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Knowledge of Alzheimer's Disease Among Family Caregivers

Elaine Eshbaugh^{1*} and Lauren Stratton²

¹Department of Gerontology, University of Northern Iowa, USA

²Department of Gerontology, Iowa State University, USA

*Corresponding author: Elaine Eshbaugh, Associate Professor, Department of Gerontology, University of Northern Iowa, United States, Tel: 3198305536; E-mail: ELAINE.ESHBAUGH@UNI.EDU

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Abstract

Objective: Although the majority of care for those with Alzheimer's is provided by informal rather than formal caregivers, family caregivers may lack knowledge about the disease. We sought to better understand the level and predictors of knowledge among family caregivers.

Design: Several Alzheimer's area support group facilitators were asked to forward a survey to their support groups via electronic mail. An email that accompanied the survey invited participants to forward the survey to others who had family members affected by Alzheimer's disease. One-hundred forty-two total participants completed the survey.

Measurements: This study examined the level of knowledge 142 family members had about the disease using the Alzheimer's Disease Knowledge Scale (ADKS).

Results: Scores on the ADKS were positively correlated with self-reported knowledge of Alzheimer's, and family members with higher levels of education were more likely to be knowledgeable about the disease.

Conclusion: Our research suggests that years of education is a predictor of Alzheimer's knowledge among caregivers. It appears that family members, particularly those with lower levels of education, have a need for more knowledge about Alzheimer's.

Keywords: Alzheimer's; Family caregiving

Introduction

Background and research questions

Alzheimer's disease impacts the person who is diagnosed, but it also affects family members who are responsible for caring for their loved one. Eighty percent of Alzheimer's care is provided by unpaid caregivers who are typically family members [1,2]. Family caregivers invest much time and effort into their caring responsibilities. However, it seems that many informal caregivers may be undereducated about Alzheimer's disease.

Family caregivers may have a general low level of knowledge of Alzheimer's disease. They do not fully understand the common characteristics, progression, symptoms, causes, or available resources [3-5]. When family caregivers have a higher level of knowledge they tend to exhibit less stress and burden [6,7]. Therefore, it is important that they learn about the disease to improve their own quality of life. It is also crucial that caregivers have adequate knowledge about the disease so they are able to provide quality care to their loved one.

Family knowledge of Alzheimer's disease

Family members often assume the role of caregiver if someone in their family is diagnosed with Alzheimer's disease. However, many of these family caregivers may have inadequate knowledge about the disease. Researchers find that families have a need for general information about Alzheimer's, such as the characteristics and stages, diagnosis, and treatments [5,8,9]. Many family caregivers, like the general population, erroneously believe that memory loss and memory disorders are part of the normal aging process [9]. It is crucial families are knowledgeable about the disease because families cope more positively if they are educated about Alzheimer's and understand the typical progression of the disease [10].

The lack of knowledge of Alzheimer's disease among families may be partially due to a lack of services that inform those in need of education [11]. Many researchers have found that caregivers have a need for education on dementia as well as a need for support services and information on care [9]. Researchers also suggest that there is a need for information about services and support groups for the person diagnosed with dementia in addition to the family [9,12].

Researchers have used several measures to determine families' level of knowledge about Alzheimer's. One of the most commonly used measures is the Alzheimer's Disease Knowledge Scale [1]. It contains thirty true/false questions that cover the knowledge of seven broad categories: risk factors, assessment and diagnosis, symptoms, course, life impact, caregiving, and treatment and management [1]. The AD Communication Knowledge Test [13] is used to measures caregivers' knowledge of communication in Alzheimer's and to determine their level of knowledge regarding effective communication strategies. Although it does not assess knowledge directly, some researchers have used the Short Sense of Competence Questionnaire, which focuses on

the amount of competence caregivers feel that they have when it comes to caring for a person with dementia [6].

Studies using these measures have identified areas in which family caregivers may have a need for education. Research has suggested that families have misperceptions about Alzheimer's in the areas of prevalence, etiology, diagnosis, financial responsibilities, and the progress of the disease. Many participants believed that it can be cured, that it is contagious, and that it is a form of insanity [8]. Family caregivers tend to have difficulty knowing the difference between memory problems that come with normal aging and memory problems that are indicative of Alzheimer's [14]. Werner [5] found that family caregivers had a low level of overall knowledge about the disease and that they were the least knowledgeable about the symptoms of the disease, causes, and prevalence. However, in a different study, Werner [14] found that the majority of participants were able to correctly identify symptoms.

Studies have identified factors that are linked to levels of knowledge in caregivers. Lower education has been correlated with lower levels of knowledge about Alzheimer's disease. Higher education may give formal and family caregivers greater access to sources that facilitate learning about the disease [5,8]. In a study of four ethnic groups (White, Black, Asian, and Latino), Whites had the highest level of knowledge about Alzheimer's. However, all four groups had low levels of general knowledge [8]. Age may also be related to knowledge of Alzheimer's disease. Increased age has been linked to lower knowledge of Alzheimer's, indicating the younger individuals are more knowledgeable about the disease than older individuals [14].

Benefits of knowledge

Increased knowledge is considered to be beneficial to most caregivers [15-17]. A family caregiver's sense of competency increases if the caregiver has a high level of efficiency and knowledge of communication skills with people that have dementia [18]. As caregiver knowledge about communication with their loved one that has Alzheimer's increases, frustration tends to decrease [13]. Wellinformed caregivers tend to be more active in their caregiving and are more comfortable making decisions on the behalf of the person for whom they are caring [5]. Caregivers who do not have adequate knowledge may have poor coping skills, may show addictive behavior, and may not be prepared to handle the increasing stress that comes as the disease progresses [10].

Interventions and other services are an important way for caregivers to increase their knowledge of Alzheimer's. When caregivers believe that they do not have available services, caregiver burden increases [19]. Therefore, service providers should make themselves known and encourage involvement by family caregivers. When caregivers are taught in interventions how to recognize and confront negative thoughts that may hinder their caring responsibilities, their negative feelings and burden decrease [9]. After an intervention, there is a decrease in caregiver stress [20] and many interventions have resulted in increased caregiver well-being and a reduction of burden, frustration, and depression [6,8,21]. Being a member of a support group has been associated with decreased depression and improved morale for family caregivers [10].

Not all studies have found all positive benefits of receiving knowledge training. In two studies, knowledge did not seem to impact caregiver depression levels or health status [17,18]. Some studies have found no relationship between the level of knowledge and the level of

caregiver burden [5,17]. However, Coen et al. [15] found that the majority of their caregiver participants had an increased knowledge of dementia after the intervention. Yet, some of these participants had no changes in burden and quality of life, and others had an increase in burden and decrease in quality of life after gaining knowledge.

Education interventions

A variety of interventions and other services are available to those who care for someone that has Alzheimer's disease. Some interventions may be aimed at family caregivers while others are designed for formal caregivers. Many interventions, even if they are behavioral or skillbased interventions, initially test the caregivers on their knowledge about progression of the disease, services available, and symptoms [22]. Along with services that provide general information about the disease, there are specific interventions available for increasing knowledge about communication between the family caregiver and care recipient [13,18] and for negotiating challenging behaviors [15,23]. For many participants, both formal and informal caregivers, participating in various interventions was helpful and useful to their situations [17,22-24]. It has been suggested that including both members of the caregiving dyad in the intervention may be the most beneficial way of delivering education and promoting positive results for both the caregiver and care recipient [22].

For programs and interventions to be successful, they have to be specific to the families' needs and must be translatable to other locations [14,20,24]. Interventions can take place over the telephone or the internet, which is helpful to those in rural communities, those who do not have transportation, and those who do not have care available for the care recipient [9,21]. Location, ethnicity of caregivers, cultural factors, and economic factors all may help or hinder the services available [8]. Furthermore, it has been noted that there is a lack of interventions pertaining to the early stages of the disease when the information and knowledge may be most beneficial to the caregivers

Methods

Design and sample

Several Alzheimer's area support group facilitators were asked to forward the survey to their support groups via electronic mail. An email that accompanied the survey invited participants to forward the survey to others who had family members affected by Alzheimer's disease. One-hundred forty-two total participants completed an online survey through SurveyMonkey.com. The online survey took around 7-10 min to complete. Data for this study was collected over three months. Because of the manner in which participants were recruited, it was not possible to calculate a response rate.

The vast majority (87%; n=124) of the participants were female and 13% (n=18) were male. Participants ranged in age from 18 to 70 years (M=40.77, SD=16.28). 5% (n=7) of participants had completed high school or GED as their highest level of education, 38% (n=54) had attended some college, 31% (n=44) had completed a bachelor's degree, 20% (n=28) had completed a master's degree, and 6% (n=9) had completed a doctoral degree. More than 96% of participants (n=137) identified themselves as White.

Measures

Demographics: Participants were asked to indicate their gender, age, ethnicity and highest level of education completed.

Self-reported Alzheimer's knowledge: Participants were asked to rate their knowledge of Alzheimer's disease by responding to the following item: "I feel that I know a lot about Alzheimer's disease." Response choices ranged from 1- "strongly disagree" to 5- "strongly agree."

Alzheimer's disease knowledge scale [1]: The Alzheimer's Disease Knowledge Scale (ADKS) is a 30-item true/false questionnaire designed to survey knowledge of Alzheimer's disease. In previous research, the internal consistency reliability for the scale was 0.71 [1]. Although the scale identifies items with one of seven content areas (course, risk factors, symptoms, life impact, treatment and management, assessment and diagnosis and caregiving), the authors suggest that the scale is best-used as an overall knowledge scale rather than as separate subscales.

Analytic strategy

Descriptive statistics were run on the ADKS and self-reported knowledge of Alzheimer's. Then correlations and partial correlations were performed using the ADKS, self-report knowledge of Alzheimer's, age, and level of education.

Results

The mean on the ADKS was 22.81 (SD=2.79, min=14, max=29) out of 30. Cronbach's alpha was 0.63. The mean for women on the ADKS was 22.66 (SD=2.81), where the mean for men was 23.89 (SD=2.47). Because of the small number of men in the sample, it was not possible to analyze mean differences by gender. Number of years of college completed was positively correlated with the ADKS, r (140)=0.33, p<0.001, indicating that those who had completed a greater number of years of college had a greater knowledge of Alzheimer's (Table 1). Age was also significantly and positively correlated with the ADKS, r (140)=0.22, p<0.007. It should be noted that, when controlling for education, age was not a significant predictor, r (139)=0.14, p=0.09. Years of education was significant while controlling for age, r (139)=0.28, p<0.01.

	1	2	3	4	
1	Age		0.29**	-0.30**	-0.29**
2	Education level	0.29**		0.09	0.33*
3	Self-reported knowledge	-0.30**	0.09		0.17*
4	ADKS	-0.29**	0.33**	0.17*	

Table 1: Correlations (N=142), *denotes p<0.05; **denotes p<0.01.

On a scale of 1 to 5, the mean for self-reported knowledge of Alzheimer's was 3.27 (SD=0.89). Responses ranged from 1 to 5, with 45.1% (n=64) indicating that they agreed or strongly agreed with the statement "I feel that I know a lot about Alzheimer's disease." There was a significant positive correlation between self-reported knowledge of Alzheimer's and the ADKS, r (140)=0.17, p<0.046. Self-reported knowledge was positively correlated with education, r (140)=0.29,

p<0.001, but negatively correlated with age, r (140)=-0.30, p<0.001. When controlling for age, education was significantly positively related with self-reported knowledge, r (139)=0.20, p<0.02. While controlling for education, age was negatively related with self-reported knowledge, r (139)=-0.34, p<0.001. Mean self-perceived knowledge and ADKS scores by level of education are displayed in (Figures 1 and 2).

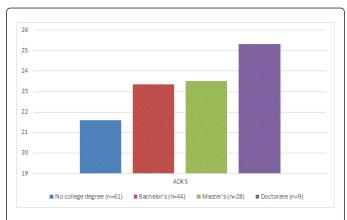


Figure 1: ADKS means by level of education (N = 142).

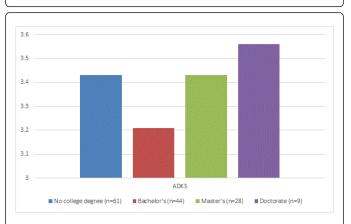


Figure 2: Self-reported knowledge means by level of education (N=142).

What families know and do not know about Alzheimer's disease (Table 2)

Greater than 92% of participants correctly indicated that "If trouble with memory and confused thinking appears suddenly, it is likely due to Alzheimer's disease" and "People with Alzheimer's disease do best with simple instructions given one step at a time." In addition, 91.5% responded correctly to "In rare cases, people have recovered from Alzheimer's disease," "Most people with Alzheimer's disease remember recent events better than things that happened in the past," and "Tremors or shaking of the hands and arms is a common symptom in people with Alzheimer's disease."

Only 36.6% responded correctly to "Having high cholesterol may increase a person's risk of developing Alzheimer's disease." In addition, 45.8% of participants responded correctly to "Having high blood pressure may increase a person's risk of developing Alzheimer's disease," and 50% responded correctly to the item "It has been scientifically proven that mental exercise can prevent a person from getting Alzheimer's disease." These three items focus on "risk factors" as classified by the authors of the ADKS [1].

Item	Content	Correct Response	Number Responding Correctly (%)
People with Alzheimer's disease are particularly prone to depression.	Life impact	True	118 (83.1%)
It has been scientifically proven that mental exercise can prevent a person from getting Alzheimer's disease.	Risk factors	False	71 (50.0%)
After symptoms of Alzheimer's disease appear, the average life expectancy is 6 to 12 years.	Course	True	94 (66.2%)
When a person with Alzheimer's disease becomes agitated, a medical examination might reveal other health problems that caused the agitation.	Assessment and diagnosis	True	116 (81.7%)
People with Alzheimer's disease do best with simple, instructions given one step at a time.	Caregiving	True	131 (92.3%)
When people with Alzheimer's disease begin to have difficulty taking care of themselves, caregivers should take over right away.	Caregiving	False	93 (65.5%)
If a person with Alzheimer's disease becomes alert and agitated at night, a good strategy is to try to make sure that the person gets plenty of physical activity during the day.	Caregiving	True	103 (72.5%)
In rare cases, people have recovered from Alzheimer's disease.	Course	False	130 (91.5%)
People whose Alzheimer's disease is not yet severe can benefit from psychotherapy for depression and anxiety.	Treatment and management	True	119 (83.8%)
If trouble with memory and confused thinking appears suddenly, it is likely due to Alzheimer's disease.	Assessment and diagnosis	False	131 (92.3%)
Most people with Alzheimer's disease live in nursing homes.	Life impact	False	107 (75.4%)
Poor nutrition can make the symptoms of Alzheimer's disease worse.	Treatment and caregiving	True	120 (84.5%)
People in their 30's can have Alzheimer's disease.	Risk factors	True	114 (80.3%)
A person with Alzheimer's disease becomes increasingly likely to fall down as the disease gets worse.	Course	True	94 (66.2%)
When people with Alzheimer's disease repeat the same question or story several times, it is helpful to remind them that they are repeating themselves.	Caregiving	False	126 (88.7%)
Once people have Alzheimer's disease, they are no longer capable of making informed decisions about their own care.	Caregiving	False	115 (81.0%)
Eventually, a person with Alzheimer's disease will need 24-hour supervision.	Course	True	122 (85.9%)
Having high cholesterol may increase a person's risk of developing Alzheimer's disease.	Risk factors	True	52 (36.6%)
Tremor or shaking of the hands or arms is a common symptom in people with Alzheimer's disease.	Symptoms	False	130 (91.5%)
Symptoms of severe depression can be mistaken for symptoms of Alzheimer's disease.	Assessment and diagnosis	True	91 (64.1%)
Alzheimer's disease is one type of dementia.	Assessment and diagnosis	True	126 (88.7%)
Trouble handling money or paying bills is a common early symptom of Alzheimer's disease.	Symptoms	True	112 (78.9%)
One symptom that can occur with Alzheimer's disease is believing that other people are stealing one's things.	Symptoms	True	126 (88.7%)
When a person has Alzheimer's disease, using reminder notes is a crutch that can contribute to decline.	Treatment and management	False	128 (90.1%)
Prescription drugs that prevent Alzheimer's disease are available.	Risk factors	False	125 (88.0%)
Having high blood pressure may increase a person's risk of developing Alzheimer's disease.	Risk factors	True	65 (45.8%)
Genes can only partially account for the development of Alzheimer's disease.	Risk factors	True	128 (90.1%)

It is safe for people with Alzheimer's disease to drive, as long as they have a companion in the car at all times.	Life impact	False	127 (89.4%)
Alzheimer's disease cannot be cured.	Treatment and management	True	128 (90.1%)
Most people with Alzheimer's disease remember recent events better than things that happened in the past.	Symptoms	False	130 (91.5%)

Table 2: Alzheimer's disease knowledge scale (N=142).

Discussion

The mean for family members is our study (22.81) was similar to the mean for dementia caregivers in Carpenter et al.'s study (22.90). However, the Cronbach's alpha in our study (0.63) was lower than in previous research [1]. Nunnally suggests that instruments used in research have a reliability of 0.70 or greater [25]. The true/false format of this measure could be partially responsible for the low internal consistency. However, the Cronbach's alpha for the same measure in previous research was 0.77 [1]. Yet, research using this measure with samples of dementia professionals, students, and older adults has yielded alpha levels of 0.43, 0.55 and 0.59, respectively [1]. In part, this might be because the scale is intended to tap multidimensional aspects of Alzheimer's knowledge.

Our research suggests that family members of those with Alzheimer's may have a low level of knowledge in the area of risk factors. A strong understanding of risk factors may not assist a family caregiver in providing competent care. However, it seems reasonable to assume that family members may have their own fears about developing dementia. Having a grasp of factors that increase the likelihood of an Alzheimer's diagnosis would be helpful to individuals who fear that they will someday be diagnosed with a dementia.

Studies have suggested that individuals with higher levels of education have greater levels of knowledge about Alzheimer's disease [5,8] and may provide a higher quality of dementia care [26]. Indeed, our research suggests that years of education is a strong predictor of Alzheimer's knowledge among caregivers. This may be because those with higher levels of education may have better access to information and may be able to more effectively use information gained [26]. It appears that family members with lower levels of education have a need for more knowledge about Alzheimer's. Interventions and educational services should target families with low levels of education [8]. Research has suggested that less educated caregivers may benefit more from caregiver education than more educated caregivers [26].

Previous research has suggested that knowledge of Alzheimer's is inversely related to age [14]. Our study contributes to this field of research by taking a closer look at the relationship between age and Alzheimer's. knowledge. We found that age was positively correlated with ADKS scores. However, this correlation was not significant when controlling for years of college completed. We found self-reported knowledge to be negatively related to age. In other words, older individuals thought they knew less about Alzheimer's than did younger individuals. This correlation remained significant when controlling for number of years of college completed. Interestingly, age does not seem to play a role in actual knowledge (when education is controlled), although it does play a role in perceived knowledge. It appears that perhaps older family caregivers are more aware of what they do not know about the disease and that their knowledge is limited. This unique finding could be useful to professionals as they interpret whether a person's statement of their own level of knowledge is accurate [27].

Despite the value of this study, several weaknesses should be noted. A convenience sample was used. An initial contact with support group facilitators was made by the first author. Although the link to the survey may have been passed on to those not involved in support groups, it is likely that many participants were actively involved in support groups and potentially linked with other services. Not surprisingly, previous research has suggested that those involved in support groups have higher levels of Alzheimer's knowledge [10,16].

Furthermore, our sample had limited ethnic diversity. The vast majority of participants identified themselves as White. Because research has suggested that individuals who identify as White have higher levels of Alzheimer's knowledge [8], one must questions how applicable these findings are to the population as a whole, especially when we consider that older African-Americans are about two times more likely to have Alzheimer's and other dementias than Whites [2]. It should also be noted that our sample was 87% female. This is slightly higher than the percentage of women (82%) in Carpenter et al.'s [1] sample of dementia caregivers. Although it would seem ideal to have a more balanced sample in terms of gender, the majority of caregivers of those with Alzheimer's are women [2].

Furthermore, it should be noted that the correlations between Alzheimer's knowledge and other variables in this study are not strong correlations. Typically, a correlation of greater than 0.7 or 0.8 (negative or positive) is considered a strong correlation. Although many of the correlations reported here reach statistical significance at the level of 0.05, they would generally be considered weak correlations based on

Conclusion

Based on our results and previous research, we suggest that interventions should attempt to target specific populations affected by Alzheimer's, such as people with lower education levels. It is possible that family caregivers with lower levels of education are less likely to seek out information on their own. Furthermore, they may not have skills to distinguish reputable and non-reputable sources on Alzheimer's if they do seek out information. Individuals with lower levels of education may be less aware of support groups and available resources. Alzheimer's is a public health crisis, and providing appropriate and accessible support to families is key in promoting the best possible quality of life for those impacted by the disease.

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