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Caregiver Perspectives on Cancer Screening for Persons with Dementia: “Why Put Them Through It?”

Alexia M. Torke, MD, MS^{1,2,3,4}, Peter H. Schwartz, MD, PhD^{3,5}, Laura R. Holtz, BS^{1,2}, Kianna Montz, MA^{1,2}, and Greg A. Sachs, MD^{1,2,3}

¹Indiana University (IU) Center for Aging Research, Indianapolis, IN

²Regenstrief Institute, Inc., Indianapolis, IN

³IU Division of General Internal Medicine and Geriatrics, Indianapolis, IN

⁴Fairbanks Center for Medical Ethics, IU Health, Indianapolis, IN

⁵IU Center for Bioethics, Indianapolis, IN

Abstract

Objectives—To describe the perspectives of family caregivers toward stopping cancer screening tests for their relative with dementia and identify opportunities to reduce harmful or unnecessary screening.

Design—Focus group study

Setting—Alzheimer’s Association support groups for family members of patients with dementia.

Participants—Four focus groups including 32 caregivers with mean age 65.5 years (range 49–85 years). There were 25 women; 24 were white, 7 African American and 1 African American/Indian.

Measurements—Focus group transcripts were transcribed and analyzed using methods of grounded theory.

Results—Caregivers considered decisions to stop cancer screening in terms of quality of life and the burdens on the patient and caregiver. Many describe having to intervene in the patient’s care to stop unnecessary or harmful screening, and others met resistance when they advocated for stopping. Physicians varied widely in their knowledge of dementia care and willingness to consider cessation of screening.

Conclusion—Many family caregivers wish to stop cancer screening tests as dementia progresses, and are relieved when physicians bring it up. Caregivers are open to discussions of screening cessation that focus on quality of life, burdens and benefits. Interventions are needed to increase caregiver/clinician discussion of screening cessation and to increase clinician awareness of the need to reconsider cancer screening in patients with dementia.

Corresponding Author: Alexia Torke, MD, MPH, IU Center for Aging Research, 410 W. 10th Street, HITS 2000, Indianapolis, IN 46202, Phone: 317-423-5500, Fax: 317-423-5653, atorke@iupui.edu. Alternate Corresponding Author: Greg Sachs, MD, Division of General Medicine and Geriatrics, 1001 West 10th street, M200, Indianapolis, IN 46202, Phone: 317-630-2564, Fax: 317-630-7066, sachsg@iupui.edu.

Author Contributions:

Concept and design: Torke, Schwartz, Sachs
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Keywords

Early Detection of Cancer; Alzheimer Disease; Dementia; Decision Making

INTRODUCTION

As the population ages, the prevalence of Alzheimer's disease (AD) in the United States is expected to rise from 5.4 million in 2012 to 6.7 million in 2025. Given this increasing prevalence, there is a pressing need to ensure that persons with dementia receive appropriate care and avoid interventions that are unnecessary or harmful.¹ Because of advanced age, patients with dementia are often at high risk for co-morbid illness such as cancer. However, screening tests for cancer have increased risk of harm in patients with dementia, including distress from the tests and complications from follow-up testing and treatment.¹⁻³ The potential for benefit from screening is also decreased given the shorter life expectancy of many persons with dementia.^{4,5} Reducing non-beneficial cancer screening is therefore a part of quality care for persons with dementia.

Unfortunately, there is evidence of over-screening in this population; 18% of older women with advanced cognitive impairment receive mammography even though their short life expectancy makes them unlikely to benefit.⁶ A similar number of persons with dementia receive colon cancer screening in the VA setting.⁷ Reducing unnecessary tests may be difficult in light of the general public's very positive view of cancer screening.⁸ Research has found that very few older adults have plans to stop screening in the future,⁹ and are skeptical about physician or guideline recommendations to stop.¹⁰ A majority of older adults believe persons with Alzheimer's disease or total functional dependency should continue screening¹¹ and screening rates continue to be high in patients with other terminal diseases such as cancer.¹²

As dementia progresses, caregivers must gradually take over the process of medical decision making. Little is known about how decisions to continue or stop screening are actually made by dementia caregivers, or if their perspectives on cancer screening are as positive as previous studies have found in other populations. To examine this, we conducted focus groups with caregivers who were attending support meetings for family members of patients with dementia.

METHODS

Study Design and Population

We conducted a focus group study of individuals attending caregiver support groups sponsored by the state Alzheimer's Association chapter. Chapters were selected to represent a range of geographic locations and socio-economic status and included one suburban church, one inner city public hospital, and 2 chapters located within the city of Indianapolis. A staff member for each support group was called and asked if we could approach group participants. We conducted focus groups at 4 of 4 groups approached. All members of the four caregiver support groups were eligible for participation. The method of approach varied slightly by group based on the preferences of Alzheimer's Association staff. For one chapter site, research staff introduced the project at one meeting and mailed a letter to those expressing interest. For the three other sites, the support group facilitator contacted participants to assess interest. Each participant received a \$50 grocery store gift card for their participation.

Data Collection

The focus group interview guide was developed by the investigators based on a review of the literature on screening decision making and consisted of open ended questions about recent experiences with cancer screening for the person with dementia and experiences making decisions about screening tests (Appendix).

Focus groups were conducted during one of the regularly scheduled meetings of the support group. At each focus group, a member of the research staff explained the study and obtained written informed consent from each participant. Groups were led by a trained focus group facilitator and by one of the physician investigators (AMT, PS, or GS). Focus groups were audio-recorded and transcribed verbatim.

Analysis

We conducted qualitative analysis of the interview transcripts guided by methods of grounded theory¹³ with careful reading of the text in order to identify major themes and build new theories based on the data. Each member of the research team individually read and coded transcripts using methods of open coding¹³ by labeling segments of text with descriptors that identify an important concept in the participants' responses.^{13,14} Investigators met weekly to refine the list of codes and to organize codes into broader themes that emerged from the data. Disagreements were resolved by consensus. At each team meeting, we discussed whether we had reached theme saturation, the point at which no new themes are identified in subsequent data collection.¹³ Transcribed interviews and codes were entered into NVivo software to allow for sorting of the coded segments of text.

We used several strategies to ensure trustworthiness of data analysis, including the use of more than one focus group co-leader, independent reading of the transcripts by each investigator, and a team with varied backgrounds including a geriatrician (GAS), two primary care physicians (PS and AMT) and non-physician team members with backgrounds in education (KM) and health care compliance (LH).

RESULTS

We conducted 4 focus group sessions with a total of 32 caregivers. Attendance at each focus group ranged from 7 to 10. Participant mean age was 65.5 years (range 49–85 years).. Caregivers were 14 daughters, 13 were spouse, and 5 other (Table 1). Each focus group included a mix of spouses and adult children and included both men and women. The primary themes that emerged from the data were: Quality not Quantity of Life; Increasing Burdens on the Patient and Caregiver; Intervening to Stop Screening; and Variability of Physician Expertise (Table 2).

Quality Not Quantity of Life

Many caregivers perceived that forgoing the proposed screening test was the best way to preserve quality of life (Table 2, quotes 1–3). Some perceived a direct trade-off between quality and duration of life. One caregiver's reasoning was based on her perceptions about what she would want if she were in similar circumstances (Quote 2). Another questioned the appropriateness of screening a patient who was unable to make an informed choice (Quote 3).

Increasing Burdens on Patient and Caregiver

Caregivers noted the particular burdens that dementia created for individuals undergoing screening tests. For example, they reported that agitation and inability to understand the procedures increased as dementia worsened (Quote 4). Caregivers' understanding of the

burden of tests came from both their experiences watching the person with dementia undergo them and from their own personal experiences with tests such as colonoscopies and mammograms. Caregivers also described the cascade of tests and treatments that may result from a positive test. Logistical issues such as the need for increased supervision were barriers to getting screening tests. Several quotes highlighted the importance of the shared experience of the patient and caregiver (Quotes 6, 7) and considered the impact of the screening test on the caregiver's quality of life. Many caregivers described the distress they experienced in providing care to the person with dementia and coping with agitation, poor understanding or complications of procedures. Screening tests such as colonoscopies often required additional supervision or support from caregivers and this, in turn, caused particular burdens for the caregiver as well as the person with dementia (Quote 6). Although respondents focused primarily on how dementia affected the burdens of screening tests, caregivers also mentioned age, overall health, and co-morbidities of the person with dementia as factors in the balance of burdens and benefits.

Intervening to Stop Screening

Several caregivers described instances where they intervened to prevent a scheduled or recommended screening test. One described how she becoming far more involved in decision making for a relative with dementia as a result of a bad experience with a screening test (Quote 8). Others reported that screening tests often were conducted after receipt of a form letter or reminder that it was time for the test. Caregivers described the need to intervene in light of the momentum of the health care system toward continued intervention. Caregivers described their role in advocating for the patient's interests within the health care system. Advocating for a change in momentum proved difficult for some caregivers. For example, one described eventually going along with a recommendation for a mammogram despite expressing reservations to the physician (Quote 11).

Variability of Physician Expertise

Caregivers spontaneously described their perceptions about physicians' knowledge and expertise caring for persons with dementia. They reported a wide variety of experiences with respect to expertise in caring for older adults and persons with dementia that impacted decisions about interventions. Caregivers appreciated physicians' willingness to take dementia and age into account in cancer screening decisions (Quote 13) and appreciated physicians who still included the patient in conversation, even if the patient couldn't fully participate (Quote 14).

DISCUSSION

This focus group study of 32 dementia caregivers found that many participants make decisions about cancer screening based on quality of life, and many had experiences of stopping or wishing to stop cancer screening in the setting of dementia. Caregivers pointed to the increasing burdens of screening that are often a direct result of the cognitive or behavioral symptoms of dementia, such as not understanding the purpose of the test or becoming agitated in new or uncomfortable situations. In addition, participants questioned the expertise of doctors who forged ahead with screening without reflecting on the overall goals, and some described intervening to stop a test being performed. Caregivers also welcomed provider-initiated discussions about stopping screening tests.

These findings are in marked contrast with studies that have asked individuals to consider their own preferences for future cancer screening. Over 90% of the older adults in a national telephone survey planned to continue screening regardless of health status or age.⁹ In another study, about a third of a national telephone sample thought the decision of an 80-

year-old to stop screening was irresponsible.⁸ In interviews with older adults at a senior health center, we found that many expressed a sense of moral obligation to continue screening and thought that a physician's recommendation to stop might threaten trust in that physician or call the physician's judgment into question.¹⁰ In contrast, we found that caregivers considered stopping screening tests on their own or over the objections of clinicians and appreciated physicians' willingness to consider stopping screening as dementia worsened.

We propose that this difference in perspective is largely due the caregivers' experience with the person with dementia. Caregivers gain knowledge about the daily burdens of dementia and the additional challenges that screening tests impose, including trips to the office or clinic and the pain and discomfort of the test. These caregiver experiences are likely to be quite different from those of older adults hypothetically considering their own future.

Caregivers were also critical of providers who did not take burdens into account when recommending "standard" screening, and some described situations in which they had to actively intervene to stop screening tests. As previously noted, they described a sense of momentum toward continued screening,^{8,15} due in part to current cancer screening guidelines, which offer conflicting guidance about age cutoffs¹⁶ and provide little guidance about when factors such as co-morbid illness should weigh against screening. In some cases, the caregiver described themselves in the role of advocate for the patient in a health care system that was not responsive to the needs of the person with dementia.

These findings suggest that there may be an opportunity to reduce the overuse of screening in those with dementia by helping caregivers engage in productive conversations with providers. A major initiative by the American Board of Internal Medicine Foundation's Choosing Wisely campaign¹⁷ encourages providers and patients to question medical interventions that may be costly but not beneficial. Our findings showed that at least some caregivers have concerns about non-indicated screening tests but that their questions were sometimes dismissed or failed to stop the momentum towards such screening. This suggests that it may be important for future initiatives aimed at decreasing overuse of screening to target providers, who can be taught to validate concerns of the caregiver and facilitate productive dialogue about cessation of screening tests. Provider discussions can be based on an individualized approach to decision making that considers life expectancy, benefits, burdens and values.¹⁶

Our study also found that caregivers considered screening decisions in terms of the benefits and burdens for the patient. Although ethical frameworks for surrogate decision making focus on patients' own preferences for care,^{18,19} we found caregivers rarely spoke of the patients' current or prior preferences. Although there has been great attention to advance care planning for end of life decisions, we suspect that few individuals have considered other future health care choices such as when to stop screening. Caregivers likely had little information regarding the patient's own preferences for future screening care, and any such preferences may have been uninformed by the reality of life with dementia and the burdens of screening in that setting. Instead, caregivers relied heavily on their perception of the patient's quality of life and the burdens and benefits of the test, both examples of best interest judgments.

Caregivers also considered the burdens of the tests on themselves. The extent of caregiver burden has been well-documented for persons with dementia.^{20,21} Our results suggest medical encounters are a source of burden that caregivers consider in their decision making process. Taking a person with dementia to the doctor, encountering resistance, and even watching the person suffer are sources of distress to the caregiver. Caregivers viewed their

own interests and those of the person with dementia as being closely interwoven if not inseparable, such that things that are burdensome for the person with dementia are also burdensome for the caregiver. Standard ethical models for surrogate decision making do not account for burdens of an intervention to the family or other individuals, although there is evidence that physicians consider these factors in surrogate decision making for adults.²²

Limitations of the study include that caregivers were all participants in Alzheimer's Association support groups and may differ from caregivers generally. For example, they may have been more activated and willing to advocate on behalf of their relative. Additionally, all caregivers resided in a single, Midwest metropolitan area and may have differed in terms of social, religious views from caregivers elsewhere. Our caregiver group included both whites and African Americans but did not include the views of Asian or Hispanic families. Finally, a small qualitative study cannot identify the prevalence of each theme, but rather characterize a framework for thinking about cancer screening in dementia that can be validated in future research.

In conclusion, caregivers of persons with dementia are not only willing to consider stopping cancer screening, many are relieved when physicians bring it up. Caregivers would be most open to discussions of screening cessation when they focus on quality of life and burdens and benefits for the person with dementia. Given the openness of dementia caregivers to considering screening cessation, interventions could potentially target clinicians in order to increase the frequency of such discussions or could target caregivers in order to empower them to advocate for screening cessation as dementia progresses and the burdens of screening tests outweigh the benefits. By reducing unnecessary screening, we have the potential to reduce patient burden, costs and caregiver distress while improving the overall quality of care for patients with dementia.

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Appendix: Semi-Structured Interview Guide Major Domains and Questions

Decision Making Process

- Can someone tell us about the most recent time that you had to make a decision with your relative with memory problems and his/her doctor about whether or not your relative should have a cancer screening test like a mammogram, colonoscopy, or a blood test for prostate cancer?
- (If not already elicited by above questions) Can you tell me about a time that the decision was made to have your relative NOT do (or skip) a cancer screening test, perhaps one that they might have had when younger and healthier?
- We’d like everyone to think about and discuss whether there are circumstances in which they might choose to no longer have their relative undergo cancer screening and what those would be.

Preferences for communication

Up until now, we've been talking about how people make decisions about cancer screening tests, one kind of preventive health care. Now, we'd like to turn to the conversations that physicians have with patients and family members who are trying to make these decisions.

- Can someone tell us about what the doctor said when you and your relative were last making a decision about cancer screening?
- (If not already discussed immediately above. Can rephrase to probe for additional examples if some already expressed.) Can someone tell us about the conversation that occurred when a doctor recommended forgoing or skipping a cancer screening test for your relative?
- In addition to what we've already discussed, are there any other things you would like doctors to include when they talk with you about these kinds of cancer screening decisions?

Impact on Relationship with Physician

- Would there be a situation where a physician may make a recommendation which would affect your trust with that doctor?
- If a doctor were to recommend that a patient not have a cancer screening test, would you be concerned about the doctor's motivations?

Table 1

Participant Demographics (N=32)

Characteristic	Number (%)
Caregiver Age, mean	65.5
Range	49–85
Caregiver Female	25 (78)
Caregiver Race	
African American	7 (22)
White	24 (75)
American Indian	1 (3)
Caregiver Education, years	13.9
Relationship to Patient	
Spouse	13 (41)
Daughter	14 (44)
Son	1 (3)
Daughter in law	2 (6)
Son in law	2 (6)
Patient Age, mean	81.5
Patient Female	21 (66)
Patient Education, years	12.8

Table 2

Themes and Quotes

Theme	Quote Number	Representative Quotation
Quality Not Quantity of Life	1	I was concerned about her quality of life and making sure that she was very, very comfortable, and I think that means more than putting people through a lot of unnecessary, uncomfortable... procedures, ... it's not going to make the person better. It might make them linger on, but are you really living?
	2	If a person is going to be miserable for three years or well or feeling better for two and they are 85, 90 years old, I think I would go for the shorter term of life. I hope somebody would for me... And I'd rather have a good quality of life for two years than a bad one for four.
	3	If you can imagine that you're telling somebody it's time to go do this and they're putting things in their veins and they have to sit there and they feel sick afterwards, I believe at a certain point, it's a form of torture if the person really hasn't chosen it for themselves, and you are not significantly going to extend their life of any quality.
Increasing Burdens on Patient and Caregiver	4	She absolutely would fight it tooth and nail because not really understanding exactly and also the older she gets, it seems like the more she responds to any kind of discomfort. Getting her shots now are a problem. Getting blood from her is now a problem. There would be no way we could do a mammogram.
	5	We were going to have my mother go through a mammogram and... I decided not to... I asked the doctor, OK, if you find something, what would be the procedure? What would you do? And he said, well, it would be the normal progression of... going through surgery. I just looked at him and said, do you think my mother could survive surgery, and, he said no. And that was my decision right there.
	6	(A)t the point where my mother is, right now, there's no way in the world I could get her to drink all that stuff and not eat. I'm thinking who's going to monitor all 24 hours a day? I can't do it. I can't do it. It's utterly impossible. So I can't send her through that and I can't go through it.
	7	Is it really going to change anything, and if it's not, then why put them through it, and not only why put them through it, why put ourselves through it as the primary caregiver?
Intervening to Stop Screening	8	I'm in charge of my father's medical care and treatment now, but I wasn't when he had his last colonoscopy... it was that experience that made me pursue that I have to take over because he was sent a letter from the place where he had the colonoscopy before, saying that it's time to come in, and he and my stepmother just said, well the doctor says it's time to go again... When she got him home, he could barely get up to their apartment and I thought, this can't happen again.
	9	And it's just usual with her physical, they go down the chart, they see which tests have been done and the last time they were done. And... one doctor suggested, maybe it's time for her to have another one. Well, when I questioned it, he agreed with me that it wasn't necessary for the colonoscopy again.
	10	Now I firmly believe that part of the problem is that our society in the medical profession is always saying, do this, do this, this is the next thing you can do, and we really have to kind of pull back from that and say, what's the quality of this person's life and the dignity.
	11	My mom hasn't had one in eons, but her doctor asked her to have one earlier this year and she said OK. And I said OK on that so I went with her to the appointment and she came through unscathed ... but I asked her, I said, she's 88. Why are you ordering this now? Tell me what's the point? He said it's just been a long time. Let's do it once just to make sure that she gets a clean bill of health. I said OK with respect.
Variability of Physician Expertise	12	I don't know whether at this point I should change primary care physicians... but she clearly doesn't know about Alzheimer's and she is clearly not very helpful... they unfortunately aren't all very well informed about Alzheimer's.
	13	We had a wonderful experience with our primary care physician... She said, Alice, you're 85. You don't have to do anything if you don't want to, but here's what I would do if I were you... And it was such a relief to know that I wasn't ... I wasn't subjecting her to anything she didn't want and I wasn't going against medical wisdom either.
	14	With H's doctor... a lot of the time she sits with her head down like this and you can't really do eye contact. But what he does is, I sit right next to her, even though he's talking to me, he looks over at her and has her hand in his hand all the time. She loves that contact, and he got it early.