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PRIMARY CAREGIVERS REPORT OF FIRST AWARENESS OF AN ALTERATION IN BEHAVIOR OF AN ELDERLY FAMILY MEMBER DIAGNOSED WITH DEMENTIA

By

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ABSTRACT

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By

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With the increasing number of elderly, dementia is an expanding problem. The most frequent cause of dementia is Alzheimer's Disease (AD). There is little documentation about the beginning symptoms of this disease. Using secondary analysis this study examines the first symptoms or awareness of AD as noted by family caregivers of those who were diagnosed with AD. Two themes were identified in the study: memory/cognitive changes, and personality changes. Caregivers noted one to three first awareness symptoms. The Advanced Practice Nurse can use this information to increase understanding of the disease and it's manifestations. The study also suggests direction for future research.

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TABLE OF CONTENTS

LIST OF TABLES vii

LIST OF FIGURES vii

INTRODUCTION 1

BACKGROUND OF THE PROBLEM 2

IMPORTANCE OF THIS STUDY 5

PURPOSE OF THIS STUDY 5

SCOPE OF THIS STUDY 5

CONCEPTUAL FRAMEWORK 6
- OVERVIEW 6
- ELDERLY 6
- DEMENTIA 6
- CAREGIVER 7
- CONTINUITY THEORY: A CONCEPTUAL FRAMEWORK 7
- RATIONALE FOR USE OF THE CONTINUITY THEORY WITH THIS STUDY 12
- IMPLICATIONS FOR ADVANCED PRACTICE NURSES 12

REVIEW OF LITERATURE 13
- RESEARCH AND ALZHEIMER'S DISEASE 13
- ALZHEIMER'S DISEASE AND CONTINUITY THEORY 13
- CRITIQUE OF LITERATURE 13

METHODOLOGY AND PROCEDURES 14
- QUALITATIVE RESEARCH ASSUMPTIONS 14
- PRIMARY RESEARCH PROJECT 15
- PRIMARY SAMPLE 15
- PROTECTION OF THE SUBJECTS 15
- DATA COLLECTION 16
- ANALYSIS 16
- RELIABILITY AND VALIDITY 17

SECONDARY RESEARCH SAMPLE 17
SECONDARY DATA ANALYSIS 17
VALIDITY AND RELIABILITY 18
METHODOLOGICAL LIMITATIONS OF QUALITATIVE RESEARCH 18

PRESENTATION OF DATA AND ANALYSIS 19
SUBJECTS 19
FINDINGS 20
THEMES 22
MEMORY/COGNITIVE CHANGES 23
PERSONALITY CHANGES 24

DISCUSSION AND IMPLICATIONS 26
CRITIQUE OF CONTINUITY THEORY AS A FRAMEWORK 26
LIMITATIONS AND STRENGTHS OF THE STUDY 27
IMPLICATIONS FOR NURSING PRACTICE, EDUCATION, AND RESEARCH 28
SUMMARY 30

APPENDICES

APPENDIX A: UCRIHS APPROVAL FOR ORIGINAL STUDY 32
APPENDIX B: UCRIHS APPROVAL FOR SECONDARY STUDY 33
APPENDIX C: INTERVIEW GUIDE 34
APPENDIX D: CODING CATEGORIES 38

LIST OF REFERENCES 41

LIST OF TABLES

Table 1: Description of Subjects 21

Table 2: Categories of Identified Symptoms 22

LIST OF FIGURES

Figure 1: Relationship of Variables in the Continuity Theory 10

Figure 2: Relationship of Variables of Continuity Theory In the presence of Alzheimer's Disease. A theorized adaptation 11

INTRODUCTION

In this decade we have seen a steady increase in the number of elderly in the United States and the aging population itself is getting older (A.A.R.P., 1991). A corresponding increase is seen in the problems and illnesses associated with this age group. Dementia is one of the increasing problems related to aging. New cases of dementia are reported to occur as frequently as heart attacks and more frequently than strokes (Katzman, 1986). Dementia is also noted to be highest in the elderly, making it a markedly age-related disorder (Katzman, 1986). Dementia is caused by many disorders but 50 to 60% of dementia patients suffer from (AD) Alzheimer's Disease (Katzman, 1986).

As the population of those over 65 rises so will the problems associated with AD, along with the cost of taking care of those with this disease. In 1987 the 65 plus age group was only 12% of the population but the health care expenditures for this group were 36% of total health care costs (A.A.R.P., 1991). With the expanding numbers of elderly suffering from AD there is an increase in financial, physical, and emotional stress on the family. This also increases the costs for the health care system which is already struggling to cope with the increasing number of elderly. Early diagnosis of AD will allow for an improvement in the planning and management of care. This decreases the stress on the family and health care system.

This study investigates: The report of first aware of an alteration in behavior of an elderly family member diagnosed with dementia as noted by the primary caregiver. This was accomplished by secondary analysis of interviews with a sample of family caregivers taking care of relatives with AD.

BACKGROUND OF PROBLEM

Alzheimer's Disease (AD) is a degenerative, progressive disease that attacks the brain and results in impaired memory, thinking and behavior (U.S. Health and Human Services, 1995). It affects over four million adults in America and is the most common form of dementing illness (U.S. Department of Health and Human Services, 1995). The disease was first described by Alois Alzheimer in 1907, who found during an autopsy, changes in brain tissue called neuritic plaques and neurofibrillary tangles. These have become the hallmarks of AD. Unfortunately these hallmarks are only noted by brain biopsy. There are no social or economic groups that are not affected by AD. AD is difficult to diagnose because only symptoms and behavioral changes are used to make a diagnosis. Although AD can strike in the 40's, most people who develop the disease are over 65 (Chipps & Victor, 1992). It begins slowly with forgetfulness, and impairment in judgment. Other symptoms may include problems handling routine tasks, lack of spontaneity, lack of initiative, disorientation of time and place, depression and terror (Severience,1994).

During the second stage, the AD patient develops an increase in disorientation and forgetfulness. The patient may start to wander or become agitated and restless, muscle twitching or seizures may develop, repetitive actions can start and the AD patient has an increased difficulty with abstract thinking (Severience, 1994).

During the final stage the AD patient becomes disorientated and completely dependent. They are unable to recognize themselves and may have various forms of severe speech impairment. The AD patient becomes emaciated, looses control of body functions and wants to touch everything in sight (Severience, 1994). These stages can overlap and vary from person to person. AD is a devastating disease for the family, caregiver and patient.

Over 100,000 people die of AD annually (Katzman, 1986). The span of AD is so different from person to person that after the onset of memory loss the patient may live from two to 20 years (Gwyther, 1985). Early detection of those with AD is needed, especially for those with a high risk for developing the disease, such as individuals with a family history of AD (Azari, Pettigrew, Schapiro, Haxby, Grady, Pietrini, Salerno, Heston, Rapoport, & Horwitz, 1993). The earlier the diagnosis is made, the higher the quality of life may be for the family and the patient who have an increased opportunity for planning. Not only is the AD patient affected by the disease but the family may be considered "hidden victims" (Given, Collins, & Given, 1988). It is the family who has to deal with the patients loss of cognitive and mental capacities and alteration in judgment (Given, Collins,& Given 1988).

There is no specific test for AD except on autopsy so it is difficult to diagnose. In order to identify AD, other problems that might cause the same symptoms must be ruled out. Depression, drug reactions, nutritional deficiencies, stroke, head injury, and metabolic changes could mimic the symptoms of AD (Alzheimer's Association, 1995).

It is usually the family that brings the family member to the health care provider for a check-up (Gwyther, 1985). Multiple and different symptoms vary, most symptoms seen in AD are the direct result of brain damage (Gwyther, 1985). A typical example of a first time office visit: A daughter brought her mother to her health care provider for a check-up. The patient states she came in because her daughter was "nagging me". The daughter states mother is "failing", she is not the same person, she forgets simple things, gets angry easy

(Gwyther, 1985). In this patient's history, the patient has no history of depression or alcoholism. The daughter noticed her mother was getting sloppy, had no interest in her hobbies, couldn't balance her checkbook, was suspicious, slept more, would get lost in a store and couldn't follow a recipe, thought Roosevelt was the president, did not remember the year she was born, she had no idea what pills she was taking or what they were for (Gwyther, 1985). This was the patient's first trip to the office because she was "failing", but according to Severience (1994) she is developing the symptoms of the second stage in AD as evidenced, by her disorientation, forgetfulness, anger and getting lost.

Each person with suspected AD needs a complete work-up, complete health history, physical exam, neurological and mental assessments, diagnostic tests, possible CT and EEG, and psychiatric assessments. Many cities have an Alzheimer's screening clinic available that will include a thorough evaluation so that a diagnosis can be made (Alzheimer's Association, 1995).

Even though there is no cure for AD, a good plan of care and understanding of the disease may ease the burden on the family and patient. An optimum level of health maintenance can be maintained with proper medications, diet, daily routines, physical activity and social activities. Tacrine, a prescription drug may slow the development of AD and sometimes tranquilizers and antidepressants can improve mood, decrease anxiety and control outbursts (Alzheimer's, 1995). Knowledge of developing AD allows family members to make plans for how to best cope with changes that occur as a result of the disease.

As AD progresses the patient will need 24 hour care and supervision, causing both financial and physical stress to the caregivers and their families (Given, Collins, & Given 1988). The caregiver can develop chronic fatigue, depression, anger or health problems of their own (Given, Collins, & Given, 1988). For these reasons it is extremely important for early detection to occur so that a long-term plan of care can begin for the benefit of both the patient and their family.

IMPORTANCE OF THIS STUDY

With early intervention and diagnosis the goal is to retard deterioration allowing for a slower progression and a longer period of stability (Gelbart & Schwarz, 1981). This will allow for reduction of stress, both financial and physical, to the caregiver, patient and the health care system. It has also been noted that up to 20% of dementia are reversible (Gelbart & Schwarz, 1981). Entrance into the health-care system is essential to the diagnosis of AD and to the treatment of reversible dementias. People have a tendency not to acknowledge that there is a problem, making first awareness of a patient's symptoms a key to diagnosis. If the symptoms associated with first awareness can be isolated, then the APN can educate the public so that early diagnosis and treatment can be started. This allows the families an increase in time to adjust and plan.

PURPOSE OF THIS STUDY

The purpose of this study is to examine the reports of first awareness of a alteration in behavior of a elderly family member by the primary caregiver of an individual diagnosed with AD. Early first awareness of symptoms will be examined and categorized to create a clearer focus of what was first noted by the caregiver. This will create an expanded knowledge base for the APN.

SCOPE OF THE STUDY

This is a secondary data analysis from a qualitative study of family caregivers of AD patients (King, 1989). Subjects were a non-random group of 34 caregivers who provided care to a family member with AD. They were a convenience sample that was contacted through the Alzheimer's Association, health agencies in southwest Michigan, and Adult Daycare Centers.

This analysis will be limited to those open-ended interview questions that deal with when the caregiver noted first awareness of a problem. The change in behavior or discontinuity that was noted by the caregiver will be based on the conceptual framework. The Continuity Theory of aging will be used as a framework to help identify and examine the caregivers awareness of change.

CONCEPTUAL FRAMEWORK

Overview

Concepts used for this study are defined in the following section. Following are a description of the elderly, dementia, caregiver, the Continuity Theory, rationale for the use of the Continuity theory, the relationship of the study question to the continuity theory, and implications for the APN.

Elderly

Atchley (1983) describes an older person as "an individual in the later maturity or old age stages of life cycle. Socially, people are usually classified as old when they are chronologically sixty-five or older" (p.294). Sixty-five also defines eligibility for medicare benefits, retirement, and is commonly used in research to describe the elderly (Tsuji, Minami, Keyl, Hisamichi, Asano, Sato, & Shinoda, 1994). Therefore, for the purpose of this study "elderly family member" will be a related person who is chronologically age sixty-five or older.

Dementia

Dementia is a syndrome characterized by intellectual deterioration of an adult that changes or interferes with social or occupational performance (Katzman, 1986). AD accounts for 50 to 60 percent of the dementia patients (Katzman, 1986).

The Alzheimer's Association describes AD as a medical condition that disrupts the way the brain works involving thought, memory and language (1995). For the purpose of this study, AD will be described as a progressive neuropsychiatric disease affecting brain matter and is characterized by the loss of cognitive function as well as affective and behavioral disturbances (Butler, 1990).

Caregiver

Webster's dictionary (1988) defines to take care of as "to have charge of or be responsible for: to look after; attend to; to provide for; protect against trouble, want" (p.212). For the purpose of this study, this definition will be used but the caregiver will be the self-acknowledged family caregiver who is responsible for care and/or supervision of the AD patient. The majority of care for the AD patient is provided by the spouses and by the adult children of the patient (Given, Collins, & Given, 1988).

Continuity Theory: A Conceptual Framework

The Continuity Theory was developed in the late 1960's and 1970's (Vander Zyl, 1979). It holds that in the process of developing into an adult, a person develops individual habits, preferences, and dispositions that become part of their personality (Vander Zyl, 1979). These dispositions continue and are maintained into old age. Continuity Theory is a psychosocial theory and infers that personality type will remain consistent as persons grow older and their behaviors and habits will be consistent throughout their life span (Burbank, 1986).

"Continuity Theory assumes evolution, not homeostasis, and this assumption allows change to be integrated into one's prior history without necessary causing upheaval or disequilibrium" (Atchley, 1989, p. 183). The Continuity Theory helps to explain how adults use concepts from the past to structure how they will respond to changes in the future that occur in the normal aging process (Atchley, 1989). Normal aging refers to an aging pattern common to all people that does not include physical or mental disease (Atchley, 1989).

The Continuity Theory is described in terms of both internal and external structures. Internal structure requires memory and deals with experiences, preferences, dispositions, a psychic structure of ideas (Atchley 1989).
The internal continuity is instrumental in decision making, ego integrity, self-esteem, and is used to meet the important needs of social interaction and social support (Atchley, 1989).

The external structure determines behavior. People have an expectation of how a person will react that is a result of how they reacted in past roles (Atchley, 1989). External continuity is determining of predictable social support, self-concept, coping with the aging process, and decreases the ambiguity of personal goals that come with changes such as retirement (Atchley 1989).

The Continuity Theory consists of four major concepts: age, role activity, personality type, and life satisfaction. Age is defined as the chronological age of the person. Role activity will be different for each person but many experience common basic roles in their lives: spouse, parent, grandparent, worker, homemaker, citizen, neighbor, group member, church member (Neugarten, Havighurst, & Tobin, 1968).

The third concept is personality. Personality, depending on the author or measuring tool, is categorized differently by various researchers and is multidimensional. The basic assumption in this concept is that one's personality does not usually change as one gets older. Personality influences role activity and maintaining relationships with others. Personality type by definition is "the extent to which the individual is able to integrate emotional and rational elements of the personality" (Burbank, 1986).

The fourth concept in the Continuity Theory is life satisfaction which has been operationalized in terms of psychological well-being. Depending on the researchers the measures are different for different studies. Neugarten, Havighurst, and Tobin (1968), indicated that life satisfaction reflects how one feels about one's life; was it meaningful?, did one achieve their life goals?, do they have a positive self-image?, are their maintaining a happy and optimistic attitudes and moods. Bearon (1989) indicated that there was a relationship between achievement and aspirations and situation factors. These concepts interrelate with each other to form the theory of continuity.

Normal continuity is seen in Figure 1. Age, personality, and role activity all affect life satisfaction. Life satisfaction is a subjective perception and is linked to each persons personal history.

"Discontinuity involves change seen by the individual as sharply diminishing her or his capacity for coherence in some aspect of his or her identity" (Atchley, 1989, p.187). Discontinuity alters identity, so that the person has no standard to assess life's integrity creating internal discontinuity (Atchley, 1989). This can lead to depression, anxiety, lack of hope and can be seen in people with dementia or illness with serious outcomes (Atchley, 1989).

Discontinuity is seen in Figure 2. As one gets older the incidence of dementia increases. Dementia will alter the personality type changing the patient's continuity. The patient no longer can remember previously established patterns in relationship with their social environment for decision making and how to act.

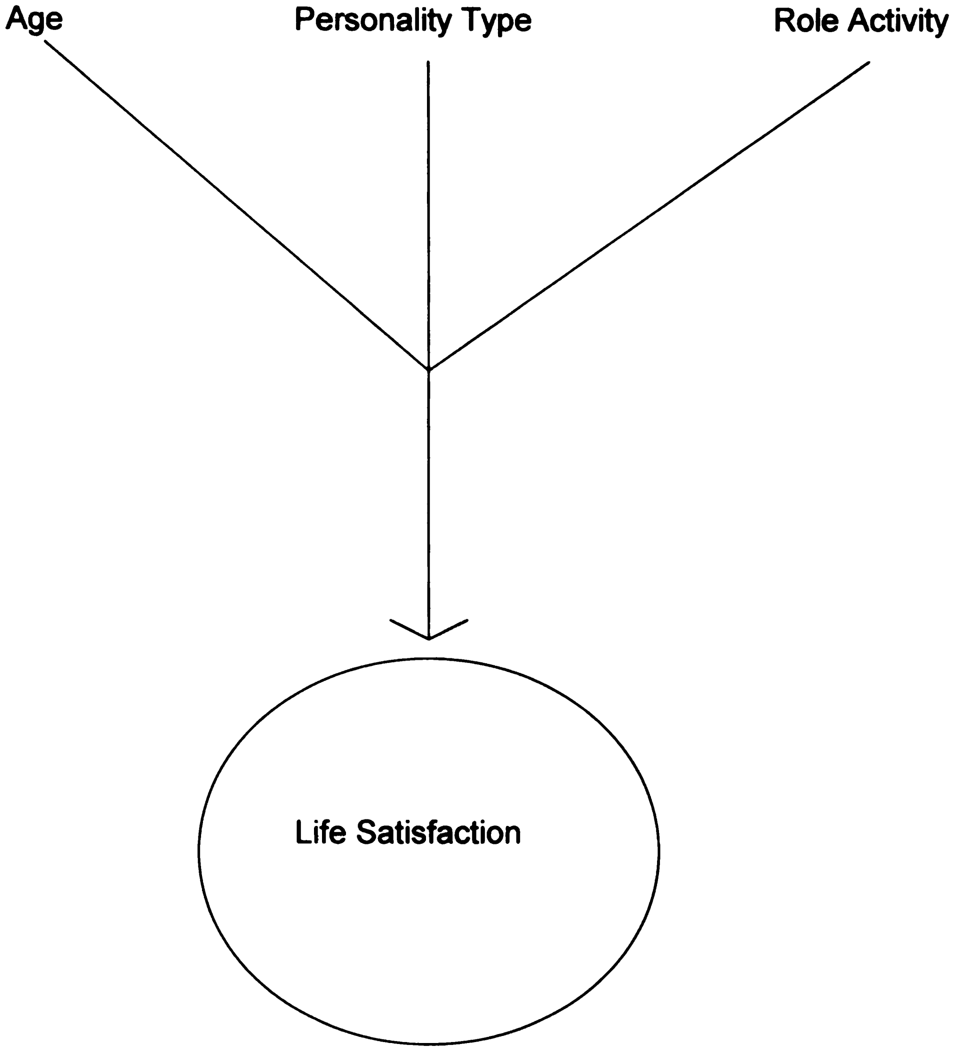

Figure 1 Relationship of Variables in the Continuity Theory. Adapted from Neugarten, Havighurst, & Tobin, (1968)

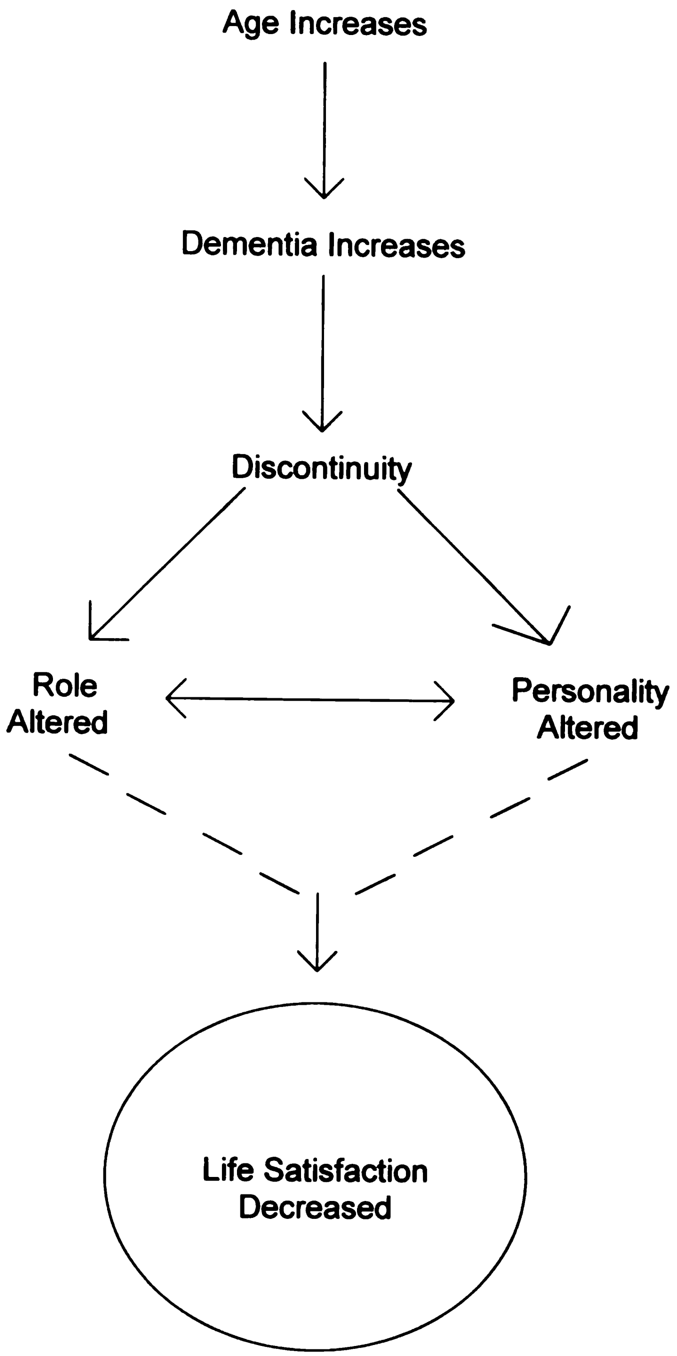

Figure 2 Relationship of Variables of Continuity Theory in the Presence of Alzheimer's Disease. A theorized adaptation. Neugarten, Havighurst, & Tobin, (1968)

Changes in personality will affects the patient's roles and increase discontinuity. The patient may have changes in or alteration of his role function. A sense of predictability is present with normal role activity and is often a major goal with older people (Atchley, 1989). A loss of continuity affects life satisfaction.

Rationale For Use Of The Continuity Theory With This Study

The purpose of this study was to look at first awareness of behavior changes as noted by the family caregiver of a patient with AD. Therefore, an internal or external discontinuity occurred indicating something was wrong as Atchley (1989) noted was seen in those with dementia.

Implications for Advances Practice Nurses

The APN needs to be knowledgeable in all aspects of care of the AD patient as well as the financial, physical, and mental stress to the patient and caregiver. The additional knowledge obtained from this study will assist in earlier detection of AD. Emphasis needs to be based on early detection and getting the patient into the health care system. Prevention of health and psychosocial problems needs to be stressed for the patient and all of the family members in addition to the treatment of pathology (Vander Zyl 1979). Using the Continuity Theory as a basis for understanding the aging process the public and health care system can reject stereotyping the elderly and look at each person with their needs and preferences, lifestyles and personalities when assessing and planning (Vander Zyl 1979).

The APN working in a primary care setting has the unique opportunity of directly working with the caregiver, family and patient. The APN can enhance the AD patient and families lifestyle with increased understanding of the disease process.

REVIEW OF LITERATURE

Research and Alzheimer's Disease

The research on AD has many different focuses but this researcher could not find any research based studies that dealt with early detection of AD. Current available studies focus on genetics, changes in brain chemistry, impact on memory, language abnormalities, degenerating nerve cells, and ways to improve the quality of life for the AD patient (Alzheimer's Association, 1989).

Alzheimer's Disease and Continuity Theory

This researcher could not find any studies on AD and the Continuity Theory. The theory itself is alluded to in AD by the family noting a change or discontinuity in behavior, memory, personality, or judgment capabilities (Gwyther, 1985). The family is unknowingly using the Continuity Theory by noting a non-typical reaction or response to the stimuli that the AD patient would normally give. Atchley (1989) indicated that a person with dementia would not have access to continuity strategies to deal with changes and adapt to new situations since they have impaired memory which would alter their internal continuity but no studies are available.

Critique of Literature

The majority of the literature falls into four categories: studies being conducted on the cause of the disease, definition of the disease, care of patient, and the caregiver. The Alzheimer's Association has a large and very informative set of publications about the disease and it's symptoms. They are also funding a large variety of research studies related to Alzheimer's disease. Many books are available on strategies for the care of the Alzheimer's patient both at home and in the nursing home with different strategies related to stages of the disease process. Little exists, however, to aid in understanding how the disease is identified during it's early stages.

Many articles are available on the diagnosis of the disease and what tests to do to assist in the diagnosis of the disease but the area not being addressed is the first symptoms of the disease. With early detection, treatment can start earlier and may result in a longer, more productive life for the patient and a less stressful life for the family.

No articles that this researcher could find dealt with the combination of the Continuity Theory and AD. There are only limited articles available on the theory itself. Most research on AD relates to the cause of the disease. None looked at the specific first symptoms.

METHODOLOGY AND PROCEDURES

Qualitative Research Assumptions

Content analysis of interview responses was used by the researcher as a qualitative method. The content analysis method is used with narrative communications for quantifying the content (Polit & Hungler, 1991). Polit and Hungler (1991) describe content analysis as "a procedure for analyzing written or verbal communication in a systematic and objective fashion, typically with the goal of quantitatively measuring variables" (p.642). Analysis begins with a search for themes that embody a common concept or idea. When the themes are identified then classification takes place so that categories are developed. The concepts are compared against each other to include similar phenomenon and grouped into categories (Strauss & Corbin, 1990). The coded date can then be analyzed using the qualitative method of content analysis (Polit & Hungler, 1991).

Primary Research Project

The primary project was a qualitative study by Dr. Sharon King "Perceptions of Community Services by Alzheimer's caregivers". The project was funded by the Alzheimer's Association. The objective of the study was to understand caregiver's use of and response to a set of specific community services. Additional data were obtained on caregiver patterns of help-seeking behavior, state of patient's disease and behavioral symptomotology (King, 1989).

Primary Sample

In the primary sample 34 caregivers of family members with AD were interviewed. The sample was a non-random, convenience sample of self-acknowledged caregivers of a family member over 55 who had a diagnosis of AD. The convenience sample was obtained through the mailing distributed to the Michigan Association of Adult Day Care, the local Alzheimer's Association and southwest Michigan health agencies. Contact was made by telephone and subjects were asked if they would participate in an interview on community services.

Protection of the Subjects

The caregivers, who were interviewed, gave written permission for the interview and were allowed to stop the interview at any time. Confidentiality was assured by the interviewer and anonymity was kept by giving the subjects numbers instead of references by name. All research was approved by University Committee on Research Involving Human Subjects (UCHIHS). The protection of human rights for subjects was achieved by adherence to the rules and regulations of the UCRIHS. Protection of human subjects rights and welfare was maintained when reviewed by the 20 member committee (IRB #89-278).

The project was reviewed and approved by the committee for primary study June, 1989 (see Appendix A). The regulations were followed for the secondary analysis and confidentiality was achieved through nondisclosure of names. Refer to Appendix B for the UCRIHS letter for approval of the secondary analysis.

Data Collection

The 34 subjects responded to questions in a semi-structured face to face interview. The Interview Guide is shown in Appendix C. Interviews were tape-recorded and were transcribed verbatim onto an ethnographic computer program. Open ended questions were used to explore first awareness of AD, chronology of the disease and response of the caregiver, current view of the caregiver, future views, and help seeking behavior (King, 1989). The Ethnograph program was used because the program was especially designed for analysis of qualitative data.

Analysis

Content analysis was used to analyze the data. Themes were identified allowing for category development. Coding was then possible for a systematic way for measuring the information.

Four groups of question were asked pertaining to: first awareness, information on the disease course, current information, and specific services. These were then broken down by the researcher to coding categories of: prior to illness, initial symptoms, and community services. Three nurse researchers in the area of caregiving developed the coding scheme (Appendix D) and entered the data in the ethnographic computer program. The principal investigator, graduate assistant and the researchers independently coded the interviews and reviewed for coding discrepancies.

Reliability and Validity

A consultant, who is a qualitative researcher and familiar with ethnographic research methodology, was asked to assist in the identification of the themes in the interview transcripts and to assist in determining validity and reliability (King, 1989). Pilot interviews were used to develop and refine the interview questions. The interviewer asked probing questions until all responses were achieved and clarified. After the interview, two trained research members independently coded the information and reviewed transcripts for coding discrepancies.

Secondary Research Sample

The secondary analysis data was taken from the same 34 transcripts from the primary study. The primary bulk of information was taken from those questions under "first awareness".

Secondary Data Analysis

The transcripts in the primary study were analyzed for those references by caregivers of first awareness of patient symptoms. The bulk of the information were responses to the question under the title "first awareness" but many references were identified throughout the transcripts. References to the first awareness of symptoms were collected and information was reviewed for themes. The Continuity Theory was used to help identify the themes using age, roles, personality changes and behavior changes as a beginning outline. A matrix was developed to aid in analysis of the interview information.

This researcher also reviewed who made the statements in terms of relationship to patient. Statements of first awareness of behavior changes were categorized by relationship of wife, daughter, son, and other.

Validity and Reliability

The methods assuring the validity and reliability in the primary study were stated earlier. To assure validity, only the data contained in the segments code with first awareness symptoms were used: Patient Symptoms (PATSYMPT), Obtaining Diagnosis (OBTDX), Diagnosis confirmation (DXCONFIX). To assure reliability the transcripts were reviewed to make sure the statements are complete and all first awareness statements were identified from the transcripts.

To assure that all pertinent data was being considered, related to first awareness, a random recoding was done. Using a research staff member familiar with the coding process, three random transcripts were selected and recoded to validate the reliability of the original coding.

Methodological Limitations of Qualitative Research

One of the drawbacks of qualitative research is the volume of data that is produced. To combat this limitation the data collected is coded to condense the qualitative materials. Polit and Hungler stated (1991) "We believe that an understanding of human behavior, problems, and characteristics is best advanced by the judicious use of both qualitative and quantitative data (p.500).

Qualitative research can give insight into an aspect of a human experience. It can not show a cause-and-effect relationship, testing for research hypotheses, determining opinions of practice or attitudes of a large group (Polit, Hungler, 1991).

Due to the large amount of narrative material for analysis only a small sample is used. The analysis is very time consuming, making a larger sample unfeasible. This makes generalizing of findings inappropriate (Polit & Hungler, 1991).

A limitation of secondary analysis is the difficulty attempting to glean information from interviews that have already been completed, frequently for a different purpose. Additional questions pertaining to this research investigation could have been asked to probe the problem more fully or clarify, but are not possible with secondary analysis. The subjects were also asked to recall events that have already occurred. Therefore, limitations also exist related to the subjects memory and the passage of time.

PRESENTATION OF DATA AND ANALYSIS

The analysis of the coded segments: PATSYMPT, OBTDX, DXCONFIR, contained information regarding initial awareness of AD. PATSYMPT (patient symptoms) was the category that was supposed to be coded for any comments that were relative to the caregiver's description of the initial awareness but often included later symptoms in the answers. DXCONFIR (confirmation of diagnosis) was found in a few interviews to contain early symptoms of AD in the transcripts. OBTDX (obtaining diagnosis) contained the coded statements the caregivers made about the experience in obtaining the diagnosis of the disease but some statements also contained some symptoms.

Subjects

The 34 caregivers represented in this sample of transcripts were primarily women: 11 spouses, 13 daughters, two daughter-in laws, and one sister. Only seven of the caregivers were male and they were all spouses.

The AD patients were fairly evenly divided between females and males. Of the 34 patients 18 were female and 16 were male. The relationships of the female patients to the caregiver included: ten who were mothers of the caregiver, seven who were wives, and one who was a sister. The male patients consisted of three who were fathers to the caregiver, 11 who were husbands, and two who were father-in-laws. See Table 1 for demographics.

Findings

The analysis of the data was based on the code segments OBTDX, DXCONFIR, and PATSYMPT from the transcribed interviews. The responses from these segments were sorted to obtain only those comments regarding initial symptoms. Many caregivers described symptoms occurring later in the disease when asked to respond to questions regarding initial symptoms. The Continuity Theory of aging was used as a guide to try to identify themes when analyzing the data.

Many of the caregivers when talking about the initial symptoms noticed one to three symptoms. Fourteen (41.2%) were able to identity only one symptom, twelve (35.3%) noted two, and eight (23.5%) of the caregivers identified three initial symptoms.

Seven categories were observed in the breakdown of the initial symptoms: a change in visual-spatial skills, a change in arithmetic skills, a language disturbance, some type of psychiatric symptoms, forgetfulness, a change in judgment skills, and a gait change.

Of the 34 caregivers in the study, twenty-three (67.6%) listed forgetfulness as a initial symptom. Twenty (58.8%) noted a psychiatric symptom, this included: mood changes, anxiety and phobias, social withdrawal, behavioral

Table 1

Description of subjects (n=34).

VARIABLE	%	(n)
SEX		
FEMALE	79.4%	27
MALE	20.5%	7
FEMALE CAREGIVER RELATIONSHIP TO PATIENT (n=27)		
WIFE	40.7%	11
DAUGHTER AND/OR DAUGHTER-IN LAW	55.5%	15
SISTER	3.7%	1
MALE RELATIONSHIP TO PATIENT (n=7)		
HUSBAND	100%	7
SEX Of Patient		
FEMALE	52.9%	18
MALE	47.0%	16

disturbances, paranoia and delusions, self neglect, and depression. Five (14.7%) noted a problem with arithmetic skills. Four (11.7%) noted a visual-spatial skill change. Four (11.7%) noted a gait change, most included falls. Four (11.7%) noted a language disturbance. Two (5.8%) noted a cognitive skill change. Zero noted no behavior change. See Table 2 for a summary of symptoms categories.

Themes

After segments of the transcriptions were sorted into categories of the different symptoms noted as first awareness the Continuity Theory was used to help identify themes from the information collected. From the study findings

Table 2

Categories of Identified Symptoms

VARIABLE	%	(n)
Forgetful	67.6%	23
Psychiatric symptoms	58.8%	20
Arithmetic skill change	14.7%	5
Visual-Spatial change	11.7%	4
Gait change	11.7%	4
Language disturbance	11.7%	4
Judgment change	5.8%	2
No behavior change	0%	0

several recurrent themes emerged; memory/cognitive changes and personality changes.

Memory/Cognitive Changes

A major theme was the memory/cognitive change. In the Continuity Theory, Atchley (1989) states "internal continuity is defined by the individual in relation to remembered inner structure, such as the persistence of a psychic structure of ideas, temperament, affect, experiences, preferences, dispositions, and skills" (p. 184). According to Atchley (1989), internal continuity requires memory. Atchley indicates that people use internal continuity as a foundation for decision making and cognitive knowledge is an large element of the persons capacity to anticipate and interpret events. Atchley indicated that without cognitive knowledge there is no predictability in the world, and without predictability competence and mastery are not possible.

Both memory and cognitive knowledge are necessary for internal continuity. When these factors are altered, Atchley (1989) indicates that a change in internal continuity will affect ego integrity, self-esteem, alter the motivation for meeting important needs, and maintenance of social interaction and social support.

Of the 34 caregivers used in the study, 23 noted a change in memory. Some transcripts included statement about behaviors such as forgetting food was on the stove, how to dress, how to add up numbers or figure out the checkbook. One caregiver noted that her mother's memory was getting worse and worse and she would forget about money, paying bills, medicine and meals. Many mistakenly assumed that this behavior was a normal part of the aging process until the symptoms were quite pronounced. Some even indicated that even when they took their family member to the health care provider, the provider didn't think anything was wrong and attributed behavior to aging. An example of a physician's attitude on one transcript was " he just lumped it as growing old and everyone goes through this one way or another". The care provider had just taken two classes on dementia and decided her mother needed an assessment done and took her to the Geriatric Assessment Center. When the assessment was completed her mother was diagnosed "in mid to late stage of the middle phase of dementia".

In nine of the transcripts a notable change in memory and/or behavior occurred following a traumatic experience. This involved a death or accident of spouse or an accident or surgery of the patient. Many of the caregivers used these experiences to rationalize the change in behavior. An example of this rationalization as stated by a care provider: "She was well, after she had broken her hip the first time, it started then. I could tell, she was losing her memory. Slow but sure". Another care provider stated about her mother dealing with her father's illness: "She was really unable to adapt to some of those changes. We thought it was just his condition and having to many things to remember."

Personality Changes

Twenty caregivers noted a change in personality as the first awareness of the disease. Atchley (1989) states "people are expected by others to present themselves in a way that is obviously tied and connected with their past role performance" (p.185). Atchley (1989) also stated that "self and identity are terms that refer to interrelated intrapsychic structures" (p.186). Atchley (1989) felt "self concept is what we think we are like: our appearance, abilities, preferences, emotionality, personal goals, level of performance, attitudes, roles, and so on..." (p.186). Identity refers to self and personality that are part of the person (Atchley, 1989). Both internal and external continuity are needed for a healthy adult.

In some of the transcripts, the caregiver just noted a change in personality. Others were more specific with their answers. Noted changes were mood, social withdrawal, behavioral disturbances, self neglect, anxiety or fearfulness. One caregiver noticed "she would do things totally alien to her personality". "She gave up all social activities". One caregiver noted her family member used to be a meticulous housekeeper, now dust was on things and disarray was evident. Another caregiver noted pacing behavior and repetitiveness. Nearly all subjects noted a change in the patient's personality but some were later symptoms in the disease process.

Caregivers have been providing care for their family member from one to nine years. Some patients needed assistance with grooming or dressing and were fairly independent while other were totally dependent at the time the interviews were conducted. Caregivers described a gradual development of forgetfulness that was so insidious in nature that it was difficult for them to describe the beginning.

Personality changes occurred, and in some cases arithmetic skills and visual-spatial orientation were the first symptoms. Some noted a change in their families members roles. Some patients had been very family oriented and now thought only about themselves and some patients limited or eliminated social connections. Some caregivers noted a gradual change in their family member that resulted in a change of life satisfaction. One patient stated to their family member "I'm no good, I want to shoot myself like this". Many didn't even remember how much they had changed and it was the caregiver who became aware of changes in the AD patient's level of life satisfaction. One caregiver noted a change in her mother's speech, "she used to be an extemporaneous talker, but now she only listens. She used to help at the Alpha Center but she changed."

DISCUSSION AND IMPLICATIONS

Over two-thirds (67.6%) noted memory problems as a initial first awareness symptoms, and/or a personality change. Interestingly, the first symptoms were usually so insidious that the family blamed the behavior changes to other factors occurring in their families lives. Adams and Victor (1990) indicated that the development of forgetfulness is a major symptom of AD that was also a major symptom noted in this study. Staab and Lyles (1990) stated "In a normal elderly person there should be no drastic change in general appearance, and behavior, level of consciousness, stream of mental activity, thought content, emotional reaction, and self image" (p. 521). Staab and Lyles (1990) indicated that there is a very gradual failing of short-term memory but in a normal adult a forgotten item will be remembered later but in a AD adult it will remain forgotten.

The two major themes of memory/cognitive changes and personality changes indicated that the behavioral changes noted by the caregivers were typical behavior changes as described in the literature on AD. However, the caregiver sometimes did not consider the change as abnormal for an aging adult. In some cases even when the families noted a change or discontinuity the care provider did not see a problem. One caregiver stated, " It was simply an exaggeration of idiosyncrasies. And I thought well he's 71, I thought well he's just getting, you know, more of the way he's always been."

Critique of Continuity Theory as a Framework

Continuity Theory was used as a guide for this study. The theory helped to categorize and develop themes. This allowed for easier analysis of the information presented. The researcher hoped to show how the concepts related to each other in normal aging, and make it easier to see abnormal or discontinuity behavior. One of the concepts on the Continuity Theory is role. In some cases a change of role was noted by the caregiver but this researcher initially hoped to use role change as a theme in the study. This did not occur. The role changes were mostly implied, such as being active in social events to limited involvement, or a change in roles from being a caregiver of children and grandchildren to being the one receiving care. The role changes were not an initial behavior change but the behavior changes did result in a change of role. Role change questions were not included in the initial study and would have been helpful with this study.

Using the Continuity Theory of aging made it easy to see how age, an alteration in roles, and change in personality affected life satisfaction with AD patients. It was helpful to see how discontinuity in one area affected the others.

Limitations and Strengths of the Study

The first limitation of the study was subjects were not randomly procured. The caregivers were volunteers who consented to the interview process. The study was a secondary study, conducted from transcripts obtained from a longitudinal study with the primary focus on community services. The study sample was small and limited to a specific area so the result might not be the same if a broader study were obtained.

A significant limitation of the study was the limited number of questions that dealt with first awareness. It would have been beneficial to have additional questions that focused on this area. Often it was very difficult, since it was a retrospective study, to identity the FIRST AWARENESS behavior the caregiver noted. The caregivers tended to ramble, lumping initial symptoms and later symptoms in one answer making it very difficult to identify what the first awareness symptom were. Additional probing questions would have been helpful to try to pin down what were the first awareness of symptoms.

A strength of the study was that in using a qualitative approach it did allow for the answers expressed to show what the caregiver actually thought and not try to pin them down to yes or no answers. Concepts could have been lost in a multiple choice response, or yes or no answers.

Implications for Nursing Practice, Education, and Research

The results of the study suggest implications for nursing practice, education, and research. With the advanced roles in which nurses are presently employed and the new expanding roles that are being created, the need for a highly skilled APN will only continue. An APN in a primary health care role functions as a health care generalist "delivering primary care place emphasis on wellness, or promoting the client's and families' ability to cope with illness, to adjust and adapt to disability and incapacitating illness" (Nursing 501 syllabus p.24). With AD, the APN needs to be knowledgeable in all aspects of care. Emphasis needs to be based on early detection and getting the patient into the health care system. Prevention of health and psychosocial problems needs to be stressed for the AD patient when an assessment is completed by the APN. Family members and the health care system need additional education on the prevent of problems with AD in addition to the treatment of pathology (VanderZyl, 1979).

The APN should conduct a thorough assessment of his/her patients especially when a behavior/personality change is noted or if there is a problem with forgetfulness. Forgetfulness should be a question explored on the history and physical to see if normal aging is present or the beginning of AD. It would be beneficial to have a family member with the patient when the history is done. Many elderly are afraid that if they are forgetful, then they are showing the first signs of senility. This fear causes many patients to hide their symptoms. With a family member present it would be easier to detect any memory changes. It is important to pick-up early symptoms to rule out reversible conditions, such as fever, poor nutrition, reaction to medication, emotional problems or a head injury (U.S. Department of Health and Human Services, 1993).

AD is irreversible and can not be cured but with early intervention by the APN there is still a lot that can be done the treat the patient and help the family to cope with the present situation. Clearly, more exploration is needed with identification of early AD for the prevention of health and psychosocial problems and stress on the families. The APN has the unique opportunity to enhance the lifestyle of the AD patient and family with early detection of the disease process.

In many of the transcripts a lack of knowledge was noted from the caregiver and in some cases the primary care provider. Education needs to start in the medical and nursing school. Not only should normal aging be included in the course work, abnormal aging should also be included. This will allow for a better understanding of the life and aging process and what is considered abnormal aging so that early intervention can be started with the first symptoms of AD.

This study indicates that more research needs to be done with AD and an increase of education in the health care system and public. A recommendation from this study is to use the Continuity Theory with a longitudinal study of AD patients. This would provide a comparison of the AD patient with the individual themselves as they age. This research design allows for looking at a specific segment and/or a different point in the subjects life of the disease. This accounts for the personality and lifestyles of the people in the study which does not occur in a cross sectional method or using a different theory as a basis for the study (Vander Zyl, 1979). It will also eliminate many of the problems dealing with a caregiver having to remember events from years prior to the study. With the lack of education within both the health care system and families, the need for community education is vital. The transcripts indicated that forgetfulness and a personality chance were some the first changes noted by the caregiver. The caregivers, at times, indicated that caregivers thought forgetfulness was normal when getting older. The concept of what is normal aging and abnormal is not well understood.

In the Continuity Theory the concept of old age is part of the life cycle and not a terminal end of life (Vander Zyl, 1979). With the assumption in the Continuity Theory that as one grows older their predisposition towards maintaining continuity continues, the caregiver can note when the family members behavior alter or attitudes change from their normal pattern. With the pattern changes the caregiver should be concerned with this first awareness and begin medical evaluation. With the increase of an aging population the age prevalent disease of AD will only increase. The public and the health care system need to be aware of what is considered a change from normal, such as forgetting a name but remembering it later, unlike the forgetfulness noted in AD (Gwyther, 1985). This type of misconception points out the lack of knowledge that is present today. The APN can use the information in this study to built upon for research, education, and in the primary healthcare setting.

Summary

The purpose of this study was to examine reports of first awareness of AD as reported by the family caregiver. The Continuity Theory was used to help identify the discontinuity behavior noted. The findings of this study showed that forgetfulness and personality changes were the two major symptoms that the caregiver noted. Present literature on AD indicates that forgetfulness is often the first symptom noted (Adams & Victor, 1985). Personality changes occur later in the disease process (Adams & Victor, 1985). The caregivers in some transcripts showed lack of knowledge about what was going on with their family member. Many could have been evaluated earlier in the disease process if the discontinuity behavior was recognized.

The APN needs to be aware of the subtle changes of AD when evaluating their patients. Additional research needs to occur on the first awareness symptoms, so that prevention of health and psychosocial problem of AD will occur, resulting in an enhancement of lifestyle for the AD family and patient.

No research is available with AD and the Continuity Theory. This would be a unique opportunity to expand the knowledge base of nursing using these two concepts. As the population ages the problems dealing with AD will only continue. The time is now to understand and use the information acquired to better the lives of the AD patient and their family.

APPENDICES

APPENDIX A

MICHIGAN STATE UNIVERSITY

UNIVERSITY COMMITTEE ON RESEARCH INVOLVING HUMAN SUBJECTS (UCRIHS)
206 BERKEY HALL
(517) 353-9738

EAST LANSING • MICHIGAN • 48824-1111

June 5, 1990 **IRB# 89-278**

Sharon King, Ph.D., R.N.
College of Nursing
A230 Life Sciences

Dear Dr. King:

RE: "PERCEIVED BARRIERS TO THE USE OF COMMUNITY SERVICES BY ALZHEIMER'S CAREGIVERS **IRB# 89-278**"

UCRIHS' review of the above referenced project has now been completed. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and the Committee, therefore, approved this project at its meeting on June 4, 1990.

You are reminded that UCRIHS approval is valid for one calendar year. If you plan to continue this project beyond one year, please make provisions for obtaining appropriate UCRIHS approval one month prior to June 4, 1991.

Any changes in procedures involving human subjects must be reviewed by the UCRIHS prior to initiation of the change. UCRIHS must also be notified promptly of any problems (unexpected side effects, complaints, etc.) involving human subjects during the course of the work.

Thank you for bringing this project to our attention. If we can be of any future help, please do not hesitate to let us know.

Sincerely,

John K. Hudzik, Ph.D.
Chair, UCRIHS

JKH/sar

APPENDIX B

MICHIGAN STATE
UNIVERSITY

May 24, 1996

TO: Deborah Oegema
1319 Madison St.
Muskegon, MI 49442

RE: IRB#: 96-364
TITLE: WHAT TO PRIMARY CAREGIVERS IS THE REPORT OF FIRST AWARENESS OF AN ALTERATION IN BEHAVIOR OF AN ELDERLY FAMILY MEMBER DIAGNOSED WITH DEMENTIA?
REVISION REQUESTED: N/A
CATEGORY: 2-H
APPROVAL DATE: 05/23/96

The University Committee on Research Involving Human Subjects'(UCRIHS) review of this project is complete. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, the UCRIHS approved this project and any revisions listed above.

RENEWAL: UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Investigators planning to continue a project beyond one year must use the green renewal form (enclosed with the original approval letter or when a project is renewed) to seek updated certification. There is a maximum of four such expedited renewals possible. Investigators wishing to continue a project beyond that time need to submit it again for complete review.

REVISIONS: UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. If this is done at the time of renewal, please use the green renewal form. To revise an approved protocol at any other time during the year, send your written request to the UCRIHS Chair, requesting revised approval and referencing the project's IRB # and title. Include in your request a description of the change and any revised instruments, consent forms or advertisements that are applicable.

PROBLEMS/ CHANGES: Should either of the following arise during the course of the work, investigators must notify UCRIHS promptly: (1) problems (unexpected side effects, complaints, etc.) involving human subjects or (2) changes in the research environment or new information indicating greater risk to the human subjects than existed when the protocol was previously reviewed and approved.

If we can be of any future help, please do not hesitate to contact us at (517)355-2180 or FAX (517)432-1171.

Sincerely,

David E. Wright, Ph.D.
UCRIHS Chair

DEW:bed

cc: Sharon King

OFFICE OF
**RESEARCH
AND
GRADUATE
STUDIES**

**University Committee on
Research Involving
Human Subjects
(UCRIHS)**

Michigan State University
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APPENDIX C

INTERVIEW GUIDE

Use Of Community Services By Alzheimer's Caregivers

The reason for this interview is to get a detailed picture of your experience taking care of a person with Alzheimer's Disease. We would like to know as much as possible about what kinds of help you need now or may have needed at times in the past. I'm interested in knowing what experiences you may have had in looking for help and what things are important for service providers to know when they are planning services for people in situations like yours.

A. FIRST AWARENESS: I would like to start out by talking about the history of your relative's Alzheimer's Disease and the events leading up to your awareness of the disease.

1. Describe yourself and your relationship with the patient before the problem with Alzheimer's Disease began.
2. Describe the situation when you first noted difficulties or what you think was the beginning of the Alzheimer's Disease.
    a. How were you spending time? What was happening in your life at the time?
    b. How did you first suspect that something was wrong?
    c. What did you do before going to the doctor? Did you ask for or receive advice from friends of family?
    d. Tell me about the experience you had getting a diagnosis for you (Parent/spouse). Was S/he diagnosed as having Alzheimer's Disease the first time that you went to the doctor?
    e. What was your reaction to finding out that (parent/spouse) had Alzheimer's Disease?

f. What did you know about Alzheimer's Disease at the time (parent/spouse) was diagnosed? Had you ever know anyone else who had it?

g. What did you need in the way of help when you (Parent/spouse) was diagnosed?

h. What help did you seek at that time?

i. What help did you think about seeking but didn't? What prevented you?

3. Help-seeking patterns. I am interested in knowing about the ways that you have gotten the kind of help for other problems that you may have had in the past.

   a. Over time, has it been easy for you to ask for for help from others?

   b. What kind to help can you ask for?

   c. What kind of help can you not ask for?

   d. How does it make you feed when you face a situation that is so difficult to handle that you need to seek help from other?

B. THOUGH THE COURSE OF THE DISEASE: People with Alzheimer's Disease go through a lot of changes. I'm interested in knowing more about what those changes have been for your (parent/spouse) and how they have affected you.

   a. As time processed, what changes occurred in you (parent/spouse) as a result of the Alzheimer's Disease?

   b. How did the demands of caregiving change for you as the disease progressed?

   c. How did your life change as the Alzheimer's Disease became more severe?

   d. What else was going on in your life at the same (besides taking care of the patient)?

e. Describe the feelings you had as your patient d developed different symptoms of Alzheimer's Disease. Were there times that you felt embarrassed? Inadequate? Afraid?

f. Did you first seek some kind of assistance with the care of your (parent/spouse)?

g. When did you first seek some kind of assistance with the care of your (parent/spouse)?

h. What kind of assistance was that? How did you know about that particular service? What did it cost for you to use it?

i. What prompted you to look for assistance at that time?

j. What did you get out of the service you used? How did they help your (parent/spouse)? How did they help?

k. What did you lose in the process?

l. Tell me all of the good things and the bad things about the services that you used to help you take care of your (parent/spouse).

C. VIEW FROM THE CURRENT MOMENT: You told me about what it was like when your (parent/spouse) first developed Alzheimer's Disease and the things that have taken place since that time. I'm also interested in what it is like for you right now and how you think things may change in the future.

1. What services are you using to help you take care of you (parent/spouse) right now?

   a. How much help are those services to you?

   b. What would make them better?

   c. How did you locate these services?

2. Looking back, if you could have found just what you needed to make this whole experience easier for you, when would that have occurred?

   a. What would it have looked like?

    b. Would you have used it?

3. What are the most important areas, form your perspective, that people like you need assistance with?
    a. Is their a "right time" and a "wrong time" for certain kinds of services (ask for example)?
    b. What kinds of things kept you form using services when you might have needed them?

D. SPECIFIC SERVICES: The things that you need to help you change over time and so do the things that you expect from different kinds of services. These questions are about what you have experienced with several different sorts of services. Answering the questions about some of these services may make you feel like you are repeating yourself. If that is the case, could you just summarize your experiences with the service.

1. Describe your experience with the following kinds of services; What do you know about them? Have you used them? Did they help?
    a. visiting nurses,
    b. home health aides,
    c. adult day care,
    d. home companions/sitters,
    e. family support groups,
    f. housekeeping/chore services.
2. Is there anything else that we should understand about how community services do and do not help you that hasn't been touched upon by any of the questions?

APPENDIX D

CODING CATEGORIES

PRIOR TO ILLNESS

CGVSELFC	Caregiver self-concept
PTPASTID PTPASTBH	Caregiver concept of patient identity, Patient's past professional identity and character traits, caregiver's characterization of patient's past behavior traits
RELATEQU	Perceived Quality of Relationship
RELATECH	Characteristics of Relationship
PREVHELP	Previous help seeking behavior (caregiver)
CGVROLES	Roles-(Work role, Social role, Family role)
FAMACTV	Family Activity
ALZEXP	Past Experience with Alzheimer's Disease
	Identified Support
SUPPNET	Quantity of supportive others-Who are supportive others? family, friend
SUPPQUAL	Quality of identified support

INITIAL SYMPTOMS

CGVREACT	Caregiver reactions (Emotional)
CGVACT	Caregiver Actions Information Seeking Assistance Seeking Taking over Patient Responsibilities
PTREACT	Patient Reactions (Emotional)

PATSYMPT	Patient Actions Memory loss, forgetting Becoming lost Confusion Questionable judgment "Inappropriate" Embarrassing Continuity with past behavior Discontinuity with past behavior
PROVREAC	Professionals" Reactions (Emotional)
PROVACT	Professionals' Actions
FFREACT	Family/friends Reactions (Emotional)
FFACT	Family/friends actions

DIAGNOSIS

COSTDX	Cost
REACTDX	Caregiver reactions to diagnosis
UNDERDX	Caregiver understanding of diagnosis
CONFIDX	Caregiver confidence in diagnosis
DXCONFIR	Confirmation of caregiver suspicions/beliefs
OBTDX	Experience of getting diagnosis

DESCRIPTION OF CAREGIVING

REACONCG	Reason for caregiving
CGVTASK	Description of the caregiving job
CGVFEARS	Caregivers fears
TASKREAC	Reaction to caregiving

COMMUNITY SERVICE USE

ACTCUE	Cues to seeking service "Critical Event"
SERVKNOW	Knowledge of service availability

SERVPROV	Perceptions of service providers
SERVATT	Pre-existing attitudes about service
INFRSOUR	Source of information about service
SERVDM	Process of decision-making in use of service (Who part/ involvement of others, Stated reason for service timing of service Cues: Patient behavior/caregiver reaction/provider)
SERVPTRE	Patient reaction to service
SERVCGRE	Caregiver reaction to service
VALUE	Caregiver's values about outside assistance
SERVPROB	Stated problems associated with service use
SERVBENE	Stated benefits associated with service use
SERVSEEK	Description of process of finding service
HELPNEED	Description of needed assistance
SUPPGR	Support Group
BOOK	"The 36 Hour Day", "Loss of Self"
AFCHOME	Adult Foster Care Home
NURHOME	Nursing Home
RESPITE	In-home respite program
DAYCARE	Out-of-home daycare program
INHOMESK	In-home skilled nursing service
INHOMECU	In-home custodial assistance
ASSESS	Assessment Center
HOUSE	Housekeeping Assistance
MEALS	on Wheels, Mobile Meals, etc.
MEDICAL	Medical services... hospital, clinic, physicians
AGINGAG	Aging agency or commission
CLASS	Programs on Dementia or related issues
ALZASSOC	ALZ Association

LIST OF REFERENCES

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Abraham, I.L., & Neundorfer, M.M. (1990, May-June). Alzheimer's: A decade of progress, a future of nursing challenges, Geriatric Nursing, pp. 117-119.

Adams, R.D. & Victor, M. (1985). Principles of neurology(3rd ed.). New York: McGraw-Hill Book Company.

Alzheimer's Disease Education & Referral Center (1995). The Alzheimer's disease: Fact sheet. Silver Springs, Md: United States Department of Health and Human Services.

Alzheimer's Association (1989). Annual reports on grants, 1989. Alzheimer's Association.

Atchley, R.C. (1989). A Continuity Theory of normal aging. The Gerontologist, 29(2), 183-190.

Atchley, R.C.(1983). Aging: Continuity and change. Belmont, CA: Wadsworth.

A.A.R.P., (1991). A profile of older Americans. pp. 1-14. Washington DC: AARP.

Azari, N.P., Pettigrew, K.D., Schapiro, M.B., Haxby, J.V., Grady, C.L., Pietrini, P., Salerno, J.A., Heston, L.L., Rapoport, S.I., & Horwitz, B. (1993). Early detection of Alzheimer's disease: A statistical approach using positron emission topographic data. Journal of Cerebral Blood Flow and Metabolism 13(3), 438-437.

Bearon, L.B. (1989). No great expectations: The underpinning of life satisfaction for older women. The Gerontologist, 29(6), 772-777.

Bulter, R.N. (1990). Senile dementia of the alzheimer type (SDAT). In W.B. Abrams & R.Berkow, The merck manual of geriatrics (pp. 933). Rahway: New Jersey

Burbank, P. (1986) Psychosocial theories of aging, a critical evaluation. Advances in nursing sciences, 9(10), 73-86.

Chipps, E.M., & Victor, C. (1992). Neurologic Disorders. St. Louis: Mosby.

Gelbart, A.O., & Schwarz, S.B. (1981). The elderly patient with dementia. American Family Physician, 1, 196-199.

Given, C.W., Collins, C.E., & Given, B.A. (1988). Sources of stress among families caring for relates with Alzheimer's Disease. Nursing Clinics of North America, 23(1) 69-82.

Gwyther, L. (1985). Care of alzheimer's patients: A manual for nursing home staff. American health care association and the Alzheimer's Association.

Katzman, R. (1986, April). Alzheimer's disease. The New England Journal of Medicine, 964-971.

King, S., Collins, C., Liken, M. (1995). Values and the use if community services by Alzheimer's caregivers. Qualitative Health Research, 5(3), 333-348.

King, S. (Principal Investigator). Perceptions of Community Services by Alzheimer's Caregiver, Alzheimer's Association. Beverly E. Duchossois Pilot Research Grant # PRG-89-098.

Michigan State University. (1992). Nursing syllabus 501. Michigan State University Press.

Neufeldt, V., & Guralnik, D.B. (1988). Webster's New World Dictionary. Cleveland & New York : Simon & Schuster Inc.

Neugarten, B. L. Havighurst, R. J., & Tobin, S.S. (1968). Personality and patterns of aging. In. Neugarten, B. (ed):Middle age and aging. Chicago: University of Chicago Press.

Polit, D.F. & Hungler, B.P. (1991). Nursing research: Principles and methods (4th ed.). Philadelphia: Lippincott.

Severience, R. (1994). Clarifying the confusion: Alzheimer's disease stages of progression (handout) Gerontology Network Services. Grand Rapids: Michigan.

Staab, A.S., & Lyles, M.F. (1990). Manual of Geriatric Nursing Glenview: Scott, Foresman/ Little Brown Higher Education.

Strauss, A., & Corbin, J. (1990). Basics of qualitative research: Grounded theory procedure and techniques. Newberry Park: Sage Publications.

Tsuji, I., Minami, Y., Keyl, P.M., Hisamichi, S., Asano, H., Sato, M., & Shinoda, K. (1994). The predictive power of self-rated health, activities of daily living, and ambulatory activity for cause-specific mortality among the elderly: A three-year follow-up in urban Japan. JAGS, 42(2), 153-156.

United States Department of Health and Human Services, (1993). Age page: Forgetfulness in old age it's not what you think. Silver Spring, Maryland. Alzheimer's Disease Education & Referral Center.

United States Department of Health and Human Services, (1995). Progress report on alzheimer's disease 1995. Silver Springs, Maryland. Alzheimer's Disease Education & Referral Center.

VanderZyl, S. (1979) Psychosocial theorizes of aging: Activity, disengagement, and continuity. Journal of Gerontological Nursing, 5(3), 45-48.