman, C.R. (1976). Detection and decision factors in pain perception in young and elderly men. Pain, 2, 253-264.

Harkins, S.W., Price, D.D., & Martelli, M. (1986). Effects of age on pain perception: Thermonociception. Journal of Gerontology, 41(1), 58-63.

Harvath, T.A., Archbold, P.G., Stewart, B.J., Gadow, S., Kirschling, J.M., Miller, L., Hagan, J., Brody, K., & Schook, J. (1994). Establishing partnerships with family caregivers: Local and cosmopolitan knowledge. Journal of Gerontological Nursing, 20, 29-35.

Herr, K.A., & Mobily, P.R. (1991). Complexities of pain assessment in the elderly: Clinical considerations. Journal of Gerontological Nursing, 17(4), 12-19.

Hinds, C. (1985). The needs of families who care for patients with cancer at home: Are we meeting them? Journal of Advanced Nursing, 10, 575-581.

Horowitz, A. (1985). Family caregiving to the frail elderly. Annual Review of Gerontology and Geriatrics, 5, 194-246.

Hurley, A.C., Volicer, B.J., Hanrahan, P.A., Houde, S., & Volicer, L. (1992). Assessment of discomfort in advanced Alzheimer patients. Research in Nursing & Health, 15, 369-377.

Jacox, A., Carr, D.B., Payne, R. Berde, C.B., Brietbart, W., Cain, J. M. et al. (1994). Management of cancer pain: Adults quick reference guide, No. 9. AHCPR Publication No. 94-0593. Rockville, MD: Agency for Health Care Policy and Research, U.S. Department of Health and Human Services, Public Health Service.

Kaufman, S.R. (1994). In-depth interviewing. In J.F. Gubrium & A. Sankar (Eds.), Qualitative methods in aging research (pp. 123-136). Thousands Oaks, CA: Sage.

Kerns, R.D., & Turk, D C. (1984). Depression and chronic pain: The mediating role of the spouse. Journal of Marriage and the Family, 46, 845-852.

Kuhlman, G.J., Wilson, H.S., Hutchinson, S.A., & Wallhagen, M. (1991). Alzheimer's disease and family caregiving: Critical synthesis of the literature and research agenda. Nursing Research, 40, 331-337.

Light, E., & Lebowitz, B.D. (Eds.). (1989). Alzheimer's Disease treatment and family stress: Directions for research (DHHS Publication No. ADM 89-1569). Rockville, MD: U.S. Government Printing Office.

Lincoln, Y.S., & Guba, E.G. (1985). Naturalistic inquiry. Newbury Park, CA: Sage.

Lofland, J., & Lofland, L.H. (1984). Analyzing social situations. Belmont, CA: Wadsworth.

Maruta, T., Osborne, D., Swanson, D.W., & Halling, J.M. (1981). Chronic pain patients and spouses: Marital and sexual adjustment. Mayo Clinical Proceedings, 56, 307-310.

Marzinski, L.R. (1991). The tragedy of dementia: Clinically assessing pain in the confused, nonverbal elderly. Journal of Gerontological Nursing, 17(6), 25-28.

McCaffery, M., & Beebe, A. (1989). Pain: Clinical manual for nursing practice. St. Louis: Mosby.

Melding, P.S. (1991). Is there such a thing as geriatric pain? Pain, 46(2), 119-121.

Miles, M.B., & Huberman, A.M. (1994). An expanded sourcebook: Qualitative data analysis (2nd ed). Thousand Oaks, CA: Sage.

Morley, J.E., Kraenzie, D.M., Bible, B., & Bundren, B. (1995). Perception of quality of life by nursing home residents. Nursing Home Medicine, 3(8), 191-194.

Mort, J.R., Gaspar, P., Pulscher, S.R., & Laird, L. (1993). Management of demented patients within the community: Techniques utilized and the impact of education. Clinical Gerontologist, 13(2), 23-45.

Moss, M.S., Lawton, M.P., & Glicksman, A. (1991). The role of pain in the last year of life of older persons. Journal of Gerontology, 46(2), 51-57.

National Institute of Nursing Research (1994). Symptom management: Acute pain. Bethesda, MD: U.S. Department of Health and Human Services, U.S. Public health Service, National Institutes of Health.

Neary, M.A. (1993). Type of elder impairment: Impact on caregiver burden, health outcomes and social support. Clinical Gerontologist, 13(2), 47-59.

Nkongho, N.O., & Archbold, P.G. (1996). Working-out caregiving systems in African American families. Applied Nursing Research, 9, 108-114.

O'Brien, J., & Francis, A. (1988). The use of next-of-kin to estimate pain in cancer patients. Pain, 35, 171-178.

Parmelee, P.A., Katz, I.R., & Lawton, M.P. (1991). The relation of pain to depression among institutionalized aged. The Journal of Gerontology, 46, P15-21.

Parmelee, P.A., Smith, B., & Katz, I.R. (1993). Pain complaints and cognitive status among elderly institution residents. Journal of the American Geriatrics Society, 41, 517-522.

Patton, M.Q. (1990). Qualitative evaluation and research methods (2nd ed.). Newbury Park, CA: Sage.

Rabins, P.V., Mace, N.L., & Lucas, M.J. (1982). The impact of dementia on the family. Journal of the American Medical Association, 248, 333-335.

Reisberg, M.D., Ferris, S.H., De Leon, M.J., & rook, T. (1982). The Global Deterioration Sale for assessment of primary degenerative dementia. American Journal of Psychiatry, 139(9), 1136-1139.

Rowat, K.M., & Knafl, K.A. (1985). Living with chronic pain: The spouse's perspective. Pain, 23, 259-271.

Roy, R., & Thomas, M.R. (1986). A survey of chronic pain in an elderly population. Canadian Family Physician, 32, 513-516.

Roy, R., & Thomas, M.R. (1987). Elderly persons with and without pain: A comparative study. The Clinical Journal of Pain, 3(2), 102-106.

Schechter, N.L. (1995). Common pain problems in the general pediatric setting. Pediatric Annals, 24(3), 139, 143-146.

Seidel, J., Friese, S., & Leonard, D.C. (1995). The Ethnograph V4.0: A users guide. Amherst,MA: Qualis Research Associates

Shanfield, S.B., Heiman, E.M., Cope, D.N., & Jones, J.R. (1979). Pain and the marital relationship: Psychiatric distress. Pain, 7, 343-351.

Silliman, R.A., & Sternberg, J. (1988). Family caregiving: Impact of patient functioning and underlying causes of dependency. The Gerontologist, 28, 377-382.

Snelling, J. (1990). The role of the family in relation to chronic pain: Review of the literature. Journal of Advanced Nursing, 15, 771-776.

Sorkin, B.A., Rudy, T.E., Hanlon, R.B., Turk, D.C., & Stieg, R.L. (1990). Chronic pain in old and young patients: Differences appear less important than similarities. Journal of Gerontology, 45(2), P64-68.

Stetz, K.M. (1987). Caregiving demands during advanced cancer: The spouse's needs. Cancer Nursing, 10, 260-268.

Stewart, B.J., Archbold, P.G., Harvath, T.A., & Nkongho, N. (1993). Role acquisition in family caregivers for older people who have been discharged from the hospital. In S.G. Funk, E.M. Taylor, S.J., & Bogdan, R. (1984). Introduction to qualitative research methods: The search for meanings. New York: John Wiley & Sons.

Taylor, S.J., & Bogdan, R. (1984). Introduction to qualitative research methods: The search for meanings. New York: John Wiley & Sons.

Villarruel, A.M., & Denyes, M.J. (1991). Pain assessment in children: Theoretical and empirical validity. Advances in Nursing Science, 14(2), 32-41.

Wagner, A.M., Baker, M., Campbell, B., Eskro, S., French, S.A., Shepherd, S.A. et al. (1996). Pain prevalence and pain treatments for residents in Oregon's Long Term Care facilities. State of Oregon Senior and Disabled Services Division, Client Care Monitoring Unit, 1-8.

Yeager, K.A., Miaskowski, C., Dibble, S.L., & Wallhagen, M. (1995). Differences in pain knowledge and perception of the pain experience between outpatients with cancer and their family caregivers. Oncology Nursing Forum, 22, 1235-1241.

Zarit, S.H., Orr, N.K., & Zarit, J.M. (1985). The hidden victims of Alzheimer's Disease: Families under stress. New York: New York University Press.

Appendix A

Key Articles

Summary Table of Relevant Research Articles

Author	Sample	Description	Results	Comments
Ferrell, Ferrell, & Osterweil (1990)	92 long term care residents from a 311-bed multilevel residential long-term care teaching facility. 83% female, mean age 88 years, Participants averaged 5 medical conditions and over 8 prescribed medications.	Focus of study: to describe the extent of pain in a long-term care facility. Data collected with semistructured interview and review of medical records. Interviews were not done within an hour of pain medication administration. Participants were asked to focus on their worst pain complaint and its character over the last 7 days. Measured: 1) prevalence of pain; 2) frequency of pain in days per week; 3) pain intensity, rated at the moment; 4) relationship between pain and function.	1) 71% experienced pain at least some of the time: 66% intermittent pain, 34% constant pain. 2) 43 patients with intermittent pain: 51% had daily pain, 16% 3 to 6 days of the last week, 19% had 1 or 2 days of pain, 14% reported no pain in the last week. 3) 52% of the participants rated pain as 3 or above (severe, horrible, or excruciating). 4) Most reported more than 1 function impaired by pain. 23% reported no functions affected by pain, 25% with more than 5 functions affected by pain.	Findings suggest pain is a major problem with the elderly of this long-term care facility. Also, elderly patients may not report pain symptoms or ask for help with pain. This suggests if pain is not asked about, it will go unidentified

Author	Sample	Description	Results	Comments
Ferrell, Ferrell, Rhiner, & Grant (1991)	Convenience sample of 85 cancer pain patients who required analgesics. Mean age 62 years; 58% female; average time since diagnosis 35 months; average time since onset of pain 14 months.	Purpose: describe family factors which influence cancer pain Data collected from four survey instruments (demographics, Profile of Moods States, Caregiver Burden Scale, Family Knowledge and Attitudes about Pain). Plus a family caregiver (CG) interview using the Family Pain Survey.	Patients pain rating: 45.5. CGs estimates of patient's pain: 69.9. CGs rated pain to be extremely distressing to the patient and for themselves. Hospice patients rated their pain as lower when compared to cancer center or the community hospital. There were no differences in CG reporting of pain across settings nor in patient's perceived distress.	Study findings suggest that a family member's pain influences the CG as well as the patient.

Author	Sample	Description	Results	Comments
Ferrell, Cohen, Rhiner, & Rozek (1991).	Cancer pain patients: N=85. Mean age 62 years, 58% female. Average time since diagnosis 35 months. Onset of pain 14 months. Caregivers (CGs): mean age 54 years. 72% female. 85% lived with the patient. 63% were spouses. 26% were adult children of the cancer pain patient.	Guided by the authors' conceptual model, "The Impact of Pain on Overall Quality of Life". This study was designed to explore family factors which influence pain management of cancer pain patients. Qualitative data collected from the Family Pain survey comprising of 6 open-ended questions. This part of the article (Part II) discusses 1) the role of family CG in pharmacologic and nonpharmacologic management of cancer pain, and 2) the primary questions and concerns expressed by CGs about management of pain.	7 themes related to family CG roles surrounding pain medications (what and when to give medication, night duty, reminding/ encouraging, records, fear of addiction, and doing everything). 8 themes related to nonpharmacologic interventions (positioning/ mobility, massage, ointments/lotion, cold, heat, touch, avoiding touch, talk). CG questions or concerns focused around the future, understanding why, death, concern about medication, and fear about what to do at home.	Authors developed a figure of the patients' experience of pain as derived from a review of the literature. Authors also developed a figure depicting the CG's experience of pain.

Author	Sample	Description	Results	Comments
Ferrell, Ferrell, & Rivera (1995)	Random sample of 217 participants from 10 community skilled nursing homes in Los Angeles. Average of 100 beds. 35% of all residents were chosen for an interview and a chart review, conducted as a quality assurance activity. Mean age 84.9 years. 85% women.	Chart review extracted the demographic data. Structured interview using the Folstein Mini-Mental State Exam, Katz Activities of Daily Living Scale, McGill Pain Questionnaire, 33-item questionnaire adapted from the authors previous research in nursing homes, Rand Coop Chart, Memorial Pain Card Subscale. Study questions: What is the rate of pain complaints in residents of skilled nursing homes? What percentage of nursing home patients with pain can be assessed with a pre-exiting pain-intensity scale.	62% reported pain complaints during the interview. 38% denied painful problems or could not provide meaningful answers. 37% of those complaining of pain had no documented source of pain. Arthritis was the most common source of pain. None of the pain intensity scales were appropriate for all cognitively impaired patients with pain. Assessment of pain was accomplished using at least one of the scales.	Use of self-ratings of pain in cognitively impaired elders is appropriate. Pain assessment for cognitively impaired elders should be consistent and frequent. These elders require extra time to comprehend and answer the assessment questions.
Ferrell, Rhiner, Cohen, & Grant, 1991	Cancer pain patients: N=85. Mean age 62 years, 58% female. Average time since diagnosis 35 months. Onset of pain 14 months. CGs: mean age 54 years. 72% female. 85% lived with the patient. 63% were spouses. 26% were adult children of the cancer pain patient.	Guided by the authors' conceptual model, "The Impact of Pain on Overall Quality of Life". This study was designed to explore family factors which influence pain management of cancer pain patients. Qualitative data collected from the Family Pain survey comprising of 6 open-ended questions. This part of the article (Part I) discusses 1) family description of patient's cancer pain, 2) CG experience of pain.	4 themes were discovered related to the caregivers' (CG) description of the patients' cancer pain: anatomic description, hidden pain, family fear and suffering, overwhelming/ unendurable pain. 3 themes were identified with respect to the CGs experiences of pain: helplessness, coping by denying feelings, and wish for death.	Family CG's have their own experiences of the cancer patient's pain. The CGs characterizepain as a metaphor for the cancer where pain was an indicator of the patient's status and a sign of progressive illness.

Author	Sample	Description	Results	Comments
Hinds (1985)	Random sample of 83 family members requiring assistance with the physical care of a family cancer patient. The cancer patient was being seen at a community cancer clinic. 40 females, average age of 54 years.	The purpose was to identify the needs of family as they provided patient care and how those needs were being met. 46-item interview questionnaire, administered in the caregivers' (CG) home, addressed the physical care of the patient, communication, resource need and use, and personal adjustment. Scores ranked according to perceived degree of coping.	Three highest areas of reported needs associated with physical care were treatments, nausea and vomiting, and pain. 31% of the families were coping poorly with respect to physical care. 22% of the families identified patient suffering as a course of psychological discomfort. The next most common problem area was uncertainty about the disease (15%).	These family CG have a number of needs which often went unmet. The most common needs centered around information and skills required to perform treatment related tasks.
Hurley, Volicer, Hanrahan, Houde & Volicer (1992)	Study 1: 45 registered, practical and nurse assistants from 3 Veteran's Administration hospital special care Alzheimer units. Study 2: 68 participants from 9 long-term care units of 2 VA hospitals Study 3: 82 participants. Average duration of dementia Alzheimer's type (DAT) 8 years, hospitalized average 2.5 years, 77 were male.	Study 1: Participants identified words to describe patients who were uncomfortable Study 2: Purpose was to develop administration and scoring procedures. The first author rated each item on 100-mm horizontal line visual analogue scale. Study 3: Purpose was to examine the internal consistency of the discomfort scale.	Study 1: 18 of 26 identified behaviors were retained. Study 2: 9 of the 18 items were retained. Study 3: 100-mm scale reduced to 4 points (0-3). Frequency, intensity and duration of each of the observed characteristic was also recorded. Cronbach's alpha ranged between .86 and .89. Interrater reliability approximately .9.	The findings of the 3 studies support the use of the Discomfort Scale in Dementia of the Alzheimer's Type.

Author	Sample	Description	Results	Comments
Marzinski (1991)	26 of 60 patients in an Alzheimer's Unit, all 26 with potentially painful conditions. 1 RN, 2 LPNs, 5 nursing assistants	Chart reviews were performed to find patients with potentially painful conditions. Pain assessments were done on the 26 patients. The nursing staff were interviewed.	A geriatric/ oncology certified practitioner could not discern pain behaviors in 23 of 26 patients. The staff accurately described most of the patients' pain behaviors; level of assessment depended on the level of education and experience of the staff member. If patient exhibited unusual behavior, the staff attempted to fit the behavior into the patients usual pattern. If the behavior did not fit, the staff assumed the patient was ill and looked for supporting signs.	Staff recognized verbal and nonverbal cues and arranged these cues into patterns. Normal behaviors are recognized, deviation from normal are explored. Author states there is no operational definition of pain for the nonverbal elderly.

Author	Sample	Description	Results	Comments
Moss, Lawton, & Glicksman (1991)	Random sample of survivors of 200 (of 534) deceased elders. Mean age 77.4 years, 54% female, 36% married, 2/3 white, median education 9 years, median income $6000 a year for single, $9500 for married. Comparison sample of 150 community dwelling residents matched by age and gender. 43% married, 67% white, median education 8 years, median income level same as deceased sample.	Focused on the role of pain in the last year of life. Compared the prevalence and intensity of pain in last year of life with those of still-living elders. Explore the relationship between pain and its antecedents and consequences. Explore the relationship between pain and quality of life. Based on Lawton's model of "the good life": behavioral competence, perceived quality of life and psychological well-being. Rated physical health (ADL, IADL), cognitive function, use of time, social behavior, personality traits, perceived quality of life, psychological well-being.	Pain analyzed as one of the 12 indicators of quality of life. Pain reported to increase over final year. 37% feeling pain frequently or all the time, increasing to 66% one month before death. Those with less pain generally less lonely, more determined, satisfied with finances and time used, greater psychological well-being. Negative effect of pain on happiness was related to the last year of life, but not to an ordinary year.	Some evidence that increased age may be related to decreased pain. Some aspects of psychological well-being suffer more than others when painful illnesses are present. Association between pain, happiness, & depression were > at 3 months prior to death than 1 month prior. This was possibly related to acceptance, denial, non communication of pain.

Author	Sample	Description	Results	Comments
O'Brien & Francis (1988)	42 pairs of cancer patients and next-of kin independently surveyed. 67% spouse, 79% lived with patient, 81% male patient, 86% female next-of-kin, 50% level 3 cancer stage, average age of patient 61.8 years, average age of next-of-kin 57 years.	Purpose: determine whether next-of-kin are able to recall subjective and objective details of pain, and to measure the amount of agreement about pain between cancer patients and their next-of-kin. 42 of 80 identified pairs were interviewed: patient first. Demographic variables; treatment of cancer; frequency and duration of pain in the last week; typical pain, worst pain, and least pain experienced in last week; McGill Pain Questionnaire.	Almost complete agreement on type of cancer treatment. Agreement as to the presence of pain, less agreement regarding frequency, duration, and quality of pain. Little agreement on areas of McGill Pain Questionnaire.	Those next-of-kin who lived with the patient and felt they were familiar with the patients pain agreed more with the patient than other next-of-kin. Agreement approached randomness as questions became more complicated and as the range of possibilities increased.

Author	Sample	Description	Results	Comments
Parmelee, Katz, & Lawton (1991)	Population of 1302 residents, sample of 598. 191 lived in a skilled or intermediate care nursing home, 407 in congregate apartments. Participants were not chronic pain patients but assumed to be a general sample of older institution-alized elders. 70% female, average age 83.6 years, average length of residence 28.8 months.	Explores the relationship between depression and pain in institutionalized elders. Interviews with self-report data: Pain intensity inventory from McGill Pain Questionnaire, Diagnostic and Statistical Manual symptom checklist (suffering major, minor or no depression), Geriatric Depression Scale, Profile of Mood States, Physical Self-Maintenance Scale, Cumulative Illness Rating Scale.	Significant relation between diagnosis of depression and experienced pain intensity. Possible major depressives reported more intense pain than those with minor or no depression. Possible major depressives reported > number of localized pain complaints than did minor depressives (who reported > complaints than nondepressives). Significant differences between major, minor, and nondepressives remained when health and functional disability were controlled for.	Results indicate that physical condition may not be the only variable influencing the relationship between pain and depression. Relationship of localized pain complaints to depression was strongest when pain was easily associated with an existing physical condition.

Author	Sample	Description	Results	Comments
Parmelee, Smith & Katz (1993)	758 of 2151 residents of a residential skilled, intermediate, and congregate apartment nursing care facility. 70% female, average age 83.3 years, average length of stay 19.7 months.	Explore the relationship between self-reported pain and cognitive impairment in frail institutionalized elderly. Interviews with each resident included, Fuld's modification of the Blessed test (cognitive status), pain intensity, localized pain complaints, Cumulative Illness Rating Sale (physical health), Physical Self-Maintenance Scale (functional disability).	Few unimpaired or mildly impaired. 79.9% with at least 1 localized pain complaint. 46.8% with 3 or more. Majority did not experience severe pain regularly. Controlling for effects of physical health and functional disability, as cognitive impairment increases, reported pain intensity and number of localized pain complaints decreases. For acute or more serious pain, no differences were found among levels of impairment.	Cognitive impairment may interfere with pain reporting. Need for use of non-verbal cues of pain. Level of impairment not based on clinical diagnosis or observed functioning. Impaired individuals are almost as accurate, and as genuine, as intact individuals in pain reports.

Author	Sample	Description	Results	Comments
Roy & Thomas (1987)	Random sample of 205 participants (out of 1200): 143 with pain, 62 without pain. Pain group: 83% women, 47% ages 70-79 years, 49% married, 41% 10 to 12 years of school, 54% < $10,000/year. Non-pain group: 81% women, 53% 70-79 years, 25% married, 30% attended 10 to 12 years of school, 50% earned < $10,000 per year. Majority of both groups lived alone.	Assess prevalence of pain problems in healthy community dwelling elders, compare healthy elders with pain to those without pain. Telephone interviews. Demographics and health questionnaire, Beck depression Scale, Illness Behavior Questionnaire.	70% reported some kind of pain. Disability related to pain very low. Few individuals viewed pain as a major issue. Absence of depression in both groups.	Many respondents felt that their pain was a part of growing older. Participants were psychologically healthy. Lack of distinction between pain and no-pain groups.

Author	Sample	Description	Results	Comments
Wagner, Baker, Campbell, Eskro, French, Shepherd, et al. (1996)	Convenience sample of 33 Oregon skilled nursing facilities. All areas of the state represented. 55% urban, 70% for profit, size ranged from 20 to 193 beds. 461 residents reviewed included those with a variety of care needs, and were selected according to the HCFA protocol which develops a stratified sample of residents.	Describe the prevalence of pain among residents in Oregon's long term care facilities and the effectiveness of pain interventions. Data collection tool: if resident was experiencing pain, what medications and nonpharmacological interventions were being used, if pain interventions were effective. Effectiveness defined as treatments and care that allowed the resident to be as free from pain as possible.	233 residents were not experiencing pain on a daily or almost daily basis. 180 (39%) were identified as having significant pain management needs and were experiencing pain on a daily basis; 101 of these were receiving effective pain treatments. 44 residents had ineffective pain management interventions.	Ineffective pain assessments & tx may be r/t a lack of: a) baseline assessments & knowledge about residents, b) assessments which are consistently performed & documented c) appropriate assessment tools for cognitively impaired elders. Nonpharmacological interventions are not planned for or used.

Appendix B

Interview Guide

Interview Guide
Mary J. Waldo, R.N., MS
OHSU, School of Nursing

Use "pain", "discomfort", or whatever the CG uses.

I. **Tell me what it's like to be a caregiver for (CR)?**
   A. Tell me about (CR).
   B. What was (CR) like before AD? After AD? Now?
   C. How long has it been since you've last noticed changes in his/her behavior?
   D. How do you get along with (CR)?

II. **How do you know when (CR) is currently experiencing pain?**
   A. What does (CR) do? How does (CR) act? How is this different from his/her usual behavior?
   B. When you think the pain is starting or is getting worse, what signs of pain do you notice?
   C. Does (CR) tell you if he/she is having pain? Do you ask if (CR) is having pain?
   D. How sure are you that (CR) is experiencing pain when you think he/she is?
   E. How did you learn to tell when (CR) was experiencing pain?
   F. What do you think are the typical (usual) sources of the pain?
   G. Can you think of a time when (CR) was in pain and no-one else was aware of it?
   H. Can you think of a time when (CR) was in pain and you couldn't convince a HCP: nurse, doctor, dentist, etc?
   I. How do you know when (CR) is not experiencing pain?

III. **In what way, if any, has (CR's) pain behaviors changed as the AD progressed?** *(Note: The levels to be assessed will depend on the care receiver's current stage of AD).*

   A. Tell me about (CRs) current memory problems and the extent to which they interfere with his/her daily life.

Now I would like to go back and trace with you the progression of (CRs) memory problems and how at different points (levels) you were able to decide if the (CR) was having pain.

   B. **Level 1 & 2**: When (CR) was not having any memory problems, or having memory problems that did not interfere with his/her work or with social situations, how did you know he/she was experiencing pain? What was done for his/her pain?
   C. **Level 3 & 4**: When (CR) complained of memory deficits that began to interfere with his/her work and/or social situations (for example, inability to perform routine tasks as marketing or managing personal and household finances) how did you know he/she was experiencing pain? What was done for his/her pain?

D. **Level 5**: When (CR) began to need you to supervise or coach him/her in things like selecting clothing appropriate for the season, or had difficulty with recalling his/her address, telephone number, or names of family members, how did you know he/she was experiencing pain? What was done for his/her pain?

E. **Level 6**: When (CR) began to require assistance with activities of daily living, such as bathing and toileting or was not able to recognize you, how did you know he/she was experiencing pain? What was done for his/her pain?

G. **Level 7**: When (CR) began to loose his/her ability to speak or to walk, how did you know he/she was experiencing pain? What was done for his/her pain?

III. Tell me what you do when you think (CR) is experiencing pain?

A. What is being done to relieve (CR) pain?
B. How often do these methods work?
C. How do you know when these methods are working or are not working?
D. If these do not work, what is done next? Why?
E. Have these methods changed as (CR's) AD progressed?
F. Who else is involved in caring for (CR's) pain?
G. How helpful have nurses, doctors, HCPs been in helping you understand (CR's) pain or in suggesting ways to relieve (CR's) pain?

IV. How did you learn what to do for (CR) when he/she is in pain?

A. Have you had previous experiences in caring for persons in pain?
B. What did you learn from your family about pain as you grew up?
C. What have you learned from your own previous pain.

V. What is it like for you when (CR) is in pain?

A. What happens when (CR) is in pain?
B. What feelings do you have when (CR) is in pain?
C. How do you cope when (CR) is in pain?

VI. If you could teach me about caring for someone in pain, what would you say?

VII. What have you gained from being a caregiver for (CR)?

A. What has been the easiest for you in caring for (CR)?
B. The most difficult?

IX. Is there anything I should have asked you but didn't?

Demographic Data

I. Participant's code number: ___________
II. Interview number: ________________
III. Date of interview: ________________
IV. Place of interview: _______________
V. Caregiver
    A. Age
    B. Gender
    C. Relationship to care receiver
    D. How long have you been providing care?
    E. Occupation
    F. Education
    G. Religious Affiliation

VI. Care Receiver

    A. Age
    B. Gender
    C. Length of AD
    D. Stage (according to Reisberg's stages)
        1. Diagnostic workup - what was done
        2. Type of AD (multi-infarct dementia, unknown cause)
    E. Time since diagnosis of AD?
    F. Duration of pain
    G. When did pain start
    H. Sources of pain
    I. Occupation
    J. Education
    K. Religious Affiliation
    L. Medications

Comment Sheet

I. What did I learn about the caregiver experiences in caring for an AD elder in pain?

II. What did I get?

III. What did I not get?

IV. What do I now need to ask?

V. Notes and Observations:

Appendix C

Consents

CONSENT FORM
OREGON HEALTH SCIENCES UNIVERSITY
Mary J. Waldo, R.N., MS
School of Nursing

Title: Caregiver's Experience: Pain and elders with Alzheimer's

Investigators
Mary J. Waldo, RN, MSN, Principal Investigator, (503) 635-9420
Jane M. Kirschling, RN, DNS, Co-Investigator, (503) 494-1425
Beverly Hoeffer, RN, DNSc, Co-Investigator, (503) 494-3894

Purpose
You have been invited to participate in this research study because you are a caregiver for an individual with Alzheimer's Disease who also experiences chronic pain or a chronic condition that is usually associated with pain. The purpose of this research study is to gain an understanding of the experiences of caregivers managing the chronic pain of elders with Alzheimer's Disease (AD).

Procedures
This study involves being interviewed two or three times. You will be interviewed by the first investigator. The interviews will take place at a place convenient to you that also insures privacy. During each interview you will be asked questions about your experiences as a family caregiver for an elder with AD who has chronic pain and/or a chronic health care problem that is typically associated with pain. You will also be asked about your previous experiences with pain, how you decide when your family member is in pain, and what you do for that pain.

The first interview may take up to one and one-half (1 1/2) hours and will be tape recorded. In addition, the investigator may take a few notes during the interview. You may refuse to answer any questions or end your participation at any time. After the interview, a second interview will be arranged in order to clarify information obtained in the initial interview and/or to explore topics brought up by other participants. The third and final contact (either by telephone, in person, or by mail) is to discuss, explain, or confirm the information obtained from the interviews.

Risks and Discomforts
Although there are no known risks that may result from this research, some of the questions during the interviews may touch on experiences that may be upsetting to you. You can stop the interview at any time. Some people become uncomfortable and nervous when they answer questions about themselves, their thoughts and their feelings. If you become upset during the interview, the interviewer will stay with you until you are no longer upset and you are comfortable with her leaving.

Benefits
Although some people may not feel that they personally benefit from this study, their participation may contribute new information which may benefit health care professionals and caregivers of elders with AD in the future.

Confidentiality
All tape recorded interviews and transcripts will be kept strictly confidential. No names will appear on any written or recorded data; data will be identified by code numbers only. No information that can be identified with you will be given to anyone at the Alzheimer's Disease Center or Movement Disorder Dementia Clinic or anyone else not connected with this research study. Neither your name nor your identity will be used for publication or publicity purposes. Upon completion of this study, the audio tapes of the interviews will be erased.

Costs
There is no cost to participate in the study, nor is there any compensation given to you for participating in the study.

Liability
The Oregon Health Sciences University, as an agency of the State, is covered by the State Liability Fund. If you suffer any injury from the research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, it's officers or employees. If you have further questions, please call the Medical Services Director at (503) 494-8014.

Participation
Mary J. Waldo, RN, MSN (503) 635-9420, has offered to answer any questions that you may have. Participation in this research is completely voluntary. You may refuse to participate, you may refuse to answer individual questions or you may withdraw from this study at any time without affecting your relationship with or treatment at the Alzheimer's Disease Center, the Oregon Health Sciences University, or the Movement Disorder Dementia Clinic. If you have questions about your rights as a research subject, you may contact the OHSU Institutional Review Board at (503) 494-7887.

You will be given a copy of this form to keep.

Your signature below indicates that you have read the foregoing and agree to participate in this study.

____
Participant's signature Date

____
Witness' signature Date

Department of Veterans Affairs

VA Research Consent Form

Subject Name: ______________________ **Date:** __________

Title of Study: Caregiver's Experience: Pain and Elders with Alzheimer's

Principal Investigator: Mary J. Waldo, RN, MS **VAMC:** Portland

Description of Research By Investigator

Description of Study

The purpose of this research study is to gain an understanding of the experiences of caregivers managing the chronic pain of elders with Alzheimer's Disease (AD). This research study will begin May 1995 and end approximately August 1996.

During a tape-recorded interview, you will be asked questions about your experiences as a family caregiver for an elder with AD in chronic pain and/or a chronic health care problem that is typically associated with pain. You will also be asked about your previous experiences with pain, how you decide when your family member is in pain and what you do for that pain. This study involves your being interviewed two or three times. The first interview may take up to one and one-half (1 1/2) hours. The purpose of the second interview, by telephone or in person, is to clarify information obtained in the first and/or to explore topics brought up by other caregivers participating in this study. The purpose of the third and final contact (either by telephone, in person, or by mail) is to discuss, explain, and clarify the information you have shared.

Procedures

If you agree to participate the following will happen. After signing this consent form, you will be interviewed by the investigator. The interview will take place at a location convenient to you that also insures privacy. The interview will take up to one and one-half (1 1/2) hours and will be tape recorded. In addition, the investigator may take a few notes during the interview. You may refuse to answer any questions or end your participation at any time. After the interview, the investigator will arrange a second interview in order to clarify

Subject's Identification (I.D. plate or give Name-last, first, middle)

Subject Name: ______________________ Date: __________

Title of Study: Caregiver's Experiences: Pain and Elders with Alzheimer's

Principal Investigator: Mary J. Waldo, RN, MS VAMC: Portland

information obtained in the initial interview. A third contact will be made (in person, by telephone or by mail) to discuss, explain and clarify the information that you have shared. The interviews will include questions about your experiences in caring for an elder with AD in chronic pain.

Benefits and Risks
Although some people may not feel that they personally benefit from this study, their participation may contribute new information which may benefit health care professionals and caregivers of elders with AD in the future.

Although there are no known risks that may result from this research, some of the questions during the interviews may touch on painful experiences that may be upsetting to you. You can stop the interview at any time. Some people become uncomfortable and nervous when they answer questions about themselves, their thoughts and their feelings. If you become upset during the interview, the interviewer will stay with you until you are no longer upset and you are comfortable with her leaving.

Confidentiality
The results of your participation in this study may be used for publication or for scientific purposed, but your identity will not be disclosed unless you give separate, specific consent to this, or unless as required by law. The taped-recorded interviews will be erased after completion of the study.

Costs
There is no cost to participate in the study, nor is there any compensation given to you for participating in the study.

Treatment in Case of Injury, Source of Additional Information
Every reasonable effort to prevent any injury that could result from this study will be taken. In the event of physical injuries resulting from the study, medical care and treatment will be available at this institution. For eligible veterans, compensation

Department of Veterans Affairs

VA Research Consent Form

Continuation Page 3 of 4

Subject Name: ______ **Date:** ______

Title of Study: Caregiver's Experiences: Pain and Elders with Alzheimer's

Principal Investigator: Mary J. Waldo, RN, MS **VAMC:** Portland

damages may be payable under 38 USC 251 or, in some circumstances, under the Federal Tort Claims Act. For non-eligible veterans and non-veterans, compensation would be limited to situations where negligence occurred and would be controlled by the provisions of the Federal Tort Claims Act. For clarification of these laws, contact District Counsel at (503) 326-2441. You have not waived any legal rights or released the hospital or its agents from liability for negligence by signing this form.

Any patient participating in a study of the Department of Veterans Affairs Medical Center, Portland, Oregon is encouraged to contact Dr. Dennis J. Mazur, Chairman, Subcommittee on Human Studies, to discuss any issues related to their research study participation. Dr. Mazur can be reached through the Research Service (503) 220-8262 extension 6620.

Your signature below indicates that you understand that the Department of Veterans Affair Medical Center, your investigators, and the sponsors of this research study bear no responsibility you may occur at other hospitals, clinics, or care institutions related to this study or to any of your medical conditions.

Right to Withdraw

Your participation in this research study is voluntary, and you may withdraw from this study at any time without prejudice to yourself or to any future medical care with this institution or with the Department of Veterans Affairs (VA).

Department of Veterans Affairs

VA Research Consent Form

(Continuation Page 4 of 4)

Subject Name: ________________ **Date:** ________

Title of Study: Caregiver's Experiences: Pain and Elders with Alzheimer's

Principal Investigator: Mary J. Waldo, RN, MS **VAMC:** Portland

RESEARCH SUBJECTS' RIGHTS: I have read or have had read to me all of the above. ~~Dr.~~ Mrs. Waldo has explained the study to me and answered all of my questions. I have been told of the risks and/or discomforts and possible benefits of the study. I have been told of other choices of treatment available to me.

I understand that I do not have to take part in this study, and my refusal to participate will involve no penalty or loss of VA or other benefits to which I am entitled.

The results of this study may by published, but my records will not be revealed unless required by law.

In case there are medical problems or questions, I have been told I can call ~~Dr.~~ Mrs. Waldo at 503-635-9420 during the day and ~~Dr.~~ Mrs. Waldo at 503-635-9420 after hours. If any medical problems occur in connection with this study the VA will provide emergency care.

I understand my rights as a research subject, and I voluntarily consent to participate in this study. I understand what the study is about and how and why it is being done. I will receive a signed copy of this consent form.

Signature of Subject	Date
Signature of Witness	Witness (print)
Signature of Investigator	

IF MORE THAN ONE PAGE IS USED, EACH PAGE (VAF 10-1086A) MUST BE CONSECUTIVELY NUMBERED AND SIGNED.

VA FORM
JAN 1990 **10-1086**

Appendix D

Time-ordered Data Display Matrix

Time ordered data display matrix, trajectory of pain intervention strategies used by the family caregiver over time. The columns are organized sequentially by progression of AD, the rows are cases. Examples of pain intervention strategies that occurred in that case at that time period are entered in each cell.

Caregiver	Pre-AD	Early	Middle	Late	Unknown
Joshua	Unknown	Tylenol			
Ruth	Tylenol Knee Brace Heat	Positioning ASA Tylenol Knee brace Heat			
Mary	Advil Fluid drained off knee	Ibuprofen	Ibuprofen	Nothing, doesn't complain	
Eve	Tylenol	Nothing, elder doesn't complain			
Sarah	He'd just take something,not very often	Care receiver took care of self	Ibuprofen ASA	Ibuprofen ASA	
Rebekah	Whatever they (health care providers) tell me to give him				Codeine Ibuprofen
Naomi	Naprosyn	ASA Tylenol Lie down	ASA Tylenol Lie down		
Hannah	Suave Extra strength Tylenol	Extra strength Tylenol	Extra strength Tylenol Suave		
Martha	ASA	Tylenol	Tylenol		
Elizabeth	ASA	ASA	ASA		
Abraham	Motrin Arthritic drugs	Motrin Being close to spouse Arthritic drugs			
Abigail	Endocin - stopped taking because upset stomach	Nothing			
Ester	Ibuprofen	Ibuprofen	Ibuprofen		