
Lay person's recommendations about interventions for Alzheimer's disease: Correlates and relationship to help-seeking behavior

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Abstract

The aim of this study was to examine lay persons' beliefs about the helpfulness of interventions for Alzheimer's disease (AD) and its correlates. Interviews were conducted with 206 Jewish Israeli adults (mean age 59.7), using an experimental vignette methodology varying in the severity of the disease. Information regarding participants' recommendations about the helpfulness of 10 interventions for the person described in the vignette was elicited. Sociodemographic and psychological correlates were examined.

We discovered that the lay public endorses the use of nonpharmacological treatments more than pharmacological ones. Engagement in social activities and participation in a support group were the treatment approaches most recommended, while the use of physical restraints and isolation were the least recommended. Beliefs about AD treatments were associated with help-seeking from professional sources.

Advances in the development of effective treatments for AD should be accompanied by research into the public's understanding of these treatments.

Key words: dementia, Alzheimer's disease, help-seeking, pharmacotherapy, intervention

Introduction

Over the last few years, we have witnessed a notable increase of scientific and clinical knowledge in the treatment of Alzheimer's disease (AD). Progress has been made in the development of pharmacological and nonpharmacological approaches. Currently, there are five

FDA-approved drugs aimed at controlling symptoms of the disease and slowing its progression. The first four (tacrine, donepezil, galantamine, and rivastigmine) are acetylcholinesterase inhibitors aimed at slowing the metabolic breakdown of acetylcholine.¹ Although different in their pharmacology and pharmacokinetics, these drugs were recently suggested by an evidence-based review of the American Academy of Neurology to be the first-line treatment in patients with mild to moderate AD.² The fifth drug (memantine) is an N-methyl-D-aspartate (NMDA) receptor antagonist, and appears to protect the brain's nerve cells against excess amounts of glutamate, a messenger chemical released in large amounts by cells damaged by AD.¹ New therapeutic approaches, such as amyloid- β -peptide vaccination, secretase inhibitors, cholesterol-lowering drugs, and anti-inflammatory agents have also been studied.^{1,3}

The role of other alternative or complementary approaches to the treatment of AD is also being examined. For example, several double-blind, placebo-controlled trials have been conducted for vitamin E, an adjunctive therapy for slowing the progress of the disease.⁴ The effectiveness of ginkgo biloba, an extract made from the leaves of the ginkgo tree, is currently being examined as a complementary therapy for its anti-inflammatory, antioxidant, and anticoagulant properties.⁴

Given the complex process involved in the treatment of AD, and because of its impact on patients and families, the American Academy of Neurology encourages the combination of pharmacological and nonpharmacological approaches in the care of persons with AD.⁵ Nonpharmacological treatments include a variety of psychosocial interventions such as cognitive training methods and behavior-oriented approaches.⁶

Several studies in the area of mental disorders, mainly depression and schizophrenia, have stressed the

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importance of assessing the public's beliefs about treatment options for a specific disease. First, findings of these studies showed that there might be some major discrepancies between public and professionals' beliefs about the helpfulness of treatment options,⁷⁻⁹ which might affect compliance rates. Second, beliefs about the helpfulness of certain pharmacological treatments were associated with their actual use,¹⁰ a fact that stresses the importance of assessing the lay public's beliefs as a first step in increasing knowledge about appropriate treatments.

Finally, beliefs about the helpfulness of interventions for mental disorders were associated with appropriate help-seeking behavior,¹¹ which might lead to early diagnosis and a more effective treatment of the disease.

This study was designed to expand our understanding of the lay public's beliefs about the helpfulness of treatment interventions for AD. Its specific aims were:

1. to assess the lay public's recommendations about various pharmacological and nonpharmacological treatments for AD and its correlates; and
2. to assess the relationship between these recommendations and help-seeking behaviors.

Methods

Participants

A convenience sample of 206 community-dwelling men and women aged 45 and over participated in the study. The sociodemographic characteristics of the participants are presented in Table 1. Their mean age was 60 years, with a range of 49 to 88. The majority were married women, born in Israel, with an average of three children. They had an average of 14 years of education and perceived their income as fairly good.

Measures

Recommendations about treatments of AD. A list of 10 pharmacological and nonpharmacological therapies were read to the participants, one at the time. For each treatment, participants were asked whether they would recommend the treatment or not for the person depicted in a vignette. Each item was rated on a 5-point Likert-type scale ranging from 1 (would not recommend at all) to 5 (would highly recommend). The list of pharmacological and nonpharmacological treatments was based on an extensive review of recent research.^{1,3,6}

Help-seeking intention from professional and non-professional sources. Participants were asked from

whom they thought they should seek help for the person described in the hypothetical situation. The sources of help were derived from previous work¹² and included spouse, friend, other family members, neighbor, family physician, psychiatrist, psychologist, neurologist, nurse, and social worker. Each response was rated on a 5-point Likert-type scale ranging from 1 (will not suggest seeking help from this source) to 5 (will suggest seeking help from this source, to a great extent).

As in a previous Werner study,¹³ two indices were derived from these items. The first index was the mean of the items reflecting professional help, and the second index was the mean of the items reflecting nonprofessional help. Both indices had good internal reliability in this sample (Cronbach alpha = .70 and .74, for nonprofessional and professional sources respectively).

Background characteristics. These include socio-demographic characteristics, personal experience with AD, and perceptions about the dangerousness of the person depicted in the vignette.

Socio-demographic characteristics included gender (female/male), age, place of birth (Israel, Asia/Africa, Europe/America, Other), year of immigration, marital status (single/married/widowed/divorced/separated), number of children, and years of education. Subjective perception of financial status was rated from 1 (very poor) to 5 (very good).

Personal experience with AD. Two categories of personal experience were examined: 1) whether the participant has a family member who has been diagnosed with AD; and 2) whether the participant knows someone within his or her circle of friends, neighbors, or acquaintances who has been diagnosed with AD.

Perceptions of dangerousness of the person depicted in the vignette. Participants were asked to rate to what extent they perceived the person depicted in the vignette to be dangerous to himself and to others. Each item was rated on a 5-point Likert-type scale ranging from 1 (not at all dangerous) to 5 (extremely dangerous). A composite index of the mean of both items was calculated ($r = .36$; $p < .001$).

Procedure

A procedure similar to the one used in studies examining lay knowledge about mental health problems was followed.¹⁴ Participants were interviewed face-to-face using a structured interview. After the aim of the study was explained and consent was obtained, participants were presented with a vignette describing a 71-year-old man (Mr. A) who had AD, according to the criteria in the DSM-IV. Two versions of the vignette were designed and are shown in Appendix 1. They varied by the stage of the

Table 1. Participants' characteristics (N = 206)	
Sociodemographic characteristics	
Mean age (SD)	59.7 (8.1)
Gender (%)	
Male	36.6
Female	63.4
Place of birth (%)	
Israel	53.9
Europe/America	34.0
Asia/Africa	11.2
Other	1.0
Marital status (%)	
Not married	20.2
Married	79.8
Mean number of children (SD)	3.2 (2.1)
Mean number of years of education (SD)	13.5 (3.7)
Mean subjective income level (SD)*	3.2 (.77)
Has an acquaintance with AD (%)	40.3
Mean perceived dangerousness**	2.6 (1.0)
* 1 = very bad, 5 = very good; ** 1 = not at all dangerous, 5 = extremely dangerous.	

disease described according to the Alzheimer's Association's web site.¹⁵ Each version was assigned alternatively to the participants: 104 participants received version 1, and 102 participants received version 2. The face validity of the vignettes was assessed by submitting them to three professionals in the field, before the interview process started.

Results

Recommendations about treatments for AD

Table 2 presents percentages of participants who did or did not recommend each of the treatments, together with the means and standard deviations for each treatment. Engagement in social activities and participation

in a support group were the treatment approaches most recommended, while the use of physical restraints and isolation were the least recommended.

To examine whether the therapies presented reflect underlying dimensions of treatment, factor analysis using principal components and varimax rotation was performed. Inspection of the final solution shows five factors, explaining 73.3 percent of the total variance. As shown in Table 3, the first factor included two treatments associated with relaxation or meditation. The second factor included natural remedies and vitamins. The third factor included pharmacological treatments (sleeping pills and sedatives), and the fourth factor included three treatments reflecting engagement in social activities, support group, and psychotherapy. Finally, the fifth factor included two treatments—the use of physical restraints and isolation.

Following these results, five indices were derived by calculating the mean of the items in each factor. The means of the indices are presented in Table 3. Participants recommended statistically more group activities and vitamins than restraint treatments or chemical and relaxation interventions ($F_4 = 209.8$; $p < .001$).

Correlates of recommendations about treatments for AD

To assess the relationships between the five factors of treatment and the independent variables, Pearson correlations were calculated for continuous variables and t-tests for dichotomous variables. The correlates examined included: age, gender, education, income, marital status, personal experience with AD, perceived dangerousness, and disease severity.

Stronger recommendations about the use of sleeping pills and sedatives (i.e., the factor named *chemical*) were associated with higher age, lower education, lower income, and higher perceptions of the dangerousness of the person depicted in the vignette ($r = .28, -.19, -.16$, and $.23$, respectively; $p < .01$). Additionally, participants presented with version 2 of the vignette (i.e., the vignette describing an advanced stage of the disease) recommended the use of pharmacological treatment more than participants presented with version 1 of the vignette, although this relationship was only marginally significant ($t_{202} = -1.92$; $p = 0.56$).

Stronger recommendations for the use of group activities as a treatment were associated with lower income ($r = -.34$; $p < .001$), and stronger recommendations for the use of vitamins were associated with higher perceptions of dangerousness ($r = .19$; $p < .01$). No other statistically significant relationships were found for other factors.

Table 2. Lay public's recommendations for treatment of Alzheimer's disease (N = 206)

Treatment	Mean	SD	Not recommended* (%)	Recommended** (%)
Engagement in support group	4.0	1.2	11.7	74.0
Engagement in social activity	4.0	1.4	6.9	70.1
Vitamins	3.5	1.3	21.8	53.4
Natural/herbal medications	3.2	1.3	27.9	44.1
Psychotherapy	3.1	1.4	31.2	43.1
Pharmacological treatment	3.1	1.4	28.7	44.5
Relaxation	2.8	1.3	36.8	31.8
Sleeping pills	2.5	1.4	53.0	24.8
Yoga or meditation	2.1	1.2	57.6	15.2
Physical restraints	1.2	0.7	94.1	2.0
Isolation	1.1	0.6	96.5	2.5

* Response categories 1 + 2; ** Response categories 4 + 5.

Relationship between recommended treatments for AD and help-seeking intention

Results of the study showed that participants would seek more help from professional than nonprofessional sources (mean = 3.5 and 3.2, respectively; $p < .05$).

Pearson correlations were calculated between the five factors of treatments and the indices of professional and nonprofessional help-seeking intentions. The results showed significant correlations between help-seeking from professional sources and all the treatments, except for restraints ($r = .20$ for relaxation, $r = .29$ for vitamin, $r = .25$ for pharmacological, and $r = .35$ for group; $p < .001$), indicating that higher levels of beliefs about the usefulness of these treatments were related to higher levels of intention to seek help from professionals. The relationship between recommendations about treatments and help-seeking from nonprofessional sources was statistically significant only for group activities ($r = .26$; $p < .01$), indicating that higher levels of beliefs about the usefulness of group activities were associated with higher intentions to seek help from nonprofessional sources.

Discussion

AD treatment research has advanced considerably during the last years. Since physicians now have several pharmacological and nonpharmacological options from which to choose, they should understand and clearly communicate their options to the patients and caregivers.

It is becoming accepted today that the beliefs of patients and the lay public about the helpfulness of various treatments are incorporated and affect physicians' decisions about treatment.¹⁶⁻¹⁸ Indeed, several recent studies have assessed the general public's beliefs about interventions for mental disorders.^{7,19-21} However, all these studies have examined the public's beliefs about helpfulness of treatments for depression and schizophrenia alone. The aim of the current study was to expand this body of knowledge by examining the lay public's beliefs about treatments for AD.

Increasing participation in social activities and engaging in a support group were the most recommended non-pharmacological interventions in this study. Vitamins were the most recommended treatment among the pharmacological interventions assessed. The use of physical

Table 3. Factor solution for treatment of Alzheimer's disease

	Factor 1 Relaxation	Factor 2 Vitamins	Factor 3 Chemical	Factor 4 Group	Factor 5 Restrains
Relaxation	.89				
Yoga or medication	.87				
Natural/herbal medications		.87			
Vitamins		.86			
Sleeping pills			.84		
Pharmacological treatment, such as sedatives			.83		
Engagement in support group				.87	
Engagement in social activity				.67	
Psychotherapy				.50	
Isolation					.83
Physical restraints					.72
Eigen value	1.77	1.65	1.65	1.53	1.46
Overall mean (SD)* for each factor	2.6 (1.2)	3.3 (1.2)	2.8 (1.2)	3.7 (0.9)	1.2 (0.5)

* All differences are statistically significant at the $p < 0.001$ level, with the exception of relaxation and chemical.

restraints and isolation were the least recommended interventions. These findings underscore several interesting conclusions:

1. Consistent with studies examining beliefs about treatments for depression and schizophrenia,^{7,20} this study shows that the lay public endorses the use of nonpharmacological interventions more than pharmacological ones.

2. The high percentage of participants recommending the use of vitamins suggests that lay persons erroneously perceive this intervention as a nonpharmacological one. This is corroborated by the results of the factor analysis, showing vitamins and herbal medicines as pertaining to one factor.

3. As in other studies,^{7,9,20} there appears to be a gap between the public's recommendations and those of professionals. This finding is especially worrisome in light of the association between beliefs about the helpfulness of pharmacological interventions and behavior;

i.e., their actual use,¹⁰ and might be associated with lay persons' strong beliefs about the harmful side effects of sedatives and psychotropic medications.⁹

4. It is clear that the use of extreme measures, such as physical restraints and isolation, are viewed as unwarranted by the general public. This belief is consistent with current standards of care that stress the importance of reducing the use of physical restraints,²² even for people with AD who show more severe behavioral problems and agitation than the person depicted in the vignette.

Examination of the correlates of beliefs about treatments for AD supports the prevailing notion that the public's recommendations depend more on attitudes than on their knowledge and information.⁷ In this study, higher education and income (attributes associated with greater access to expert knowledge) were also associated with decreased recommendation of pharmacological treatments, while increased age (an attribute associated with increased use of medications) was associated with increased support of these treatments.

Of interest is the finding that although the severity of the vignette presented was not associated with AD treatment recommendations, the perception of the dangerousness of the person depicted in the vignette was. Indeed, higher perceptions of dangerousness were associated with higher recommendations of pharmacological interventions.

Several explanations are possible for these findings. The first relates to the validity of the vignettes. Although they were developed to describe different levels of severity of the disease, it is possible that they were not sufficiently different from each another, which might explain the lack of association with the severity of the disease. An alternative explanation for this negative finding might be associated with the characteristics of mentally ill people that elicit reactions in the lay public. Studies on the lay public's perceptions about mental health problems and their treatment, and the literature on stigma in general, show that the lay public's beliefs are associated with the threat feelings elicited by the sick person.^{23,24} Since neither one of the vignettes in this study described a physically aggressive person, it can be assumed that no feelings of threat were elicited, which translated to a lack of difference in the reactions to the person in the vignettes and in the treatments recommended for this person.

An additional explanation relates to the conceptual meaning of perceptions of dangerousness. These perceptions might be associated with increased concerns and anxiety about developing AD. Indeed, perceptions about developing AD and perceptions about the consequences of the disease were significantly associated with perceptions of dangerousness (data available from the author). As such, it is not the dangerousness of the person depicted in the vignette that is the factor affecting the beliefs about treatment but rather the concern of the participant about developing the disease.

As demonstrated in other studies,¹¹ beliefs about treatments were associated with increased help-seeking from professional sources. However, given the cross-sectional design of the study, we are unable to determine whether having sought help from a professional increases the perception of helpfulness of the various interventions, or whether a stronger belief about the helpfulness of the interventions promotes help-seeking. Only one study hints at the causal direction of this relationship. In a longitudinal study assessing 422 persons with a high level of depression symptoms, Jorm and colleagues¹⁰ found that with the exception of the use of antidepressants, beliefs about the helpfulness of interventions for depression were not associated with the actual use of the intervention. Future longitudinal studies should be conducted to disentangle these relationships.

Several limitations of the study must be recognized. First, the use of a convenience and relatively homogeneous sample does not allow generalizability, nor does it provide an accurate representation of all people in Israel. Future studies should use probability samples, including participants from various cultural and ethnic backgrounds. Second, as mentioned above, the use of cross-sectional data does not allow us to draw any conclusions regarding causality. Finally, the use of the vignette methodology limits our conclusions to the responses given to the cases presented and cannot be assumed to be identical to the responses in actual situations, mainly as a consequence of a social desirability bias. However, this methodology has been widely used for assessing lay beliefs about mental disorders.^{6,7,20,21}

In conclusion, our findings stress the need to further study the lay public's opinions about the helpfulness of various pharmacological and nonpharmacological interventions for AD. Special attention should be paid to the public's beliefs about the helpfulness of pharmacological treatments other than vitamins. There is a need to address the negative attitudes toward "chemical" medicines and provide appropriate information about the uniqueness of these treatments for slowing the progression of the disease.³ Moreover, the importance and effectiveness of nonpharmacological treatments should be discussed within the limitations of the partial evidence based on randomized controlled trials.

In sum, advances in the development of effective and valid treatment options for AD should be accompanied by research into the public's understanding of these treatments. This study intends to be a first step in this direction.

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Appendix 1

Version 1

At 3 PM, while waiting for your physician at your HMO office, John (a 71-year-old man) arrives with his son. You approach them and ask them how they are doing, and why are they at the doctor's office? You notice that John does not recognize you, even though you have been neighbors for a long time, and until last year, he frequented the local grocery store where you buy your groceries. John's son tells you that they came to the doctor because John has been having memory problems of late. He forgets where he puts things and even forgot to pay his bills several times. On one occasion, he also had problems remembering his way back from the post office at its new location. John's son tells you quietly that his father might have Alzheimer's disease.

Version 2

At 3 PM, while waiting for your physician at your HMO office, John (a 71-year-old man) arrives with his son. You approach them and ask them how they are doing, and why are they at the doctor's office? You notice that John does not recognize you, even though you have been neighbors for a long time, and until last year, he frequented the local grocery store where you buy your groceries. John's son apologizes and tells you that John frequently does not even recognize him or his other son. He tells you that they came to the doctor because lately, John has also been having memory and language problems (he forgets a word or repeats the same word time after time). While you are talking to his son, John starts shouting, "I want to go home. I'm healthy. He just wants to kick me out of my house and sell it." John's son tells you quietly that his father might have Alzheimer's disease.