Efficacy of an Educational Program for Relatives of Persons in the Early Stages of Alzheimer’s Disease

Daniel Kuhn, MSW
Bradley R. Fulton, MA

ABSTRACT. This article describes the results of an educational intervention for family caregivers of persons in the early stages of Alzheimer’s disease. A total of 45 family caregivers participated in this intervention that consisted of five weekly educational sessions about the disease and aspects of caring for someone in the early stages. Measures of knowledge about Alzheimer’s disease, self-efficacy, reactions to patients’ memory impairment, and level of depression at pretest and posttest were analyzed. Participants’ knowledge about the disease improved substantially, self-efficacy and reactions to patients’ impairments improved moderately, and level of depression showed no significant improvement. Results suggest that this intervention has merit for family caregivers coping with the early stages of Alzheimer’s disease. Implications for implementation and evaluation are discussed. [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: docdelivery@haworthpress.com] Website: <http://www.HaworthPress.com> © 2004 by The Haworth Press, Inc. All rights reserved.

Daniel Kuhn is Director of Education, Mather Institute on Aging, Mather LifeWays, 1503 Orrington Avenue, Suite 1800, Evanston, IL 60201 (E-mail: dkuhn@matherlifeways.com).

Bradley R. Fulton is Senior Research Associate, Mather Institute on Aging, Mather LifeWays, 1503 Orrington Avenue, Suite 1800, Evanston, IL 60201 (E-mail: bfulton@matherlifeways.com).

KEYWORDS. Alzheimer's disease, dementia, early stage, education, efficacy, evaluation, family caregivers, intervention, knowledge, measures

INTRODUCTION

Alzheimer's disease (AD) is a growing public health problem, and the trend toward early diagnosis over the past decade has created a need for new and expanded services to persons with the disease and their families. It is estimated that nearly five million Americans currently have AD, and the number of individuals and families affected by the disease is projected to grow to 11 million by 2040 (Hebert et al., 2003). Early diagnosis has been prompted by the advent of several medical treatments approved by the U.S. Food and Drug Administration since 1994. Early diagnosis is also more likely due to advances in diagnostic techniques such as brain scans and psychological tests (National Institutes of Health, 2003). In addition, the ongoing public awareness campaign by the Alzheimer's Association and public announcements by prominent figures such as Ronald Reagan and Charlton Heston about their diagnosis of AD have contributed to earlier diagnosis than in the past (Murphy et al., 2003). This increase in the number of people diagnosed in the early stages of AD has profound implications for clinical practice and the delivery of health care and social services to patients and their families.

AD may last three to twenty years, and the rate of progression varies from person to person (Wilson et al., 1999). Some persons may remain in the early stages for five years or more. For the most part, however, the current array of printed materials, support groups, educational programs, and other community resources target the needs of caregivers of persons in the middle to late stages of AD. This study and a related one (Kohn & Mendes de Leon, 2001) address this concern that family members caring for relatives in the early stages of AD have few educational and support services to address their needs at this particular stage of the disease. Families caring for relatives in middle to late stages often face issues such as incontinence, behavioral disturbances, and nursing home placement. Such issues are neither relevant to families dealing with the early stages nor will these issues be of interest to them in the near future. These issues are potentially frightening and misleading to newcomers to the disease. Nevertheless, family members are often troubled during the early stages by their changing roles and responsibilities as well as
other changes in the relationship with their relative with AD (Kuhn, 2003). Gerontologists in human service and health care organizations need to be aware of the special needs of this growing subgroup of family caregivers as well as persons in the early stages of the disease.

Numerous studies have documented that the emotional, physical, and financial stressors involved in caring for a relative with AD often result in negative outcomes for caregivers, including increased rates of depression, anxiety, poorer physical health, and decreased levels of social support (Alzheimer's Association and National Alliance for Caregiving, 1999; Harwood et al., 1998; Schulz & Beach, 1999). Caregivers differ widely in the level and type of stress they experience and their perceptions of burden. Theoretical frameworks on stress and coping aimed at explaining the process and outcomes of caregiving have examined mediating factors such as the past and current relationship between the patient and caregiver, appraisal of the situation, coping skills, and resource utilization (Gallagher-Thompson, 1994; Kramer, 1997; Pearlman et al., 1990). A variety of programs including respite services, support groups, and educational programs and services have been examined to determine their moderating effects for AD caregivers (see review by Ory et al., 1999).

As Toseland and Rossiter (1989) point out, an important limitation of educational interventions for caregivers of persons with AD is that they have not considered the wide range of patients' symptoms and caregivers' reactions that may occur at different stages of the disease. In their review of research on AD caregiving, Vitaliano and colleagues (1997) emphasize the need to target interventions to specific subsets of caregivers. Especially lacking are interventions aimed at caregivers of persons in the early stages of AD. A similar view is offered by Bourgeois, Schulz and Burgio (1996), who state that "in the early stage of the illness, caregivers may need more help in coming to terms with the impending decline and loss of the patient as opposed to requiring specific behavior management skills" (p. 81). Based on experience with 139 AD family caregivers who took part in educational groups, Farran and Keane-Hagerty (1994) observe that "data also suggest that it may be most appropriate for caregivers to participate in such a group during the early phases of caregiving" (p. 253). Chiverton and Caine (1989) as well as Montgomery and Koslowski (1999) similarly have addressed the issue of "timing" in the caregiving trajectory, noting that attention must be paid to matching interventions with the stage-specific needs of caregivers. Walker and colleagues (1994) also note that group interventions
with AD family caregivers must take into account the different stages of the disease.

A variety of educational interventions have been developed to assist family caregivers of persons with AD. These interventions are generally designed to reduce distress or caregiver burden, improve knowledge, or teach more effective coping skills. A number of studies have examined the efficacy of educational support group interventions for caregivers of persons with AD, although there has been considerable variation in terms of the format, process, and outcome measures used to evaluate these interventions (Bourgeois et al., 1996). In spite of these variations, educational interventions have generally been successful on a short-term basis in reducing burden, anxiety, and depression of AD family caregivers (Farren & Keane-Hagerty, 1994; Gallagher-Thompson et al., 2001; Hebert et al., 2003; Mittelman et al., 1995; Ostwald et al., 1999; Sorenson, Pinquart, & Duberstein, 2002.)

Thus far, only two psychoeducational interventions targeting relatives of persons with early stage AD have been evaluated. Cummings and colleagues (1998) reported significant benefits for 13 participants of a support group. Kuhn and Mendes de Leon (2001) reported significant benefits for 58 participants of the educational program examined in the current study, the AD Knowledge Building Program. However, they recommended alternative ways of measuring outcomes to better assess the program’s effectiveness. This recommendation prompted the use of the measures in the study described here. Schulz and other intervention researchers (2002) have recently highlighted the importance of using measures that are sensitive to targeted caregiver interventions.

THE EDUCATIONAL INTERVENTION

In response to the unique challenges of the early stages of AD, an education program was developed based on a series of interviews that revealed the learning needs of primary caregivers of relatives in the early stages (Kuhn, 1998). The goal of the five-part curriculum, known as the AD Knowledge Building Program, was to increase participants’ knowledge about key medical, legal, financial, and psychosocial aspects of AD and to enhance participants’ coping skills. The intervention consisted of five consecutive weekly sessions, each two hours long. Four groups were conducted at community-based settings with seven to fifteen participants each. The sessions included lectures, slides, group discussions,
and written materials. One or two instructors with extensive experience in AD taught the sessions with a prescribed curriculum.

METHODS

Participants and Patients

Family members were recruited in the metropolitan Chicago area from two memory disorder clinics, a continuing care retirement community, a senior center, and the local chapter of the Alzheimer’s Association. Criteria for eligibility required that participants have a relative in the early stages of AD. This was determined in one of two ways. First, their relatives were considered in the early stages if they had been diagnosed with probable AD and had scored 20 points or above on the Mini-Mental State Exam (MMSE; Folstein, Folstein, & McHugh, 1975) within the past six months. A score of 20 on the MMSE is often cited by experts as the cutoff point for the early/mild stage of AD. In the absence of this measure, another set of criteria were used to define the early stages of AD: (1) the relative with AD did not require help with any personal activities of daily living such as bathing and (2) the relative with AD exhibited no significant behavioral challenges such as hallucinations. These two criteria encapsulate the definition of early AD by Reisberg and colleagues (1982). Telephone interviews with prospective participants were sufficient to confirm that eligibility criteria were met. Those persons not meeting the above criteria were referred to support groups or educational seminars sponsored by the local chapter of the Alzheimer’s Association.

A total of 51 eligible persons agreed to participate, of whom 45 (88%) completed at least four of the five intervention sessions. These 45 persons form the basis of the present report. Participants ranged in age from 25 to 83 years, were primarily female (73.3%), Caucasian (95.5%) and married (73.3%). They were typically either the child of the patient (57.8%) or the spouse of the patient (28.9%). All participants had graduated high school, but most had attended some college (35.6%) or graduated college (28.9%). Most participants worked full time (52.3%) or were retired (29.5%). See Table 1 for more details.

Relatives with AD cared for by participants of the intervention ranged in age from 51 to 85 years, and were primarily female (66.7%) and Caucasian (97.8%). Participants reported that AD symptoms had
TABLE 1. Demographics of Caregivers

<table>
<thead>
<tr>
<th></th>
<th>Mean (Standard Deviation) or % of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>54.3 (15.3; Range: 25 to 83)</td>
</tr>
<tr>
<td><strong>Female</strong></td>
<td>73.3%</td>
</tr>
<tr>
<td><strong>Caucasian</strong></td>
<td>95.5%</td>
</tr>
<tr>
<td><strong>Married</strong></td>
<td>73.3%</td>
</tr>
<tr>
<td><strong>Single, Never Married</strong></td>
<td>15.6%</td>
</tr>
<tr>
<td><strong>Divorced</strong></td>
<td>8.9%</td>
</tr>
<tr>
<td><strong>Widowed</strong></td>
<td>2.2%</td>
</tr>
<tr>
<td><strong>Child of Patient</strong></td>
<td>57.8%</td>
</tr>
<tr>
<td><strong>Spouse of Patient</strong></td>
<td>28.9%</td>
</tr>
<tr>
<td><strong>Other Relationship to Patient</strong></td>
<td>13.3%</td>
</tr>
<tr>
<td><strong>High School Graduate</strong></td>
<td>13.3%</td>
</tr>
<tr>
<td><strong>Some College</strong></td>
<td>35.6%</td>
</tr>
<tr>
<td><strong>College Graduate</strong></td>
<td>28.9%</td>
</tr>
<tr>
<td><strong>Advanced Degree</strong></td>
<td>22.2%</td>
</tr>
<tr>
<td><strong>Employed Full Time</strong></td>
<td>52.3%</td>
</tr>
<tr>
<td><strong>Employed Part Time</strong></td>
<td>18.2%</td>
</tr>
<tr>
<td><strong>Retired</strong></td>
<td>29.5%</td>
</tr>
</tbody>
</table>

been evident for a mean of 17.1 months (SD = 16.9) and the actual diagnosis had taken place a mean of 11.9 months (SD = 11.1) prior to the intervention. Relatives with AD were usually either married (55.6%) or widowed (26.7%). Roughly one-third of persons with AD lived with the participant (38.6%), lived with someone else (31.8%), or lived alone (29.5%). A few persons with AD had not graduated high school (15.5%), but most had either graduated high school (33.3%), attended college (17.8%) or graduated college (26.7%). See Table 2 for more details.

**Measures**

Outcome measures were selected to evaluate whether the educational intervention resulted in improved AD knowledge, management of AD-related problem behaviors and emotions, self-efficacy, and in reductions of depressive symptoms. Given the absence of a measure that assesses family caregivers’ knowledge about AD, an AD Knowledge Test was devised and used in the prior study (Kuhn & Mendes de Leon,
TABLE 2. Demographics of Relatives with AD

<table>
<thead>
<tr>
<th></th>
<th>Mean (Standard Deviation) or % of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>74.3 (7.4; Range: 51 to 85)</td>
</tr>
<tr>
<td>Female</td>
<td>66.7%</td>
</tr>
<tr>
<td>Caucasian</td>
<td>97.8%</td>
</tr>
<tr>
<td>Number of Living Children</td>
<td>28 (1.6; Range: 0 to 7)</td>
</tr>
<tr>
<td>Family History of Dementia</td>
<td>38.6%</td>
</tr>
<tr>
<td>Months Since Symptoms Evident</td>
<td>17.1 (16.9)</td>
</tr>
<tr>
<td>Months Since Diagnosis</td>
<td>11.9 (11.1)</td>
</tr>
<tr>
<td>Married</td>
<td>55.6%</td>
</tr>
<tr>
<td>Widowed</td>
<td>26.7%</td>
</tr>
<tr>
<td>Divorced</td>
<td>11.1%</td>
</tr>
<tr>
<td>Single, Never Married</td>
<td>6.7%</td>
</tr>
<tr>
<td>Lives with Participant</td>
<td>38.6%</td>
</tr>
<tr>
<td>Lives with Someone Else</td>
<td>31.8%</td>
</tr>
<tr>
<td>Lives Alone</td>
<td>29.5%</td>
</tr>
<tr>
<td>Spouse Is Decision Maker</td>
<td>46.7%</td>
</tr>
<tr>
<td>Adult Child Is Decision Maker</td>
<td>44.4%</td>
</tr>
<tr>
<td>Someone Else Is Decision Maker</td>
<td>8.9%</td>
</tr>
<tr>
<td>Some High School or Less</td>
<td>15.9%</td>
</tr>
<tr>
<td>High School Graduate</td>
<td>33.9%</td>
</tr>
<tr>
<td>Some College</td>
<td>17.0%</td>
</tr>
<tr>
<td>College Graduate</td>
<td>26.7%</td>
</tr>
<tr>
<td>Advanced Degree</td>
<td>6.7%</td>
</tr>
</tbody>
</table>

2001). The degree of difficulty of the 20 questions (12 four-choice items and 8 true/false items) appeared too easy and may have accounted for the modest change noted from pre- to post-testing in that study. Since more difficult questions might yield lower pre-intervention knowledge levels, and greater change from pre- to post-testing, the AD Knowledge Test was revised for this study and now comprises 31 five-choice questions (see Appendix A). This Test was designed to evaluate a range of issues pertaining to the medical aspects of AD (e.g., risk factors, diagnosis, treatment options) as well as the psychosocial, financial and legal aspects of providing care to a relative with AD. For the analyses, the AD Knowledge Test score is a count of the number of correct items.

In the prior study, the entire 24-item Revised Memory and Behavior Problems Checklist (RMPBC: Teri et al., 1992) was used to measure
management of AD-related memory and behavior problems. The RMBPC assesses the occurrence of specific memory and behavior problems observed in the person with AD during the past week, as well as the degree of upset the caregiver felt with each reported problem on a four-point scale (0 = not at all; 1 = a little; 2 = moderately; 3 = very much; 4 = extremely). The validity of the RMBPC has been confirmed through comparison with well-established indexes of depression (Hamilton, 1967; Radloff, 1977), cognitive impairment (Folstein, Folstein, & McHugh, 1975), and caregiver burden (Deimling & Bass, 1986). Most of the RMBPC items were devised with middle and late stage AD in mind, so they may not be applicable to the population of early stage caregivers. In the prior study, a decrease in the levels of upset on this scale was noted. Since the items on the memory subscale of the RBMPC that relate to the early stages of AD might yield higher pre-intervention levels of caregiver upset, and possibly greater change from pre- to post-testing, an eight-item subscale was used for the present study. In the analysis, two measures were computed: (1) a count of the number of items considered problems by caregivers, (2) the mean of the severity of reported level of upset by caregivers for these same problems.

The prior study assessed the prevalence of depressive symptoms with the Center for Epidemiological Studies Depression Scale (CES-D), a widely used and well-validated self-report measure of depressive symptoms designed for use in the general population (Radloff, 1977; Radloff & Teri, 1986). A slight but nonsignificant increase in depressive symptoms was noted in the prior study, and this measure was used again in the present study. The CES-D consists of 20 items that assess the occurrence of each symptom during the last week on a four-point scale (0 to 3). In the analyses, the depression scores are the mean of the non-missing items. If less than 70% of the items were non-missing, the scale was coded as missing.

Although knowledge about AD is important in making informed decisions regarding the care of the patient, knowledge alone may not necessarily lead to a greater degree of confidence to cope with the challenges or reduce the burden of caregivers. Furthermore, Bandura's social cognitive theory (1989) posits that a high degree of self-efficacy will increase the likelihood that caregiving tasks will be performed successfully. Therefore, the intervention also addressed the need to increase caregivers' self-efficacy with respect to caregiving tasks. A measure of Caregiver Self-Efficacy was devised because no such scale suited specifically to AD caregiving existed at the time of the present study (see Appendix B). The Caregiver Self-Efficacy scale consists of
15 statements in which caregivers report their level of confidence in dealing with caregiving tasks using a five-point Likert scale (range of 1 = not at all confident to 5 = extremely confident). In the analyses, the Caregiver Self-Efficacy scores are the mean of the non-missing items. If less than 67% of the items were non-missing, the scale was coded missing.

**Analyses**

Data were analyzed using the Statistical Package for the Social Sciences version 11.5 (SPSS, 2002). Paired t-tests were used to examine differences between pre-intervention and post-intervention scores. Distributions of the mean differences were examined using graphical methods and the Shapiro-Wilk statistic to identify departures from normality. Significant departures were identified in the distribution of AD Knowledge Test scores, W(44) = .917, p = .004; the number of memory and problem behaviors, W(44) = .939, p = .021; and the severity of caregiver upset regarding memory and problem behaviors, W(43) = .947, p = .048. However, because the t-test is known to be robust against departures from normality (Dunn, 2001), and the Wilcoxon test showed identical results, the paired t-tests will be reported. Effect size is computed using Cohen’s $d$. Demographics of the participants and patients, and the internal consistency reliability of the outcome measures (using Cronbach’s coefficient alpha), are also reported.

**RESULTS**

Internal consistency reliability was examined for the depression scale and self-efficacy scale. This was not addressed for the remaining outcome measures because they count the occurrence of or index the severity of a phenomenon rather than measure an underlying construct. Both the depression scale ($\alpha = .90$) and the self-efficacy scale ($\alpha = .90$) demonstrated high internal consistency. The corrected item-total correlations for the self-efficacy scale (range = .33 to .76) were all moderate to high suggesting all the items are contributing to internal consistency. Except for one item (−.04), the corrected item-total correlations for the depression scale (range of .25 to .82) were also all moderate to high.

There was a significant increase in the mean number of correct items on the AD Knowledge Test, t(43) = −6.976, p < .0005, from pre-intervention (M = 16.4, SD = 5.3) to post-intervention (M = 22.3, SD = 4.9).
According to Cohen (1988), effect sizes of .2, .5, and .8 correspond to small, medium, and large effects, respectively. By this definition, the increase in knowledge can be considered a very large effect ($d = 1.2$).

There was also a significant increase in the mean Caregiver Self-Efficacy, $t(43) = -4.619$, $p < .0005$, from pre-intervention ($M = 3.0$, $SD = 0.7$) to post-intervention ($M = 3.3$, $SD = 0.7$). However, this difference was moderate in effect ($d = 0.4$).

Finally, the mean severity of caregiver upset regarding the subscale of the RMBPC significantly decreased, $t(42) = 2.769$, $p = .008$, from pre-intervention ($M = 0.9$, $SD = 0.6$) to post-intervention ($M = 0.6$, $SD = 0.5$). Again, this difference was moderate in effect ($d = 0.5$).

Neither the depression scale, $t(31) = 1.414$, $p = .167$, nor the number of reported memory and behavior problems, $t(43) = 0.308$, $p = .760$, showed significant differences between pre-intervention and post-intervention. See Table 3 for details of these analyses.

**DISCUSSION**

By focusing on the early stages of AD, this study aimed to fill a void in the educational and supportive services available for family caregivers of persons with AD. The original study of the AD Knowledge Building Program (Kuhn & Mendes de Leon, 2001) reported an increase in caregivers’ knowledge about AD, a decrease in caregivers’ levels of upset about memory problems commonly seen in AD, and no significant change in caregivers’ depression. The results of the present

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>Pre-Intervention Mean (SD)</th>
<th>Post-Intervention Mean (SD)</th>
<th>Significance of t-Test</th>
<th>Effect Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge</td>
<td>44</td>
<td>16.4 (5.3)</td>
<td>22.3 (4.9)</td>
<td>$&lt; .00005$</td>
<td>1.2</td>
</tr>
<tr>
<td>Depression</td>
<td>32</td>
<td>0.7 (0.5)</td>
<td>0.7 (0.4)</td>
<td>0.167</td>
<td>---</td>
</tr>
<tr>
<td>Self-Efficacy</td>
<td>44</td>
<td>3.0 (0.7)</td>
<td>3.3 (0.7)</td>
<td>$&lt; .00005$</td>
<td>0.4</td>
</tr>
<tr>
<td>RMBPC Subscale-Number of Problems</td>
<td>44</td>
<td>4.1 (1.6)</td>
<td>4.0 (2.1)</td>
<td>0.760</td>
<td>---</td>
</tr>
<tr>
<td>RMBPC Subscale-Severity of Caregiver Upset</td>
<td>44</td>
<td>0.9 (0.6)</td>
<td>0.6 (0.5)</td>
<td>0.008</td>
<td>0.5</td>
</tr>
</tbody>
</table>
study are consistent with the prior study and address the need for sensitive outcome measures. Results suggest that the intervention was successful in increasing caregivers’ knowledge about the disease, improving caregivers self-efficacy, and decreasing caregivers’ levels of upset about memory problems commonly seen in persons with AD. No difference in level of depressive symptoms or frequency of reported memory problems was noted. The largest effect by far was seen in increased knowledge, consistent with findings about the benefits of caregiver education programs reported in a recent meta-analysis of intervention studies (Sørensen, Pinquart, & Duperstein, 2002).

The study had a number of limitations that need to be considered in evaluating these findings. The most important limitation was the lack of a control group, which made it impossible to conclusively attribute any change in outcome measures to the intervention itself. Other shortcomings include a relatively small number of participants who were mostly white and mostly well educated. Application of the AD Knowledge Building Program in other populations will reveal the generalizability of this program for caregivers of persons in the early stages of AD.

Several programmatic issues arose in the course of recruitment and implementation of this program. First, the focus on the early stages of AD presents a recruitment challenge due to the need to define this stage and screen for the intended audience. There are no well-accepted or simple criteria for separating the early stage from other stages of the disease, except through arbitrary definitions such as those used in this study. Also, there is no easy method of screening for this specific stage of the disease except through a clinical evaluation. However, the criteria used in this study seemed to attract those caregivers who were indeed dealing with early stage issues. Another recruitment challenge stems from the requirement that a diagnosis of probable AD be obtained in advance of participation. Many primary care physicians often do not recognize dementia or are reluctant to apply the diagnosis of AD and alternatively use nonspecific labels such as dementia (Ross et al., 1997; Vallerou et al., 2000). To encourage caregivers to obtain a thorough evaluation of dementia symptoms and provide them with proper information about care issues, this educational program could be more inclusive by expanding enrollment to any family caregiver dealing with the early stages of dementia, regardless of etiology.

Two final issues concern the choice of outcome measures. The measures of knowledge, reactions to memory problems (RMBPC memory subscale), and self-efficacy appear to be fitting tools for evaluating the challenges that caregivers face in the early stages of AD. Both the new
measure of knowledge and self-efficacy developed for this study require further investigation regarding their psychometric properties. One or more subscales of a recently validated measure of caregiver self-efficacy (Steffen et al., 2002) might be adapted to serve as a suitable alternative. Also, although the CES-D is useful in assessing caregivers' depression, this intervention does not successfully treat depression nor was it primarily intended to do so. Depression is an important concern in any type of caregiver intervention but other means to address it through individual and/or family counseling and antidepressant medication should be emphasized in the course of group education programs.

In light of the growing public health problem of AD, it will become increasingly important to develop a continuum of services for family caregivers at all stages of this chronic disease, especially at the early stage when information and coping skills are critical. Clearly there is a need for further research about the nature of caregiving in the early stages of AD and interventions aimed at minimizing the negative outcomes associated with caring for relatives with the disease. Gerontologists can play key roles in developing, implementing, and evaluating such services.

REFERENCES


DATE MANUSCRIPT RECEIVED: 04/29/03
DATE MANUSCRIPT SENT FOR BLIND REVIEW: 05/05/03
DATE MANUSCRIPT RE-RECEIVED
IN ACCEPTABLE FORM: 07/05/03
APPENDIX A. Alzheimer’s Disease Knowledge Test

1. Which of the following is the most common cause of memory impairment in people over age 65?
   _1. Alzheimer’s disease
   _2. Senility
   _3. Normal aging
   _4. Hardening of the arteries
   _5. Benign senescent forgetfulness

2. Which of the following is the most common risk factor for Alzheimer’s disease?
   _1. Hardening of the arteries
   _2. Advancing age
   _3. Nutritional deficits
   _4. Environmental toxins
   _5. Alcoholism

3. Persons suspected of having Alzheimer’s disease should be medically evaluated because
   _1. Treatment may halt the progression of the disease
   _2. Reversible disorders should be ruled out or treated
   _3. Driving privileges need to be reviewed
   _4. Other living arrangements can be facilitated
   _5. All of the above

4. Which of the following conditions may resemble Alzheimer’s disease?
   _1. Major depression
   _2. Pernicious anemia
   _3. Thyroid disorder
   _4. Parkinson’s disease
   _5. All of the above

5. Drugs currently approved for the treatment of Alzheimer’s disease
   _1. Also reduce the risk of small strokes in Alzheimer’s disease
   _2. Reverse symptoms in some cases
   _3. Also reduce depression in Alzheimer’s disease
   _4. Lessen symptoms temporarily in some cases
   _5. Are believed to stimulate the growth of new brain cells

6. The prevalence of Alzheimer’s disease among people age 85 years and older living in the community is about
   _1. 70%
   _2. 50%
   _3. 20%
   _4. 15%
   _5. 10%

7. Genetic testing for Alzheimer’s disease is currently
   _1. A reliable way of predicting if symptoms will develop later in life
2. Useful only as a research tool
3. A definitive means of diagnosis after the onset of symptoms
4. An accurate means of diagnosis in most cases
5. Approved for home use by the U.S. Food and Drug Administration

8. A drug proven to temporarily improve or maintain memory among some persons with Alzheimer's disease in the early to middle stages is
1. Prozac
2. Gingko biloba
3. Aricept
4. Haldol
5. None of the above

9. A simple screening test for dementia is the
1. Global Deterioration Test
2. Mini-Mental State Examination
3. Brief Symptom Inventory
4. Geriatric Dementia Scale
5. Wechsler Memory Scale

10. A symptom of Alzheimer's disease usually NOT seen in the early stage is
1. Disorientation to time and place
2. Word finding difficulty
3. Aggressive behavior
4. Recent memory loss
5. Difficulty with calculations

11. Giving reminders such as the date and place to persons with Alzheimer's disease will
1. Improve memory for a time
2. Improve orientation for a time
3. Not change memory or orientation
4. Increase confusion
5. Be useful temporarily but will have no lasting effect on memory orientation

12. Agitated behavior is MOST LIKELY when the person with Alzheimer's disease is being helped with
1. Housekeeping
2. Bathing
3. Preparing meals
4. Shopping
5. Walking outside the home

13. When persons with Alzheimer's disease constantly repeat questions directed to you the BEST approach is to
1. Ignore the question
2. Redirect to another topic or activity
3. Patiently repeat your response
4. Gently explain that the question has been asked and answered

5. Provide a written response

14. The BEST way to make someone with Alzheimer's disease understand you is to
   1. Logically explain your reasoning
   2. Write out a detailed note
   3. Repeat yourself until the point is made
   4. Give brief and simple instructions
   5. Speak in a quiet tone

15. When a person with Alzheimer's disease begins to have difficulty performing self-care tasks, it is recommended that you
   1. Discourage the person from trying these tasks
   2. Hire someone to help
   3. Take over the tasks
   4. Assist as a last resort option
   5. Assist the person as needed

16. Which of the following is NOT likely to be a problem for a person in the early stage of Alzheimer's disease who is living alone?
   1. Forgetting to turn off the stove
   2. Making travel plans
   3. Managing money
   4. Remembering to take medications
   5. Getting dressed in the morning

17. Which of the following approaches is NOT HELPFUL for persons with Alzheimer's disease in completing tasks?
   1. Breaking tasks down into small steps
   2. Encouragement to try harder
   3. Repeating old, familiar skills
   4. Having others assist them as needed
   5. Companionship

18. A person diagnosed with Alzheimer's disease in the early stage is presumably
   1. In need of guardianship
   2. Competent to make all decisions
   3. Partially competent and unable to complete Powers of Attorney
   4. Incompetent but may consent to a medical procedure
   5. Incompetent

19. According to state law, a person with Alzheimer's disease who still drives a car
   1. Must be reported to state authorities for a re-evaluation
   2. Will not be permitted to pass the license renewal test
   3. Faces no specific driving restrictions
   4. Must have a companion at all times while driving
5. Must complete a driver rehabilitation program

20. The BEST way for persons in the early stage of Alzheimer's disease to ensure that their rights and personal preferences will be protected in the future is to
   ___ 1. Sign a living will for health and financial decisions
   ___ 2. Complete Durable Powers of Attorney for Property and Health Care
   ___ 3. Have a legal guardian appointed
   ___ 4. Have a loved one speak up in their behalf as needed
   ___ 5. Transfer their assets into the name of a loved one

21. Which of the following is NOT a good reason for disclosing the diagnosis to persons with Alzheimer's disease?
   ___ 1. They have a right to know the truth about their condition
   ___ 2. They can choose whether or not to participate in research studies
   ___ 3. They can feel free to discuss advance directives and other future plans
   ___ 4. They can opt for a brain biopsy if they want a definitive diagnosis
   ___ 5. Their symptoms can be explained as part of a disease, not a personal failing

22. The rates of motor vehicle accidents for drivers aged 65 and older are
   ___ 1. Lower compared to middle-aged drivers
   ___ 2. About the same compared to middle-aged drivers
   ___ 3. Higher compared to middle-aged drivers
   ___ 4. Lower compared to middle-aged male drivers, about the same for females
   ___ 5. Lower compared to middle-aged female drivers, about the same for males

23. In regard to financial affairs, persons with Alzheimer's disease can
   ___ 1. Be persuaded of the need for a legal guardian
   ___ 2. Usually be trusted to manage their own income and assets
   ___ 3. Be exploited if safeguards are not put in place
   ___ 4. Be responsible for paying their bills if in the early stage of the disease
   ___ 5. Make transactions after thorough consultation

24. Medicare covers which one of the following for persons with Alzheimer's disease?
   ___ 1. Doctor's visits on an out-patient basis
   ___ 2. Nursing home care on a long-term basis
   ___ 3. Adult day care
   ___ 4. Companion services at home
   ___ 5. Medications

25. Most persons with Alzheimer's disease live...
26. The cost of nursing home care in the U.S. is paid for mainly through
   ______1. Private funds, an out-of-pocket expense
   ______2. Medicare
   ______3. Medicaid
   ______4. Long-term care insurance
   ______5. Supplemental Security Income

27. Primary caregivers of persons with Alzheimer's disease suffer from major depression
   ______1. At about the same rate as the general population
   ______2. At a lower rate than the general population
   ______3. At a much higher rate than the general population
   ______4. At a slightly higher rate than the general population
   ______5. At a much lower rate than the general population

28. For a married person with Alzheimer's disease to qualify for Medicaid in order to pay the cost of nursing home care,
   ______1. The spouse is required to spend down their liquid assets to $2000
   ______2. The spouse must sell their residence and exhaust all assets
   ______3. The spouse is entitled to a protected level of income and assets
   ______4. The spouse may transfer most of their assets to their children
   ______5. The spouse must file for bankruptcy or divorce

29. Those LEAST likely to be primary caregivers of persons with Alzheimer's disease are
   ______1. Their sons
   ______2. Their daughters
   ______3. Their daughters-in-law
   ______4. Their husbands
   ______5. Their wives

30. The level of distress experienced by primary caregivers immediately following relocation of a relative with Alzheimer's disease to a nursing home is generally
   ______1. Much lower compared to before relocation
   ______2. Slightly lower compared to before relocation
   ______3. Higher compared to before relocation
   ______4. About the same compared to before relocation
   ______5. Not an issue if the basic needs are met by the nursing home staff
31. A potential outcome of providing care to a relative with Alzheimer's disease is
   ___1. Family conflict
   ___2. Stronger family ties
   ___3. Social isolation
   ___4. Personal fulfillment
   ___5. All of the above

APPENDIX B. Self-Efficacy Scale

Instructions: Please indicate how confident you are that you can do these things. Record a number from 1 to 5 using this scale:

   1——-2——-3——-4——-5
Not at all confident A little confident Somewhat confident Mostly confident Extremely confident

In relation to the person with Alzheimer's disease, how confident are you that you can deal effectively:

   1. With his or her losing or misplacing things around the house. ___
   2. With your need to maintain enough time for other family members or friends. ___
   3. If he or she is no longer able to go outside the home alone. ___
   4. With your need to maintain most of your daily activities (e.g., chores, work). ___
   5. With knowing when to ask for help with a particular problem about him or her. ___
   6. With helping him or her to take medications properly. ___
   7. If he or she is no longer able to bathe independently. ___
   8. If his or her condition may worsen over time. ___
   9. With making necessary decisions when he or she is no longer able to make them. ___
   10. With whom to contact if you need help with a problem concerning him or her. ___
11. If he or she is no longer able to dress independently.  
12. With handling all of the responsibilities in caring for him or her in the future.  
13. With his or her repeating the same question over and over again.  
14. With engaging in a pleasant activity with him or her at least once a week.  
15. With giving yourself a chance to spend time for your hobbies or other pleasant activities.