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A survey of family members' knowledge when dealing with Alzheimer's Disease and dementia

Mark A. Hicks

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To the Graduate Council:

I am submitting herewith a thesis written by Mark A. Hicks entitled "A survey of family members' knowledge when dealing with Alzheimer's Disease and dementia." I have examined the final electronic copy of this thesis for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Master of Science, with a major in Counseling.

Marla P. Peterson, Major Professor

We have read this thesis and recommend its acceptance:

William A. Popper, Lawrence M. DeRidder

Accepted for the Council:
Carolyn R. Hodges

Vice Provost and Dean of the Graduate School

(Original signatures are on file with official student records.)

To the Graduate Council:

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We have read this thesis
and recommend its acceptance:

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Lawrence M. DeRidder

Accepted for the Council:

CWMinkel

Associate Vice Chancellor and
Dean of the Graduate School

A SURVEY OF FAMILY MEMBERS' KNOWLEDGE WHEN DEALING WITH ALZHEIMER'S DISEASE AND DEMENTIA

A Thesis
Presented for the
Master of Science
Degree
The University of Tennessee, Knoxville

Mark A. Hicks
May 1999

DEDICATION

In appreciation of my wife, Mary, who has provided unwavering support during this and all other life challenges.

ACKNOWLEDGEMENTS

I would like to express my sincere thanks to Dr. Marla Peterson, my major professor, for her guidance, support, and encouragement during this study. I am also grateful to Dr. Bill Poppen and Dr. Larry DeRidder for their service on my thesis committee.

I acknowledge with appreciation the agencies and individuals who helped in the distribution of the survey that was used in this study. The staff of the Alzheimer's Association of East Tennessee, Shannondale Nursing Home and Independent Living Facility, Weston Court Specialized Assisted Living Facility, Jefferson County Nursing Home, and Mrs. Vonnie Oaks M.S., L.P.C. made this study possible by generously giving their assistance. Appreciation is also extended to Carrie Springer at the University of Tennessee Statistical and Computational Consulting Center for her assistance in the statistical analysis of the data.

Special appreciation goes to Corinne Patrick of the Alzheimer's Association of East Tennessee for her review and critique of the survey, as well as, her enthusiastic support and encouragement during the course of the study.

I would also like to express my gratitude to my parents, Bob and Jane Hicks, for their lifelong support and the use of their new computer. My wife, Mary, also has my eternal gratitude for her invaluable assistance in every area of my academic career.

ABSTRACT

This study addressed whether there is a difference in the knowledge level of family members in East Tennessee regarding Alzheimer's Disease and dementia based on location of the patient: home, nursing home, or assisted living facility. The researcher developed a survey instrument to measure knowledge of behavioral characteristics, communication, and physical characteristics. Twenty instruments were completed at each type of patient location. Results of the Kruskal Wallis Test indicated that, at the .05 level of significance, there were no significant differences based on location. However, there were significant differences, $p<.001$, when the Friedman Test was used to compare all sixty respondents by category of knowledge. The Wilcoxon Signed Ranks Test revealed that scores on physical characteristics were significantly lower than communication. Family education efforts need to continue with greater emphasis on physical characteristics of Alzheimer's Disease and dementia. It was also recommended that a future study test the same family members multiple times in the course of the disease.

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CHAPTER I

INTRODUCTION

Need for the Study

There are numerous professionals and agencies, representing multiple disciplines, attempting to serve the needs of Alzheimer's Disease victims and their families. Approximately four million Americans have Alzheimer's Disease. This number will increase to fourteen million by the middle of the next century unless a cure or prevention is found (Alzheimer's Association Statistics 1994). In 1994 the Alzheimer's Association of East Tennessee published what it considered to be "safe minimum estimates" of the population suffering with some form of dementia. The East Tennessee counties formally served by this organization were home to 14,545 individuals with dementia of some form. Of that number, 5,053 cases were estimated to be in Knox County (Alzheimer's Association, 1994).

With the rising elderly population and the ever increasing number of Alzheimer's victims, there is a growing number of types of organizations that serve the Alzheimer's population. Assisted Living facilities, for example, are a relatively new phenomenon but the industry is growing rapidly. Medical facilities are branching out to deal with Alzheimer's and dementia concerns as evidenced by Senior Health Centers. In addition to the caregivers who work in these institutional settings, numerous home-based caregivers provide care for Alzheimer's and dementia victims. Non-profit groups such as the Alzheimer's Association provide workshops, classes, and free literature to supplement the many books and publications dealing with the subject of Alzheimer's Disease and dementia.

With all of these services and resources available, what is the need for the study? While information and services are readily available and increasing quickly, there is no quantitative information on how much family members actually know about Alzheimer's Disease and dementia.

Family caregivers are bombarded on multiple fronts when faced with a loved one who has Alzheimer's Disease or dementia. It is an aspect of life most Americans do not anticipate or plan for in advance (Wallshleger, Lund, Caserta, and Wright, 1996, p. 5). When faced with caring for a loved one most deal with some or all of the following factors: family disruptions, psychological stress, physical fatigue, social isolation, financial problems, and legal difficulties (Dhooper, 1991, p.23).

Not surprisingly, sixty-eight percent of caregivers reported caregiving as being the most stressful situation they ever experienced. If family or friends cannot serve as primary caregiver in the home, the alternative is paid in-home care costing approximately $12,500 per year. This money is almost entirely out-of-pocket to the families making Alzheimer's Disease the third most expensive disease in the United States after heart disease and cancer (Alzheimer's Association, 1994).

When faced with such a situation, families typically go through a process of adjustment that includes five stages: (a) denial, (b) overinvolvement which consists of trying to compensate for the loved ones diminished capacity, (c) anger, (d) guilt, and (e) acceptance (Dhooper, 1991, p. 21). During this time of change, struggle, and high levels of emotion, family members are called upon to learn about the disease their family member is facing.

Dealing with Alzheimer's Disease and dementia is often a long ordeal for the family. Varying stages of the disease present various obstacles. The family must deal with more than one agency during the process. Typically, a family member cares for the patient at home until this is no longer possible. At this point the service of an assisted living facility may be needed. Later, a nursing home may be necessary. At each point in the process the family may receive information, education, and ever increasing experience with the disease. A cumulative effect may be suspected.

Little is known, however, about the knowledge level of these caregivers and no studies of caregivers have been done in East Tennessee. In fact, the staff of the Alzheimer's Association of East Tennessee encouraged this study because data are needed to aid in determining what additional information needs to be provided. With recognition that Alzheimer's and dementia patients may be cared for in a variety of settings, the question is raised, are there any differences in the knowledge level of family members based on the location of the loved one? If location is found to affect knowledge, this information may be pertinent to the specific agencies and professionals that give service to the family members as well as the Alzheimer's Association of East Tennessee.

Problem Statement

The problem under investigation was, do differences in caregiving situations affect the knowledge level of Alzheimer's Disease and dementia possessed by family members in three broad categories: (a) behavioral characteristics, (b) communication, and (c) physical characteristics?

Hypotheses

Four hypotheses were tested:

Ho_1: There are no significant differences among caregivers who care for their loved one at home, caregivers whose loved one is being cared for in an assisted living facility, and caregivers whose loved one is being cared for in a nursing home in their knowledge of behavioral characteristics of Alzheimer's Disease and dementia patients.

Ho_2: There are no significant differences among caregivers who care for their loved one at home, caregivers whose loved one is being cared for in an assisted living facility, and caregivers whose loved one is being cared for in a nursing home in their knowledge of communications with Alzheimer's Disease and dementia patients.

Ho_3: There are no significant differences among caregivers who care for their loved one at home, caregivers whose loved one is being cared for in an assisted living facility, and caregivers whose loved one is being cared for in a nursing home in their knowledge of physical characteristics of Alzheimer's Disease and dementia patients.

Ho_4: There are no significant differences among caregivers who care for their loved one at home, caregivers whose loved one is being cared for in an assisted living facility, and caregivers whose loved one is being cared for in a nursing home in their overall knowledge level of Alzheimer's Disease and dementia.

Assumptions

In the completion of this study, certain assumptions were made. It was assumed that knowledge of Alzheimer's Disease and dementia can be measured by the instrument provided to the family members. It was assumed that those responding were indeed family members of Alzheimer's and dementia patients and have some level of contact with the patient. It was assumed that those responding were able to understand the items on the instrument.

Limitations

This study did not assess the degree to which a family member is directly involved in caregiving whether it be financial, emotional, or physical; nor, did it assess the length of time a person has been caregiving or the length of a family member's stay in a facility outside the home. In addition, the instrument is based on knowledge that is current at the time the instrument was distributed. New research, however, may render an item on the instrument invalid at any time.

Furthermore, the study was limited to participants in the East Tennessee area and may or may not generalize to other segments of the population. Finally, detractors on the multiple choice items on the instrument were created by the primary investigator who is not a professional in the area of test creation. However, the instrument was reviewed and approved for content and determination of correct responses by Dr. Marla Peterson, President of the Alzheimer's Board of East Tennessee and Corinne Patrick, Program Director of the Alzheimer's Association of East Tennessee.

Definition of Terms

Definition of pertinent terms were obtained from the *Random House Unabridged Dictionary* Second Edition, or brochures published by the Alzheimer's Disease and Related Disorders Association, Inc. In some cases the definition is accompanied with a further explanation of how the term is being used within the specific context of this study.

Alzheimer's Disease. Defined by the Alzheimer's Association as a progressive, degenerative disease of the brain and the most common form of dementia. The cause is unknown and can only be confirmed after death by autopsy. It is characterized by memory lapses, confusion, emotional instability, and progressive loss of mental ability. It is named after Alois Alzheimer 1864-1915, German neurologist, who described it in 1906 (Alzheimer's Association, 1994).

Dementia. The loss of intellectual functions of sufficient severity to interfere with a person's daily functioning. It is not a disease in itself, but rather a group of symptoms which may accompany certain diseases or physical conditions (Alzheimer's Association, 1990).

Family member. Family member is used in general terms and is not intended to imply any particular kinship. It may also refer to adopted family, step family or in-laws.

Caregiver. A broad term meaning to watch over or to be responsible. Literature references generally use the term to refer to the primary caregiver of the patient. Within this study, however, the contribution of those beyond the primary caregiver is recognized. Therefore, the term is used synonymously with family member.

Instrument. A devise for measuring the present value of a quantity under observation, used here to refer to the Caregiver Knowledge Survey, a forty-eight question survey consisting of multiple choice and true/false questions (See Appendix A).

Behavioral Characteristics. Manner of behaving or acting; the action or reaction to any material under given circumstances. In this case the actions or reaction of an individual with Alzheimer's Disease or dementia.

Communication. To give or interchange thoughts, feelings, information or the like, by writing, speaking, etc. Communication with a patient and communication by a patient to another person are both applicable here.

Physical Characteristics. Of or pertaining to the body.

Three categories. Refers to behavioral characteristics, communication, and physical characteristics.

Group one. Family members whose loved one is being cared for at home.

Group two. Family members whose loved one is being cared for in a nursing home.

Group three. Family members whose loved one is being cared for in an assisted living facility.

Three groups. Refers to groups one, two, and three.

A more thorough discussion of the literature related to Alzheimer's Disease and dementia will be presented in Chapter II. The researcher exerted great effort to find research on Alzheimer's Disease and dementia as it relates to caregivers' knowledge. As will be seen, Alzheimer’s Disease and dementia literature is plentiful, but literature related to caregiver knowledge is not.

CHAPTER II

LITERATURE REVIEW

The review of the literature that is discussed in the chapter is conducted within the parameters of the study. No literature was found addressing the specific subject of family members' knowledge levels related to Alzheimer's Disease and dementia. For this reason the review centers on works, which have as their purpose, educating family caregivers. After an overview, the discussion will be categorized into the three areas that were surveyed, behavioral characteristics, communication, and physical characteristics of Alzheimer's Disease and dementia.

Overview

In 1907, Alois Alzheimer published his case report of a fifty-five year old female patient with progressive dementia. He described the cerebral cortex of the woman pointing out the presence of "abnormal nerve cells that contained not only tangles of fibers (neurofibrillary tangles), but clusters of degenerative nerve endings (neuritic plaques) as well" (Zec, 1993, p. 3). The condition came to be known as Alzheimer's Disease.

The decades since Alzheimer's report have seen professionals from various fields address treatment options, caretaking methods, and possible cures. The efforts continue today as approximately four million Americans have Alzheimer's Disease and unless a cure is found, a projected fourteen million Americans will be living with the disease by the middle of the next century (Alzheimer's Association, 1994).

With Alzheimer's Disease presently listed as the fourth leading cause of death among adults (Alzheimer's Association, 1994), the literature is understandably plentiful but it is not without its flaws. Much of the literature seems to be concentrated in two categories: (a) neurological/medical research and (b) caregivers' coping skills. Neurological/medical research pushes toward greater understanding of the physical causes of Alzheimer's Disease and dementia in hopes of finding treatments, preventions, or a cure. Caregiver stress and burden, briefly addressed in Chapter I, is a serious problem and is examined in numerous books and articles.

Few authors, however, have as their intent to educate family members in the behavioral characteristics, communication, and/or physical characteristics of Alzheimer's Disease and dementia. The reason for this is simple. Alzheimer's Disease and other types of dementia are profoundly unpredictable. Cutler and Sramek (1996), in their book, Understanding Alzheimer's Disease, note that when dealing with Alzheimer's, "Flexibility is important. The situation will change from day to day. What worked yesterday may not work today" (p. 65). Most of the educational material addressing the three areas studied here is weaved within material that addresses the two categories of research and coping skills.

Those who seek to educate themselves on behavioral characteristics, communication, and physical characteristics of Alzheimer's Disease and dementia will primarily have to do so through selected chapters, articles, and subheadings within the text. Even then the reader will often find "helpful hints," "profiles," "general guidelines," and "common symptoms." Those hoping for specific facts or a "how to" book will be disappointed. Before continuing, two other points of explanation should be made. The terms "Alzheimer's Disease" and "dementia" are used here, as in the literature, in conjunction with one another or even used interchangeably. This is due to the fact that, at this point, Alzheimer's Disease cannot be distinguished with 100% accuracy from other types of dementia without an autopsy. While the review of the literature is primarily focused on Alzheimer's type dementia, it must be discussed within the larger context of dementia.

Finally, one must understand the literature in this area to be a work in progress and, at this point, incomplete. While common characteristics and points of education can be discussed, comparative studies are lacking. "Because there are no normative population standards for many of these (neuropsychological) tests, abnormal performance can be determined only by comparison with a normal control group matched for age, sex, and local education" (Zec, 1993, p. 8). This is according to a work group under the auspices of the Department of Health and Human Services Task Force on Alzheimer's Disease (Zec, 1993, p. 74).

Normative neuropsychological data on the elderly population are lacking as are data for socio-economic groups, cultural groups, and geographical regions. Comprehensive normative databases for senior adults are needed. Without these norms those undergoing neuropsychological testing may score average or higher despite cognitive decline. This is due to the individuals' original high aptitude. Since this report was published, books such as <u>A Compendium of Neuropsychological Test: Administration, Norms, and</u>

Commentary by Spreen and Straus in 1991 and Aging and Neuropsychological Assessment by LaRue in 1992 have improved the situation but more work needs to be done (Zec, 1993, p. 8).

Behavioral Characteristics

While the ambiguity and need for further research has been emphasized, there are some characteristics that are so common that virtually every caregiver must address the behaviors. These are discussed quite thoroughly in Alzheimer's: A Caregiver's Guide and Sourcebook by Howard Gruetzner (1992).

Gruetzner included a chapter entitled "How to Respond Positively to Alzheimer's Behavior." In it he lists, in laypersons' terms, twenty-seven common behavioral characteristics of the Alzheimer's patient. A few examples are:

The person asks the same questions over and over.

The person's personality appears to have changed.

The person denies his memory problems and makes excuses for mistakes, blames others, or seems unaware of the problem.

The person mishandles her money and monthly bills; she accuses you and others of stealing her money; she claims her banker is handling money matters.

The person tells ridiculous stories or says unusual things.

The person accuses you, family, and friends of doing things or makes up stories about you.

The person becomes disinterested and withdrawn.

The person wanders aimlessly.

After each behavior, Gruetzner provides the reader with common responses, which are generally not helpful. He then gives an explanation of why the patient behaves in that way and a list of helpful responses for the caregiver to employ (p. 145-169).

In Alzheimer's Disease: A Practical Guide for Those Who Help Others, Judah L. Ronch (1989) addresses the same behaviors discussed in Gruetzner's work with two additions that should be mentioned. While the following behaviors are appropriate for discussion, it is questionable whether they should be included as common behavioral characteristics of Alzheimer's Disease and dementia. The first is suicide. Ronch argues that families should guard against suicide by removing harmful objects and securing windows. However, the author acknowledges that, "Impaired cognition may make planning a suicide difficult" (p. 140).

Suicide, therefore, may not be a characteristic of

Alzheimer's Disease but a reaction of a person beginning to experience periods of demented behavior and thought. This reaction is a possibility, however, with a diagnosis of any painful or fatal disease and is therefore not a behavioral characteristic of Alzheimer's Disease and dementia.

The second characteristic addressed by Ronch (1989) is Sundowning. This is not, however, a characteristic in itself. It is instead an intensification of any or all of the characteristics of Alzheimer's Disease and dementia. Sundowning is a phenomenon in which the patient gets worse during the late afternoon. As the sun goes down and it grows dark, many patients become more restless, confused, or anxious. The cause of this phenomenon is not known (p. 135-136).

While the two issues addressed by Ronch are not necessarily behavioral characteristics, this author is only an example of many that address these issues within the behavioral discussion. Like Ronch, most see these issues as strong concerns and not necessarily characteristic behavior. The goal is to alert the family to the concerns.

The behavioral characteristics and issues discussed above are consistent throughout the literature with the differences being in style and format. The styles range from the easy reading of Mace and Rabins (1991) in The 36-Hour Day to Holly Tuokko's (1993) work entitled "Psychosocial Evaluation and Management of the Alzheimer's Patient." Tuokko's writing addresses behavioral characteristics from a highly scientific point of view. She references numerous surveys and inventories providing the reader with statistical analysis. In the end, however, it is the same behaviors that are addressed consistently in the literature.

Communication

Within the book, Alzheimer's Disease: A Practical Guide for Those Who Help Others, Judah L. Ronch (1989) includes a chapter entitled, "Communicating with the Demented Elderly Person." The author writes, "A major source of frustration in taking care of a demented person is caused by the wide array of communication difficulties that are primary disabilities in dementing disorders" (p. 70).

In an attempt to alleviate some of this frustration, Ronch gives twenty-seven "General Hints about Communication with Demented Persons." These hints are brief, direct, and easily understandable to the nonprofessional. Some examples of these hints are:

Use short, simple sentences or questions

Avoid the use of pronouns

Ask one question or give one direction at a time

Avoid metaphors and analogies (p. 70-75).

Doreen Kotik-Harper and Robert G. Harper (1996) provide a similar list in their essay, "Techniques for Enhancing Memory, Orientation, and Communication in the Alzheimer Patient." These writers, however, expand their discussion to include nonverbal communication techniques and communication with the agitated patient. In both cases, appropriate gestures, facial expressions, and a calm demeanor take on added importance (p. 117-121).

The references discussed above represent the standard in communication literature as it relates to Alzheimer's Disease and dementia. The numerous hints listed in these works are repeated in many others. No source of contradiction was found.

Physical Characteristics

In 1997, the American Psychiatric Association published Practice Guideline for the Treatment of Patients with Alzheimer's Disease and Other Dementias of Late Life. Within the discussion of common features of dementia it reads, "Dementia is sometimes accompanied by motor disturbances which may include gait difficulties, slurred speech, and a variety of abnormal movements. Other neurological symptoms such as myoclonus and seizures, may also occur" (p. 8)

It is clear from this statement that there is a physical element to Alzheimer's Disease and dementia, yet, the literature's focus on behavior and communication is much more prevalent when the target audience is family caregivers.

Those works that address physical characteristics on a lay persons level tend to do so within a discussion of exercise and activities for the demented patient. Case in point is Keeping Busy: A handbook of Activities for Persons with Dementia by James R. Dowling (1995). The reader learns of physical characteristics and limitations in the context of developing a reasonable exercise and activity program for the patient.

A much more thorough discussion is found in The 36-Hour Day by Nancy L. Mace and Peter V. Rabins (1991). This work includes discussion of numerous physical characteristics such as: eating problems, weight loss, choking, exercise, hygiene, incontinence, gait, vision and hearing problems, seizures, jerking movements, pneumonia, and death (p. 64-113).

Of course there is a wealth of information on physical characteristics of Alzheimer's and dementia in the technical books and journals of the medical field. Within this study, however, the focus is on family member education. Few laypersons would gain knowledge from such technical works. On the level of family education, the material on physical characteristics is less prevalent than the other two categories of knowledge being studied here.

Conclusion

No works were found which addressed the specific focus of this study, that being, family members' knowledge of Alzheimer's Disease and dementia. The literature discussion has, therefore, centered on works that provide family members with knowledge in the three categories of the study: behavioral characteristics, communication, and physical characteristics of Alzheimer's Disease and dementia.

Within the tremendous amount of literature focused on Alzheimer's Disease and dementia, two main sources rise to the top as easily readable, yet, thorough sources of information for family caregivers. The first is the aforementioned The 36-Hour Day by Nancy L. Mace and Peter V. Rabins (1991). It is a well known industry standard which discusses all three categories of concern giving real life examples and practical advice to caregivers.

The second primary source is the local chapter of the Alzheimer's Association. The Alzheimer's Association of East Tennessee provides family members with a number of informative brochures, free of charge, upon request. A listing of these brochures follows:

Alzheimer's Disease: Statistics (1994).

Alzheimer's Disease: Fact Sheet (1994).

Alzheimer's Disease and Related Disorders Fact Sheet: An Overview of the Dementia (1990).

Alzheimer's Question and Answer Sheet (1989).

Stages of Symptom Progression in Alzheimer's Disease

Myths and Truths about Alzheimer's Disease

Dementia Statistics (1994)

Is It "Normal" Memory Loss or Alzheimer's Disease

Is It Alzheimer's? (1996).

Based primarily on these brochures, the researcher developed the survey used in this study. This survey (See Appendix A) was distributed to family members of

Alzheimer’s and dementia patients in the East Tennessee area. Data collection methods and procedures are discussed in Chapter III.

CHAPTER III

METHODS AND PROCEDURES

In this chapter, the research design, subjects, apparatus, and procedures used in the study will be presented.

Research Design

This study was conducted using a one-shot, survey research design. The investigator was primarily interested in finding out the status of what caregivers know about behavioral characteristics, communication, and physical characteristics of Alzheimer's Disease and dementia, and whether their knowledge level has a relationship to the location of care (home, nursing home, or assisted living facility). The design chosen was, thus, appropriate for answering the questions and testing the hypotheses of the study.

Subjects

Subjects for the study were obtained from a variety of settings. Prior to distribution of the instrument, a Form A was submitted in accordance with University of Tennessee policy and was approved for Compliance with Human Subject Research Guidelines.

Sixty surveys were sent by mail or hand delivered by employees of the Alzheimer's Association of East Tennessee. Six surveys were delivered by a geriatric counselor in private practice in the East Tennessee area. She agreed to distribute the instrument to a few of her clients where appropriate. Twenty surveys were distributed by the employees of a nursing home and assisted living facility. These twenty were divided evenly between the nursing home and assisted living facility. Ten surveys were distributed by the employees of a second nursing home, and thirty surveys were distributed by employees of a second assisted living facility. Finally, twelve surveys were distributed by friends, acquaintances, and colleagues of the researcher. Total distribution was 138 surveys with 69 surveys returned for a response rate of 50%.

Since the mailing lists and patient rosters of the various facilities and agencies are confidential information, the specific subjects are known only by the employees who distributed the surveys. Those friends and colleagues who distributed surveys also kept the identity of the respondent confidential at the investigator's request. Therefore, no participant's identity was revealed in the course of the study.

It was impossible to stratify the sample into the three categories of caregiving (home, nursing home, and assisted living) prior to the distribution of the survey instrument. However, the instrument did ask each respondent to indicate the location of the family member. The responses were as follows:

Cared for at home: n = 29
Cared for in a nursing home: n = 20
Cared for in an assisted living: n = 20

In order to place an equal number of participants in each group, the twenty-nine surveys in group one were randomly assigned a number 1-29. Surveys 1-20 were used for the study.

Apparatus

A questionnaire was designed by the primary investigator with the correct answers based on Alzheimer's Association brochures listed in Chapter II. The questions referred to behavioral characteristics of Alzheimer's Disease and dementia, communication issues concerning Alzheimer's Disease and dementia, and physical characteristics of Alzheimer's Disease and dementia. To ensure proper placement of the test items in the proper category, the instrument was reviewed by three doctoral students in the Counseling Psychology

Program at the University of Tennessee, and three professionals in the field of aging in the East Tennessee area. Each reviewer was asked to place a B, C, or P beside each item to indicate behavior characteristics, communication, or physical characteristics. Reviewers' answers were compared to the primary investigator's original categorization of the item. The categorization of survey items is listed in Appendix B. To test for reliability, a split-half test was used along with the Spearman-Brown procedure. The results were as follows:

Behavioral Characteristics:	99% reliability
Communication:	99% reliability
Physical Characteristics:	99% reliability

The instrument was reviewed by the President of the Alzheimer's Board of East Tennessee, and the Program Director of the Alzheimer's Association of East Tennessee. Minor changes were made for the sake of clarity for a diverse audience and some questions were eliminated at the recommendation of the Program Director. After these minor alterations the instrument was approved for content and accuracy of correct responses by both reviewers.

After obtaining approval of the Form A, the instrument was pilot tested for clarity and to measure the length of time necessary to complete the survey. The instrument was distributed to nine graduate students in the College of Education at the University of Tennessee. The completion time of these students was well within the estimated time listed in the informed consent. These participants also found the items on the test clear and understandable with the exception of item #11. Item #11 was altered for clarity and remained as an item in the survey. When the calculations were made to test the reliability of categorization as discussed above, item #11 was a source of contradiction among the reviewers. This item was included in the survey distributed to the 138 recipients and is, therefore, included in the instrument found in Appendix A. Due to these multiple problems, however, item #11 was eliminated from the statistical study.

Procedures

The Alzheimer's Association of East Tennessee was enlisted to help with the project. The Program Director and her staff agreed to select names and addresses from their mailing list and mail the instrument in the envelopes provided by the researcher. She also agreed to be the support person for the project. This meant that she agreed to having her name and office phone number listed on the Informed Consent Form. Subjects who developed questions or concerns as a result of completing the survey were encouraged to contact her for support or counsel.

Copies of the instrument and informed consent were then provided to the Alzheimer's Association staff. Each copy of the instrument was accompanied by a stamped envelope addressed to:

MARK A. HICKS
C.E.C.P.
229 Claxton Addition
University of Tennessee
Knoxville, TN 37996-3400

The return envelope and instrument were placed in a stamped envelope with a blank address and a return address label same as above. The Alzheimer's Association staff placed the name and address of the subject on the envelope and mailed the instrument. In some cases the exterior postage was omitted and the instrument was hand delivered during home visits by the Alzheimer's Association staff. The same procedure was followed with the other facilities and agencies listed in the Subjects section.

The data were analyzed in the following manner.

There were three independent variables: (a) caregivers who care for their loved one at home, (b) caregivers whose loved one is being cared for in an assisted living facility, and (c) caregivers whose loved one is being cared for in a nursing home.

There were four dependent variables: (a) the caregiver's score on instrument items dealing with behavioral characteristics of Alzheimer's Disease and dementia, (b) the caregiver's score on instrument items dealing with communication with Alzheimer's Disease and dementia patients, (c) the caregiver's score on instrument items dealing with physical characteristics of Alzheimer's Disease and dementia, and (d) the caregiver's total score for all items. The Kruskal Wallis test was performed, one for each of the dependent variables. Results of these procedures are discussed in Chapter IV.

CHAPTER IV

RESULTS

The results of the statistical analysis of the data are discussed in this chapter. Results for the four hypotheses of the study will be presented first and will be followed by the results of some additional tests that were conducted. The Kruskal Wallis test was used to test the four hypotheses. The Friedman test, the Wilcoxon Signed Ranks Test, and the Pearson Product Moment Correlation were used to test additional questions that developed as the research progressed. Unless otherwise stated, all data were tested for significance at the .05 level.

Results for Hypotheses 1, 2, 3, and 4

The sixty participants in the study were grouped based on the location of the Alzheimer's or dementia patient (home, nursing home, or assisted living facility) with twenty in each group. In addition to the total score, the knowledge level was measured in three categories (behavioral characteristics, communication, and physical characteristics). Data were not normally distributed, prompting the decision to use nonparametric statistical procedures in the course of analysis.

The Kruskal Wallis Test was performed for each of the three categories as well as the total. The mean score for each category based on the patient's location is shown in Table 1. No significant differences were found among the three groups in any of the categories or the total with the results as follows:

Behavioral: $x^2(2, N = 60) = .666, p = .717$

Communication: $x^2(2, N = 60) = 2.046, p = .359$

Physical: $x^2(2, N = 60) = .468, p = .791$

Total: $x^2(2, N = 60) = 1.214, p = .545$

With the results showing no significant difference, there was a failure to reject all four null hypotheses.

Results for Additional Research Questions

Attention was then turned to other research questions that arose during the course of the study. The researcher became curious about whether there was a significant difference in any of the three categories taking all sixty participants as one group. Did the group of sixty participants do better or worse when tested on behavioral characteristics versus communication versus physical characteristics?

The data in Table 2 indicate that the mean percent score for items pertaining to communication was 76, behavioral characteristics was 70, and physical

Table 1

Descriptive Information on Categories of Knowledge Possessed by Caregivers of Alzheimer's Disease and Dementia Patients Based on Three Locations of Patients

Location		N	Minimum	Maximum	Mean	SD
Home	Behavioral	20	4.00	16.00	11.9500	3.4561
	Communication	20	1.00	10.00	7.3000	2.0800
	Physical	20	1.00	13.00	8.2500	3.1267
	Total	20	10.00	37.00	27.5000	7.7562
Nursing Home	Behavioral	20	8.00	18.00	12.7500	2.7886
	Communication	20	4.00	10.00	7.3000	2.0545
	Physical	20	3.00	14.00	8.3500	3.1166
	Total	20	19.00	42.00	28.4000	6.4677
Assisted Living	Behavioral	20	8.00	18.00	13.2500	3.0066
	Communication	20	6.00	10.00	8.1500	1.2680
	Physical	20	5.00	12.00	8.9000	2.1497
	Total	20	22.00	40.00	30.3000	5.3518

Table 2

Summary of Percent Scores for Categories of Knowledge

	N	Minimum	Maximum	Mean	SD	Mean Rank
Behavioral	60	.22	1.00	.7028	.1717	2.08
Communication	60	.10	1.00	.7583	.7853	2.43
Physical	60	.07	1.00	.6071	.2001	1.49

characteristics was 61. A Friedman Test was performed to determine if a significant difference could be found. There was a significant difference among the three categories, x^2 (2, *N* = 60) = 28.779, *p* < .001.

To determine whether all three categories were significantly different from each other, a Wilcoxon Signed Ranks Test was performed and the results are presented in Table 3. All three categories were found to be significantly different from each of the other two (Communication/Behavior: Z = -2.636, p = .008; Physical/Behavior: Z = -3.834, p < .001; Physical/Communication: Z = -5.181, p < .001). Type I error was controlled by performing a Bonferromi Adjustment dividing the p value of .05 by 3 resulting in a p = .017. At this level the results remain significantly different.

Table 3

Comparison of Total Sample by Category of Knowledge

		N	Mean Rank	Sum of Ranks
Communication/ Behavioral	Negative Ranks	20	23.75	475.00
	Positive Ranks	36	31.12	1121.00
	Ties	4		
	Total	60		
Physical/ Behavioral	Negative Ranks	42	32.15	1350.50
	Positive Ranks	16	22.53	360.50
	Ties	2		
	Total	60		
Physical/ Communication	Negative Ranks	47	32.44	1524.50
	Positive Ranks	11	16.95	186.50
	Ties	2		
	Total	60		

Another pertinent question was, "What is the correlation between the participants' education level and their total score?" Each participant was asked to report their education level at one of five levels: less than high school, high school graduate, college graduate, graduate degree, or doctoral degree. A Pearson Product Moment Correlation procedure was performed to compare education levels to total scores and the results are shown in Figure 1. In this particular sample a correlation of .33 was found showing only a small positive correlation.

Also of note is where the participants gained their knowledge of Alzheimer's Disease and dementia. Percentages were calculated to determine what percent of the sixty participants reported gaining knowledge in each of seven areas. The results are shown in Table 4.

Finally, participants were asked if they thought there was an adequate amount of informational and educational material available to them concerning Alzheimer's Disease and dementia. Of sixty respondents, 60% indicated "yes", 15% indicated "no", and 25% were "not sure".

In summary, there were no significant differences found among individuals whose loved ones are being cared

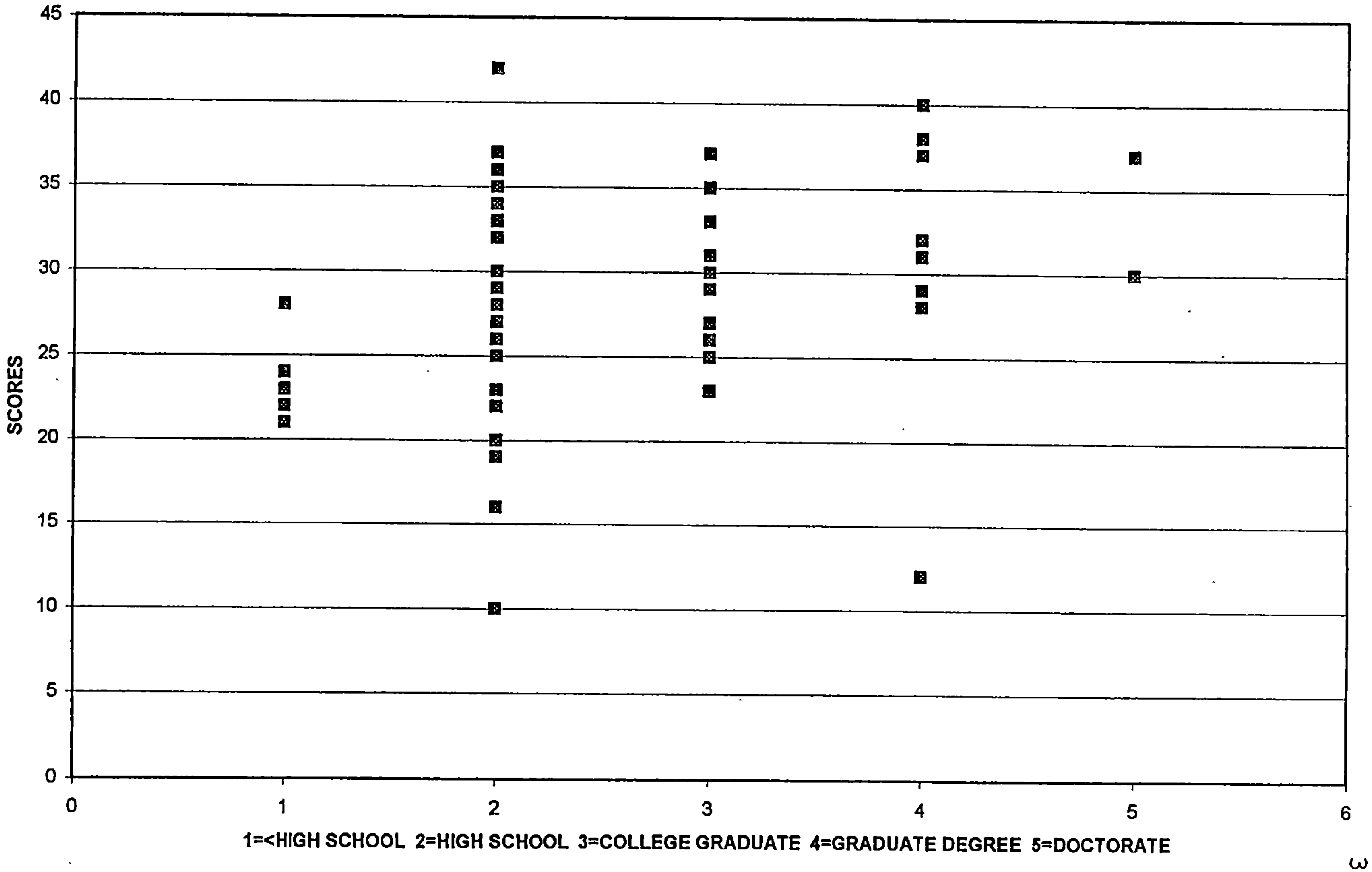

Figure 1: Scattergram of Correlation of Scores and Education Level

Table 4

<u>Percent of Sixty Participants Gaining Knowledge from Each Source</u>

books and magazines	85%
physicians, nurses, counselors, and other professionals	53%
friends	37%
other family members	35%
training seminars	30%
support groups	23%
clergy	6%

for at home, in an assisted living, or in a nursing home in any of the three categories of knowledge or the total score. Significant differences were found, however, among the scores of all 60 participants in their knowledge of behavioral characteristics, communication, and physical characteristics. All three categories were found to be significantly different. There was only a slight correlation between the respondents' total score and education level, and the majority of participants believed there was adequate information available to them concerning Alzheimer's

Disease and dementia. Further discussion of these findings will be presented in Chapter V.

CHAPTER V

DISCUSSION

The results reported in the preceding chapter will now be discussed. In addition, recommendations for application and future study will be presented.

Analysis of the Results

There were four hypotheses tested on a sample group of 60 family members of Alzheimer's Disease and dementia patients:

Ho_1: There are no significant differences among caregivers who care for the loved one at home, caregivers whose loved one is being cared for in an assisted living facility, and caregivers whose loved one is being cared for in a nursing home in their knowledge of behavioral characteristics of Alzheimer's Disease and dementia patients.

Ho_2: There are no significant differences among caregivers who care for their loved one at home, caregivers whose loved one is being cared for in an assisted living facility, and caregivers whose loved one is being cared for in a nursing home in their knowledge of communication of Alzheimer's Disease and dementia patients.

Ho_3: There are no significant differences among caregivers who care for their loved one at home, caregivers whose loved one is being cared for in an assisted living facility, and caregivers whose loved one is being cared for in a nursing home in their knowledge of physical characteristics of Alzheimer's Disease and dementia patients.

Ho_4: There are no significant differences among caregivers who care for their loved one at home, caregivers whose loved one is being cared for in an assisted living facility, and caregivers whose loved one is being cared for in a nursing home in their overall knowledge level of Alzheimer's Disease and dementia.

It is interesting to speculate as to why no differences occurred based on location of the patient. It may be that in the East Tennessee region, outreach efforts by the Alzheimer’s Association, health care facilities, hospitals, and others may be fairly equally distributed to family members regardless of where the patient is located. Since 85% of the respondents indicated that they received information from books and magazines, it may be that a variety of distribution channels for printed information are being used.

The physical characteristics of Alzheimer’s Disease are not as well understood by family members as communication and behavioral characteristics. Again, it is only possible to speculate as to why this is occurring. Perhaps printed information and other educational outreach activities place less emphasis on the physical aspects of the disease. Since some of the items dealt with length of life, potentially reversible conditions, certainty of diagnosis, and prevention and curability of the disease, it may be that family members are simply blocking information that speaks to the mortality of their loved one. There may also be a feeling that there is little the family member can do in regard to physical characteristics; yet, it becomes important to know that loss of weight, difficulty in swallowing, and difficulty in controlling bladder and bowel functions may require certain types of actions by the caregiver. Perhaps, too, family members may view the items related to physical characteristics as being in the realm of medical or scientific information that will be provided to them by medical professionals when physical conditions begin to change.

Suggestions for Future Study

Since there is a need for increased knowledge, future studies might explore whether knowledge improves over time. Generally speaking, the patient is cared for by family in the home setting in the earliest stages of Alzheimer's Disease or dementia. As the patient needs more care, an assisted living facility may be appropriate and, finally, a nursing home. In broad terms, then, these locations could represent the development and increasing difficulty of the disease. In addition, patients are generally kept in each of these settings for significant periods of time, sometimes years in each setting. Yet, there is no significant increase in the knowledge level of family members whose loved one is in a nursing home or assisted living compared to those in presumably the earliest stages and who are keeping the patient at home. It could be hypothesized, then, that there is no increase in the family members' knowledge over the course of the disease. What is learned is apparently learned early and knowledge levels hold steady throughout the course of the disease.

To test this hypothesis, family members could be tested repeatedly over time particularly when the patient is in various locations. Testing the same family members multiple times would give a more accurate picture of improvement of knowledge over time or lack thereof.

Future studies may also want to focus on the sources of information. Books, magazines, and various professionals top the list. Interestingly, however, clergy was reported as helpful by only 6% of the participants. East Tennessee is home to numerous churches of various faiths and denominations. Church attendance is rather common, yet, ministers seemed to be of little help in this area. Also of note, the Alzheimer's Association of East Tennessee provides the Helping Hands program (Alzheimer's Association, Helping Hands), a training seminar for clergy so that they may be a source of knowledge and support to families.

Church leaders and denominational officials may do well to study why clergy appeared to be of little help in increasing family members' knowledge of the disease despite having training available. Presumably, clergy are providing spiritual support even if they are not increasing the knowledge level of family members. Further study would be necessary to determine what impact clergy are having on families during this time.

In addition, based on the level of difficulty in acquiring data from the three groups, future studies may need to be performed to determine the level of enmeshment of family members. During the course of this study, family members whose loved one was at home or in a nursing home seemed willing and even anxious to participate in the study. Notes were occasionally written on the test thanking the investigator for the efforts in this area of study. Twenty or more participants were obtained in these two categories fairly easily. Acquiring twenty participants within the assisted living category, however, required persistent effort and substantially more time. For example, twenty surveys were sent specifically through nursing homes. Of this twenty, fifteen were returned. Forty survey were sent specifically through assisted living facilities. Of this forty, seven were returned. While there was no difference in the knowledge levels of the three groups, the increased difficulty of gaining responses from assisted living family members, leads one to question the attitude of each group in regard to the disease.

It could be hypothesized that family members who keep a patient at home are strongly enmeshed in the lives of the patient. Furthermore, those whose loved one is in a nursing home are generally seeing the worst parts of the disease. Grief issues may also come into play since the patient may be closer to death than in the other two locations, thus enmeshing the family. Assisted living families, however, may be more distant or show more apathy. If the patient is not at home and is not close to death, family members may be taking some time off from the stress of the disease and are less willing to participate in activities related to the disease. Further study is needed to determine the state of enmeshment a family member has with a patient based on the location of the patient. Is there a measure of apathy on the part of family members' whose loved one is in an assisted living facility?

Finally, perhaps the most important finding of the study is that there is room for caregivers to improve their knowledge of Alzheimer's Disease and dementia. This point should be emphasized since even on the communication category, where caregivers had the highest scores, they correctly answered, on the average, 76% of the items. With caregivers correctly answering, on the average, 61% of the items pertaining to physical characteristics, the need for more knowledge becomes apparent. Convincing the public of the need for additional education may be challenging, however, given the fact that only 15% of respondents indicated that there was not enough informational and educational materials available.

Based on the analysis of the data, the recommendations of the researcher are summarized as follows:

1. Future research should be conducted to see if caregiver's knowledge of Alzheimer's Disease increases as the disease progresses.

2. Future studies might examine the degree of family enmeshment at various stages of the disease and in terms of the type of setting (home, assisted living, and nursing home), given the low response rate of families with loved ones in an assisted living.

3. The Alzheimer's Association of East Tennessee should continue caregiver training efforts with additional emphasis placed on physical characteristic of Alzheimer's Disease and dementia since this seems to be the category where caregivers have the least amount of knowledge.

4. Efforts being made to train clergy need to be evaluated and perhaps refocused since clergy as a source of information was listed by only 6% of the respondents.

5. The Alzheimer's Association, churches, assisted living facilities, nursing homes, physicians offices, and other professionals need to provide quality printed

information at an appropriate reading level since 85%, the highest number of respondents, indicated that books and magazines were a source of information.

6. Future studies might explore barriers to retention of material given that 60% of respondents believe they already have enough informational and educational material available to them, yet scores show room for improvement.

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APPENDIXES

APPENDIX A

CAREGIVER KNOWLEDGE SURVEY

Please answer all of the following questions. If you think you know the correct answer, circle the appropriate response. If you do not know the answer to a question, please do not make wild guesses. Simply mark the "don't know" or "not sure" response.

1. Is your loved one who is diagnosed with Alzheimer's Disease or dementia being cared for:
   - A. at home
   - B. in an assisted living facility
   - C. in a nursing home
   - D. other: please specify________________________

2. Where have you gained knowledge about Alzheimer's Disease and dementia? (Please circle all that apply)
   - A. books and magazines
   - B. training seminars provided by (please specify) ________________________
   - C. physicians, nurses, counselors and other professionals
   - D. clergy
   - E. friends
   - F. other family members
   - G. support groups
   - H. other: please specify________________________

3. What is your relationship to the Alzheimer's Disease or dementia patient?
   - A. I am the spouse of the patient
   - B. I am a sibling of the patient
   - C. I am a child of the patient
   - D. I am an in-law of the patient
   - E. other: please specify________________________

4. Do you think that there is an adequate amount of informational and educational material available to you concerning Alzheimer's Disease and dementia?

yes no not sure

5. What is your highest level of education?
   - A. less than high school
   - B. high school graduate
   - C. college graduate
   - D. graduate degree
   - E. doctoral degree

6. Often the <u>first</u> visible sign of Alzheimer's disease is:
   - A. dramatic changes in mood.
   - B. loss of memory of the recent past
   - C. loss of memory of the distant past
   - D. all of the above
   - E. don't know

7. When caring for an Alzheimer's or dementia patient who has become confused it is best to:
   - A. join in <u>his or her</u> reality
   - B. firmly argue with them in an effort to orient them to the here and now
   - C. ignore them so as not to reinforce confused behavior
   - D. explain reality to them rationally and in detail until they are able to grasp reality again
   - E. don't know

8. People with Alzheimer's Disease and dementia may commonly:
   - A. become suspicious and may say tactless or unkind things
   - B. hoard or hide the belongings of themselves and others
   - C. withdrawal from social interaction
   - D. all of the above
   - E. none of the above
   - F. don't know

9. Since an Alzheimer's or dementia patient is confused and has lost much of the knowledge they once had it is best to simply treat them as a child.

true false don't know

10. Since an Alzheimer's or dementia patient cannot participate in the work and recreation they once did, it is important to provide change often and avoid routine so the patient does not become bored.

true false don't know

11. Independent activity (i.e. dressing and bathing themselves) should be encouraged taking into account the state of the disease.

true false don't know

12. Giving encouragement and showing affection for an Alzheimer's or dementia patient
    A. will only make them feel put down and childish
    B. may help them feel good about themselves
    C. is usually a waste of time due to the patient's confusion
    D. don't know

13. Exercise at levels appropriate for the individual
    A. can provide a sense of accomplishment
    B. may be beneficial physically and emotionally
    C. is not necessary for persons over 65
    D. none of the above
    E. both A and B
    F. don't know

14. When explaining a point to an Alzheimer's or dementia patient
    A. careful, detailed explanations are best
    B. stern, authoritative explanations are best
    C. short, simple explanations are best
    D. don't know

15. When communicating, it is common for Alzheimer's or dementia patients to sometimes use one word and actually mean another word.

true false don't know

16. Speaking slowly to an Alzheimer's or dementia patient
    - A. maybe be helpful because it gives them time to process the information
    - B. will insult them because it makes them appear stupid
    - C. rarely has any more affect than speaking rapidly or at a normal rate
    - D. don't know

17. The use of gestures when speaking to Alzheimer's or dementia patient
    - A. may frighten them
    - B. is distracting and therefore not recommended
    - C. may be helpful in communication
    - D. don't know

18. Speaking very loudly to an Alzheimer's or dementia patient
    - A. is necessary due to the hearing loss almost all elderly experience
    - B. is helpful because it establishes you as the caregiver
    - C. is not necessary unless there is a diagnosed hearing loss
    - D. don't know

19. When giving instructions to the Alzheimer's or dementia patient
    - A. it is best to explain everything up front so they know what to expect
    - B. it is best to give instructions in small steps, one step at a time
    - C. it is best to do things for them rather than give instructions on how to do it
    - D. don't know

20. The practice of wearing several shirts or blouses is
    - A. quite common
    - B. quite unusual
    - C. don't know

21. At times, Alzheimer's and dementia patients are fearful of familiar places or things.

true false don't know

22. Those with Alzheimer's or dementia may find learning new tasks
    A. a welcomed change of routine
    B. quite difficult
    C. both A and B
    D. don't know

23. For those with Alzheimer's or dementia, signs of extremely poor judgement such as opening a moving car door
    A. are not common
    B. are only rarely seen and normal safeguards are sufficient
    C. are common and need to be guarded against
    D. don't know

24. Once a physician confirms the existence of Alzheimer's or dementia the patient will usually live
    A. 1-2 years
    B. 2-4 years
    C. 10-18 years
    D. 3-20+ years
    E. don't know

25. Potentially reversible conditions such as depression, adverse drug reactions, metabolic changes and nutritional deficiencies can mimic the early signs of Alzheimer's and dementia.

true false don't know

26. Social activity for the Alzheimer's or dementia patient
    A. is important and should be encouraged
    B. is not necessary due to their confusion and withdrawal
    C. will increase the state of confusion
    D. Both B and C
    E. don't know

27. If an Alzheimer's or dementia patient is highly agitated or anxious
    A. there is little or nothing that can be done
    B. the caregiver should give detailed explanations of why everything is all right
    C. caregivers should consult a physician regarding appropriate medication
    D. don't know

28. The cause of Alzheimer's disease
    A. is genetic
    B. is caused by a virus
    C. is a natural, unavoidable reality of aging
    D. is unknown at this time
    E. don't know

29. Alzheimer's disease can be diagnosed with 100% certainty
    A. with a simple medical exam
    B. only with sophisticated medical equipment
    C. only after death by an autopsy
    D. both B and C
    E. don't know

30. The loss of weight, difficulty swallowing, and difficulty controlling bladder and bowels are common symptoms in
    A. first stage Alzheimer's
    B. second stage Alzheimer's
    C. terminal stage Alzheimer's
    D. don't know

31. Alzheimer's or dementia patients are commonly at risk to develop
    A. bladder infections
    B. cancer
    C. pneumonia
    D. heart disease
    E. both C and D
    F. both A and C
    G. don't know

32. Violent outbursts and loss of impulse control are common with Alzheimer's disease and dementia

true   false   don't know

33. Alzheimer's and dementia patients may resist common events such as bathing

true false don't know

34. If an Alzheimer's or dementia patient claims to be seeing or hearing things that are not there

A. this is a sign of mental problems unrelated to Alzheimer's or dementia
B. they are usually simply trying to get attention
C. this is a common symptom of Alzheimer's and dementia
D. don't know

35. Alzheimer's and dementia patients will commonly

A. repeat statements and/or movements
B. forget even close friends and/or family
C. have a shorter attention span
D. all of the above
E. B and C only
F. don't know

36. It is common for Alzheimer's and dementia patients to lose their spark, spontaneity, and zest for life

true false don't know

37. Muscle twitches or jerking is a normal occurrence with Alzheimer's and dementia patients

true false don't know

38. A person with Alzheimer's or dementia may fail to recognize themselves in the mirror

true false don't know

39. During the terminal stage of Alzheimer's, if the patient is kept on a good diet body weight will usually remain stable

true false don't know

40. Putting objects in his or her mouth
   A. is a common occurrence with Alzheimer's and dementia patients
   B. is a childish, attention seeking behavior
   C. is not a common occurrence with Alzheimer's and dementia patients
   D. don't know

41. When attempting to communicate, Alzheimer's and dementia patients may
   A. groan
   B. make grunting noises instead of words
   C. scream
   D. all of the above
   E. don't know

42. Factors such as stress, grief, and family conflict are known to contribute to the development of Alzheimer's and dementia

true false don't know

43. Hardening of the arteries is a common cause of Alzheimer's and dementia

true false don't know

44. Alzheimer's disease and dementia are a normal part of the aging process

true false don't know

45. Alzheimer's disease and dementia are NOT preventable or curable

true false don't know

46. One must take precautions when dealing with Alzheimer's and dementia patients since these conditions are contagious in some cases

true false don't know

47. Agitation and anxiety is often worse
    - A. in the early morning
    - B. in mid afternoon
    - C. in the evening
    - D. no time of day is worse than any other
    - E. don't know

48. An Alzheimer's or dementia patient is most likely to have clear memories of events in the
    - A. distant past (many years ago)
    - B. recent past (a few days ago)
    - C. immediate past (a few seconds ago)
    - D. don't know

APPENDIX B

Categorization of Survey Items

Behavioral Characteristics	Physical Characteristics	Communication
6	13	7
8	24	9
10	25	12
20	28	14
21	29	15
22	30	16
23	31	17
26	37	18
27	39	19
32	42	41
33	43	
34	44	
35	45	
36	46	
38		
40		
47		
48		

APPENDIX C

INFORMED CONSENT

You are invited to participate in a research study titled, "A Survey of Family Members' Knowledge When Dealing with Alzheimer's Disease or Dementia." The purpose of the study is to determine whether the efforts of multiple agencies to educate family members about Alzheimer's Disease and dementia has been effectively communicated. In addition, we are interested in determining whether the location in which the Alzheimer's or dementia patient is receiving care (home, assisted living facility, or nursing home) effects the level of knowledge a family member has about these diseases. This research is being conducted in partial fulfillment of a Master's Thesis at the University of Tennessee, Knoxville.

Participation in this study involves answering a variety of questions and should take less than twenty minutes of your time. You will not be asked to give your name or any other identifying information and all data collected will be reported as group data. There may be some risk that answering questions about Alzheimer's Disease and dementia may raise questions or concerns for some participants. If this should be the case, participants are encouraged to seek support and counsel from Corinne Patrick of the Alzheimer's Disease and Related Disorders Association Knoxville Area Chapter at (423) 544-9091. If you received the survey through a counselor, receptionist or assistant, the only foreseen risk with your participation in this study is that this individual assisting with data collection will know whether you decided to participate. In addition, although those assisting with data collection have been clearly instructed not to open the envelope with your responses, I cannot personally guarantee that he or she will follow these instructions. In the unlikely event that someone does see your answers and is able to link them to you, your responses would not be damaging to your financial standing, employability or reputation. Your participation is voluntary and you may discontinue your involvement at any time without penalty.

Your participation may help counselors better understand the levels of knowledge about Alzheimer's Disease and dementia that is being effectively communicated to family members. Should you have any questions, please feel free to contact me or my supervisor at:

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If you decide to participate, please keep the top copy of this Informed Consent form for your own records. Please return the second copy along with your completed survey in the envelope that has been provided. Please return your completed survey and informed consent form by mail (an addressed stamped envelope has been provided) or return the sealed envelope containing the materials to the counselor, receptionist or assistant who provided you with the survey. All sealed envelopes will be returned to the lead researcher. Please complete and return the survey within **ONE WEEK** of the day you receive it. It is important that all questions on the survey be answered.

We do not request your signature on the informed consent form because it would provide identifying information. Please note, however, that by returning the completed survey, you will be giving your consent to participate in this study.

Your participation is greatly appreciated. Thank you.

APPENDIX D

Answers To Survey Questions

QUESTION	ANSWER	QUESTION	ANSWER
1	DATA	22	B
2	DATA	23	C
3	DATA	24	D
4	DATA	25	T
5	DATA	26	A
6	B	27	C
7	A	28	D
8	D	29	C
9	F	30	C
10	F	31	F
11	T	32	T
12	B	33	T
13	E	34	C
14	C	35	D
15	T	36	T
16	A	37	T
17	C	38	T
18	C	39	F
19	B	40	A
20	A	41	D
21	T	42	F

Answers To Survey Questions

QUESTION	ANSWER
43	F
44	F
45	T
46	F
47	C
48	A

VITA

Mark A. Hicks was born in Kassel, Germany where his father was stationed in the United States Army. After only seven weeks, he was brought to the United States and raised in Sweetwater, Tennessee. He received his high school diploma from Sweetwater High School in 1987, and subsequently received an Associate of Arts degree from Hiwassee College in Madisonville, Tennessee in 1989, and a Bachelor of Arts degree from Carson-Newman College in Jefferson City, Tennessee in 1991. In August of 1991, he began study toward a Master of Divinity degree at The Southern Baptist Theological Seminary in Louisville, Kentucky. This degree was awarded in December 1994. For the next year, he served as pastor of New Columbus Baptist Church in New Columbus, Kentucky. In 1995, he published an article entitled, "Shattered Dreams: Ministering to Parents After the Loss of a Child" in the *Journal of Family Ministry*. In January of 1996, he began work toward a Master of Science in Counseling at the University of Tennessee and is presently scheduled to receive that degree in May 1999. He currently serves on the advisory council of the Retired Senior Volunteer Program, a program of the

Knoxville/Knox County Office on Aging, and is an intern in the Senior Life Skill program at Baptist Hospital of East Tennessee.