

The Two Voices of Alzheimer's: Attitudes toward Brain Health by Diagnosed Individuals and Support Persons

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Abstract:

Purpose: Most individuals with Alzheimer's are cared for in their homes by unpaid family members. Research on caregiving focuses disproportionately on costs of care, service utilization, and negative psychosocial outcomes. Few narrative accounts of Alzheimer's exist; those that do suffer similar pejorative framings and narrow foci. No studies that we are aware of examine the health beliefs of diagnosed individuals and support persons, or their attitudes about brain health. This research reports perceptions of "aging well" held by those most intimately acquainted with Alzheimer's. Design and Methods: Diagnosed individuals and their support persons (N = 85) were enrolled into 14 focus groups. Grounded theory methods were used to collect, code, and analyze textual interview data into overarching themes. Results: Respondents found physical and mental health, social activity, independence, and happiness integral to aging well. An acceptance of various limitations was also deemed crucial. Support persons placed more emphasis on lifestyle factors and memory loss as potential obstacles. Diagnosed respondents defined memory loss in less medicalized terms, whereas support persons labeled it Alzheimer's and negatively characterized those affected. Both groups warned against discussing "prevention" of dementia: Diagnosed individuals noted the implication of "aging poorly" and support persons cautioned against blaming diagnosed individuals. Implications: These findings can be used to encourage positive health beliefs and behaviors tailored to the needs of diagnosed seniors and their families, to help practitioners and researchers identify and become sensitive to differences between and among older adults, and to further advance the utility of narrative accounts for informing health interventions and education efforts.

Article:

Existing research demonstrates that perceptions of brain health, particularly of Alzheimer's disease (AD), are negative (Mackenzie, 2006); involve significant misconceptions about the cause, treatment options, and experiences of AD (Adamson, 2001); and vary by racial/ethnic, socioeconomic, and gender status (Connell, Roberts, & McLaughlin, 2007; Purandare, Luthra, Swarbrick, & Burns, 2007). The health beliefs of individuals living with the condition and those supporting them remain missing from the literature. The present research aimed to address this gap by using narrative accounts of AD to understand the attitudes about brain health of those most intimately affected.

Rowe and Kahn's (1987, 1998) theory of "successful aging" includes being free of disease, socially engaged, and cognitively intact. This definition threatens to characterize individuals with dementia as having aged unsuccessfully. The model has also been critiqued for being too narrow because so few older adults meet the criteria (10% according to von Faber et al., 2001), and it assumes a universal path of aging (Holstein, 2006). Others highlight the importance of incorporating the perspectives of older adults into the conceptualization of aging well (Phelan, Anderson, LaCroix, & Larson, 2004; Tate, Lah, & Cuddy, 2003). Von Faber and colleagues argue that the concept of successful aging has multiple interpretations: as a state of being that can be objectively measured and as a process of continuous adaptation. The latter argues that defining successful aging as a quantifiable state of being is too restrictive and does not resonate with the everyday experiences of the vast majority of older adults.

Background

AD is a major public health concern. The majority of the estimated 5.2 million Americans with AD are cared for in their own homes; there are almost 10 million persons providing care to individuals with AD or other dementias in the United States alone (Alzheimer's Association, 2008). The number of informal support persons is projected to quadruple over the next 50 years (Brookmeyer & Gray, 2000) with the aging of the baby boomers and subsequent increase of individuals with AD. In the majority of cases, family support comes from spouses, who are often frail themselves and at increased risk for medical illness and physical injury (Alzheimer's Association, 2008; Aneshensel, Pearlin, Mullan, & Zarit, 1995).

The recent advent of diagnosing AD in its earliest stages, and preclinically in the case of mild cognitive impairment (MCI), identifies a growing population of affected individuals capable of expressing their experiences. Nonetheless, much of the existing biomedical research, public opinion, and attention remains situated within a discourse of loss assuming that everyday interaction is no longer of interest or relevant to those diagnosed and that providing care is primarily a “burden” (Beard & Fox, 2008). Arguably, reports that more than two thirds of the population would rather die than live with any form of cognitive impairment (a number that is significantly higher than that for either physical illness or pain; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991) can be at least partially attributed to the negative perceptions, or so-called stigma, associated with AD. Despite the impressive movement to counter such depictions (Beard & Fox, 2008; Cheston & Bender, 1999; Harris & Sterin, 1999; Kitwood & Bredin, 1992; Sabat & Harré, 1992), this pejorative view exacerbates the existing schism between diagnosed individuals and their informal support persons. These factors have obvious potential ramifications on health-promoting and health-maintaining behaviors because individuals may avoid or postpone medical evaluation for memory loss or behavioral/psychological concerns to avoid the negativity associated with the condition, may delay interventions for treatable ailments, and may subsequently fail to have their needs met. Further, it reinforces notions of AD as a “death sentence” despite noteworthy reports of positive and spiritual experiences of Alzheimer's and caregiving (Beard, 2004; Belgrave, Allen-Kelsey, Smith, & Flores, 2004; MacKinlay, 2006; Paun, 2004; Roff et al., 2004; Stuckey, 2001).

The health beliefs of those diagnosed with or providing support to someone with AD have been largely neglected in the social and behavioral science literature. Although attempts to disseminate subjective experiences of dementia have surged in recent years (e.g., Beard, 2004; Mills, 1997; Usita, Hyman, & Herman, 1998; Vittoria, 1998), autobiographical accounts of memory loss are often dismissed as anecdotal. Despite the vast literature studying the negative consequences of being a support person for someone with AD, the modifiable psychosocial risk factors, the utilization of respite services, and the health beliefs, including positive experiences, of those most directly affected remain relatively unexplored. A comparison of how diagnosed individuals and those who support them define memory loss and aging well and perceive the potential for preventing further decline, in particular, remains absent in the social and behavioral science literature. This article will explore the attitudes of the two groups most directly affected by AD to address this empirical gap. These data on “aging well” will also be contrasted with past research on successful aging from samples of persons not affected by Alzheimer's to elucidate any significant differences in attitudes. Our data support the notion of aging well as a process of adaptation according to qualitative subjective experiences of older adults living with AD and their support persons.

Methods

Data

The data for this article come from the Healthy Brain Initiative Focus Group Study, a Prevention Research Centers (PRC) Healthy Aging Research Network collaboration among nine PRCs throughout the United States. Data reported here are from 85 individuals who participated in 14 focus groups conducted by four of the nine sites involved in the larger research project: the University of Illinois at Chicago (UIC; 9 focus groups, 35 respondents; the number of participants per group is considerably lower than average due to increased rates of “no-shows” associated with populations affected by AD and all groups were scheduled with six to eight persons confirmed), the University of Pittsburgh (2 focus groups, 30 respondents), West Virginia University (2 focus

groups, 15 respondents), and the University of Colorado at Denver (1 focus group, 5 respondents). Participants included both those diagnosed with early-stage AD or MCI ($n = 17$ from UIC; it is important to note that although MCI does not necessarily lead to AD, many scientists believe that memory loss exists on a continuum and MCI is commonly diagnosed in specialty clinics as a potential precursor to AD) and family support persons ($n = 68$ from all sites). As part of the Brain Health Initiative, a focus group design was employed (see J. N. Laditka et al., 2009, for a detailed description of the project's methods and management).

Focus group facilitators used a common interview guide developed collaboratively across sites. Questions used for the present analysis include the following: (a) Please tell us about someone who you think is aging well; (b) Is it important to you to “stay sharp?” If so, why? What do you call “staying sharp?”? What words do you use to describe seniors who do not stay sharp, when they have a loss of memory or thinking ability?; and (c) Is there anything we can do to keep our brains healthy and sharp? If so, what? In addition, each group was asked to describe what it was like to be diagnosed with AD/MCI or provide support to someone diagnosed. All focus groups were audiotaped and then sent to the lead center (University of South Carolina) for verbatim transcription. The transcribed interviews yielded more than 450 pages of textual data (for more information on the processes of data collection or transcription, please see S. B. Laditka et al., 2009).

Each respondent completed a survey questionnaire to collect demographic data. Table 1 describes the demographic characteristics of the complete sample analyzed in this article. The majority of respondents (77%) were older than 56 years of age. Although the sample was predominantly Caucasian (73%), African American (20%) and Hispanic (5%) groups were also represented. Most of the participants were married (72%), had at least some college (84%), had annual incomes above \$20,000 (94%), and lived in urban areas (85%). Respondents volunteered for the study based on either having “a family member with Alzheimer's or dementia” or having “minor memory loss or dementia of the Alzheimer's type.” Diagnosed respondents, including those with MCI, reported minor memory loss and were attending AD support groups. There were no statistically significant differences between the two populations (see Table 2 for the disaggregated data on diagnosed individuals).

Table 1.
Participants' Demographic Characteristics by Each Site

Variable	Total ($N = 85$)		WV ($n = 14$)		Pittsburgh ($n = 30$)		UIC ($n = 35$)		CO ($n = 6$)	
	<i>F</i>	%	<i>F</i>	%	<i>F</i>	%	<i>F</i>	%	<i>F</i>	%
Age (years)										
35–44	5	5.88	4	28.57	1	3.33	—	—	—	—
45–55	15	17.65	5	35.71	4	13.33	4	11.43	2	33.33
56–64	18	21.18	2	14.29	14	46.67	—	—	2	33.33
65–74	25	29.41	2	14.29	7	23.33	14	40.00	2	33.33
75–84	19	22.35	1	7.14	4	13.33	14	40.00	—	—
85+	3	3.53	—	—	—	—	3	8.57	—	—
Race/ethnicity										
African American	17	20.00	—	—	2	6.67	15	42.86	—	—
White, not Hispanic	62	72.94	12	85.71	27	90.00	20	57.14	3	50.00
Hispanic or Latina/Latino	4	4.71	1	7.14	—	—	—	—	3	50.00
Other	2	2.35	1	7.14	1	3.33	—	—	—	—
Marital status										
Single	5	5.88	1	7.14	2	6.67	1	2.86	1	16.67
Married	61	71.76	12	85.71	23	76.67	22	62.86	4	66.67
Separated	1	1.18	—	—	1	3.33	—	—	—	—
Divorced	8	9.41	—	—	2	6.67	5	14.29	1	16.67
Widowed	10	11.76	1	7.14	2	6.67	7	20.00	—	—
Highest education completed										
<High school	1	1.18	—	—	—	—	1	2.86	—	—
High school graduate or GED	12	14.12	1	7.14	6	20.00	4	11.43	1	16.67

Variable	Total (N = 85)		WV (n = 14)		Pittsburgh (n = 30)		UIC (n = 35)		CO (n = 6)	
	F	%	F	%	F	%	F	%	F	%
Some college, technical or vocational	24	28.24	6	42.86	6	20.00	11	31.43	1	16.67
≥College degree	48	56.47	7	50.00	18	60.00	19	54.29	4	66.67
Annual income (\$)										
<20,000	5	6.02	—	—	2	6.67	1	2.94	2	33.33
20,000–39,999	26	31.33	4	30.77	8	26.67	12	35.29	2	33.33
40,000–64,999	18	21.69	—	—	8	26.67	8	23.53	2	33.33
65,000–99,999	14	16.87	4	30.77	5	16.67	5	14.71	—	—
>100,000	18	21.69	5	38.46	5	16.67	8	23.53	—	—
Residence										
Rural	6	15.00	—	—	—	—	1	2.86	5	100
Urban	34	85.00	—	—	—	—	34	97.14	—	—

- Note: WV = West Virginia University; CO = University of Colorado at Denver; UIC = University of Illinois at Chicago; GED = General Educational Development.

Table 2: Demographic Characteristics of Diagnosed Individuals

Variable	UIC (n = 17)	
	F	%
Age (years)		
35–44		
45–55		
56–64		
65–74	9	52.94
75–84	7	41.18
85+	1	5.88
Race/ethnicity		
African American	7	41.18
White, not Hispanic	10	58.82
Hispanic or Latina/Latino		
Other		
Marital status		
Single		
Married	9	52.94
Separated		
Divorced	2	11.76
Widowed	6	35.29
Highest education completed		
<High school		
High school graduate or GED	3	17.65
Some college, technical or vocational	7	41.18
≥College degree	7	41.18
Annual income (\$)		
<20,000		
20,000–39,999	8	50.00
40,000–64,999	5	31.25

Variable	UIC (<i>n</i> = 17)	
	<i>F</i>	%
65,000–99,999		
>100,000	3	18.75
Residence		
Rural	10	58.82
Urban	7	41.18

- *Note:* UIC = University of Illinois at Chicago; GED = General Educational Development.

Analytical Strategy

Analysis utilized the constant comparative method and coding paradigm of grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1997). The aim was to uncover common themes “grounded” in the data itself. Analysis began with the lead center compiling a master codebook for the larger project. The four sites each consolidated their thematic categories into a condensed codebook and then the first author conducted “open coding” (Strauss & Corbin, 1997), using line-by-line identification of the dimensions and properties of emerging themes. Themes were consolidated to identify “core variables” present in the majority (i.e., more than 60%) of interviews until saturation resulted when no new themes emerged. Thematic categories were then relayed back to the coauthors (who facilitated the groups) to ensure consensus. All data were also entered into ATLAS.ti to validate the reliability of those themes identified manually by verifying that the most common themes were consistent across analytical formats.

Results

Three overarching themes emerged, including important differences concerning definitions of aging well and memory loss as well as preventing (further) cognitive decline.

Perceptions of Aging Well

Those who were diagnosed with either early AD or MCI defined *aging well* as being physically and mentally healthy, socially active, independent, accepting of changes (or decline), and happy. The following quotes depict the most common aspects of aging well, physical and mental health:

My minister [has aged well]. He's real sharp mentally. And physically. He plays tennis. ... [Successful aging is] having excellent judgment and being able to decipher changes and insight into how you were doing and rationalization.[Aging well] means good health, and especially mental health. To be healthy and to be physically fit ... to be active.

The closely related role of social support and engagement was also highlighted:

Work as long as you can ... and then get involved in a good organization [like a choir, senior center, or the Red Hat Society©].I think that that [aging well] comes if you're happy and you have people around you who you like. I mean that's part of ... social support.

The majority of respondents expressed a relationship between independence, or not having to depend on others, and their own aging well:

Loss of function ... would change one's life ... in a negative way. The loss of independence for me is very important ... that would be major. And having to depend on someone else. I'm just not able to do that.

Successful, at say 80, [means] I'd be able to function and care for myself ... stand on my own.

Participants felt that adaptation to their various limitations, including memory loss, was necessary for aging well:

[K]nowing how to adjust to ... limitation and whatever disease process may be going on, living it healthy, or there's a healthy way of living with disease and then an unhealthy way. [I]t's a matter of adaptation. You know that it's happening and then you try to figure out how to make it as graceful as possible.

Being able to accept that your body is changing and that physically you might not be able to do some of the things that you've done before. ... I think we should all realize that we're going to age ... knowing that you have a disease that some people feel is really awful, but other people like me, feel it's something that is, in some ways, part of me.

Similarly, diagnosed respondents felt that aging well involved appreciating life and continuing to have fun:

Being able to do what you want to do. Have fun. In that case, we are aging well.

And enjoying life. ... [If you] have some limitation or something you can't do anymore, or won't do, or shouldn't do and, and, and, but there's so much more that you can, have an appreciation for living.

This desire to accept limitations and appreciate life demonstrates that individuals wish to remain living rather than focus on what has been lost, or the so-called stigma often accompanying dementia.

Participants also cited various activities, such as reading, learning, and eating well, as important components of aging well. A few participants noted that cognitive health, referred to as "being intelligent/smart," "having knowledge," or "staying sharp," was also crucial to aging well, although no one specifically referenced memory loss or dementia as precluding aging well. "Feeling good" was also deemed more crucial to definitions of aging well than "looking good" or having a perfect memory.

Respondents providing informal support to diagnosed individuals reported views that were both similar to and different from those described previously. Similarly, their definitions of aging well included physical and mental health: [I have] a friend of the family and I think she's aging well, even though she has some mobility problems. She has a lot of energy, is very alert. She still has a broad range of interests and is just interested in a lot of things; mental and physical interests.

Someone who is not ill, meaning they're physically well ... one person that I know has worked up until I'd say, he's about 87 and worked and loved doing it. That's the thing, if you work and you love to do it ... [and] if they engage in some sort of intellectual stimulation.

Support persons believed that successful aging involved being engaged socially and maintaining independence:

I have a church member that's 102 this month ... and she's still active. She still cooks. ... She's been regular in her church attendance. And she plays bridge and beats me and she's sharp, still in her bridge. So mentally, she's still alert ... she gets along very well. Very involved.

They can live independently without a lot of assistance. They pay their bills and they can differentiate between things that matter and things that don't matter.

Aging well also entailed having a positive attitude, stimulating the brain, and accepting the changes/decline associated with growing older. Unlike their diagnosed counterparts, however, changes in memory were not specifically mentioned:

I have an uncle who's 101. He's very, he has a wonderful disposition. He's always upbeat. ... He never seems to be upset about anything. Of course, when you're 101, I guess you don't have too much to be upset about. But he's always positive. He thinks, his thinking is always positive.

My dad was 96 when he passed away and ... he aged well, I thought. One thing that I was always impressed with was he was always curious, always willing to learn something. He had a big family and whatever anybody was doing, he was curious.

My feeling is if you don't use it [your brain], you're going to lose it. So, the more you use your brain, the less you will lose of it.

Differences between the two groups included the role of lifestyle factors and the threat memory loss posed to aging well. Support persons placed more emphasis on diet, exercise, and other health behaviors than did diagnosed individuals:

She just retired and I think she has the potential of having a good active life. She's doing everything right health wise, diet wise. She's a stickler for, you know, the rules. And she gets the, I think the biggest thing is the exercise that she gets.

Well, she takes good care of herself ... like her eating habits and she's never stressed out.

Explicit reports that memory loss jeopardizes a person's ability to age well were mentioned by support persons:

Of course, what we're seeing is the change from aging well to not aging well, which is hard for us to see in our spouse, somebody who presumably was very educated, very skilled, very successful, very knowledgeable, and so on, is rapidly losing those abilities. Now, is that aging well? I think the answer is no. It is not something that Alzheimer folks seem to be able to handle well.

I have several friends that are aging well but then, I mean, they're of different age groups 80, 77, 68 and they're all aging well. I mean, they don't show any signs of memory loss. They're aging very well.

Diagnosed individuals and support persons agreed that being physically and mentally healthy, socially active, independent, accepting of changes (or decline), and happy were integral to aging well. This supports other research suggesting that factors such as having a positive attitude, not worrying, and accepting one's limitations or aging itself are crucial components of aging well cited by older adults (S. B. Laditka et al., 2009; Tate et al., 2003). In addition, support persons placed more emphasis on lifestyle factors and memory loss as potential barriers to aging well. "Being alert" and "having a good memory" were cited as important components of aging well in other studies with older adults not diagnosed (S. B. Laditka et al., 2009).

Defining Memory Loss/Brain Health

Both groups of respondents felt that staying sharp was an integral aspect of brain health and noted that the vast majority of people they knew were similarly concerned. Not surprisingly, staying sharp was important because it promoted aging well in the manner and for the reasons described previously. The most common explanation for wishing to stay sharp was to prevent the loss of independence believed to accompany significant memory loss. Diagnosed individuals, in particular, worried about how loss of function would change their lives, whereas family members providing support noted the lack of independence in their loved ones and subsequently in their own lives.

Support persons were particularly concerned about potential difficulties with their own memory or physical health: [S]ometimes I feel like I got that tremor in this hand and I said, "Lord is this what's happening to me now?" You know, that, just a little tremor. Is that telling me something? Alzheimer's?

Well, I'm concerned about forgetting myself. Seniors taking care of seniors. My own forgetting and then, you know, trying to take care of somebody else and having some kind of an ailment or—I'm concerned that if I have it, I won't have nobody to take care of me. ... You worry about seniors taking care of seniors.

These respondents expressed concern that their memory loss, or poor health, would negatively affect the person they provided care for:

Well, you know, the one thing you worry about, too, in my situation anyway, if something happens to me, what on earth would happen to him? That, you know, because—you know, there's nobody—well his family, they're all older, you know, and he has a son, but his son is kind of incapacitated, so, there's nobody but me, so that's why I wonder. And, you know, you feel a little guilty, but then you [think], of making some arrangements now because at the rate I'm going I could leave any day.

Given that support persons witness Alzheimer's so intimately, it is perhaps not surprising that they fear the condition, including the possibility of burdening others or not having someone to care for them should they become affected.

Although both groups were generally concerned about memory loss, diagnosed persons were more likely to talk about (minimal) memory loss as a normal accompaniment to aging rather than something that, in and of itself, signaled dementia or an inability to stay sharp. Support persons, in contrast, typically perceived memory loss as symptomatic of larger progressive problems. Consequently, diagnosed individuals defined memory loss in largely folk terms, such as senility, having a “senior moment,” or “the computer sometimes slows down ... the retrieval is slower.” Support persons, in contrast, were more likely to define memory loss as Alzheimer's or dementia. Adjectives such as “demanding,” “defenseless,” and “needy” were used to characterize persons with memory loss, whereas those without memory loss were described as “blessed”; “lucky”; “fortunate”; “vibrant”; “growing old gracefully”; “mentally, physically, and spiritually sound”; and, of course, aging well. Support persons generally held views about brain health that were significantly more negative and medicalized than those held by diagnosed individuals themselves.

Preventing (Further) Decline

The majority of respondents spoke about the importance of being proactive in promoting their brain health. They noted the potential benefits of eating well, being physically/mentally active, and staying socially involved for their brains. As reported elsewhere (S. B. Laditka et al, 2009), both groups talked about concrete strategies to minimize (further) decline as well as the positive impact of healthy lifestyles on the brain:

If you sit at home and don't use your brain then you [forget]. So I think it's real important to become, stay involved with younger people cause it seems that affects your brain also. ... I think it's important to maintain good health. ... You have to maintain your health so you've got good blood to go to the brain. ... If you don't take care of the diabetes and so forth it affects the brain.

Fish is supposed to be good [for your brain] and so I think it's part of general health.

I think that the main thing is staying active. To me, exercise the brain whenever you get the opportunity because I think that the brain goes idle real quick if you don't use it.

Well, if I think of the alternative, which would be a couch potato just watching mindless activity and not exercising. I mean, first I would get depressed. So, if I get depressed, then you know, that's not good for my brain. So, it's all inter-connected.

Exercise, thinking, vitamin E, crossword puzzles, Omega 3. ... I know prayer helps ... and keeping your brain active.

As depicted previously, both diagnosed respondents and support persons felt that there were things to be done that could specifically help improve brain health but not necessarily prevent (further) decline. Diagnosed individuals, however, suggested that health promotion approaches only help so much and certainly do not prevent cognitive decline:

I think we can make efforts in that direction [staying sharp as you age]. I do think behaviors, lifestyle has something to do with it, but not everything.

They cautioned, however, that discussion of brain health under the rubric of prevention suggests that people with AD have “aged badly.” Support persons also noted that cognitive decline could occur even if someone did “everything right” in taking care of themselves due to the fact that “some brains are just stronger”: It [prevention] sounds very nice, reasonable, [but] it's not a guarantee. There's no guarantee that if you do this, you will avoid that.

I think [the possibility of prevention] is true, but I don't think there's anyone that had a healthier lifestyle than my husband and he has early-onset Alzheimer's.

When probed about the ability to prevent AD, in particular, respondents in both groups were adamant that this was not possible:

I just don't believe there's anything we can do. I think it's such a croc when they say, “Oh, do crossword puzzles.” ... I just think when it comes to the brain, unless they come up with a drug or some kind of intervention, I really don't see eating fish or exercising or any of that is gonna keep Alzheimer's and dementias [away]. ... I don't think there's anything we can do right now that if we have that process in us that's gonna stop it.

I think until we really know what the physiologic precursors to Alzheimer's disease are that we are not in a position to prevent the onset of Alzheimer's ... right now working crossword puzzles will not keep me from, will not postpone Alzheimer's disease. [Prevention strategies] may not be something that's going to help you in the long run, I mean once you have brain disintegration nothing out there is going to help you.

Support persons also talked about the role of genetics or a family history of AD more often than their diagnosed counterparts. In particular, adult children were aware of and worried about their own increased risk of developing AD:

My mother is one of 10 siblings. All but one of them were diagnosed with Alzheimer's. ... So, my concern is ‘Am I really doomed here?’ You know, I do worry about that.

Despite acknowledging the importance of lifestyle and other modifiable risk factors affecting brain health, such as cognitive stimulation, which was found to be a common health-promoting belief within a general population of aging Americans (S. B. Laditka et al., 2009), both groups questioned the utility of discussing “prevention” in reference to Alzheimer's. Arguably, due to the perceived negative connotation associated with AD, respondents wanted to remove any personal accountability for memory loss, and diagnosed individuals were particularly concerned about the conflation of brain health and aging well (i.e., that having Alzheimer's means a failure to age well). Likewise, support persons were particularly quick to note that diagnosed individuals were not to be blamed for their memory loss.

Discussion

Our data clearly demonstrate that the individuals most intimately affected by Alzheimer's hold different views about brain health than members of society without personal experience. For example, S. B. Laditka and colleagues (2009) report that cognitive health (i.e., having a good memory and being “cognitively alert”) was perceived as essential to aging well, which diagnosed individuals in the present study refute. Further, memory loss was considered more important to aging well than physical impairment to those respondents because it was seen as a threat to one's independence. The present study, in contrast, suggests that part of aging well is to cope well with the loss of cognitive function, which supports research demonstrating that success should be measured by how well various losses are integrated into one's life (von Faber et al., 2001). Whereas S. B. Laditka and

colleagues found notable variation in perceptions of aging well by race/ethnicity, our findings demonstrate differences by exposure to Alzheimer's. These data highlight the importance of taking the views and values of those affected into consideration in the planning and education efforts for promoting and maintaining the brain health of society at large.

Diagnosed individuals and support persons themselves held differing views on definitions of memory loss and what constituted aging well. Both groups defined aging well as being physically, mentally, and socially active; independent; and happy. As reported elsewhere (von Faber et al., 2001), respondents also defined aging well as being accepting of physical decline. The diagnosed respondents in our study suggest that adapting to cognitive decline is also essential to aging well. These participants placed emphasis on feeling good rather than looking good physically or having a perfect memory. Support persons highlighted the importance of having a positive attitude and doing mental exercises for aging well. In general, support persons stressed the role of lifestyle factors and expressed views suggesting that memory loss typically precluded aging well, the latter of which was not reported by their diagnosed counterparts.

Both groups felt that staying sharp was key to brain health, namely, for maintaining their independence. Whereas those diagnosed were concerned with how memory loss changes their social status, support persons talked about the logistical difficulties Alzheimer's poses. Support persons were also worried about their own health, including memory loss as well as physical ailments, and how problems in these areas would affect their diagnosed family member. These fears could begin to explain why these support persons were more severe in their attitudes than might be expected. Diagnosed individuals generally defined memory loss in less medicalized terms, or as "normal" accompaniments to aging, whereas support persons used negative adjectives to describe "Alzheimer's" or "dementia." Here, diagnosed individuals provide support for the discontinuation of medicalizing cognitive change suggested by leading neurologists (Whitehouse & George, 2008), which could help reverse some of the negative assumptions about memory loss and those with it.

Beliefs regarding the potential for preventing (further) cognitive decline also vary between those diagnosed and support persons. Strategies to prevent memory loss or promote brain health were reported by both groups, and the majority of respondents were aware of the potential benefits of good nutrition, mental/physical exercise, and social engagement. Both groups acknowledged, however, that someone could get Alzheimer's even if they "did everything right," that is, they demonstrated a lay understanding of brain plasticity and the hereditary aspects of the condition. We argue that some of their reticence to discuss AD in terms of prevention may stem from the social trend in the Western world to conflate aging well with brain health (itself now conceptualized on a spectrum with dementia). To avoid a "malignant social psychology" (Kitwood & Bredin, 1992) or equating personhood with cognitive function (Post, 1995; Whitehouse & George, 2008), it is crucial to understand the perceptions of those most intimately affected by the condition when planning and delivering services as well as educating the public about Alzheimer's.

Our data corroborate that far more older adults perceive themselves as aging well when it is defined as a subjective process of accepting and adjusting to various age-related limitations than as a quantifiable state of being (von Faber et al., 2001). Accordingly, discourse about "success" in aging "is unrealistic and ignores the value of adaptation to limitations and losses that are inherent to aging" (von Faber et al., 2001, p. 2700) because the aging process is personal, social, and context bound. Since a society's value system predetermines how successful aging is defined (Tate et al., 2003), beliefs about aging well, including the importance of mental acuity, are ultimately cultural artifacts. We suggest that discourse on successful aging threatens to reinforce the notion that Alzheimer's is an end to life for both diagnosed individuals and those who provide support to them, which our data strongly dispute. Because conceptions of Alzheimer's are socially and culturally constructed, more research should incorporate the perspectives of those most intimately affected by the condition. To understand various differences according to race, class, gender, and cognitive status, in particular, more qualitative studies with older adults should be conducted.

The findings from this study can also have a broad public health impact by encouraging health-promoting and self-efficacious interventions that are tailored to the needs of diagnosed seniors and their families, by helping practitioners and researchers identify and become sensitive to the diversity of older adults, and by further advancing the utility of narrative accounts for informing health interventions and education efforts. In particular, understanding how the two groups under study differ from each other and the general population as regards defining aging well and memory loss and beliefs regarding preventing cognitive decline is vital to person-centered care. For example, support persons' concerns about their own (physical or brain) health might be a topic for targeted mental health interventions. Further, these data can also encourage health-promoting and health-maintaining behaviors, such as self-care practices, for diagnosed individuals and support persons alike, and inform lifestyle interventions to increase or maintain brain health and quality of life.

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