What people know about Alzheimer's disease: A study of public knowledge

Janie S. Steckenrider, PhD

Abstract

Given the frequent attention and focus on Alzheimer's disease by the mass media over the recent decades, it is assumed that the American public is fairly well-informed and knowledgeable about the disease. However, what the public actually knows about Alzheimer's disease and the characteristics of those persons most informed have generally remained a mystery as only a few aspects of disease awareness have been sporadically measured. Thus, this study explicitly explores the level of overall public knowledge about Alzheimer's disease measured through survey research based on a nationally representative sample of 1498 persons age 45 and over. The Alzheimer's Disease Aware-



Janie S. Steckenrider, PhD, Loyola Marymount University, Los Angeles, California.

ness Test (ADAT) was developed and utilized with 17 items dealing with disease etiology, symptoms, and misconceptions.

While almost everyone (91 percent) has heard of AD, there are wide gaps in disease knowledge among a significant portion of the public. Two tiers of knowledge are found to exist indicating the different types of information known:

- The Easy/General Knowledge Tier is comprised of eight items tapping disease aspects that are less technical in nature, require little conceptual sophistication and tend to be facts widely disseminated by the mass media; and
- The Hard/Specific Knowledge Tier is comprised of nine items requiring more complex understanding and deal with more scientific disease aspects.

Most persons score moderately high on the Easy/General Index while few do well on the Hard/Specific Index. Correlates of a high level of knowledge on both tiers are education, age, knowing someone with AD as well as the closeness and relationship of the effected person, and having parents who are living.

Introduction

What do Americans know about Alzheimer's disease? It is apparent that some level of consciousness exists

within the public about AD, but very little research has been done specifically in the area of the public's knowledge of the disease. No previous national survey nor even specific items in any survey have been pursued to establish

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a baseline as to what the American public knows about the disease — or if certain segments of the population are more informed about Alzheimer's disease than others. The few studies conducted have focused on specific groups, e.g., health care professionals, older persons in senior centers, or have been based on a relatively small number of respondents. Since these few studies have consistently found that lack of knowledge about the disease is common, this raises the question of how informed the American public is about Alzheimer's disease. The level of disease understanding as well as existing knowledge gaps and misconceptions are important because they can have important consequences on health behavior. Lack of information or

misperceptions on the part of family and friends can result in inadequate care for disease sufferers, misinterpretation of disruptive behavior, inappropriate expectations of the patient, and

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failure to seek support groups providing tips on care, management, stress reduction, respite - all of which can increase caregiver stress and ultimately lead to premature institutionalization of the person with Alzheimer's disease. Further, lack of knowledge that other diseases or even medications can cause Alzheimer-like symptoms may mean that a treatable and reversible disease goes undiagnosed and the symptoms remain unabated. Measuring what the public knows about AD and what misperceptions prevail is the first step toward improving public education about the disease and devising the best strategies for information dissemination to address the most pertinent knowledge gaps.

Prior to the 1970s, Alzheimer's disease was an issue virtually confined to medical textbooks and scientific journals. However, during the last 15 years, the topic of Alzheimer's disease has shifted to a "public issue" as the disease has become a frequent topic and focus for the mass media. AD has been the subject of television movies (i.e., "Do You Remember Love?") as well as documentaries, radio and television news segments, innumerous newspaper and

magazine articles and often has been the featured story (i.e., *People* (1987), *Newsweek* (1984), *U.S. News and World Report* (1991)) for major mainstream publications. Sun and Helmick confirm this trend of an increased proportion of popular and professional publications being devoted to Alzheimer's disease over the last decade.² They substantiate this increase in disease attention by comparing the amount of Alzheimer articles during the 1980s to a 1960s and 1970s baseline.

Given the increased focus of the mass media on Alzheimer's disease over the last 10 to 15 years, it is assumed that the public's knowledge about the disease has experienced a parallel increase. Unfortunately, very little research has been done in the area of the public's knowledge about AD. Those few studies exploring disease knowledge have tended to utilize small samples or nonrepresentative subgroups and there are no early studies in the 1960s nor 1970s measuring disease understanding prior to the AD rise to a public issue. Since 1985, an occasional question on the disease has appeared in public opinion polls (e.g., Gallup, Roper, AP, Harris, etc.) but nearly all have merely included Alzheimer's disease among a list of diseases most feared instead of questions probing disease understanding.

The assumption is that the American public is fairly knowledgeable concerning the facts and aspects of AD, but the lack of empirical data has allowed only inferential assessments of such understanding. Patrick Fox states that, "public awareness of Alzheimer's disease has increased dramatically within the last 10 years," yet he provides no quantitative measures of awareness among the public or health providers.3 Sun and Helmick infer that the marked increase in the proportion of publications devoted to Alzheimer's disease throughout the 1980s may reflect an increased disease awareness among the public and health care providers. They note that this interpretation is made with caution since without direct measures of knowledge of AD over time, they cannot determine the degree of correlation of publication rates and disease awareness.

Lack of knowledge about AD is consistently found among those few specific subgroups who have been investigated. A mailed questionnaire study of 148 elderly persons in senior housing or centers concludes that among this older population overall disease knowledge was poor.4 The test consisted of 20 knowledge items and only eight were answered correctly by over 50 percent of those sampled. Price et al determined that among this older population, education and experiential exposure of having a friend or relative with Alzheimer's disease predict higher levels of knowledge. Another study affirming the importance of experiential exposure in disease awareness is based on a random sample of 370 households in three rural Ohio counties.⁵ This study finds that over 80 percent of those knowing someone with AD can correctly identify the definition of the disease compared to 69 percent

Granted, merely having heard of the disease does not mean that a person is informed about Alzheimer's, but it is the first step toward that end.

of the entire sample. Boling's findings of awareness, however, are based on only this one item of the respondent selecting the appropriate disease definition from three possible choices.

A few knowledge tests have been conducted on caregivers and health providers. The Pennsylvania Department of Aging used a focus group approach with physicians and nurses for the purpose of improving sensitivity to Alzheimer patients and family needs. They found that even among this

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group of health care providers, knowledge of Alzheimer's disease is scant and inconsistent.⁶ Assessing disease knowledge among 500 caregivers, George used 10 true/false items with an average 7.6 correct.7 She found that over 90 percent of caregivers gave correct answers regarding irreversible brain changes, disease symptoms, and causes of AD. In developing an Alzheimer's Disease Knowledge Test for caregivers, professionals and other personnel involved in the care of Alzheimer patients, Dieckmann et al pretested a 20 question instrument on four samples including undergraduate gerontology students, graduate students in gerontology, social work or counseling, and mental health professionals attending an extension class on Alzheimer's disease.8 They then administered the knowledge test to over 200 families in a Minnesota Chapter of the Alzheimer's Association. Among all these groups, they found that a lack of knowledge about Alzheimer's disease was common and that the most frequent response category was "Don't Know."

The extent to which understanding of Alzheimer's disease has reached the American public needs to be tested. What does the public know about the disease? Are there prevailing misconceptions or extensive knowledge gaps held by a large number of persons?

What types or demographic groups of people are most informed about the disease? The present research is formed around these questions through an examination of responses from a nationally representative sample of 1498 individuals over the age of 45. This study focuses on awareness of AD, variability in disease understanding and identification of existing knowledge gaps.

Research methods

Data for this study were collected in the first public opinion survey conducted specifically on Alzheimer's disease. This survey research utilizes telephone interviews from a nationally representative probability sample of 1498 persons over age 45. The demographic profile of the sample reflects the actual population in terms of distribution on age, gender, education, race and marital status. The sampling error is +/-3 percent.

The Alzheimer's Disease Awareness Test (ADAT) was created for this study and pretested on samples of undergraduate students and elderly volunteers at the Andrus Gerontology Center, University of Southern California. ADAT consists of 17 factual questions asked in an agree/disagree format which deal with a wide range of information and myths about Alzheimer's disease. The questions investigate knowledge about disease symptoms, etiology, care, diagnosis, public policy affecting reimbursement, prevalence and whether it is normal aging. (See Appendix A for the 17 questions comprising the ADAT.)

In addition to the standard questions tapping demographic characteristics, respondents were also asked if they knew someone with Alzheimer's disease and whether their parents were presently alive.

Findings

The first and most basic aspect of knowledge simply is awareness of the disease or whether one has heard of Alzheimer's disease. A high disease awareness exists with almost everyone (91 percent) having at least heard of AD (see Table 1). This indicates the depth to which AD has permeated the public since almost all people have gained this basic disease awareness in a relatively few years. Granted, merely having heard of the disease does not mean that a person is informed about Alzheimer's disease, but it is the first step toward that end.

Table 1. Heard about Alzheimer's disease			
	N	%	
Yes	1348	90.7	
No	138	9.3	

The Alzheimer's Disease Awareness Test (ADAT) has a possible score ranging from 0 to 17 based on the number of items answered correctly. The mean number correct on the ADAT is 9.1 pointing to an overall moderate level of disease knowledge existing within the public. However, concluding that most persons are fairly knowledgeable about Alzheimer's disease is somewhat misleading once the individual items are explored. (See Appendix A for the percentage of correct responses for each item.)

Some of the 17 items find that vast proportions of the public are informed and can correctly respond regarding that disease aspect. For example, 83 percent know that Alzheimer's disease is not contagious, 78 percent know that it is not a form of insanity, and 75 percent know there is presently no disease cure. Most of the public distinguishes AD from normal aging as 80

^a The survey was part of the Alzheimer's Public Opinion Project, Andrus Gerontology Center, University of Southern California, and directed by Neal E. Cutler. This project received support from the Administration on Aging. Interviews were conducted between October 15 and November 10, 1985.

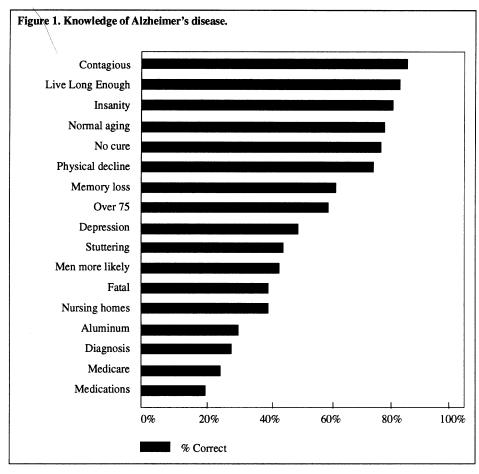
percent correctly answer the items that a person will almost certainly get AD if they just live long enough and that Alzheimer's disease is not a normal part of aging like grey hair and wrinkles. Yet, there are important areas where large gaps in knowledge are found. Less than a quarter of persons sampled knew that:

- Alzheimer's disease cannot be diagnosed by a blood test;
- Medicare does not cover nursing home expenses for the disease; and
- Medicine for high blood pressure can cause symptoms that look like Alzheimer's disease.

Figure 1 graphs the dramatic range in knowledge on the 17 items of the ADAT and indicates a clustering of the items into two distinct information tiers. The top eight items are answered correctly by more than 60 percent of respondents while the bottom nine are known by less than half of those interviewed. (The calculation of the percentage correct includes the Don't Know responses since they also represent a lack of knowledge relative to that dis-

In fact, there is considerable drop-off in disease knowledge among those over age 75.

ease aspect.) In order to distinguish a more accurate assessment of existing knowledge about Alzheimer's disease, these two sets of items are compiled into separate additive indices. The eight items known by over 60 percent comprise the Easy/General Knowledge Tier and the remaining nine items com-



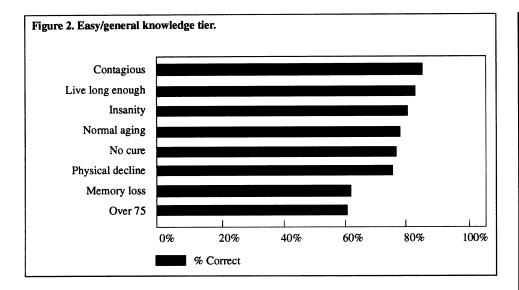
prise the Hard/Specific Knowledge Tier.

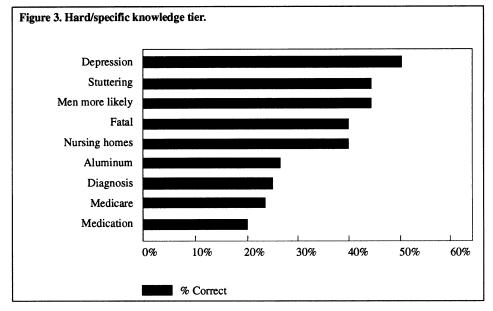
The items of the two tiers are also different with regard to the nature of the information tapped. The items of the Easy/General Knowledge Tier tend to be less technical in nature, require little conceptual sophistication or scientific understanding. These are also the items most widely disseminated by the mass media in most stories or news segments concerning Alzheimer's disease. Included on the Easy/General Tier are the Contagious, Live Long Enough, and No Cure items. In contrast, the items of the Hard/Specific Knowledge Tier tend to be more difficult and require more complex understanding. These nine items deal with the more scientific and medical disease aspects such as:

 Alzheimer's disease cannot be diagnosed by a blood test; • There are no gender differences in prevalence and certain medications can cause Alzheimer-like symptoms. In addition, these items tend to be less discussed by the mass media and therefore are more likely to require active information gathering through reference books, disease information brochures or through personal association with an individual who has AD.

Figures 2 and 3 individually graph the two information tiers.

The items for the two tiers are transformed into simple additive indexes measuring disease knowledge. These can then be correlated with key variables. The respondent's score on the Easy/General Tier ranges from 0 to 8 and from 0 to 9 on the Hard/Specific Tier. Each index is categorized into





knowledge levels of low (0-2), medium (3-5) and high (6-8 on the Easy/General Tier and 6-9 on the Hard/Specific Tier). Over 70 percent of respondents are in the high knowledge level of the Easy/General Tier which has a mean of 5.9 correct. The Hard/Specific Knowledge Tier, with a mean correct of 3.1, finds only 11 percent in the high level, but 50 percent in the medium level. The relationship between the two tiers is moderately strong (r = .50, p < .001) as most respondents in the medium and high levels on the Hard/Specific Tier not

surprisingly are located in the high knowledge level of the Easy/General Tier. Table 2 indicates the distribution on each tier.

Assuming that those with higher education and women (due to their role as potential caregivers) would be more knowledgeable about Alzheimer's disease, the two indexes are correlated with gender and education. Those with higher education are found more likely to be in the high knowledge levels on both tiers, but the differences in knowledge levels by education are small. Likewise, no significant gender

differences in disease understanding are found. It is quite possible that the differences on these two variables are suppressed since most persons score high on the Easy/General Tier and low on the Hard/Specific Tier.

Alzheimer's disease has an age-related component as it generally strikes persons over age 65 and is even more prevalent among those over age 75. Consequently, age was expected to relate to disease knowledge as older persons, considering themselves at greater risk, were anticipated to be more active in information-seeking about AD than younger persons. Interestingly, there is only a slight relationship between knowledge level and age on both tiers (Easy r = -.12, Hard r = -.10, p < .001), but it is younger persons who are more informed about the disease. In fact, there is considerable drop-off in disease knowledge among those over age 75. Nearly 75 percent of all age groups under age 75 are located in the high level on the Easy Tier compared to only 56 percent of those over age 75. Similarly, the low level of the Hard Tier has only 35 percent of those age groups under age 75, but contains 50 percent of those age 75 and over. Even though Alzheimer's disease is most prevalent among older persons, this does not seem to prompt greater information-seeking about the disease among the elderly.

Table 2. Distribution of information tiers.		
Easy/general knowledge tier	N	%
Low (0-2) Medium (3-5) High (6-8)	143 283 1072	9.5 18.9 71.6
Hard/specific knowledge tier		
Low (0-2) Medium (3-5) High (6-9)	568 763 167	37.9 50.9 11.1

Having parents who are living also makes a slight difference in terms of knowledge about Alzheimer's disease. Those with living parents are slightly more informed on both the Easy and the Hard Tier than are those whose parents are not alive. Having parents who are alive is assumed to make individuals more interested in Alzheimer's disease and more attentive to information disseminated about the disease. It is also expected that the potential of caregiving responsibilities, should a parent be stricken with AD, encourages more information-seeking. Yet, these differences are small.

The most crucial element in knowledge of Alzheimer's disease is experiential exposure or knowing someone with the disease. It is personal experience that helps to provide insight about various disease aspects tapped by the Alzheimer's Disease Awareness Test. In addition, knowing someone with AD, as with any disease, makes one more attuned to stories and news about the disease as well as more likely to actively seek out information through reference materials.

It is also expected that the potential of caregiving responsibilities, should a parent be stricken with AD, encourages more information seeking.

Most people (53.1 percent) state that they know someone with Alzheimer's disease (see Figure 4). It is this group that is most informed about the various disease aspects shown by the significant difference in knowledge between those who know someone with Alzheimer's disease versus those who do not (see Table 3). Although the

Table 3. Disease knowledge by knowing someone with Alzheimer's disease.

Easy/general tier	Know someone (%)	Not (%)
Low	.9	15.7
Medium	14.0	23.2
High	85.1	61.1
(N)	(685)	(779)
Hard/specific tier		
Low	24.4	48.8
Medium	61.3	42.4
High	14.3	8.9
(N)	(685)	(779)

majority among both groups are located in the high knowledge level of the Easy/ General Tier, 85 percent of those knowing someone have high Easy knowledge compared to 61 percent of those who do not — a 24 percent difference. Similar differences are apparent at the low level of the Easy/ General Tier where less than 1 percent of those who know someone with AD are located, but 16 percent of those do not know a person with Alzheimer's disease. Thus, even on these less technical, widely publicized disease aspects many who do not know someone with Alzheimer's disease are relatively uninformed.

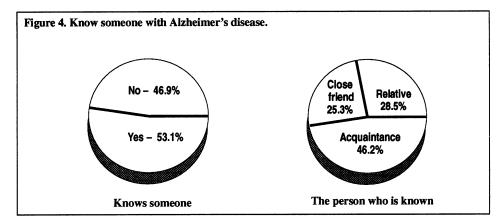
Parallel differences are found on the Hard/Specific Tier between those who know someone with AD and those who do not. While 76 percent of those who know an Alzheimer patient are located in the medium or high levels on this index, only 51 percent of those who do not know someone are found in these levels — a 25 percent difference. The low level of this tier is equally indicative of the importance of experiential exposure as almost half of those who do not know someone have low Hard/Specific Knowledge compared to less than a quarter of those knowing someone with the disease. Thus, first hand experience from knowing someone with Alzheimer's disease provides information about the more scientific and less frequently publicized disease aspects. For example, how AD is diagnosed and whether Medicare covers Alzheimer's disease expenses are more likely to have been discussed or read about within the context of knowing someone with the disease.

The person one knows with Alzheimer's disease may conceivably be as important an element in determining disease knowledge and this hypothesis was tested. Having a family

The most crucial element in knowledge of Alzheimer's disease is experiential exposure or knowing someone with the disease.

member with the disease has vastly different consequences and a greater personal involvement than merely having knowledge of an acquaintance with AD. Having a relative with the disease is more likely to mean frequent interaction with the disease behaviors and symptoms, more extensive contact with the medical community, and encourages actively seeking out information and support groups for Alzheimer's disease. This is expected to translate into a higher level of disease understanding especially in regard to those items on the Hard/ Specific Tier. While an individual who has a close friend or an acquaintance with Alzheimer's disease is expected to be more informed than an individual who does not know someone with AD, he or she is likely to be less informed than an individual having a relative with Alzheimer's disease.

The person one knows with Alzheimer's disease and the effect on



disease understanding can be conceptualized as spheres of influence represented by five concentric circles. Figure 5 shows how the individual or self is in the middle circle and then the person one knows with the disease radiates from the center with decreasing experiential influence. Closest to the center of self is a relative with the disease and the spheres of influence move outward through close friends and acquaintances. The degree of influence from Alzheimer's disease is greatest closest to the center and lessens as the person with the disease moves farther from the self.

Thus, first hand experience from knowing someone with Alzheimer's disease provides information about the more scientific and less frequently publicized disease aspects.

Almost half (46 percent) of those who know someone with Alzheimer's disease indicate that the afflicted person is an acquaintance. The remainder are almost equally divided between close friend (25 percent) and relative (29 percent) (see Figure 4).

Although the differences in disease understanding in terms of the person

one knows are not as dramatic occurwith knowing someone with Alzheimer's disease directly, significant patterns do exist. Regardless of whom one knows with the disease, about 85 percent of all three groups have high knowledge on the Easy/General Tier. Since this information is less technical and fairly attainable, merely knowing someone with the disease is enough to prompt knowledge of these aspects. The Hard/Specific Tier comprised of the more scientific and less publicized items tells a different story through the low and high knowledge levels. Few (18 percent) of those with relatives afflicted with Alzheimer's disease are in the low Hard knowledge level while 27 percent of those with close friends and acquaintances have low disease understanding on the Hard/

derstanding on the Hard/ Specific Tier. The opposite is found at the high knowledge level. Almost twice as many of those with relatives have high Hard knowledge than either those with close friends or acquaintances.

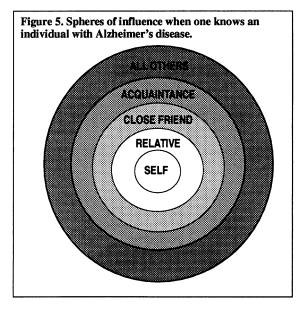
The concept of spheres of influence reflects these differences in the importance of experiential exposure on disease understanding. The closer the person with Alzheimer's disease is to oneself, the greater the personal involvement and experience with the disease — and the greater the disease knowledge. As the location of

the Alzheimer patient moves toward the outer circles, there is less personal involvement and interaction leading to the accumulation of less disease knowledge.

Discussion

From the data of this study, the American public has acquired an awareness of Alzheimer's disease and is moderately informed about the disease. Although longitudinal data of disease knowledge is nonexistent, it is assumed that the public's disease understanding has developed over the relatively short time period that Alzheimer's disease has been a public issue. Not too long ago Alzheimer's disease was an issue found only in medical textbooks and scientific journals, whereas now it is frequently discussed on television, in newspaper articles and featured in popular magazines.

Nearly everyone is at least aware of Alzheimer's disease and in terms of some disease aspects the public is quite knowledgeable. Over 75 percent of individuals know that AD is not contagious nor insanity, that it is neither normal nor inevitable with age and that there is no cure. These figures are impressive. They demonstrate that the



Appendix A. Items for Alzheimer's Disease Awareness Test

Items are listed in order of percent giving the correct answer. Included in parentheses is the correct answer and the percent correct. The name of the item used in other tables is also listed. The first eight items comprise the Easy/General Tier and the remaining nine items comprise the Hard/Specific Tier.

CONTAGIOUS

Alzheimer's disease can be contagious. (false: 83.0 percent)

LIVE LONG

A person will almost certainly get Alzheimer's disease if they just live long enough. (false: 79.8 percent)

INSANITY

Alzheimer's disease is a form of insanity.

(false: 77.8 percent)

NORMAL

Alzheimer's disease is a normal part of getting older, like gray hair and wrinkles.

(false: 76.5 percent)

NO CURE

There is no cure for Alzheimer's disease at present.

(true: 75.1 percent)

DECLINE

A person who has Alzheimer's disease will experience both mental

and physical decline. (true: 73.8 percent)

MEMORY LOSS

The primary symptom of Alzheimer's disease is memory loss.

(true: 62.1 percent)

OVER 75

Among persons over age 75, forgetfulness most likely indicates the

beginning of Alzheimer's disease.

(false: 60.9 percent)

DEPRESSION

When the husband or wife of an older person dies, the surviving spouse may suffer

from a kind of depression that looks like Alzheimer's disease.

(true: 49.1 percent)

STUTTERING

Stuttering is an inevitable part of Alzheimer's disease. (false: 45.8 percent)

MORE MEN

An older man is more likely to develop Alzheimer's disease than an older woman.

(false: 45.1 percent)

FATAL

Alzheimer's disease is usually fatal. (true: 40.5 percent)

NURSING HOMES

The vast majority of persons suffering from Alzheimer's disease live in

nursing homes. (false: 40.3 percent)

ALUMINUM

Aluminum has been identified as a significant cause of Alzheimer's disease.

(false: 25.3 percent)

DIAGNOSIS

Alzheimer's disease can be diagnosed by a blood test. (false: 24.4 percent)

MEDICARE

Nursing home expenses for Alzheimer's disease patients are covered by Medicare.

(false: 22.6 percent)

MEDICINE

Medicine taken for high blood pressure can cause symptoms that look like

Alzheimer's disease. (true: 19.5 percent)

public is paying attention to information being disseminated about Alzheimer's disease and has a formidable foundation of disease understanding. This basic level of disease knowledge is especially dramatic given the lack of significant differences by education, gender and age.

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family member
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This study also finds important gaps in disease knowledge in areas with potentially critical consequences. One crucial gap is the knowledge that other conditions can cause Alzheimer- like symptoms. Only 49 percent recognize that depression can cause memory loss and less than 20 percent know that medications like those prescribed for high blood pressure can cause Alzheimer-like symptoms. This lack of knowledge can lead to the assumption that an individual has Alzheimer's disease without seeking a medical diagnosis. This can mean the real possibility that a treatable and reversible condition goes undetected. In fact, due to a lack of knowledge, a person with diminished capacities may be placed in a long term care facility on the assumption of having Alzheimer's disease when their health condition is treatable and with proper medical attention they could be returned to their full functioning potential.

The most important predictor of disease understanding is knowing someone with AD. Individuals who know

someone with the disease are generally well-informed on a wide variety of disease aspects. It is this experiential exposure that encourages the person to pay more attention to information disseminated about Alzheimer's disease, to actively seek out disease information and to witness the effects of the disease first-hand. The person one knows with Alzheimer's disease also impacts on knowledge in terms of spheres of influence. The most informed and knowledgeable group are those who have a relative afflicted with Alzheimer's disease, while the least informed are those who do not have any experiential exposure to the disease (do not know anyone with Alzheimer's disease.)

This study points out the need to improve public knowledge about Alzheimer's disease and close the gaps in understanding. Even though the number of persons with Alzheimer's disease will continue to increase in the coming years as the American population of older persons increases, this aspect of experiential exposure is not the answer to increased public awareness. Increasing disease knowledge must be done through continued efforts in dissemination of disease information and public education. The basic foundation for disease understanding

It is personal
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Alzheimer's Disease
Awareness Test.

has been created in a fairly short time and now can be built upon. New efforts need to be directed toward advancing the type of information widely disseminated about Alzheimer's disease up a notch in terms of complexity and scientific nature. Given their basic foundation of disease knowledge created over

The concept of spheres of influence reflects these differences in the importance of experiential exposure on disease understanding.

the last decade, the public is now at the threshold for expansion of disease understanding. Over the next decade, with appropriate public education and information dissemination, the public can develop to the stage of being intelligently informed about Alzheimer's disease and these crucial knowledge gaps can be eliminated.

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