

A Systematic Review of Dementia-related Stigma Research: Can We Move the Stigma Dial?

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Stigma negatively affects individuals with cognitive impairment and dementia. This literature review examined the past decade (January 2004 to December 2015) of world-wide research on dementia-related stigma. Using standard systematic review methodology, original research reports were identified and assessed for inclusion based on defined criteria. Initial database searches yielded 516 articles. After removing duplicates and articles that did not fit inclusion criteria (419), 97 articles were reviewed, yielding a final total of 51 publications, mainly originating in the United States and Europe. Studies were assessed for date, geographic region, sample description, methodology, and key findings. Reports were evaluated on 1) how stigmatizing attitudes may present in various subgroups, including in racial or ethnic minorities; 2) stigma assessment tools; and 3) prospective or experimental approaches to assess or manage stigma. Stigma impedes help-seeking and treatment, and occurs broadly and world wide. Stigmatizing attitudes appear worse among those with limited disease knowledge, those with little contact with people with dementia, in men, in younger individuals, and in the context of ethnicity and culture. In some cases, healthcare providers may have stigmatizing attitudes. In research studies, there does not appear to be consensus on how to best evaluate stigma, and there are few evidence-based stigma reduction approaches. Given the projected increase in persons with dementia globally, there is a critical need for research that better identifies and measures stigma and tests new approaches that can reduce stigmatizing attitudes. (Am J Geriatr Psychiatry 2018; 26:316–331)

Key Words: Stigma, discrimination, Alzheimer disease, dementia, aging, attitude

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Article Highlights

- Across the globe, dementia stigma is pervasive and affects quality of life of people with dementia and their families.
- Evidence-based approaches to reduce stigma are lacking.
- Research to identify approaches to reduce dementia stigma is needed.

Cognitive decline associated with Alzheimer disease (AD) and other dementias has become increasingly prevalent.¹ AD prevalence in the United States is approximately 11%,² with some minority subgroups such as African American and Hispanic individuals more likely to have AD compared with non-Hispanic white individuals.³⁻⁸ Absolute numbers and relative proportion of individuals with AD will increase dramatically in the upcoming decades. In 2015, it was estimated that 46.8 million people are living with AD world-wide, including 9.4 million in the Americas, 10.5 million in Europe, 4.0 million in Africa, and 22.9 million in Asia.⁹

The projected increase in AD and other dementias¹ brings concerns about the ability of formal and informal care systems to provide appropriate support for those affected by cognitive decline. Some individuals with dementia experience stigma, a set of negative and often discriminatory beliefs that society may have about their neurological condition. Blay and Peluso¹⁰ found that over 40% of the lay public hold negative stereotypes and prejudice towards individuals with dementia; Piver et al.¹¹ found average dementia stigma scores in the “moderate” range in a survey of over 500 individuals in France. Notably, the study by Piver et al. found that perceived stigma was higher among health professionals (14% of the sample) than other groups.

Stigma is a potential barrier to care and support¹⁰⁻¹⁵ that can manifest in such behaviors as excluding the person with dementia in healthcare decisions¹⁶ or the shunning of family members of the person with dementia.¹⁷ Unfortunately, research that specifically targets dementia-related stigma is limited, and there are few evidence-based interventions that specifically target stigma.¹⁸ A recent book chapter on dementia stigma by Werner¹⁹ that reviewed English language articles from 1990 to 2012 found that existing research has mostly described the subjective experience of stigma. That review also described the consequences of stigma and posited conceptual components, noting

that the vast majority (nearly 75%) of published reports do not include a theoretical model of stigma.

The public health impact of reducing dementia stigma could potentially lead to better care access, greater support engagement, and ultimately a higher quality of life for people with dementia and their families. This systematic literature review examines world-wide evidence over the past decade on dementia-related stigma. As this review was intended as a preparatory step in designing and testing stigma reduction interventions, the focus is on 1) how stigmatizing attitudes may present in various subgroups, including in racial or ethnic minorities, 2) stigma assessment tools, and 3) prospective or experimental approaches to assess or manage stigma. Because this review was undertaken to help develop a U.S. dementia-related stigma reduction initiative, stigma in American minorities was of particular interest. Lastly, gaps in knowledge guided a set of recommendations for future research.

METHODS

This literature search focused on peer-reviewed research reports on AD-related and dementia-related stigma. The CINAHL, Cochrane Media Library, PubMed, and PsycINFO databases were searched for original research studies and reviews published between January 2004 and December 2015. Search terms used were *Alzheimer disease*, *dementia*, *mild cognitive impairment*, and *cognitive decline*; with keyword 2: *stigma*; and keyword 3: *minority* or *minorities* or *discrimination management* or *reduction* or *social interaction* or *avoidance* or *pity*. Filters included program, curriculum, and intervention. A Web of Science search was done using *dementia*, *neurocognitive disorders*, *Alzheimer*, or *mild cognitive impairment* as first term and *stigma* as second term. Additional searches used *dementia* as first term, *stigma* as second term, and *fear*, *discriminat** or *minorit** as third term (* was used as wild

card, to include several forms of the term). Reports from all countries were included in this review.

Inclusion criteria required that the report have a specific and main focus on stigma or dementia attitudes, was published in a peer-reviewed journal between January 2004 and December 2015, was published in English, and specifically measured stigma using either quantitative or qualitative methods. Studies with only a peripheral mention or focus on stigma were excluded, as were reports that were available in non-peer-reviewed formats such as society meeting proceedings or reports, book chapters, or dissertations. The term *stigma* did not have to be used as long as the thematic focus was negative attitudes or other discriminatory thoughts/behaviors consistent with the definition of stigma. Abstracts were first screened by one reviewer (LH) for relevance by examining titles and abstracts. To minimize bias, one of the authors reviewed every abstract (LH) and the second reviewer was one of the key authors of the review (MS or EW). A third reviewer served as the tie-breaker /consensus

leader in the case of inclusion discrepancy and if there were differences of opinion regarding elements of data abstraction.

Data Collection and Synthesis

Studies were assessed for inclusion confirmation, date/geographic region, sample description, methodology, and key findings. Reports were evaluated on: 1) how stigmatizing attitudes may present in various subgroups, including in racial or ethnic minorities, 2) stigma assessment tools, and 3) prospective or experimental approaches to assess or manage stigma.

RESULTS

As noted in [Figure 1](#), database searches yielded 516 articles. After removing duplicates and articles that did not fit inclusion criteria (419), 97 articles were reviewed. Seven were not included because they were

FIGURE 1. Literature review flow diagram.

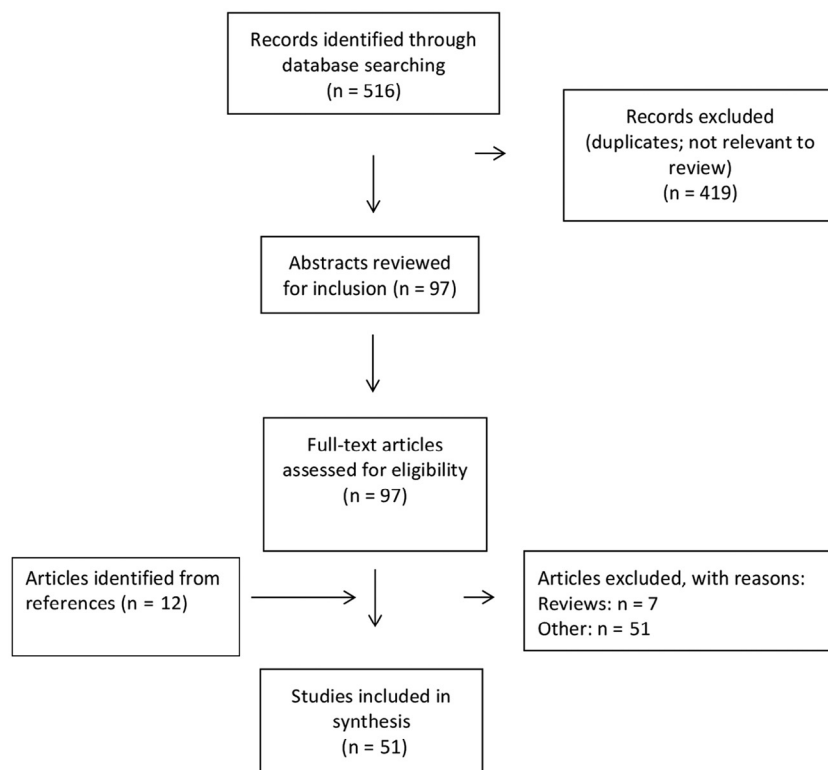
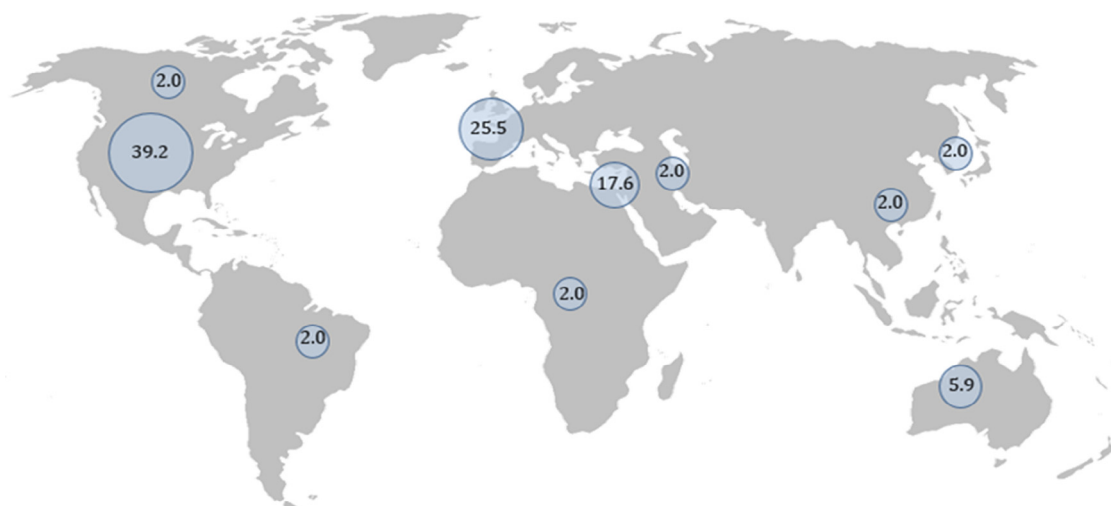


FIGURE 2. Geographical distribution of dementia stigma research (%).



literature reviews and 51 were not included because they lacked a stigma measurement. Twelve articles were identified from references and included in the review, leaving a final total of 51 articles.^{10-18,20-60} Some publications represented multiple analyses from a single database including reports by Burgener et al.^{12,13} and Phillipson et al.^{57,58} Werner et al. derived four publications from two data sets.^{18,51,52,55}

As noted in [Figure 2](#), most research has been conducted in the United States and Europe. This included 20 studies in the United States^{12,13,15,21,23,28,29,33-36,38,40,41,44,48,56,59,60} and 13 in Europe, including Belgium (N = 1),⁴⁶ Luxembourg (N = 1),³² Germany (N = 1),⁴⁹ France (N = 2),^{11,39} Ireland (N = 2),^{24,61} the Netherlands (N = 2),^{31,47} and the United Kingdom (N = 4).^{16,27,37,43} There were nine articles from Israel^{17,18,26,50-55} and three from Australia.^{42,57,58} Other countries with a single publication represented included Brazil,¹⁰ Iran,⁴⁵ Japan,¹⁴ Canada,²⁰ the Republic of Congo,³⁰ and China.²⁵ Studies that were conducted in, or included data from, more than a single country were included in the country of the lead publication author.

Stigmatizing Beliefs in Specific Subgroups

[Table 1](#) shows papers, grouped by major subgroup focus, that address stigmatizing beliefs in specific

populations such as healthcare professionals, the general public, people with cognitive impairment, and in families. Although some subgroups had findings indicating more negative attitudes towards AD, significant correlations were not consistent among these populations.

Healthcare Professionals

Vernooij-Dassen et al.⁴⁷ found that stigmatizing attitudes in health professionals can delay diagnosis and treatment. An Irish study found that stigma may lead general practitioners (GPs) to delay a dementia diagnosis.²⁴ Among GPs, perceptions of societal views of people with dementia centered on a lack of reciprocity related to how dementia can cause of failure to respond to human interaction, a lack of return on social investment, and societal burden.³² A French study found that health professionals expressed higher stigma compared with social workers, students, retired people, and the general public.¹¹ Another study found that the level of inclusion of the person with dementia by the GP in care planning varies widely from making all efforts to include patients to not including patients at all.¹⁶ Some GPs may be more concerned with loss of patient autonomy than other issues relevant to cognitive impairment.³⁹ Also, GPs may prefer referral to a specialist to confirm diagnosis, and if a GP was

Dementia-Related Stigma Research: A Review

TABLE 1. Studies that Described Stigmatizing Beliefs in Population Subgroups

Subgroup	Study	Sample	Study Design	Key Findings
Combined groups: HCP, and/or PWD, families	Brannelly ¹⁶	UK N = 15 HCP and N = 50 PWD and their families	Qualitative: observation of HCP/social workers interacting with PWD	Upholding the humanity and citizenship of PWD may help address stigma.
	Piver et al. ¹¹	France N = 517	Cross-sectional stigma assessment	Perceived stigma is more prevalent in HCPs than the general public; the main dimensions of stigma were shame and loss of self-esteem.
	Cahill et al. ²⁴	Ireland N = 300 GPs; N = 7 rural GPs in focus groups	Mixed-methods; cross-sectional quantitative (survey) and qualitative (focus group)	Stigma can prevent GPs from being more proactive in diagnosing dementia.
	Lahjibi-Paulet et al. ³⁹	France N = 25 GPs	Qualitative; focus groups	AD is a “disease of autonomy,” with more significance than cognitive decline. Family is an essential partner in care/coping. Stigma is a barrier to AD diagnosis.
HCPs only	Werner and Giveon ⁵³	Israel N = 501 family physicians	Cross-sectional; interview with structured questionnaire; use of 2 vignettes	Attributions of dangerousness, negative emotions and more severe stage of disease drive discriminatory behavior.
	Vernooij-Dassen et al. ⁴⁷	Europe N = 23 National experts in dementia and primary care from eight European countries	Qualitative; focus groups	Stigma affects professional’s willingness to provide an early diagnosis. Attitudes varied by country. Stigma may be lower in countries with strong advocacy
	Gove et al. ³²	UK N = 23 GPs	Cross-sectional semi-structured interviews	GP perception of structural discrimination and lay stigma, along with their own anxiety, may hinder timely diagnosis.
Lay Public and PWD	Devlin et al. ²⁷	Scotland/UK General public, 10 focus groups with up to 8 people; 6 interviews, age 50 +	Qualitative; focus groups; paired & one-on-one interviews	The extent of fear and stigma associated with dementia is described.
	Gerritsen et al. ³¹	Movies around the world (Released in or after 2000) identified in IMDB with N = 23	Qualitative; examined portrayal of dementia stigma in popular films	Dementia portrayal in movies may be misleading and can influence viewer attitudes.
	Dobbs et al. ²⁸	US N = 309 (153 residents, 80 staff, 76 family members at 6 residential/long term facilities)	Observations and semi-structured interviews over a 4-year period	Stigma presents in four themes: (a) ageism; (b) stigma as related to disease and illness; (c) sociocultural aspects; and (d) care setting related stigma.
	Aminzadeh et al. ²⁰	Canada N = 30 patients/family	Qualitative; longitudinal interviews; focus groups; field observation	Dementia diagnosis may invoke fear of stigma and devaluation of the person.
Lay Public	Werner ⁵¹	Israel N = 206 aged 49 +	Cross-sectional; questionnaire based on vignettes	PWD do not elicit strong social rejection, but rather increased social distancing with more severe dementia. Familiarity with the disease is associated with less discrimination.
	Phillipson et al. ⁵⁷	Australia N = 616 Australian aged 45–60 years	Cross-sectional; online questionnaire	Attitudes indicative of stigma included personal avoidance, fear of labeling, and fear of discrimination. Demographic factors (age, gender, education) were significantly associated with some attitudinal factors.
	Justiss et al. ³⁶	US & UK N = 245 aged 65 +	Cross-sectional; questionnaire	Dementia appears to carry greater stigma and greater impact on independence and suffering in the UK versus US.
	Werner ⁵²	Israel N = 206, aged 49 +	Cross-sectional; interviews using vignettes	Perceived competence of PWD affects behavioral discrimination and social isolation.

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TABLE 1. (continued)

Subgroup	Study	Sample	Study Design	Key Findings
	Robinson et al. ⁶²	Ireland N = 132 (86 in-patients aged 65 + ; 46 aged 65+)	Semi-structured interview; 3-item questionnaire at baseline and follow-up	Following presentation of positive and negative aspects of AD diagnosis and disclosure, participants' preferences changed as they think about consequences.
	Werner and Davidson ⁵⁰	Israel N = 150 aged 45 +	Cross-sectional; structured interview following vignettes	Most survey respondents expressed compassion and desire to help; Men and people with greater concern about developing AD had a stronger negative reaction.
	von dem Knesebeck et al. ⁴⁹	Germany—general population N = 1795; 18–79 years	Cross-sectional; survey	Most respondents expressed pro-social reactions, many expressed fear, few expressed anger. Respondents who knew a PWD had fewer negative reactions
Family and Caregivers	Faure-Delage et al. ³⁰	Africa N = 27 PWD; 31 relatives; 90 cognitively impaired; 92 relatives; 33 HCPs	Mixed-methods; Quantitative + qualitative	Relatives of people with cognitive impairments and with dementia had similar levels of perceived stigma. There is no significant relationship between stigma and socio-demographic variables.
	Navab et al. ⁴⁵	Iran N = 10 family caregivers	Cross-sectional; qualitative semi-structured interview	Shame related to unusual behaviors or speech and fear of judgement by others is associated with social isolation.
	Werner ⁵⁴	Israel N = 61 caregiver of PWD	Cross-sectional; telephone interview questionnaire	Nearly half of respondents would conceal AD diagnosis from family and friends and HCPs. Most would conceal it from neighbors.
	Werner et al. ¹⁷	Israel N = 10 family caregivers	Cross-sectional; in-depth, semi-structured interviews	Three main dimensions of family stigma are described: caregivers' stigma, lay public's stigma, and structural stigma.
Rural vs. Urban	Burgener et al. ¹²	US N = 50 PWD & N = 47 HCP	18-month longitudinal, quantitative + qualitative assessment	Perceived stigma remains stable during early stages of the disease. Persons living in urban areas have more stigmatizing attitudes compared to rural counterparts.
	Burgener et al. ¹³	US N = 50 PWD & N = 47 HCP	18-month longitudinal, quantitative and qualitative assessment	Perceived stigma was associated with quality of life outcomes
	Umegaki et al. ¹⁴	Japan—urban population N = 950 (40–64 years) and 3132 (65+)	Longitudinal population-based structured interviews repeated after 4 years	4 year follow-up shows better understanding of dementia but still approximately 40% of younger and 50% of older individuals think that dementia is a shameful condition.
International Immigrant sub-groups	Low et al. ⁴²	Australia N = 350 Italian, N = 414 Greek, N = 437 Chinese and N = 500 3rd generation Australians	Cross-sectional; telephone survey	Immigrants had more negative attitudes about PWD than 3rd generation Australians.
	La Fontaine et al. ³⁷	UK N = 49 South Asians living in UK, aged 17–60 years	Cross-sectional; focus-groups and questionnaires; use of vignettes	Perception that dementia may result from lack of effort by the person and lack of family care. There is a sense of stigma about mental illness.
	MacKenzie ⁴³	UK N = 11 Pakistani carers, N = 5 Indian carers, N = 4 Polish, N = 1 Ukrainian carer	Qualitative; interviews, field observation	Ways to manage stigma vary depending on country of origin; cultural differences need to be taken into account when developing support services.
U.S. Minorities	Jang et al. ³⁴	US N = 675 Korean American age 60 +	Cross-sectional; standardized questionnaires	Misconceptions are prevalent; feelings of shame about dementia are lower with higher levels of education and acculturation.
	Laditka et al. ³⁸	US N = 396 (AA, American Indians, Latino Americans, Vietnamese Americans, Non-Latino Whites)	Cross-sectional; focus groups	There are differences among ethnic groups. Across most groups, people used pejorative and stigmatizing terms like “senile” and “nuts.”
	Eng and Woo ²⁹	US N = 150 Chinese Americans	Cross-sectional; survey	Chinese American immigrants are likely to seek dementia services/resources.

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TABLE 1. (continued)

Subgroup	Study	Sample	Study Design	Key Findings
	Liu et al. ⁴¹	US N = 23 Caregivers of Chinese Americans, N = 9 and Vietnamese Americans	Cross-sectional; interviews	Stigma was prevalent and included both the stigma of chronic/severe mental illness and of aging.
	Lee et al. ⁴⁰	US N = 209; 40–79 year old Korean American immigrants	Cross-sectional; standardized instruments	First-generation Korean Americans may consider dementia a form insanity. AD knowledge is lacking.
	Sun et al. ⁶⁰	US N = 6 service providers, N = 6 family caregivers (Asian—Chinese Americans)	Cross-sectional; qualitative, focus groups	Barriers to care include lack of culturally appropriate programs, HCP lack of understanding of the Chinese language and culture, lack of knowledge about services, and stigma.
	Vickrey et al. ⁴⁸	US N = 47 caregivers African Americans, Chinese Americans, European Americans, Hispanic Americans	Cross-sectional; qualitative, focus groups	Minorities may have more concerns about discrimination compared to European Americans. Minorities more often identified spirituality/religion as a source of caregiver comfort compared to European Americans.
	Woo and Chung ⁵⁶	US N = 89 Chinese-Americans	Cross-sectional; survey	Stigma and lack of knowledge about dementia are prevalent among Chinese-Americans.
	Mahoney et al. ⁴⁴	US N = 22; minority family caregivers (African Americans, Latino and Chinese)	Meta-synthesis of three qualitative studies; focus groups for AA; interviews for Latinos and Chinese	Results showed clear cultural differences including a normalization of symptoms most prolonged among African Americans; stigmatization is the highest among Chinese Americans; fear that acculturation may affect caregiving is the biggest concern among Latinos.
	Dao and Woo ¹⁵	US N = 182 Chinese Americans	Cross-sectional; survey	Stigma and misconceptions about dementia are prevalent among Chinese Americans.

Notes: AA: African American; AD = Alzheimer disease; HCP: healthcare professionals; GP: general practitioner; PWD: people with dementia.

providing a diagnosis, there was a preference for family to be present, as well as to “soften” the diagnosis by describing it euphemistically.³⁹ In line with the notion that knowing a person with a stigmatizing condition can reduce stigma, an Israeli study of family physicians found those with relatives having AD were less likely to stigmatize their patients.⁵³

Lay Public

General Public

Fear of negative emotional and behavioral response can prevent people with memory concerns from seeking care, and may differ among various groups. In a study that compared American versus British elders on dementia screening acceptance and perceived stigma, British elders had higher scores on perceived stigma, perceived loss of independence, and higher perceived suffering than Americans.³⁶ An Israeli

study⁵⁰ found that poor understanding of AD and negative reactions can add to stigma burden, particularly among men and those who were fearful that they could themselves develop dementia. An Irish study suggested that some patients who want to know their diagnosis may reconsider after further focusing on potential consequences of disclosure.⁶²

Similar to findings among clinicians, lay people having a personal relationship with a person with dementia may be less likely to have stigmatizing attitudes. An Australian study found mostly pro-social attitudes,⁵⁷ which were more pronounced in those having familiarity with a person with dementia. Those with negative reactions towards people with dementia were less likely to want to care for them. A French study found lowest stigma among older people,¹¹ possibly because older people know someone with dementia their own age. A German mail survey found that almost half of the general public would feel uncomfortable with a person with dementia, and one in four expressed that they

would react with fear.⁴⁹ An Israeli study of Jewish adults^{51,52} found that pro-social feeling decreased dementia discrimination, and that disease familiarity was associated with less discrimination. In contrast, increased discrimination occurred with more severe AD. Lay perceptions of activity competence in people with AD also found lower competence perception associated with behavioral discrimination.⁵²

Individuals with Cognitive Impairment

Discrepancies between perceived normal aging versus dementia may affect help-seeking in individuals who have cognitive impairment.²⁷ There may be a lay perception that if dementia is untreatable, seeking diagnosis will not help. Perpetuation of stigma may be further amplified by the popular media. In a review of popular films, researchers found cinema to contain misleading and stigmatizing depictions or messages about dementia.³¹ Emotional and behavioral reactions after diagnosis can perpetuate stigma, with responses ranging from ignoring symptoms to covering up behaviors.²⁰ Education on coping with dementia may be helpful, however, and family involvement may help reduce stigma in long-term care settings.²⁸

Families and Caregivers

In addition to delaying diagnosis and treatment, and contributing to social isolation, stress, and low self-esteem for individuals with dementia, stigma has serious consequences for families and caregivers. Caregivers' life histories may impact care. Among Eastern European caregivers, early-life trauma of war and persecution could impact willingness to utilize services.⁴³ Some South Asians may see dementia as a curse or punishment from God.⁴³ This may impede disclosure and help-seeking.

Family stigma appears to be common, and is a major concern of caregivers, with sub-themes of shame and fear of judgment.^{17,45} An Israeli study found that caregivers experience minimal stigma for themselves, but recognized stigma for the person they cared for.⁵⁴ With respect to stigma in developing countries, Faure-Delage et al.³⁰ addressed the growing concern of dementia stigma in the Republic of Congo and how dementia may impact families. Although mainstream medicine is widely accepted and often preferred,

traditional healing is also used, thus sociocultural factors and health literacy should be considered when developing public health efforts in that country.

Urban and Rural Populations

Residential location may impact stigma perception. Burgener et al.^{12,13} examined stigma in urban versus rural Americans and found that people with dementia living in urban areas were more susceptible to perceived stigma and internalized shame compared with rural counterparts. Authors attributed this to a greater sense of community in rural settings. A Japanese study¹⁴ found that urban dwellers may see AD as a shameful condition, although that perception improved over the four years of the study, possibly due to national awareness efforts.

U.S. Minorities

Stigma may be particularly harsh among ethnic or immigrant minorities. The literature found 10 studies focused on American minorities, including three that compared and contrasted multiple minority groups^{38,44,48} and seven that focused on Asian American populations.^{15,29,34,40,41,56,60} No studies focused solely on Latinos or African American populations. In U.S. minorities, stigma is associated with lack of knowledge about AD.³⁸ Cultural factors may also worsen stigma. In a study of African American, Latino, and Chinese American caregivers, there were both overlapping and differing concerns.⁴⁴ Outreach, education, and clinician services were all deemed important, but some groups considered early signs of dementia as part of normal aging.⁴⁴

A study of Korean Americans found shame in being diagnosed with AD.³⁴ Among Chinese Americans, the harmful effects of shame and discrimination on people with dementia and their families have been documented.^{41,56} Another study of Chinese American individuals²⁹ noted an inverse relationship between dementia services awareness and stigma. Although stigma clearly leads to service barriers among Chinese Americans,⁶⁰ there are demographic factors within these subgroups that may also impact stigma. Among Chinese American men and women, women were less likely to stigmatize, perhaps because women are more likely to be caregivers.¹⁵

Focus groups with African American, Chinese American, white American, and Hispanic American populations suggested that minority or immigrant groups, in contrast with white Americans, felt that a dementia diagnosis should not be shared with others outside the immediate family.⁴⁸ Nevertheless, there are also beneficial attributes involved with being a member of an American minority subgroup as it relates to social support. Minority families may be more likely to provide home care, and this can decrease as family cultural identification lessens over time. One study found that Latino individuals expressed concerns that diminished home care for relatives is a sign of acculturation.⁴⁸

Cultural or language barriers between clinicians and minority patients may impede help-seeking and treatment. One study found that African American caregivers felt that physicians did not respect their concerns.⁴⁸ Interestingly, in a study of African American, Chinese American, and Latino caregivers, lack of disease recognition was deemed more of a concern than language or culture barriers.⁴⁴

International Studies Focused on Minority Subgroups

Although AD stigma among racial and ethnic minorities may be greater than among the majority population in a given country, findings from U.S. minority groups likely cannot be generalized to minorities in other countries given that stigma may differ depending on information access and mainstream cultural beliefs. For example, Italian, Greek, and Chinese im-

migrants living in Australia had more stigmatizing attitudes compared with other Australians.⁴² A study of British South Asians found that they tend to consider dementia as partly due to the persons themselves not trying hard enough and to a lack of family support.³⁷

Stigma Assessment Tools

Table 2 shows standardized measures used to assess dementia stigma in included studies. There does not appear to be a consistent or common stigma evaluation tool used in research. There were two instruments used to assess stigma in caregivers,^{54,55} four in patients,^{12,13,21,23,59,63} and three in the general public.^{11,25,56} The Family Stigma in Alzheimer’s Disease Scale (FS-ADS)⁵⁵ was developed by Werner et al., and later used in modified form in other studies. Another tool was the Stigma Scale for Chronic Illness (SSCI).⁵⁹ The most commonly used validated tool was the Perceptions Regarding Investigational Screening for Memory in Primary Care (PRISM-PC), which examines dementia screening attitudes.^{21,22,36,57,58} Other scales included the Stigma Impact Scale (SIS), originally developed for HIV/AIDS and cancer,⁶¹ and the Stigma Experience Scale (SES), developed for mental health,⁶³ both were adapted by Burgener et al.^{12,13,23} One study¹¹ used the STIG-MA, which examines perceived stigma in AD based on the Explanatory Model Interview Catalogue.⁶⁴ Additional stigma scales, based on other scales/research were used in the reports by Werner,⁵⁴ Woo et al.,⁵⁶ and Cheng et al.²⁵ Additional questionnaires that included substantial assessment of stigma were used by a number of groups.^{10,14,15,24,34,40,42,49,62}

TABLE 2. Standardized Measures Used to Assess Dementia-Related Stigma

Measure	Publication	Target Population	Measure Description
Perceptions Regarding Investigational Screening for Memory in Primary Care (PRISM-PC)	Boustani et al. ²¹	People with dementia	10 questions related to stigma; validated
Stigma Impact Scale (SIS)	Fife and Wright ⁶¹	People with dementia	24 items adapted and validated for dementia by Burgener et al. ^{12,13,23}
Stigma Experience Scale (SES)	Wahl ⁶³	People with dementia	9 stigma items adapted and validated for dementia by Burgener et al. ^{12,13,23}
Stigma Scale for Chronic Illness (SSCI)	Rao et al. ⁵⁹	People with dementia	24 items; validated
Stigma by Association	Werner and Heinik ⁵⁴	Caregivers	17 items, based on other research
Family Stigma in Alzheimer’s Disease scale (FS-ADS)	Werner et al. ⁵⁵	Caregivers	62 items, validated
STIG-MA	Piver et al. ¹¹	General public	10 items, self-administered
Dementia Stigma Questionnaire	Woo and Chung ⁵⁶	General public	15 items, based on previous studies / self-administered
Stigma Questionnaire	Cheng et al. ²⁵	General public	11 items, based on other stigma scales

Another key gap in dementia stigma assessment is that no standardized stigma tool was used to assess change in stigma over time in a pre–post fashion. Umegaki et al.¹⁴ re-administered a structured questionnaire on dementia perceptions in a Japanese sample 4 years after the original survey was conducted, finding improvement over time. There was no specific stigma intervention in that report, however, and the study design did not permit conclusions regarding the effects of education or awareness efforts.

Prospective Experimental Approaches and Interventions that Addressed Stigma

As noted in Table 3, there were 9 studies with 10 publications that included an experimental intervention or exposure intended to prospectively assess or intervene in dementia-related stigma.^{10,25,26,33,35,46,51–53,58} Only the study by Harris and Caporella³³ tested a real-world interaction between individuals with dementia and those without dementia (college students), whereas the other studies assessed study participant beliefs in response to an experimental exposure to hypothetical scenarios or vignettes. Nearly half of experimental reports were conducted by a single group in Israel. Interventional/experimental study quality was evaluated with a modified version of the Methodological Quality Score described by Miller et al.⁶⁵ Study domains scored included group allocation (0–4 scale), quality control (0–1), participant contact method (0–1), statistical analysis (0–1) and site specifications (0–1). The possible score range was 0 to 8 with higher scores indicating greater study rigor. MQS scores were variable, but generally low with an average of 4. The studies by Cheng et al.²⁵ and Johnson et al.³⁵ scored highest on methodological quality with a score of 7.

Prospective Experimental Approaches

Phillipson et al.⁵⁸ exposed 619 Australian adults to a hypothetical scenario of early signs of dementia in themselves and a hypothetical scenario involving a friend or family member with early dementia. Four factors indicated dementia attitudes: 1) personal avoidance, 2) fear of labeling, 3) fear of discrimination, and 4) a “person-centered” factor that valued an individual for their knowledge, company, skills, or familiarity with traditions. Findings underscored the importance of formal providers, such as GPs, as a source of

help. The authors promoted the ability of GPs to create improve public confidence that individuals with dementia will not be discriminated against.

Johnson et al.³⁵ exposed 789 adults to one of nine vignettes depicting early dementia. Conditions were labeled using one of three options, “Alzheimer’s” versus “Traumatic Brain Injury” versus no label, as well as three prognostic options including improvement, static, and worsening. Four stigma outcomes were evaluated: discrimination, negative cognitive attributions, negative emotions, and social distance. The AD label in itself was not associated with more stigmatizing attitudes, although expecting symptoms to get worse (regardless of diagnosis) resulted in worse stigma. The authors suggested that stigma depends on expected prognosis and that stigma-reduction approaches need to incorporate the inherent variability in AD course and trajectory.

Cheng et al.²⁵ randomly assigned 494 adults to three groups differentiated by experimental conditions. Those who had a friend or relative with dementia, were younger, more educated, and those with a more positive expectation for individuals with dementia expressed less stigma. The authors noted the high levels of dementia stigma seen in some Asian communities as well as the positive effects of education, awareness, and contact with individuals with dementia in potentially reducing stigma.

Van Gorp et al.⁴⁶ conducted an online advertising campaign and survey testing whether defined counterframes (conceptions that contrast with dominant thinking or attitudes) could contribute to a more nuanced image of AD. Respondents were exposed to three different photos of people with AD and messages that reflected a dominant-concept negative view of AD (death and degeneration) versus counterframes that reflected more positive or human-centered messages. The more dramatic death and degeneration message seemed to get the most attention, but counter-framing concepts could be reasonable offsetting alternatives. Younger respondents, compared with older respondents, appeared to be most in favor of the idea of a campaign, possibly reflecting connection to the online aspect of this advertising campaign.

Two reports by Werner et al.,^{51,52} derived from the same study sample (206 Jewish Israeli adults), used experimental vignettes which varied by AD disease stage. Participant preferences for social distance were assessed within the context of an attributional model.

TABLE 3. Studies that Included an Experimental Approach Intended to Test or Intervene in Dementia-Related Stigma

Reference	Country	Design	Sample	Study Quality Rating ^a	Stigma Assessment	Key Finding
Werner ⁵¹	Israel	Cross-sectional assessment of emotional response after being presented with vignette of individual with dementia (earlier vs. later stage)	N = 206 Age: 49 + years	4	Likert-type scale assessed social distance; emotional reaction; perception of dangerousness	Person with AD does not elicit strong social rejection, but there is increased social distancing with more severe dementia. Familiarity with the disease led to decreased discrimination.
Werner ⁵²	Israel	Same study as Werner (11)	Same sample as Werner ¹¹	4	Likert-type scale assessed perceived competence as well as measures noted in Werner ¹¹	Perception of the competence of people with AD affects behavioral discrimination, with greater social isolation.
Werner and Giveon ⁵³	Israel	Cross-sectional	N = 501 Family physicians	4	Instrument developed by investigators to assess physician emotions and attributions towards person with AD	Physicians showed discriminatory behavior towards people with AD, especially in the dimension of avoidance and coercion. Attributions of dangerousness and negative emotions contribute to these behaviors. More discrimination associated with more severe stage AD.
Cohen et al. ²⁶	Israel	Cross sectional; four vignettes followed by questions	N = 170 Israeli Arabs, Age: 40-85 years	4	Likert-type scale of emotional reactions and perceptions of threat and dangerousness	Reactions overall more positive than negative; viewing illness as God's will may increase acceptance of people with AD.
Blay and Peluso ¹⁰	Brazil	Cross-sectional; vignette followed by in person structured questionnaire	N = 500, Age: 18-65 years	4	Assessed three dimensions of stigma: stereotypes, prejudice, and discrimination using yes/no categories	41.6% of the participants expressed stereotypes; 43.4% prejudice; and 35.5% discrimination; 14.8% expressed all three dimensions of stigma. Level of education affected presence of stigma.
Cheng et al. ²⁵	China (Hong Kong)	Cross-sectional assessment post-exposure to a theoretical vignette; 3 arms: A: questionnaire only B: vignettes then questionnaire C: same vignettes with info on diagnosis, then questionnaire	N = 494, Age: 18-92 years	7	11 items derived from other stigma scales	Stigma lower in those with relative or friend with dementia; in younger and more educated.
Van Gorp et al. ⁴⁶	Belgium	Cross-sectional on-line survey of individuals exposed to an advertising campaign and pictures/descriptions of individuals with AD	N = 1000	3	Ad campaign evaluation that included attitudes towards campaign and feelings towards the presented individuals with AD	While the dramatic death and degeneration message seemed to get the most attention, counter-framing that promoted body-mind unity and enjoyment of life's small pleasures could be reasonable alternatives. Young respondent appeared to be most in favor of the idea of a Web-based campaign.

(continued on next page)

TABLE 3. (continued)

Reference	Country	Design	Sample	Study Quality Rating ^a	Stigma Assessment	Key Finding
Harris and Caporella ³³	U.S.	8-week prospective intergenerational choir implementation with data collection at three time points	N = 26; 13 undergrad students, 6 people with early stage dementia, and 7 family members	3	Qualitative stigma evaluation	Intervention allowed people with dementia and their caregivers to lessen the feeling of isolation and stigmatization. Young people had less stigmatizing attitudes.
Johnson et al. ³⁵	U.S.	Cross-sectional; 3x3 randomization to one of 9 vignettes	N = 789 adults	7	Modified version of the FS-ADS	Perceived poor prognosis correlated with higher levels of perceived structural discrimination, higher pity, and greater social distance.
Phillipson et al. ⁵⁷	Australia	Cross-sectional; online survey with 2 scenarios: 1: Help-seeking for self 2: Help-seeking for significant other (proxy)	N = 611 Age: 45–60 years	3	31 item questionnaire consisting of PRISM-PC; Scale of Ageism; additional items ; Help Seeking Scale	Most participants indicated they would seek early help for themselves (82.2%) or for a proxy (78.7%). However, many would delay seeking help because of stigma.

Notes: AD: Alzheimer disease.

^aStudy quality as evaluated with a modified version of the Methodological Quality Score (MQS) described by Miller et al.⁶⁵ Study domains scored included group allocation (0–4 scale), quality control (0–1), participant contact method (0–1), statistical analysis (0–1), and site specifications (0–1). The possible score range was 0–8 with higher scores indicating greater study rigor.

Prosocial feelings decreased discrimination behavior, whereas rejection increased discrimination. The 2006 publication focused on perceived competence, which affected discrimination in the direction of lower perceived competency being related to worse stigma. In another study, Werner et al.⁵³ interviewed 501 family physicians using a computer-assisted telephone interview that featured hypothetical vignettes of individuals with different AD stages. Respondents were evaluated on discriminatory behavior, emotion reaction, attribution of responsibility, and perception of danger using a structured questionnaire building upon an expanded version of attribution theory. Two central emotions (anger-fear and pity) were found to affect discriminatory behavior.

Blay and Peluso¹⁰ conducted a study in which 500 Brazilian adults were exposed to a hypothetical vignette describing a person with early to intermediate AD. Stigma was assessed in three dimensions, including stereotypes, prejudice, and discrimination. All three dimensions of stigma were widely prevalent and more likely in those with lower education.

Cohen et al.²⁶ exposed 170 Israeli Arab adults to vignettes that depicted a person with dementia and

then assessed their emotional response. Four dimensions of emotional reaction were observed including anxiety, aggressiveness, prosocial reactions, and rejection. Levels of education, self-reported religious identification, and perceived dangerousness of the person with AD were the main factors associated with emotional reactions.

Intervention Approaches

Harris and Caporella³³ tested effects of an intergenerational choir composed of college students, individuals with dementia or mild cognitive impairment, and family members of those with dementia. Qualitative data were collected at three time points over an 8-week time period. Findings suggested decreased social isolation for the older participants. Younger participants had a decrease in negative attitudes, stigma, and social discomfort, and an increase in positive attitudes. The authors suggested that shared meaningful activity lessened social distance and negative attribution that people without AD may have towards those with AD.

DISCUSSION

This systematic review of a decade of published, original research on dementia-related stigma noted relatively few reports (N = 51), considering ongoing demographic trends. As this review was conducted in preparation for the development and testing of a future stigma reduction approach, a key thrust of the review was on 1) how stigmatizing attitudes may present in various subgroups, including in racial or ethnic minorities; 2) stigma assessment tools; and 3) prospective or experimental approaches to assess or manage stigma.

Although it is not surprising that most reports (nearly 70%) were from developed countries, it is striking that very few reports originated from the developing world. A recent publication⁶⁶ noted that in 2010, 58% of all people with dementia lived in countries with low or middle incomes, with this proportion anticipated to rise to 63% in 2030 and 71% in 2050, underscoring the need for new research on dementia stigma in the developing world. It must be noted that because one of the inclusion criteria in this review was that reports be published in English, a limitation of this report is that key findings published in other languages are not presented.

Stigmatizing attitudes about AD occur in both healthcare workers and in the lay public. Health providers, in particular primary care workers or GPs, are likely to be the first clinical personnel sought by individuals and families concerned about early signs of dementia. Thus the finding that some primary care clinicians or GPs have stigmatizing attitudes is a concern and research suggests that delay or avoidance of help-seeking occurs when patients and families feel that providers do not understand their needs or suffering. Providers with more stigmatizing attitudes may also fail to appropriately involve patients with dementia in healthcare decision-making. As with the general population, having a personal or family connection with a person with dementia can serve to reduce stigmatizing attitudes among healthcare providers.

Among the lay public, media portrayals of AD, which tend to present a “worst case” scenario, may worsen stigma. The literature suggests that stigmatizing attitudes are more pronounced in those with limited AD knowledge, in those with little contact with people with dementia, in men, in younger individuals, and in the context of cultural interpretations of dementia.

Although research on U.S. minorities is very limited, available evidence suggests that stigma burden is higher among some minority groups, and that people with dementia and their families may feel shame and embarrassment in their communities. On the positive side, some cultural groups have more family support for elders generally, including for those with cognitive impairment. Increased acculturation among U.S. immigrants may be a potential harbinger of less family support later in life for people with cognitive decline. Given the predicted increase in minority groups within the United States, research focused on Latinos and African Americans is greatly needed. Effective communication efforts to reduce stigma should target the population broadly as well as groups that may have higher levels of misconceptions.

With respect to stigma evaluation in research, there is no uniformly accepted “gold standard”. A number of studies did not use standardized tools, making across-study comparisons difficult. As with any research tool, information gathering needs must be balanced with minimizing assessment burden on survey respondents. Stigma scales used in included studies had anywhere between 9 and 61 items, reflecting differences in domains of assessment (family stigma, societal stigma, etc.) and target population. As noted by Werner,¹⁹ stigma assessment tools based upon a theoretical model may help to advance progress in understanding the formative factors underpinning stigma and factors that may help to diminish stigma.

In spite of the limited research, several conclusions and recommendations can be drawn regarding the existing evidence-base on possible approaches to reduce dementia stigma. First, the relative paucity of studies is quite striking, with only one study conducted using a pre–post design with actual individuals with dementia.³³ Although promising, the study by Harris and Caporella³³ enrolled only six individuals with dementia, and it is difficult to make generalizations to the wider population of people with dementia. None of the 10 studies that featured in experimental exposure specifically addressed minority groups.

Among the nine studies that used experimental vignettes, pictures, or hypothetical scenarios, it appears that providing education and support can reduce stigma. This is consistent with the World Alzheimer’s 2012 Report recommendations⁶⁷ and ongoing efforts by other Alzheimer’s Association groups.⁶⁸ Individuals have beliefs about dementia that are based

upon their personal experience with AD, beliefs about prognosis, as well as cultural and prevailing attitudes. Potentially promising approaches to address negative beliefs based upon existing evidence include making certain that the public understands the variability of outcomes with AD, conceptual “re-framing” to provide a more positive and nuanced understanding of AD, and involvement in shared meaningful activities that promote a focus on abilities and strengths outside of cognitive performance.

Directions for Future Research

Involving healthcare providers in anti-stigma efforts will be essential to future efforts. This is very much in line with recent efforts by healthcare professional and advocacy groups for appropriate and early disclosure of a dementia diagnosis to patients and families. In 2015, the American Academy of Neurology and the American Psychiatric Association formed a multidisciplinary workgroup to improve an existing dementia management quality measurement set and to identify opportunities to operationalize delivery of the best possible care for patients with dementia.⁶⁹ Importantly, a new quality measure was the recommendation that patients (and caregivers as appropriate) be provided with disclosure of the dementia diagnosis, for both the dementia syndrome and the most likely etiologic dementing disorder. The measure would be evaluated as a proportion/percentage of individuals with a dementia who have received appropriate diagnostic information. It can be expected that sites or practitioners with low rates of disclosure or those who wish to improve their quality rankings could benefit from training that specifically focuses on stigma. Training programs for general practitioners as well as geriatric specialties such as geriatric psychiatry or geriatric medicine needs to address stigma reduction in educational curricula in order to have lasting impact on our clinician workforce.

As this review emphasizes, increasing personal exposure to persons with dementia more broadly may be another way to improve stigma. Advocacy groups such as the Alzheimer’s Association already

make good use of personal outreach to individuals with cognitive decline (<http://www.alz.org/i-have-alz/programs-and-support.asp>). For example, in the Alzheimer’s Association’s Peer-to-Peer Program, individuals with early stage dementia are linked through a supervised telephone peer support program to share information and coping strategies, and provide emotional support. To maximize scale-up of such approaches, research is needed to develop and test whether personal exposure delivered via social media or other mass delivery platforms can effectively reduce stigma.

To test effects of stigma-reduction initiatives it will be important to validate tools in various subgroups, especially considering language, health literacy, and cultural preferences. A brief, evidence-based stigma measure that can evaluate the pre–post effect of a given intervention still needs to be developed. Finally, as there are no existing effective, data-driven approaches to combating dementia stigma, additional studies are needed to determine whether intergenerational initiatives or other approaches can genuinely modify attitudes and stigma.

In conclusion, the published literature on AD and dementia-related literature is limited, particularly with respect to evidence-based stigma reduction approaches. Future research needs to include larger and more representative samples, use validated stigma assessment tools, and build upon findings from the current evidence base.

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