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Caregivers and Non-Caregivers Attitudes about Dementia Screening

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Abstract

Objectives—We compared the attitudes about dementia screening among older adults with and without an experience of dementia caregiving.

Design—A cross-sectional study.

Setting—Primary care clinics in Indianapolis, Indiana.

Participants—Eighty one subjects with dementia caregiving experience (CG) and a random sample of 125 subjects without dementia caregiving experience (NCG).

Measurements—Attitudes of dementia screening, including acceptance of dementia screening and its perceived harms and benefits, as determined by the PRISM-PC questionnaire.

Results—After adjusting for age, race, gender, and education and in comparison to NCG, CGs had a lower dementia screening acceptance mean score (53.9 vs. 60.6; $p < 0.05$) and a higher perceived suffering score (61.6 vs. 55.9, $p < 0.05$). However, there were no differences in perceived benefits of dementia screening (72.8 vs. 69.0; $p > 0.05$), perceived stigma (32.9 vs. 37.5; $p > 0.05$), and perceived negative impact on independence (47.6 vs. 54.0; $p > 0.05$). The top three barriers to screening identified by both groups were emotional suffering by the family (86% of CGs and 75% of NCGs), loss of driving privileges (75% of CGs and 78% of NCGs), and becoming depressed (64% of CGs and 43% of NCGs).

Conclusion—The experience of being a dementia caregiver may influence one's own attitude about accepting dementia screening for oneself.

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Keywords

Dementia; Primary Care; Caregivers; Screening Acceptance; Perceived Harms; Benefits

INTRODUCTION

Early detection and screening for dementia have been suggested as strategies to decrease the burden of Alzheimer disease (AD).[1-6] Over the next decade, potential disease modifying pharmacological interventions and preventive strategies such as immunotherapy or neuro-protection may require implementation of systematic screening for dementia as a public health intervention to identify persons with early stage of AD and thus have the highest potential of benefiting from the disease modification therapies.[7-9] The success of such strategies will depend on the public's attitude about the benefits and harms of screening.[3,10-13]

Support and care for persons suffering from dementia is typically provided by family who witness the impact of the syndrome, not only on their loved one's cognitive status, but also on their daily function, behaviors and mood, and ability to interact within physical and social contexts.[1-4] These caregivers also witness the way our health care system and our society address, treat, and interact with individuals suffering from dementia. Therefore, the perception and attitudes of caregivers about the benefits and harms of screening and early detection for dementia in general and AD in particular is important. Receiving a diagnosis of dementia may provide a sense of relief for some families and facilitate intervention strategies and support services. Other families may fear that a diagnosis of dementia will result in the loss of a normal life, and subsequently would rather not know.[5]

An investigation into the psychosocial determinants of intention to screen for AD among community dwelling older adults (n=1039) identified *knowledge about dementia* as a crucial predictor toward intention.[13] Similar results were identified for acceptance of other types of health screenings such as colon or breast cancer. Understanding the caregivers' attitudes about dementia screening and contrasting such attitudes with the attitudes of Americans who had no caregiving experience may shed some light on the barriers and facilitators to implementing an early dementia screening program in primary care practices. In addition, such comparisons may facilitate the development of counseling programs that reduce the negative impact of early dementia detection on the patient and family and prepare them for the challenges ahead.

Over the past decade, the Indiana University Center for Aging Research has developed the Perceptions Regarding Investigational Screening for Memory in Primary Care (PRISM-PC) Questionnaire as a reliable and valid instrument for capturing the acceptance and perceived harms and benefits of dementia screening.[10,12,14,21] We have used this instrument to compare the attitudes about dementia screening among subjects with and without the experience of dementia caregiving. The cohort with dementia caregiving experience included informal caregivers of AD patients whose disease was detected via a dementia screening and diagnosis program.[11] The cohort without dementia caregiving experience included older adults receiving primary care services in the community. Due to the negative impact of caregiving for patients with dementia on the well being of the informal caregiver and the current sub-optimized dementia care provided by the American health care system, we hypothesized that the subjects with dementia caregiving experience would have more negative attitudes toward dementia screening than those with no such caregiving experiences.

METHODS

Study Cohorts

The caregiver cohort was recruited from the entire pool of participants that were part of a randomized controlled trial investigating the effectiveness of dementia collaborative care model in a primary care setting between January 2002 and August 2004.[6,11,12] Informed consent as approved by the Indiana University-Purdue University Institutional Review Board was obtained from all subjects attending primary care practices in Indianapolis, Indiana. Seven community-based health centers affiliated with Wishard Health Services (WHS) participated in the clinical trial. These facilities serve approximately 5,000 medically indigent older adults.[6,11,12] Eligible subjects were recruited following a written prompt for physician referral that they had screened positive for cognitive impairment by the research team. Primary caregivers of subjects with possible or probable AD, receiving care in an urban primary care system, were considered eligible for the study. A sample of 81 (90%) of the entire 90 eligible caregivers were enrolled; no information was collected on the nine caregivers that declined participation and we did not collect data on the relationship between the caregiver and the subjects with AD. A trained research assistant contacted the eligible caregivers and administered the PRISM-PC Questionnaire via telephone.

The comparative non-caregiver cohort included 125 older adults randomly sampled from those residing in Indianapolis and receiving their care from Wishard Health Services (WHS) from September 2004 through June 2005.[10] We excluded subjects who were aged younger than 65, prisoners, residing in nursing homes, unable to speak English, having a mental health illness such as schizophrenia or bipolar disorder, having a chart-based diagnosis of a memory problem or dementia, and those who had not been seen by a WHS primary care physician within two years prior to the study's initiation.

The PRISM-PC Instrument—The Perceptions Regarding Investigational Screening for Memory in Primary Care (PRISM-PC) Questionnaire was developed to capture the acceptance and perceived harms and benefits of dementia screening. Guided by the health belief model, 16 clinical researchers in the United States and United Kingdom, with expertise in dementia care and instrument development, established face and content validity for the questionnaire.[10,21] Exploratory factor analysis identified five domains: Acceptance of dementia screening (6 items); Benefits of dementia screening (8 items); Stigma of dementia screening (10 items); Negative impact of dementia screening on independence (6 items); and Suffering from dementia screening (4 items). The internal consistency for all subscales of acceptance and perceived harms and benefits had a Cronbach's alpha range of .58-.89. Each item was rated on a 5-point Likert scale ranging from “strongly agree” to “strongly disagree”.

Statistical Analysis

Domain scores were calculated for dementia screening acceptance, benefit, stigma, loss of independence, and suffering. All items within each domain were reverse-coded such that a higher score indicated stronger agreement with the statement. Each domain score was transformed to a 0-100 scale by subtracting the minimum score from the sum of the reverse coded items and dividing by the range. Although we were interested in patients' acceptance and their perceptions of the harms and benefits of dementia screening, we used the term Alzheimer's disease as an alternative to dementia because our earlier work showed “Alzheimer's disease” to be a more readily understood term.[10] In addition to using the Likert scale and to help interpret our data more easily, individual items within each domain were also recoded into dichotomous outcomes by collapsing the five response categories into two categories (strongly agree, agree vs. all other categories).

Descriptive statistics were used to explore the caregiver and non-caregiver response profiles on the perceived acceptance, benefits and harms of dementia screening. We compared the two samples using the two-sample T-test for continuous scale variables and the two-sided Fisher's exact test for dichotomous item variables. We used linear regression to test whether differences in the scale scores and individual items remained significant after adjusting for age, gender, race, and education.

RESULTS

Demographics of the two samples are presented in table 1. Caregivers were younger, more educated, and more likely to be female than the non-caregiver respondents. They were also more likely to be married and less likely to live alone. Caregiver respondents were, by definition, more likely to have known someone with AD. Interestingly, they also were more likely to believe they are at a higher risk of developing AD than others in their age group.

Acceptance

The caregiver sample had a significantly lower mean acceptance score for screening than the non-caregivers (53.9 vs. 60.6; $P < 0.05$). This difference appears to be driven primarily by non-caregiver respondents agreeing that they would like to be tested for AD with a blood sample (66.4% vs. 44.4%; $P < 0.05$) and that they would like to have an MD examine them for AD (76% vs. 55.6%; $P < 0.05$). Less than half of both samples agreed with wanting to be tested with any type of brain imaging (42% and 45.6%). These significant differences remained after adjusting for age, race, gender, and education (table 2).

Perceived Benefit

Both caregivers and non-caregivers agreed with the benefits of the dementia screening, with caregivers having a significantly higher mean score (72.8 vs. 69.0; $P < 0.05$). Caregivers were more likely to cite having more time to talk with their family about health care and finances (93.8% vs. 82.4%; $P < 0.05$). Caregivers were also more likely to agree about being more motivated to have a healthier lifestyle (80.3% vs. 64.8%; $P < 0.05$) and to sign an advance directive or a living will (91.4% vs. 80.8%; $P < 0.05$). The differences in the overall perceived benefits and other individual benefit items were not significant after adjusting for age, gender, race, and education (table 2).

Perceived Stigma

Both caregivers and non-caregivers generally disagreed that they perceived stigma would be a consequence of dementia screening. The stigma mean score was significantly lower for the caregiver sample (32.9 vs. 37.5; $P < 0.05$), even though both scores indicated that neither sample thought stigma to be a major issue. There were no significant item differences in this domain. The most common concerns (> 25% of participants) for both groups were that they would no longer be taken seriously and that their employer or health insurance company would find out that they have AD. Very few participants (<10%) had concerns that they might receive inadequate care from health care providers, would give up on life, or would not want their family to know. After adjusting for all demographics, the difference in overall perceived stigma was no longer significant (table 2).

Perceived Negative Impact on Independence

The independence score was significantly lower for the caregiver sample (47.6 vs. 54.0; $P < 0.05$), although the scores indicated that both samples were neutral with respect to loss of independence. Although the groups viewed screening to marginally impact independence overall, both groups identified the greatest perceived impact on independence to be fear of losing one's driver's license or other privileges (>75%). After adjusting for demographics, the difference in perceived independence was not significant and concern about the obtaining health insurance was less in the non-caregiver cohort.

Perceived Suffering

Caregivers had a significantly higher mean suffering score (61.6 vs. 55.9; $P < 0.05$). Caregivers had higher agreement scores for all four questions of the scale, with the largest differences for financial suffering (59.3% vs. 44.8%; $P < 0.05$) and being depressed (64.2% vs. 43.2%; $P < 0.05$). The difference for overall perceived suffering remained significant after adjusting for demographics. Additionally, African-Americans had lower perceived suffering scores than whites. Only financial suffering item remained significant after adjusting for demographics.

Regression models for the five domains are presented in table 3. After adjusting for age, gender, race, and education, only two domains remained significantly associated with being a caregiver. Those with caregiving experience had significantly lower screening acceptance scores and significantly higher perceived suffering scores. Experience as a caregiver was not significantly associated with the other three domains (benefits, stigma, and independence) after adjusting for age, race, gender, and education. The loss of significance from the bivariate association seems to be from the difference in age and education between the two cohorts as well as the association of age and education with these three scales (table 3).

Discussion

Our study found that the caregivers of older adults with dementia were less enthusiastic about being screened themselves for dementia and had a higher perceived suffering related to screening than those who lacked a caregiving role. Some individual barrier items were ranked high by both groups and may influence screening. The highest barrier item identified for negative impact on independence was the fear of losing a driver's license or other privileges. The impact of driving cessation on quality of life and independence is well documented.[15-18] The driver's license is often identified synonymously with independence and the loss of driving privileges often leads to depression and social isolation.[15,19,20] Many older adults who are no longer safe to drive will rely predominately on family caregivers for their transportation needs. These caregivers may have experienced the phenomenon of being transportation disadvantaged and the negative impact that it can have on a person with AD, however the non-caregiver perceptions did not differ significantly. As the number of older adults with AD increases, so will the number of those that will outlive their ability to safely operate a motor vehicle. Addressing the fear of losing a driving license may improve the likelihood of participation in AD screening for both caregivers and non-caregivers.

The top five barriers identified by both samples were related to perceived suffering and perceived impact on independence; 75% to 86% felt they would suffer emotionally; 75% to 78% were concerned they would lose their driving license and other privileges; 43% to 64% felt they would be depressed; 45% to 59% were concerned they would suffer financially; and 37% to 51% felt they would be anxious. By targeting these barriers, we can tailor our counseling and patient education programs to minimize perceived suffering and impact on independence and increase the likelihood for intention to screen for the disease.

Our study has some limitations. The measurement of attitudes about dementia screening focused on perceived acceptance rather than the actual screening acceptance behaviors. Although random sampling was utilized, geographic and temporal generalizability is limited due to the cross-sectional nature of the study. Furthermore, it is possible that the differences between the caregivers and non-caregivers in their attitudes about dementia screening was driven by factors not measured by our study such as the reason for being a caregiver and the type of relationship between caregiver and their loved one (e.g., being a spouse or an adult child).

Our findings identified a complex interaction of perceived harms and benefits which made it difficult to determine whether the benefits of dementia screening outweighed the potential harms.[3] It is important to follow up on our study findings and evaluate the effects of time and becoming a caregiver on older adults' attitudes about dementia screening. By identifying the differences in the perspectives between non-caregivers and caregivers with firsthand experience with dementia, we are in a better position to understand the risks and benefits of early identification in order to improve its process. A subsequent step in our line of investigation is the development of an individualized counseling program embedded within the primary care system that would facilitate early diagnosis of dementia and thus set the stage for early intervention where appropriate.[21] Such an early intervention program may help patients with AD and their caregivers to prepare for the medical, financial, legal and emotional consequences of AD.

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Table 1

Demographic characteristic and beliefs of the two cohorts

Characteristics	**Caregivers (n = 81) Mean (SD) or Percentage**	**Non-caregivers (n = 125) Mean (SD) or Percentage**
Age*	66.1 (12.1)	73.8 (6.3)
Education*	12.6 (2.2)	10.8 (3.0)
Education Categorized *		
- 0 -11 years education	21.0	46.0
- 12 years education	39.5	32.3
- 13+ years education	39.5	21.8
Female*	92.6	60.8
African-American	48.8	60.0
Live alone*	16.1	39.2
Married*	81.3	28.8
Relative or friend with AD*	71.6	27.2
Believe higher risk of AD than others in age group*	25.0	8.3
Think more problems with memory than others same age	9.0	7.3
Told by doctor have memory problems	2.5	2.4
Taking medication to help with memory	2.5	1.6
Don't believe treatment for AD currently available	29.6	34.4
Accepted screening for colon cancer	66.7	63.7
Accepted screening for depression	53.1	60.8

Percentages are defined as percent of patients agree or strongly agree with the statement.

*$p < 0.05$

Table 2

Acceptance and perceptions of benefits and harms of dementia screening among the two cohorts.

PRISM-PC Domains and Items	**Caregivers (n = 81) Mean (SD)**	**Non-caregivers (N = 125) Mean (SD)**	**p-value**[*]
Dementia screening acceptance score	53.9 (21.8)	60.6 (17.7)	
Like to know if at higher risk for AD	3.25 (1.2)	3.49 (0.9)	0.029
Like to know if I have AD	3.46 (1.1)	3.66 (0.9)	0.161
Like to be tested for AD with short questionnaire	3.31 (1.1)	3.41 (0.9)	0.514
Like to be tested for AD with blood sample	2.90 (1.1)	3.38 (1.0)	0.002
Like to be tested for AD with CT-scan or MRI	2.85 (1.2)	3.02 (1.0)	0.273
Like MD to examine me for AD	3.16 (1.1)	3.57 (0.9)	0.009
Be motivated to have a healthier lifestyle	3.65 (0.9)	3.51 (0.8)	0.254
More willing to participate in research about this disease	3.80 (0.9)	3.75 (0.7)	0.656
Stigma score (SD)	32.9 (12.1)	37.5 (10.3)	
Would not want my family to know	1.99 (0.8)	2.19 (0.7)	0.059
Feel humiliated by my family members and/or others who would treat me poorly or laugh at me	2.07 (0.9)	2.27 (0.8)	0.101
No longer be taken seriously	2.58 (1.0)	2.87 (1.0)	0.036
Be considered stupid and unable to do things	2.07 (0.8)	2.38 (0.8)	0.011
Be ashamed or embarrassed	2.27 (0.9)	2.41 (0.8)	0.265
Give up on life	1.96 (0.7)	2.00 (0.6)	0.702
My doctor would not provide the best care for my other medical problems	2.17 (0.7)	2.23 (0.7)	0.540
My doctor and other health professionals would not listen to me	2.28 (0.8)	2.39 (0.7)	0.323
Be concerned that my health insurance company would find out	2.76 (1.1)	3.05 (0.9)	0.050
Be concerned that my employer would find out	2.99 (1.1)	3.23 (1.0)	0.114
Negative Impact on Independence score	47.6 (16.9)	54.0 (11.4)	
Not be able to get health insurance	2.69 (0.9)	3.13 (0.7)	<0.001
Not be able to get life insurance	2.93 (1.0)	3.26 (0.7)	0.013
Not be able to get long-term care insurance	3.21 (1.0)	3.29 (0.7)	0.543
Lose my home	2.38 (0.9)	2.65 (0.8)	0.037
Be living in a nursing home	2.59 (1.0)	2.91 (0.9)	0.021
Lose my driver's license and other privileges	3.63 (0.9)	3.71 (0.6)	0.480
Suffering score (SD)	61.6 (18.5)	55.9 (14.5)	
Family would suffer financially	3.36 (1.2)	3.06 (1.0)	0.051
Family would suffer emotionally	3.91 (0.8)	3.67 (0.8)	0.032
Be depressed	3.40 (1.0)	3.13 (0.9)	0.051
Be anxious	3.19 (1.1)	3.10 (0.8)	0.538

[*] p is based on a bivariate comparison using t-test

Table 3

Association between attitudes of dementia screening and having dementia caregiving experience adjusting for, age, gender, education, and race.

	Caregivers$^{\$}$		**Age**		**Female**		**Education**		**African-American**	
	Est. (SE)	**P***	**Est. (SE)**	**P**	**Est. (SE)**	**P**	**Est. (SE)**	**P**	**Est. (SE)**	**P**
Acceptance	−7.4 (3.4)	0.03	−0.19 (0.16)	0.25	−1.7 (3.4)	0.61	0.05 (0.52)	0.92	2.1 (2.8)	0.46
Benefits	1.4 (2.0)	0.49	−0.24 (0.09)	< 0.01	−0.2 (1.9)	0.91	0.30 (0.30)	0.32	−1.3 (1.6)	0.42
Stigma	−3.0 (1.9)	0.12	0.17 (0.09)	0.06	−1.0 (1.8)	0.61	−0.41 (0.29)	0.15	−1.2 (1.6)	0.48
Independence	−3.0 (2.3)	0.20	0.23 (0.11)	0.04	−0.2 (2.3)	0.92	−1.06 (0.35)	< 0.01	−0.2 (1.9)	0.91
Suffering	5.8 (2.8)	0.04	0.04 (0.13)	0.74	−4.4 (2.8)	0.11	0.29 (0.42)	0.49	−6.9 (2.3)	<0.01

[\$] Caregiver versus non-caregiver cohorts; SE: standard Error; P: P value, Est: Regression Parameter Estimate