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CHAPTER 40

The stigma of dementia

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List of abbreviations

AD Alzheimer's disease
ADRC Alzheimer's Disease Research Center
BPSDs behavioral and psychological symptoms of dementia
DAC dementia awareness campaign
GP general practitioner
MLT modified labeling theory

Mini-dictionary of terms

Courtesy stigma negative perceptions attributed to the caregivers of patients with stigmatized conditions, often leading to increased caregiver burden.

Behavioral and psychological symptoms of dementia Mood and personality changes presenting early in the progression of dementia. They are often misunderstood by friends and family and are difficult for caregivers to manage.

Instrumental activities of daily living (IADL) Activities requiring a higher level of cognitive functioning that are often necessary for fully independent living.

Promotora A community member trained by medical experts to disseminate health information in a culturally relevant manner.

Vascular dementia A form of dementia resulting from atherosclerotic blockages of vessels to the brain that result in cellular hypoxia.

Introduction

Rates of dementia continue to rise steadily, with recent estimates of Alzheimer's disease (AD) approaching 11% of the US population (Hebert, Weuve, Scherr, & Evans, 2013). By 2050 the incidence rate is expected to double, yielding a new case of AD every 33 s and up to a million cases per year (Alzheimer's Association, 2013). Globally, 46.8 million individuals were living with AD in 2015 (Prince, 2015). The financial cost of treating dementia in the US is substantial, with estimated healthcare costs in 2013 nearing \$203 billion excluding contributions by families, friends, and other unpaid caregivers (Alzheimer's Association, 2013). The burden of disease associated with dementia calls for a concerted effort by physicians, caregivers, and community members to review and improve upon the current management of and approach to treatment.

A topic gaining increasing attention in the context of dementia is stigma. Stigma is defined as a set of negative beliefs and attitudes, often discriminatory in nature, toward a specific group of individuals (Herrmann et al., 2018). While the literature on dementia-related stigma is limited, there is evidence to suggest that stigma impedes proper patient care, leading to poorer outcomes for individuals with dementia (Herrmann et al., 2018). Several misconceptions regarding dementia have led to negative associations with the condition. Many view memory loss as a natural part of aging, while others see dementia purely as a mental illness (Gove, Downs, Vernooij-Dassen, & Small, 2016). Researchers surveying population attitudes toward individuals with dementia found a substantial amount of associated negative emotion (Kessler & Schwender, 2012). In the UK and US, dementia is perceived as one of the most feared conditions, second only to cancer (Kessler & Schwender, 2012). Forced to imagine being diagnosed with dementia, many individuals over the age of 75 suggested that life would no longer be worth living (Lawton et al., 1999).

Dementia is impacting healthcare systems around the world, and negative attitudes toward the condition often manifest differently across cultural subgroups (Prince, 2015). In the West, a variety of cultural beliefs are contributing to the growing stigma (Herrmann et al., 2018). While the reasons may differ, the results are often similar, with increasing levels of social isolation and decreased patient access to resources. One study exploring dementia among minority communities in the UK revealed specific cultural-based stigma toward both patients and caregivers (Mackenzie, 2006). Caregivers of Eastern European descent were often noted as keeping their relative's dementia diagnosis private, believing that publicizing the diagnosis would lead to condemnation from community members (Mackenzie, 2006). Within this community, many caregivers emphasized the need to carry the burden of care alone, rarely expecting support from family or friends (Mackenzie, 2006). The tendency to socially isolate patients in an effort to avoid feeling stigmatized is believed to stem from a historical background of trauma and violence. Sharing such a diagnosis might evoke negative emotions in fellow community members and is thus generally avoided (Mackenzie, 2006). The result is social isolation for both patients and their caregivers, leading to diminished access to desperately needed resources (Mackenzie, 2006).

A similar situation is encountered in South Asian communities. Caregivers within this community allude to religious-based cultural beliefs that depict patients with dementia as possessed by evil spirits (Mackenzie, 2006). Often this negative perception regarding patients extends to their caregivers, separating whole families from the community. Faced with the fear of stigmatization, families often resort to hiding relatives with dementia, isolating the patient socially, which also has the effect of reducing access to resources. In the Chinese American population, exceedingly delayed diagnoses and treatment have been documented among community members (Woo, 2017a, 2017b). Individuals in this population are much less likely to utilize mental health services (Zheng, Chung, &

Woo, 2016). This is in part due to cultural barriers to access coupled with an underlying stigma toward mental illness within the community (Woo, 2017a, 2017b). Dementia is also a concern in the Latino community. Due to high rates of cardiovascular disease, Latinos are currently 1.5 times more likely to develop Alzheimer's or vascular dementia (Alzheimer's Association, 2017). They are currently the fastest-growing population in the US, with the potential for a substantial burden of disease (Alzheimer's Association, 2017). Both of these groups face limited access to educational resources and support due to language barriers that only further augment the prevailing cultural stigma.

Stigma is also a concern on a global scale, especially in developing countries with limited literacy levels (Faure-Delage et al., 2012). One study explored perceptions of dementia in the Republic of Congo, where no term for dementia exists within the population's language (Faure-Delage et al., 2012). Among community members, dementia was recognized based on specific symptom patterns (Faure-Delage et al., 2012). While primarily associated with old age and hardship, the use of witchcraft and evil intentions were attributed to those with the condition (Faure-Delage et al., 2012). While community members demonstrated understanding of the illness, being in close contact with such an individual was nonetheless considered to have negative repercussions (Faure-Delage et al., 2012). It is important to continue exploring the cultural perceptions surrounding dementia in order to work toward tangible solutions that address stigmatization within the community.

Location also can affect the amount of stigma that patients with dementia encounter. Patients in urban settings are often susceptible to a greater degree of stigma relative to those in more rural settings (Burgener et al., 2015). This may be due to a stronger sense of community among rural populations, which could mean increased support and acceptance (Burgener et al., 2015). Similarly, in assisted living facilities, increased stigmatization is directed at residents with dementia despite being among a community of peers (Burgener et al., 2015). Evidently, the fear of developing dementia encourages unaffected residents to disassociate themselves, alienating those with the condition (Burgener et al., 2015). These findings reveal that social isolation is often less dependent on the concentration of individuals in close proximity and more concerned with the support and openness afforded by surrounding community members.

Stigma: theory and development

Stigma has seen a significant transformation throughout the course of history, initially directed primarily at social deviants and only recently encompassing individuals with physical and mental illness (Bos et al., 2013). Today, stigma is recognized as a means of discrediting the identity of an individual or group within society, thereby creating widespread social disapproval (Bos, Pryor, Reeder, & Stutterheim, 2013). Stigma is furthermore dependent on social interaction, as no inherent stigma resides in an

individual outside of a social context (Bos et al., 2013). In order for stigma to develop, two criteria must be met—the recognition that a difference exists among a specific group and the devaluation of the group based on that difference (Dovidio, Major, & Crocker, 2000). In the context of medical illness, its stigma may have served an evolutionary purpose. Historically, separating and isolating sick individuals might have protected community members from contracting an illness (Kurzban and Leary, 2001). While this approach may appear reasonable in cases of communicable disease, its implicit manifestation within the context of behavioral disorders serves only to perpetuate disdain and mistreatment.

Stigmatizing beliefs are by no means limited to dementia and have long been recognized as an important factor in mental illness. Modified labeling theory (MLT), developed by Link, expanded on the idea that labeling an individual with a psychiatric diagnosis could negatively impact their health (Scheff, 1966). MLT built upon the work of Scheff, who noticed specific behavioral changes in individuals after receiving a psychiatric diagnosis (Scheff, 1966). Once labeled, responses from the surrounding community would reinforce an individual's behavior, eventually causing them to adopt the role of “mentally ill patient” (Scheff, 1966). Link expanded this theory, asserting that stigma develops both on an individual level, as an internal cognitive process, and through exposure to external behaviors in the environment (Link, Cullen, Struening, Shrout, & Dohrenwend, 1989). Through media and socialization with others, individuals form an idea of how mental illness is perceived in society. Once diagnosed, these same individuals begin to self-attribute these negative perceptions (Link et al., 1989). According to Link, both patients and society ultimately conclude that stigma devalues an individual's inherent worth and leads to inevitable discrimination (Link et al., 1989).

Beliefs regarding negative community attitudes are likely to lower a patient's self-esteem and negatively impact social interaction (Link et al., 1989). As a result, these individuals face a diminishing support network and decline in upward social mobility (Link et al., 1989). These findings are further supported by Scheff's “deference-emotion system,” which argues that individuals derive their self-esteem based on the amount of respect they perceive from their contemporaries (Mackenzie, 2006). Similarly, perceived condemnation by community members contributes to an individual's sense of shame and negative self-worth (Mackenzie, 2006). The theories proposed by Scheff and Link serve as important paradigms. They exemplify how stigma forms both in the community and on a personal level, providing valuable insight into the consequences stigma can have on patient wellness.

The development of stigma

Several symptoms inherent in the presentation of dementia may contribute to the stigma toward individuals with the condition. This bias often develops even before dementia is

formally diagnosed. It has been well documented that several behavioral and psychological symptoms of dementia (BPSDs) present early in the disease process, often before classic neurocognitive signs (Smith-Gamble et al., 2002). These personality changes often manifest as early as 2 years prior to a dementia diagnosis (Smith-Gamble et al., 2002). Changes to personality often vary but may include an increase in apathy, neuroticism, and eccentricity as well as a decrease in extroversion and agreeableness (Smith-Gamble et al., 2002). These early changes in personality are closely related to premorbid personality structure (Welleford, Harkins, & Taylor, 1995). One study investigating the relationship between dementia and psychiatric comorbidity found that patients with higher premorbid agreeableness presented with increased hallucinations and aggressiveness, while those with increased neuroticism were more likely to present with delusional ideation (Low, Brodaty, & Draper, 2002). Additionally, patients that exhibited increased premorbid dependence showed increased social withdrawal during their disease course (Gould and Hyer, 2004). Thus the progression of dementia leads to an exaggeration of the personality traits present before disease onset (Welleford et al., 1995). These personality changes are less associated with age and more closely related to a decrease in functional activity level (Gao, Dolan, Hall, & Hendrie, 2000). Because neuropsychiatric symptoms of dementia often develop insidiously, they can have a large impact on negative external biases directed toward patients. This is exacerbated by the fact that individuals without formal experience with dementia are often unaware of the behavioral manifestations of the disease (Hooker et al., 2002, pp. P453–P460).

One of the primary groups affected by BPSDs are family caregivers. Studies have demonstrated a strong correlation between caregiver distress and the severity of neuropsychiatric symptoms (Storti, Quintino, Silva, Kusumota, & Marquesm, 2016). Interestingly, increases in caregiver stress directly parallel worsening neuropsychiatric symptoms, while decreases in independent activities of daily living showed no such correlation (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). Often, the emphasis in dementia morbidity is on cognitive deterioration, with much less attention being paid to the behavioral aspects of the disease (Hooker et al., 2002, pp. P453–P460). In caregivers unaware of this presentation, these behaviors may go unrecognized as symptoms and lead to increased levels of stress (Hooker et al., 2002, pp. P453–P460). This inevitable increase in caregiver stress, and the inability to properly cope, may result in negative emotions by caregivers toward patients with dementia.

Perceived lack of reciprocity in patients with dementia is another major contributor to the development of stigma among health providers and the population at large. General reciprocity can be understood as recognizing a helpful or beneficial act and responding in a reciprocal manner (Adams and Sharp, 2013). The ability to reciprocate can increase the quality of care an individual receives, whereas a perceived lack of reciprocity may diminish an individual's social value (Kurzban and Leary, 2001). Patients with dementia are often perceived as lacking the ability to recognize, show interest in,

or even acknowledge others (Gove, Small, Downs, & Vernooij-Dassen, 2017; Woo and Mehta, 2017). This can often lead to caregivers feeling underappreciated. However, reciprocal behaviors demonstrated by patients with dementia often go unrecognized by caregivers (Vernooij-Dassen, Leatherman, & Rikkert, 2011). Subtle displays of reciprocity are often overshadowed by caregiver expectations of a patient's premorbid level of social functioning (Graham and Bassett, 2006). This perceived lack of reciprocity in patients with dementia also extends to primary care physicians. When asked about their personal experience with such patients, general practitioners often refer to a lack of "meaningful presence" and a decreased sense of sincere social contact (Gove et al., 2017).

Many also report a diminished return on social investment due to the perceived inability of patients to respond appropriately to family members (Gove et al., 2017; Woo, 2017a, 2017b). The notion that patients with dementia are not fully present contributes to a belief that any attempt to socially engage the patient is a wasted effort. This can lead to increased avoidance and social isolation by extended family and friends (Gove et al., 2017). It is especially detrimental in the case of close family members who are responsible for major decisions of care. Additionally, dementia patients may be perceived as a burden to society and a major financial investment (Gove et al., 2017). This is especially true in a society that values hard work and independence (Gove et al., 2017). While several of these negative perceptions regarding dementia are based on late-stage presentations of the disease, they are often generalized to all patients with dementia regardless of disease severity (Gove et al., 2017). Furthermore, while there is a general understanding that patients are not responsible for their disease, the perception that patients with dementia lack the ability to reciprocate on an emotional level encourages stigmatization nonetheless (Gove et al., 2017).

In the general population, pervasive misconceptions regarding normal aging and the clinical manifestations of dementia have further contributed to the stigma facing patients. Many unfamiliar with dementia believe that memory loss is a natural process of aging (Banerjee, 2010). Among those aware of the symptoms associated with dementia, there is a tendency to believe that very little can be done medically for those with such conditions (Banerjee, 2010). These misunderstandings surrounding dementia, a product of lacking public awareness about the condition, largely contribute to late presentations and missed diagnoses (Banerjee, 2010).

Stigma among the general population is further exacerbated by inaccurate depictions in popular film and media. Films may depict individuals with dementia in a sensationalized fashion, distorting popular perceptions. Researchers analyzing several popular films over the last two decades with themes centering on dementia found that the condition is often overly romanticized (Gerritsen, Kuin, & Nijboer, 2014). The challenges and burdens facing both patients and caregivers were vastly underrepresented (Gerritsen et al., 2014). As a consequence, viewers may not realize the degree of burden facing this population and might respond with less empathy and support (Gerritsen et al., 2014).

Films also depict moments of full lucidity in patients with dementia, misrepresenting disease progression and offering unrealistic expectations (Gerritsen et al., 2014). It remains to be seen whether more accurate depictions of dementia might evoke greater understanding and support for those with the condition (Gerritsen et al., 2014). As it is, false depictions may very well be contributing to the underlying stigma observed toward patients with dementia and their caregivers.

Repercussions of stigma

Misguided beliefs, reinforced by subtle behavioral symptoms and decreased public awareness, have resulted in a multitude of negative repercussions for individuals with dementia. One repercussion with a lasting impact on both patients and caregivers is the delay in timely diagnosis by primary care physicians. Recent estimates reveal that more than 60% of individuals with dementia remain undiagnosed (Lang et al., 2017). Misinformation regarding the “typical” presentation of dementia among general practitioners (GPs) is a contributing factor causing physicians to mistake early signs of dementia as part of the normal aging process (Lang et al., 2017). GPs are often under the impression that a lack of reciprocity is inherent to the presentation of dementia (Gove et al., 2017). In less experienced physicians, this stereotype, which is often only true in advanced dementia, is used to screen for the disease in the general patient population (Gove et al., 2017). Even when physicians are able to recognize early signs of the disease, physicians may be reluctant to officially diagnose a patient due to the inherent negative associations (Gove et al., 2016). While not all physicians subscribe to the negative perceptions that stigmatize dementia, most physicians are aware of these perceptions in the general population. This may dissuade them from wanting to “label” a patient before absolutely necessary (Gove et al., 2016). While the delay in diagnosis affects all patients with dementia, some individuals may be at a higher risk for remaining undiagnosed. Several factors have been implicated, with lower educational level and nonwhite ethnicity being the most significant contributors (Amjad et al., 2018).

Whatever the reason may be for delayed diagnosis, the consequences are salient. In older adults with probable dementia, the likelihood of engaging in unsafe activities is significantly higher for individuals without a formal diagnosis (Amjad, Roth, Samus, Yasar, & Wolff, 2016). Several instrumental activities of daily living may be compromised in early-stage dementia including cooking, driving, and managing finances (Arrighi, Gélinas, McLaughlin, Buchanan, & Gauthier, 2013). These activities must be properly addressed with patients, ideally around the time a diagnosis is made. In undiagnosed patients, safety is not appropriately assessed, placing these individuals at increased risk for injury and poor health outcomes (Amjad et al., 2016). Undiagnosed patients report a higher incidence of unattended doctor visits, self-management of finances, meal preparation, and driving (Amjad et al., 2016). Without proper awareness of their

deficits and the necessary resources to manage activities of daily living, patients are at a higher risk for exploitation of finances, increased annual falls, and medication-related hospital admissions (Amjad et al., 2016). Early detection and diagnosis of dementia plays an important role in future planning for both caregivers and patients, preventing future safety risks and additional health complications (Amjad et al., 2018).

However, late diagnoses alone are not the only consequence a negative perception of dementia can have on an individual. In fact, while a formal diagnosis may reduce certain risk factors for patients, it can have a negative impact on an individual's self-esteem and social support structure (Burgener et al., 2015). Patients with dementia report numerous negative interactions with friends and family as well as coworkers and healthcare providers (Alzheimer's Association, 2008). Many voice concern that they feel misunderstood and misrepresented (Alzheimer's Association, 2008). This may stem from a generalized fear of dementia in the general population that results in avoidance of these individuals and inevitably pushes them toward social isolation (Sutherland, 2010). Patients with dementia express a common trend whereby people begin to act differently toward them, at times even avoiding them (Sutherland, 2010). These feelings are especially notable in individuals with a higher level of cognitive functioning who develop early signs of dementia (Burgener et al., 2015). These individuals are often more socially engaged, and thus the higher social demands required often reveal early pathological deficits (Burgener et al., 2015). Faced with expectations necessitating a high level of cognitive function, these patients are met with negative perceptions and social isolation earlier in their disease progression (Burgener et al., 2015). This only emphasizes the fact that many individuals with dementia continue to display keen insight and social awareness throughout the early stages of the disease, thus exacerbating the emotional repercussions associated with stigma (Clare et al., 2012).

Future developments

Despite the prevalence of stigma surrounding dementia as well as obstacles to proper care and support for patients and caregivers, the future remains bright. Work is being done to change negative attitudes within communities at home and abroad through education, scientific research, and technological innovation.

Groups are working tirelessly toward increasing the level of dementia education within their respective communities. This is especially significant in communities with underlying cultural biases and a lack of educational resources. In the Chinese American population, community members are raising awareness through health fairs, seminars, and culturally relevant educational materials (Woo, 2017a, 2017b). Media-based education distributed through radio, television, and web-based platforms has shown great success (Woo, 2017a, 2017b). One example is "Radio Beneath the Sky," a Cantonese

radio broadcast in Los Angeles that created a dementia awareness program designed to specifically engage Chinese American community members (Woo, 2017a, 2017b).

Similarly, the Chinese Phoenix Television Station created a series on AD in Cantonese, which was subsequently uploaded to YouTube (Woo, 2017a, 2017b). Both programs yielded fairly successful results and provided invaluable feedback on how to improve media-based awareness campaigns in the future (Woo, 2017a, 2017b; Zheng and Woo, 2017). Emphasis was placed on the importance of utilizing stories about real-life individuals when providing education about dementia (Woo, 2017a, 2017b). An appeal to pathos was found to be highly effective in educating community members as compared with facts and figures alone. Another important finding revealed by these awareness campaigns is the importance of culturally relevant educational materials (Woo, 2017a, 2017b). Oftentimes the lack of awareness about dementia in immigrant communities is less a result of general disinterest and more a product of inaccessibility to coherent educational materials (Zheng et al., 2016).

Stanford University's Alzheimer's Disease Research Center (ADRC) chose to approach the issue of dementia awareness in the Latino community by creating and implementing a dementia awareness campaign (DAC). Collaborating with a local community health advocacy organization, the group aimed to educate community member intermediaries known as promotoras (Askari, Bilbrey, Garcia Ruiz, Humber, & Gallagher-Thompson, 2017). Promotoras received education on the topic of dementia from the ADRC and then disseminated that information within their respective neighborhoods (Askari et al., 2017). This allowed community members with very little knowledge about the condition to access culturally relevant and coherent information (Askari et al., 2017). This approach to raising awareness aims to tackle the recurring theme of cultural and language barriers that too often impede accurate transfer of information in minority communities. Although performed on a small scale, the results of this study were hugely successful in both training promotoras and increasing awareness in the community (Askari et al., 2017). The DAC has continued to run successfully in East Palo Alto, and plans have been made to expand the program to other nearby communities in the Bay Area (Askari et al., 2017).

The theoretical foundation utilized by the Stanford ADRC is based on contemporary research in the field of outreach and engagement in minority populations. The group made sure to hire "culturally competent" staff members, healthcare professionals with a similar demographic to the target community (Askari et al., 2017). This is important, as it cultivates a sense of trust among community members, increasing their willingness to listen and comply with health recommendations (Askari et al., 2017). Another important implementation was of staff with specialized knowledge in the field of dementia who could provide the most up-to-date, patient-specific knowledge (Askari et al., 2017).

Community-based awareness programs have also achieved success on a much larger scale. In Japan, a 10-year government-funded public awareness project successfully

altered the Japanese word for dementia in order to remove its derogatory quality (World Health Organization, 2012). The change was implemented into administrative, academic, and media channels, demonstrating patient solidarity while equally acting as a nationwide awareness program (World Health Organization, 2012). The Japanese government simultaneously created a network of seminars across the country to educate citizens about dementia, which 2.4 million citizens had already attended by 2011 (World Health Organization, 2012).

National campaigns utilizing media outlets have also been successful in the UK and Brazil. The UK designed a campaign featuring everyday citizens with dementia in an effort to normalize the condition (World Health Organization, 2012). As a response to qualitative research revealing growing fears of the condition and avoidance of affected individuals, the campaign depicted citizens with the condition under the headline “I have dementia, I also have a life” (World Health Organization, 2012). The Brazilian Alzheimer’s Association also successfully utilized media outlets, creating a television campaign to raise awareness and funds with the help of a well-known Brazilian actress (World Health Organization, 2012). Calls to the association helpline increased from 1000 to 2500 per month, an increase directly attributable to the television campaign (World Health Organization, 2012).

In Australia, a government-funded program created a campaign aimed at educating citizens about lifestyle modifications to reduce dementia risk factors (World Health Organization, 2012). “Mind your Mind,” which was initiated in 2005, promoted seven factors found to reduce future risk of dementia: diet, tobacco and alcohol use, exercise, and several others (World Health Organization, 2012). Educational sessions were created for the general public and coupled with a modern approach utilizing web-based mobile applications to connect directly with users (World Health Organization, 2012). More recently, an awareness project in the city of Kiama created educational seminars with the added dimension of featuring actual patients with dementia as seminar educators (Phillipson et al., 2019). The idea was based on earlier research that emphasized that increasing the amount of direct communication with dementia patients could lead to decreased avoidance of the condition among community members (Phillipson et al., 2019).

Promotion of dementia awareness has also been achieved in the political sphere. The US Alzheimer’s Association led a grassroots effort to mobilize constituents to pressure their respective congressperson into supporting dementia-friendly legislation (World Health Organization, 2012). This eventually led to the Alzheimer’s Project Act, signed by President Obama in 2011, that aimed to address the dementia epidemic on a national scale (World Health Organization, 2012).

Another promising development is the steady growth of “dementia friendly communities,” which work to facilitate a supportive environment in which individuals with dementia can live and maintain their independence (Wiersma & Denton, 2016).

These communities, many of which have appeared across the UK as well as the rest of Europe, are based in a more rural setting and offer social, emotional, and instrumental support (Wiersma & Denton, 2016). They also offer local facilities for comprehensive dementia care (Wiersma & Denton, 2016). These communities allow for full integration of individuals with dementia into a nurturing community and are a tangible example of the continued campaign to end the associated stigma.

Much work must still be done in order to rid dementia of its negative associations and offer patients the proper support and respect they deserve. However, there is ample evidence to suggest that positive change is on the horizon. Physicians, caregivers, and community members must continue working together to educate and advocate on behalf of patients with dementia. Only then will patients receive the proper attention, care, and support required for a rewarding and satisfying future.

Key facts of the national Alzheimer's Project Act

- National legislation signed by president Barack Obama in 2011
- A national plan to increase funding for dementia research while expanding services and care for patients and their caregivers
- Created an advisory council with leading experts in the field working together to formulate a national action plan
- Set a national goal to effectively prevent and treat dementia by 2025 by accelerating treatment development
- International coalition formed among governments to address dementia globally

Summary points

- As dementia rates rise, finding sustainable ways to effectively manage the condition is of great importance.
- Negative perceptions of dementia, often based on misinformation, are major detriments to proper care.
- Stigmatizing beliefs surrounding dementia differ across cultures but often result in similar consequences for patients and caregivers.
- Behavioral and psychological symptoms of dementia are often misunderstood by the general population and are a major contributor to stigma.
- Stigmatizing beliefs often lead to delayed diagnosis by physicians, leading to patient participation in dangerous activities and thus increased injury burden.
- Encouraging progress is being made toward raising awareness and educating the general population about dementia.

References

- Adams, V., & Sharp, R. (2013). Reciprocity in caring labor: Nurses' work in residential aged care in Australia. *Feminist Economics*, 19(2), 100–121.
- Alzheimer's Association. (2013). 2013 Alzheimer's disease facts and figures. *Alzheimer's and Dementia*, 9(2), 208–245.
- Alzheimer's Association. (2017). 2017 Alzheimer's disease facts and figures. *Alzheimer's and Dementia*, 13(4), 325–373.
- Alzheimer's Association. (2008). *Voices of Alzheimer's disease report*. Chicago, IL: Alzheimer's Association.
- Amjad, H., Roth, D. L., Samus, Q. M., Yasar, S., & Wolff, J. L. (2016). Potentially unsafe activities and living conditions of older adults with dementia. *Journal of the American Geriatrics Society*, 64(6), 1223–1232.
- Amjad, H., Roth, D. L., Sheehan, O. C., Lyketsos, C. G., Wolff, J. L., & Samus, Q. M. (2018). Underdiagnosis of dementia: An observational study of patterns in diagnosis and awareness in US older adults. *Journal of General Internal Medicine*, 1–8.
- Aneshensel, C. S., Pearlin, L. I., Mullan, J. T., Zarit, S. H., & Whitlatch, C. J. (1995). *Profiles in caregiving: The unexpected career*. Elsevier.
- Arrighi, H. M., Gélinas, I., McLaughlin, T. P., Buchanan, J., & Gauthier, S. (2013). Longitudinal changes in functional disability in Alzheimer's disease patients. *International Psychogeriatrics*, 25(6), 929–937.
- Askari, N., Bilbrey, A. C., Garcia Ruiz, I., Humber, M. B., & Gallagher-Thompson, D. (2017). Dementia awareness campaign in the latino community: A novel community engagement pilot training program with promotoras. *Clinical Gerontologist*, 1–9.
- Banerjee, S. (2010). Living well with dementia—development of the national dementia strategy for England. *International Journal of Geriatric Psychiatry*, 25(9), 917–922.
- Bos, A. E., Pryor, J. B., Reeder, G. D., & Stutterheim, S. E. (2013). Stigma: Advances in theory and research. *Basic and Applied Social Psychology*, 35(1), 1–9.
- Burgener, S. C., Buckwalter, K., Perkhounkova, Y., Liu, M. F., Riley, R., Einhorn, C. J., et al. (2015). Perceived stigma in persons with early-stage dementia: Longitudinal findings: Part 1. *Dementia*, 14(5), 589–608.
- Clare, L., Nelis, S. M., Martyr, A., Whitaker, C. J., Marková, I. S., Roth, I., et al. (2012). Longitudinal trajectories of awareness in early-stage dementia. *Alzheimer's Disease and Associated Disorders*, 26(2), 140–147.
- Dovidio, J. F., Major, B., & Crocker, J. (2000). *Stigma: Introduction and overview*.
- Faure-Delage, A., Mouanga, A. M., M'belesso, P., Tabo, A., Bandzouzi, B., Dubreuil, C. M., et al. (2012). Socio-cultural perceptions and representations of dementia in Brazzaville, Republic of Congo: The EDAC survey. *Dementia and Geriatric Cognitive Disorders Extra*, 2(1), 84–96.
- Gao, S., Dolan, N., Hall, K. S., & Hendrie, H. C. (2000). The association of demographic factors and physical illness with personality change in a community sample of elderly African Americans. *The American Journal of Geriatric Psychiatry*, 8(3), 209–214.
- Gerritsen, D. L., Kuin, Y., & Nijboer, J. (2014). Dementia in the movies: The clinical picture. *Aging and Mental Health*, 18(3), 276–280.
- Gould, S. L., & Hyer, L. A. (2004). Dementia and behavioral disturbance: Does premorbid personality really matter? *Psychological Reports*, 95(3_Suppl. 1), 1072–1078.
- Gove, D., Downs, M., Vernooij-Dassen, M., & Small, N. (2016). Stigma and GPs' perceptions of dementia. *Aging and Mental Health*, 20(4), 391–400.
- Gove, D., Small, N., Downs, M., & Vernooij-Dassen, M. (2017). General practitioners' perceptions of the stigma of dementia and the role of reciprocity. *Dementia*, 16(7), 948–964.
- Graham, J. E., & Bassett, R. (2006). Reciprocal relations: The recognition and co-construction of caring with Alzheimer's disease. *Journal of Aging Studies*, 20(4), 335–349.
- Hebert, L. E., Weuve, J., Scherr, P. A., & Evans, D. A. (2013). Alzheimer's disease in the United States (2010–2050) estimated using the 2010 census. *Neurology*, 80(19), 1778–1783.
- Herrmann, L. K., Welter, E., Leverenz, J., Lerner, A. J., Udelson, N., Kanetsky, C., et al. (2018). A systematic review of dementia-related stigma research: Can we move the stigma dial? *The American Journal of Geriatric Psychiatry*, 26(3), 316–331.

- Hooker, K., Bowman, S. R., Coehlo, D. P., Lim, S. R., Kaye, J., Guariglia, R., et al. (2002). Behavioral change in persons with dementia: Relationships with mental and physical health of caregivers. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 57(5), P453–P460.
- Kessler, E. M., & Schwender, C. (2012). Giving dementia a face? The portrayal of older people with dementia in German weekly news magazines between the years 2000 and 2009. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 67(2), 261–270.
- Kurzban, R., & Leary, M. R. (2001). Evolutionary origins of stigmatization: The functions of social exclusion. *Psychological Bulletin*, 127(2), 187.
- Lang, L., Clifford, A., Wei, L., Zhang, D., Leung, D., Augustine, G., et al. (2017). Prevalence and determinants of undetected dementia in the community: A systematic literature review and a meta-analysis. *BMJ open*, 7(2). e011146.
- Lawton, M. P., Moss, M., Hoffman, C., Grant, R., Have, T. T., & Kleban, M. H. (1999). Health, valuation of life, and the wish to live. *The Gerontologist*, 39(4), 406–416.
- Link, B. G., Cullen, F. T., Struening, E., Shrout, P. E., & Dohrenwend, B. P. (1989). A modified labeling theory approach to mental disorders: An empirical assessment. *American Sociological Review*, 400–423.
- Low, L. F., Brodaty, H., & Draper, B. (2002). A study of premorbid personality and behavioural and psychological symptoms of dementia in nursing home residents. *International Journal of Geriatric Psychiatry*, 17(8), 779–783.
- Mackenzie, J. (2006). Stigma and dementia: East European and South Asian family carers negotiating stigma in the UK. *Dementia*, 5(2), 233–247.
- Phillipson, L., Hall, D., Cridland, E., Fleming, R., Brennan-Horley, C., Guggisberg, N., et al. (2019). Involvement of people with dementia in raising awareness and changing attitudes in a dementia friendly community pilot project. *Dementia (London)*, 18(7–8), 2679–2694. <https://doi.org/10.1177/1471301218754455>.
- Prince, M. J. (2015). World Alzheimer's report 2015: The global impact of dementia: An analysis of prevalence, incidence, cost and trends. *Alzheimer's Disease International*, 10–27.
- Scheff, T. J. (1966). *Being mentally ill: A sociological theory*. Transaction Publishers.
- Smith-Gamble, V., Baiyewu, O., Perkins, A. J., Gureje, O., Hall, K. S., Ogunniyi, A., et al. (2002). Informant reports of changes in personality predict dementia in a population-based study of elderly African Americans and Yoruba. *American Journal of Geriatric Psychiatry*, 10(6), 724–732.
- Storti, L. B., Quintino, D. T., Silva, N. M., Kusumota, L., & Marques, S. (2016). Neuropsychiatric symptoms of the elderly with Alzheimer's disease and the family caregivers' distress. *Revista Latino-Americana de Enfermagem*, 24.
- Sutherland, R. (2010). *British broadcasting company telecast (March 1)*.
- Vernooij-Dassen, M., Leatherman, S., & Rikkert, M. O. (2011). Quality of care in frail older people: The fragile balance between receiving and giving. *British Medical Journal*, 342, d403.
- Welleford, E. A., Harkins, S. W., & Taylor, J. R. (1995). Personality change in dementia of the Alzheimer's type: Relations to caregiver personality and burden. *Experimental Aging Research*, 21(3), 295–314.
- Wiersma, E. C., & Denton, A. (2016). From social network to safety net: Dementia-friendly communities in rural northern Ontario. *Dementia*, 15(1), 51–68.
- Woo, B. K. (2017a). Dementia health promotion for Chinese Americans. *Cureus*, 9(6).
- Woo, B. K. (2017b). Family history and its relationship with dementia stigma beliefs among Chinese Americans. *Geriatrics and Gerontology International*, 17(1), 122–125.
- Woo, B. K., & Mehta, P. (2017). Examining the differences in the stigma of dementia and diabetes among Chinese Americans. *Geriatrics and Gerontology International*, 17(5), 760–764.
- World Health Organization. (2012). *Dementia: A public health priority*. World Health Organization.
- Zheng, X., Chung, J. O., & Woo, B. K. (2016). Exploring the impact of a culturally tailored short film in modifying dementia stigma among Chinese Americans: A pilot study. *Academic Psychiatry*, 40(2), 372–374.
- Zheng, X., & Woo, B. K. (2017). E-Mental health in ethnic minority: A comparison of youtube and talk-based educational workshops in dementia. *Asian Journal of Psychiatry*, 25, 246–248.