



Stigma in dementia: It's time to talk about it

There's much you can do to address stigmatizing attitudes, beliefs, and behaviors

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Dementia is a family of disorders characterized by a decline in multiple cognitive abilities that significantly interferes with an individual's functioning. An estimated 50 million people are living with a dementia worldwide.¹ Alzheimer's disease (AD) is the leading cause of dementia, accounting for approximately two-thirds of dementia cases.¹ These numbers are expected to increase dramatically in the upcoming decades.

Sociologist Erving Goffman defined stigma as "an attribute, behaviour, or reputation which is socially discrediting in a particular way: it causes an individual to be mentally classified by others in an undesirable, rejected stereotype rather than in an accepted, normal one."² Goffman² defined 3 broad categories of stigma: public, self, and courtesy (*Table 1, page 18*).

Considerable evidence shows that the combined impact of having dementia and the negative response to the diagnosis significantly undermines an individual's psychosocial well-being and quality of life.³ Persons with dementia (PwD) commonly report a loss of identity and self-worth, and stigma appears to deepen this distress.³ Stigma also negatively affects individuals associated with PwD, including family members and professionals. In this article, we discuss the impact of dementia-related stigma, and steps you can take to address it, including implementing

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Health care providers can sometimes contribute to the perpetuation of stigma



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Table 1

3 types of stigma

Public stigma	The attitudes and beliefs of the general public toward persons with mental health challenges or their family members
Self- or personal stigma	When people internalize these public attitudes and experience negative consequences as a result
Courtesy stigma or stigma by association	The emotions and behaviors toward family and professionals involved with the person with dementia

Source: Reference 2

person-centered clinical practices, promoting anti-stigma messaging campaigns, and advocating for public policy action to improve the lives of PwD and their families.

A pervasive problem

Although the Alzheimer's Society International and the World Health Organization acknowledge that stigma has a central role in defining the experience of AD, how stigma may present, how clinicians and researchers can recognize and measure stigma, and how to best combat it have been understudied.³⁻⁵ A recent systematic literature review examined worldwide evidence on dementia-related stigma over the past decade.⁶ Hermann et al⁶ found that health care providers and the general public may hold stigmatizing attitudes toward PwD, and that stigma may be particularly harsh among racial and ethnic minorities, although the literature is scarce in this area. Cultural factors may also worsen stigma, and stigma may be associated with reduced awareness of dementia services and reduced help-seeking among minority groups.^{7,8} Studies show that stigmatizing attitudes are more pronounced in people with limited knowledge of dementia, in those with little contact with PwD, in men, in younger individuals, and in the context of cultural interpretations of dementia.⁶ Health care providers can also sometimes contribute to the perpetuation of stigma.⁶

In terms of standardized scales or instruments for evaluating dementia-related stigma, there is no uniformly accepted "gold standard" measure, which makes it difficult to compare studies.⁶ In order to effectively study efforts to reduce stigma, researchers

need to identify and establish a consensus on rating scales for evaluating stigma among PwD, caregivers, and the general public. Three instruments that may be used for this purpose are the Family Stigma in Alzheimer's Disease Scale (FS-ADS),⁹ the Stigma Scale for Chronic Illness (SSCI),¹⁰ and the Perceptions Regarding Investigational Screening for Memory in Primary Care (PRISM-PC).¹¹

The detrimental effects of stigma

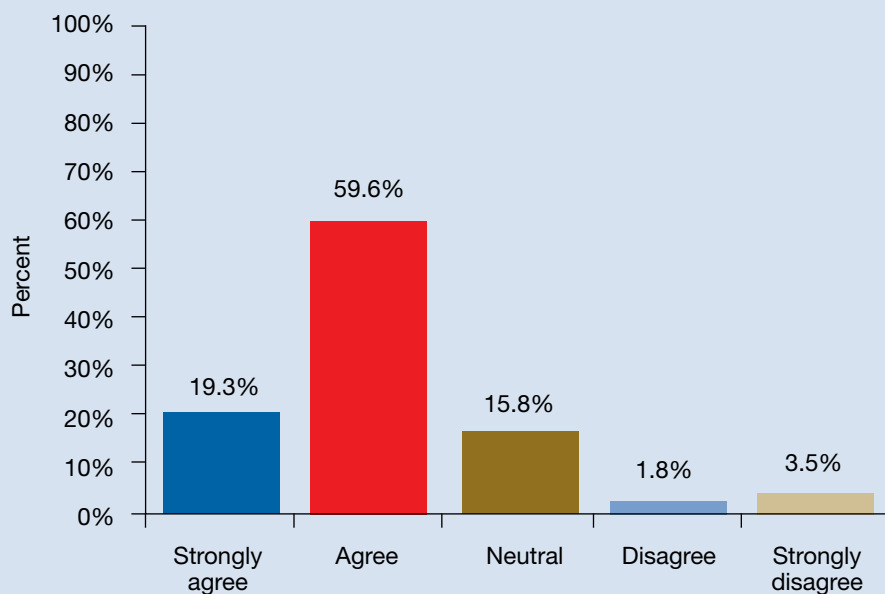
Burgener et al¹² reported that personal stigma impacted functioning and quality of life in PwD. Higher levels of stigma were associated with higher anxiety, depression, and behavioral symptoms and lower self-esteem, social support, participation in activities, personal control, and physical health.¹² Personal characteristics that may affect stigma include gender, location (rural vs urban), ethnicity, education level, and living arrangements (alone vs with family).¹²

In a subset of PwD with early-stage memory loss (n = 22), Burgener and Buckwalter¹³ found that 42% of participants were reluctant to reveal their diagnosis to others, with some fearing they would no longer be allowed to live alone and would be "sent to a facility." In addition, 46% indicated they did not want "to be talked about like they were not there." More than 50% of participants reported changes in their social network after receiving the diagnosis, including reducing activities and limiting types of contacts (ie, telephone only) or interacting only when "people come to me." Participants were most comfortable with good friends "who understand" and persons within their faith communities. When asked about how

Figure 1

Online survey results: People with Dementia blog, Statement 1

“After visiting the People with Dementia blog, I have a better understanding of the changes that may occur as a result of cognitive impairment/dementia.”



they were treated by family members, >50% of participants described being treated differently, including loss of financial independence, more limited contact, and being “treated like a baby” by their children, who in general were uncomfortable talking about the diagnosis.

In a recent study by Harper et al,¹⁴ stigma was prevalent in the experience of PwD. One participant disclosed:

“I think there is [are] people I know who don’t ask me to go places or do things ‘cause I have a dementia...I think lots of people don’t know what dementia is and I think it scares them ‘cause they think of it as crazy. It hurts...”

Another participant said:

“I have had friends for over thirty years. They have turned their backs on me...we used to go for walks and they would phone me and go for coffee. Now I don’t hear from any of them...those aren’t true friends...true friends will stand behind you, not in front of you. That’s why I am not happy.”

Overall, quantitative and qualitative findings indicate multiple, detrimental effects of personal stigma on PwD. These effects fit well with measures of self-stigma, including social rejection (eg, being treated differently, participating in fewer activities, and having fewer friends), internalized shame (eg, being treated like a child, having fewer responsibilities, others acting as if dementia is “contagious”), and social isolation (eg, being less outgoing, feeling more comfortable in small groups, having limited social contacts).¹⁵

Receiving a diagnosis of dementia presents patients and their families with psychological and social challenges.¹⁶ Many of these challenges are the consequence of stigma. A broad range of efforts are underway worldwide to reduce dementia-related stigma. These efforts include programs to promote public awareness and education, campaigns to develop inclusive social policies, and skills-based training initiatives to promote delivery of patient-centered care by clinicians and educators.^{3,17,18} Many of these efforts share a common focus on

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Detrimental effects of personal stigma on persons with dementia include social rejection, internalized shame, and social isolation

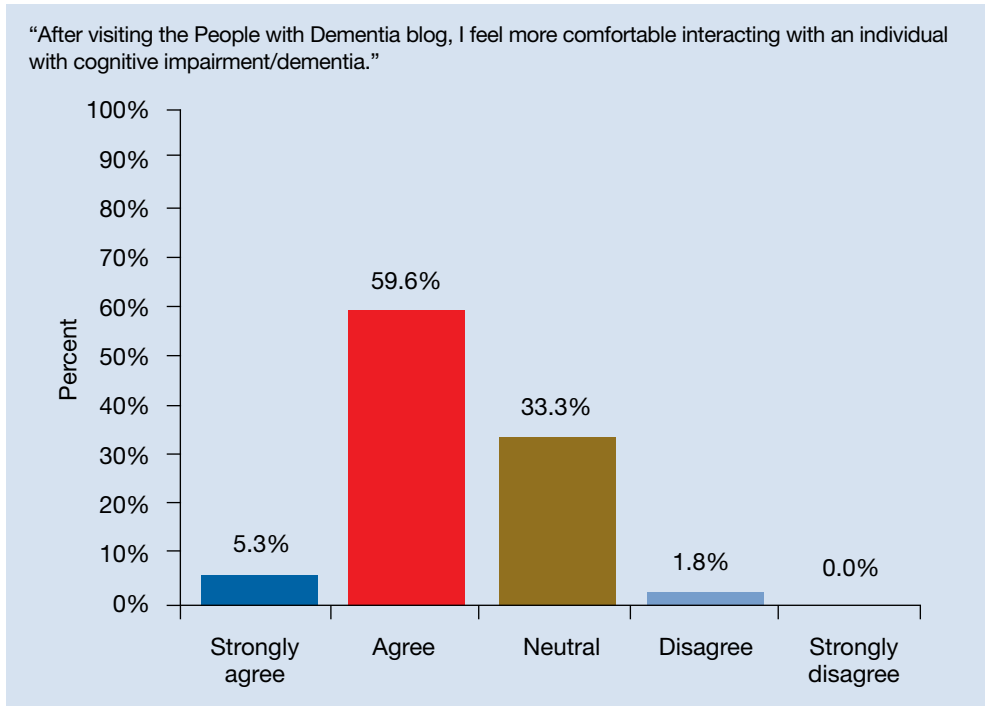


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Direct discussion that encourages the use of effective and sensitive communication can help limit passing on stigmatizing beliefs

Figure 2
Online survey results: People with Dementia blog, Statement 2



promoting the “dignity” and “personhood” of PwD in order to disrupt stereotypes or fixed, oversimplified beliefs associated with dementia.

Implementing person-centered clinical care

In clinical practice, direct discussion that encourages reflection and the use of effective and sensitive communication can help to limit passing on stigmatizing beliefs and to reduce negative stereotypes associated with the disease. Health care communications that call attention to stereotypes may allow PwD to identify stereotypes as well as inaccuracies in those stereotypes. Interventions that validate the value of diversity can help PwD accept the ways in which they may not conform to social norms. This could include language such as “There is no one way to have Alzheimer’s disease. A person’s experience can differ from what others might experience or expect, and that’s okay.” In addition, the use of language that is accurate, respectful, inclusive, and empowering can support

PwD and their caregivers.^{19,20} For example, referring to PwD as “individuals living with dementia” rather than “those who are demented” conveys respect and appreciation for personhood. Other clinicians have provided additional practical suggestions.²¹

Anti-stigma messaging campaigns

The mass media is a common source of stereotypes about AD and other dementias. They typically present a “worst-case” scenario that promotes ageism, gerontophobia, and negative emotions, which may worsen stigma and discrimination towards PwD and the people who care for them. However, public messaging campaigns are emerging to counter negative messages and stereotypes in the mass media. Projects such as Typical Day, People with Dementia, and other online anti-stigma messaging campaigns allow a broad audience to gain a more nuanced understanding of the lives of PwD and their caregivers. These projects are rich resources that offer education and personal stories that can counter common stereotypes about dementia.

Table 2

Approaches to address dementia-related stigma

Approaches	Action steps	Examples
Deliver person-centered clinical care	<p>Patient-level activities to address harmful beliefs and misunderstandings of an individual patient and his/her caregivers</p> <p>Strategies include personalizing and validating experiences by asking about beliefs, worries, experiences related to Alzheimer's disease dementia; using language that fosters dignity</p>	<p>Challenge stereotypes through direct discussion</p> <p>Correct misinformation and adjust expectations to be more accurate; refer to allied health professions for psychological therapy and social support, as appropriate</p> <p>Use person-centered terms that are accurate, respectful, inclusive, and empowering phrases; leave room for individual experience by avoiding "absolutes"</p>
Educate and build community	<p>Share resources to demystify what it means to live with dementia</p> <p>Support educational programs and community outreach that highlights needs and strengths of dementia community</p>	<p>Typical Day (www.mytypicalday.org)</p> <p>People of Dementia (www.peopleofdementia.com)</p>
Advocate for public policy action	<p>Implement practice-level interventions to address societal and social inequities of patients with dementia and their caregivers</p> <p>Carry out activities to advance policy change that supports access to resources and person-centered language</p>	<p>Lobby the government for financial and legislative reform, such as improved access to services and programs for persons with dementia and their caregivers, and health care standards that support person-centered care</p> <p>Petition the public and private sector for direct health care resources and to help address societal inequities of caregivers of persons with dementia</p>

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Public messaging campaigns can counter negative messages and stereotypes about persons with dementia that are found in the mass media

Typical Day is a photography project developed and maintained by clinicians and researchers at the University of Pennsylvania. Since early 2017, the project has provided a forum for individuals with mild cognitive impairment or dementia to document their lives and show what it means to them to live with dementia. Participants in the project photo-document the people, places, and objects that define their daily lives. They review and explain these photos with researchers at Penn Memory Center, who help them tell their stories. The participants' stories, the photos they capture, and their portraits are available at www.mytypicalday.org.

People of Dementia. Storytelling is a powerful way to raise awareness of and reduce the stigma associated with dementia. For PwD, telling their stories can be an effective and therapeutic way to communicate their emotions and deliver an important

message. In the blog People of Dementia (www.peopleofdementia.com),^{22,23} PwD highlight who they were before the disease and how things have changed, with family members highlighting the challenges of caring for a person with dementia.

The common thread is the enduring "person" behind the exterior that is obscured by dementia. By allowing the audience to form a connection with who the individual was prior to the disease, and understanding the changes that have come as a result of dementia to both PwD and their support network, readers gain a greater appreciation of those affected by dementia. Between May 1, 2017 and May 31, 2019, the blog had more than 3,860 visitors. In an accompanying online survey (N = 57), 79% of respondents agreed/strongly agreed that after visiting the People of Dementia blog, they had a better understanding of the changes that occur as a result of cognitive impairment/dementia (*Figure 1, page 19*). Almost



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Clinicians can support public policy through education and advocacy both in the delivery of care and as spokespersons

Related Resources

- Khoury R, Shach R, Nair A, et al. Can lifestyle modifications delay or prevent Alzheimer's disease? *Current Psychiatry*. 2019;18(1):29-36,38.
- Burke AD, Burke WJ. Antipsychotics for patients with dementia: The road less traveled. *Current Psychiatry*. 2018;17(10):26-32,35-37.

two-thirds of respondents (65%) agreed/strongly agreed that they felt more comfortable interacting with PwD (*Figure 2, page 20*). Additionally, 60% of respondents agreed/strongly agreed that they were more encouraged to work with PwD, and 90% agreed/strongly agreed that they had a greater appreciation of the challenges of being a caregiver for PwD. Overall, these findings suggest that the People of Dementia blog is useful for engaging the public and promoting a better understanding of dementia.

Work for policy changes

Clinicians can support public policy through education and advocacy both in the delivery of care and as spokespersons and stakeholders in their local communities. Public policies are important for providing access to medical and social services to meet the needs of PwD and their caregivers. The absence—real or perceived—of sufficient resources exacerbates dementia-related stigma. In addition to facilitating access to resources, national dementia strategies or legal frameworks, such as the National Alzheimer's Project Act in the United States, include policy initiatives

to identify and promote communication approaches that are effective and sensitive with respect to people living with dementia and their caregivers.

State and local legislators and patient advocates are leading policy efforts to reduce dementia-related stigma. For example, Colorado recently changed statutory references from being specific to diseases that cause dementia to the broader, more inclusive phrase “dementia diseases and related disabilities.”¹⁸ In addition to making funds available to support caregiving services for PwD, this legislative change added training for first responders to better meet the needs of missing PwD, and shifted the terminology used to diagnose and communicate about diseases causing dementia. The shift in language added new terminology that was chosen for being more person-centered to replace prior references to “senior senility,” “senility,” and other terms with pejorative meanings.

In Canada, a National Dementia Strategy will commit the Canadian government to action with definitive timelines, targets, reporting structures, and measurable outcomes.²⁴

Table 2 (page 21) summarizes approaches to addressing dementia-related stigma.

An open discussion

Larger studies and testing of diverse approaches are needed to better understand whether intergenerational initiatives or other approaches can genuinely modify stigmatizing attitudes in various dementia populations, especially considering language, health literacy, cultural preferences,

Bottom Line

Stigma has multiple, broad-reaching, and negative effects on persons with dementia and their families. In clinical practice, direct discussion that encourages reflection and the use of effective and sensitive communication can help to limit passing on stigmatizing beliefs and to reduce negative stereotypes associated with the disease. Anti-stigma messaging campaigns and public policy changes also can be used to address societal and social inequities of patients with dementia and their caregivers.

and other needs. The identified effects on physical and mental health, quality of life, self-esteem, and behavioral symptoms further support the extensive, negative effects of self-stigma on PwD, and emphasize the need to develop and test interventions to ameliorate these effects.

We presented at a Stigma Symposium at the 2018 Gerontological Society of America Annual Scientific Meeting in Boston, Massachusetts.²⁵ Attendees of this conference shared our concerns about the detrimental effects of stigma. The main question we were asked was “What can we do to reduce stigma?” Perhaps the most immediate response is that in order to move the stigma dial, clinicians need to recognize that stigma has multiple, broad-reaching, and negative effects on PwD and their families.⁶ Bringing the discussion into the open and targeting stigma at multiple levels needs to be addressed by clinicians, researchers, administrators, and society at large.

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Targeting stigma at multiple levels needs to be addressed by clinicians, researchers, administrators, and society at large