Research Progress on Dementia Stigma: Postprint

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Abstract

Cognitive impairment is also known as dementia. With the acceleration of population aging, the population affected by dementia and Alzheimer' s disease continues to grow. Although stigma associated with dementia is widely acknowledged as universally prevalent in the international community, related research remains extremely limited. This article, by reviewing existing research findings on dementia stigma, reveals that the definition and measurement approaches for dementia stigma require standardization; studies on economically underdeveloped regions are severely inadequate; evidence capable of supporting causal inference is lacking, and both the quantity and quality of intervention research have substantial room for improvement. Research on dementia stigma offers a rare opportunity to challenge the binary subject perspective prevalent in traditional stigma research domains. Furthermore, discussions on the mechanisms underlying dementia stigma formation can deepen scholarly engagement with labeling theory and attribution theory.

Full Text

Research Progress on Stigma of Cognitive Disorders

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Abstract

Cognitive impairment, also known as cognitive disorders, is becoming increasingly prevalent as populations age. The stigma associated with cognitive disorders is widely recognized internationally, yet research in this area remains limited. This review examines existing literature on dementia-related stigma and identifies several critical gaps: the need for standardized definitions and measurement tools; a dearth of research in economically underdeveloped regions; a lack of evidence supporting causal inferences; and considerable room for improvement in both the quantity and quality of intervention studies. Research on cognitive disorder stigma offers a unique opportunity to transcend the binary subject perspective traditionally dominant in stigma research. Furthermore, discussions on the mechanisms underlying stigma formation can deepen theoretical explorations of labeling theory and attribution theory.

Keywords: Cognition disorders; Cognition; Alzheimer disease; Dementia; Stigma; Review

Cognitive impairment, also referred to as cognitive disorders, refers to deficits in one or more cognitive domains. When two or more cognitive functions are affected and impact an individual' s daily or social functioning, dementia may be considered [1]. The most common form of dementia is senile dementia, with Alzheimer' s disease being the most prevalent type. According to a report from Alzheimer' s Disease International [2], approximately 50 million people worldwide had Alzheimer' s disease in 2017, a number projected to reach 113.5 million by 2050. About 58% of individuals with Alzheimer' s disease live in low- and middle-income countries, a proportion expected to rise to 68% by 2050.

Despite the growing number of people affected by cognitive disorders, public understanding has not kept pace. A 2012 report from Alzheimer' s Disease International found that nearly 20% of dementia patients concealed their diagnosis due to feelings of shame, while 40% reported being excluded from daily activities. Nearly two-thirds of patients and caregivers believed their countries lacked adequate understanding of dementia [3]. Misconceptions and stereotypes about dementia fuel public fear and prejudice, leading to avoidance, discrimination, and social isolation. This causes some patients to experience shame, delaying or refusing to seek help, resulting in a state of "high prevalence, low consultation rates, low diagnosis rates, and low treatment rates" that severely impacts quality of life for both patients and caregivers [4].

Consequently, there is an urgent practical need to understand stigma related to cognitive disorders to develop better interventions. Although stigma associated with cognitive disorders is internationally recognized as widespread [5], it has received scant attention in the stigma literature. This review synthesizes previous research on dementia-related stigma, examining its geographic distribution, primary study populations, definitions and measurement approaches, research methodologies, and key findings. We conclude by summarizing the characteristics and unique significance of research on cognitive disorder stigma.

1 Literature Search Strategy

We searched the EBSCO comprehensive database using the formula: “TI (dementia or alzheimers or cognitive impairment or memory loss or cognitive decline or mild cognitive impairment) AND TI stigma* Peer Reviewed AND Apply equivalent subjects” on December 3, 2022, at 11:53 AM. The search initially yielded 320 articles, which reduced to 152 after automatic deduplication, and further to 135 after importing into EndNote. After screening abstracts, we excluded 26 articles (4 irrelevant, 14 commentaries or news pieces, and 8 non-English papers). Additionally, 5 articles were unavailable in full text and were not included. The final number of articles included in this review was 104.

2 Definitions and Measurement of Dementia-Related Stigma

The literature reveals five primary concepts and definitions of dementia-related stigma: public stigma, self-stigma, anticipated stigma, courtesy stigma, and affiliate stigma (see Table 1 for details).

Public stigma typically refers to stereotypes, prejudice, and discriminatory behaviors held by the general public toward out-group members. This form of stigma is commonly termed “stigma,” “public stigma,” “dementia-related stigma,” or “AD stigma.” Measurement typically involves directly surveying public attitudes toward people with dementia. The most frequently used scales are the Family Stigma in Alzheimer’ s Disease Scale (FS-ADS) and the Attribution Questionnaire (AQ), along with The Dementia Attitudes Scale (DAS), self-developed scales, and the Dementia Stigma Assessment Scale (DSSS).

Self-stigma generally refers to personal experiences, self-awareness, and cognitive processes of out-group members (patients) in stigmatizing social environments, with emphasis on consequences including economic insecurity, social exclusion, internalized shame, and social isolation. In the literature, this is variously termed “stigma,” “stigma consciousness,” “self-stigma,” or “perceived stigma.” The most commonly used measurement tool is the Stigma Impact Scale (SIS).

Notably, in English literature, both public stigma and self-stigma use the term “stigma.” Similarly, “perceived stigma” sometimes refers to self-stigma experienced by stigmatized individuals, while in other contexts it denotes anticipated stigma. **Anticipated stigma** typically refers to attitudes that the general public (stigma perpetrators not currently in a stigmatized position) believe the public (usually not themselves) holds toward out-group members.

Courtesy stigma and affiliate stigma are often discussed together. Researchers generally consider **courtesy stigma** as occurring when certain groups, having gained recognition from stigmatized populations, frequently serve as understanding, accepting advocates for them in society. These advocates experience stigma due to their association with stigmatized groups. Consequently, this form of stigma is sometimes called family stigma in some literature. Definitions encompass experiences of stigma, prejudice and discrimination, public image, structural discrimination, and difficulties in fulfilling social roles. Direct measurement of courtesy stigma is rare; one Israeli study used a self-developed scale to measure caregivers' perceptions of public stereotypes [8].

Affiliate stigma is often defined as internalized courtesy stigma, primarily studied among informal caregivers (typically family caregivers) of people with dementia. Definitions typically focus on negative emotions, maladaptive behaviors, and negative cognitive consequences. The most commonly used standardized scale is the Affiliate Stigma Scale (ASS), followed by the FAMSI8 and Family Stigma Scale (FSS).

Regarding measurement innovations, a UK study [9] employed the Implicit Relational Assessment Procedure (IRAP) to test implicit stigma among young adults and care workers by measuring reaction times to associations between dementia and negative words. The study found anti-dementia biases among young people but positive attitudes among care workers. It also revealed inconsistent correlations between implicit stigma, explicit stigma (self-reported via scales), and behavioral or emotional outcomes (burnout, depression, etc.). Exploration of implicit stigma remains in its early stages, requiring more research to understand its scientific and practical implications.

Overall, many studies on dementia stigma lack clear definitions and measurement approaches. Among existing definitions and measurements, there is no consensus on core terminology, conceptualization, or assessment. Future research should systematically review different definitions and measurement methods and better integrate them with theory.

3 Research Progress on Dementia Stigma

3.1 Geographic Distribution of Research The geographic distribution of dementia stigma research is highly uneven. The United States leads in quantity (32 articles, 30.8%), followed by the United Kingdom and Europe (27 articles, 26%). Israel ranks third (13 articles, 12.5%). Beyond these top three, China (including Hong Kong, Macau, and Taiwan) and Australia each contributed 7 articles (6.7% each), tying for fourth place. Only one study focused on African populations, with a sample from Nigeria. Three studies examined South American populations from Brazil, Chile, and Colombia, all conducted by North American or European research teams. Scholars from economically underdeveloped regions have limited voice in this academic field.

3.2 Research by Target Population Studies on dementia stigma can be categorized into eight groups by target population: the general public, informal caregivers, patients, professional service personnel, mixed populations, programs or services, media content, and literary works. We focus on the first four categories.

3.2.1 General Public Studies

Research on public stigma is most numerous (34 articles, nearly one-third of the total), almost exclusively using quantitative data collection and analysis. These studies typically target community members with minimal direct exposure to dementia, including students, older adults, and immigrant populations. Most employ scale-based surveys of public attitudes toward dementia.

Findings indicate that dementia stigma transcends culture and ethnicity. Studies in Nigeria [10], Brazil [11], the United States [12-13], France [6], Israel and Australia [14], and China [15] all reveal moderate to high levels of stigma. Unlike other conditions, public stigma toward dementia often manifests as emotional sympathy alongside cognitive negativity and behavioral avoidance.

Regarding influencing factors, research consistently shows that women and more educated groups exhibit lower stigma levels than men and less educated groups. Age-related findings are inconsistent: Chinese research indicates younger people show higher stigma than older adults [16], while younger older adults worry more about dementia symptoms [17]. Conversely, US [13] and Australian [18] studies find older adults more likely than younger people to anticipate social exclusion and discrimination for dementia patients.

Knowledge about dementia and personal involvement (having relatives or being a practitioner) show complex effects. Some studies find that participation in dementia training and activities reduces public stigma and anti-discrimination awareness [19], while others reveal that higher self-rated knowledge correlates with greater stigma [14]. Having relatives with dementia increases willingness to disclose the condition but also leads to perceptions that patients are less aware of others' concerns [20]. A French study found healthcare professionals exhibited higher dementia stigma than social workers, students, retirees, and the general public [6].

3.2.2 Professional Service Personnel Studies

Eleven articles examined stigma among professional service personnel, including physicians, nurses, non-medical institutional staff, medical students, social workers, and lawyers. Six qualitative studies explored stigma attitudes and experiences among dementia care professionals in the UK, EU, Australia, and Israel. These studies reveal professionals' unique dual role: they experience stigma due to association with patients while simultaneously stigmatizing and excluding patients in their care.

Geriatric health practitioners [21] and foreign care workers [22] experience multiple layers of stigma and identity crises. General practitioners [23-24] and judges [25] also hold stigmatizing attitudes toward dementia patients. A study across eight EU countries found that GPs' dementia stigma, ageism, and feelings of helplessness in disease progression reinforced their reluctance to identify and diagnose early-stage dementia, creating "diagnostic barriers" [26].

Quantitative studies demonstrate stigma' s consequences among practitioners. Greek research found nurses' and caregivers' stigmatizing attitudes (cognitive, emotional, behavioral) exacerbated their burnout [27]. An Israeli study of medical students revealed that stigma mediated the relationship between professional knowledge and help-seeking recommendations for patients [28]. A German longitudinal study found GPs' diagnostic accuracy for dementia was only 51.4%, with 48.6% of patients who should have received diagnoses being missed, while 23.6% of those diagnosed did not actually have dementia, creating unnecessary burdens for families and healthcare systems. Older adults living alone, those with mobility or hearing problems, self-reported memory complaints, or documented depression diagnoses were more likely to be misdiagnosed [29].

3.2.3 Informal Caregiver Studies

Twenty-three articles addressed stigma among informal caregivers, including 4 on scale development and cross-population validation, 8 quantitative studies, and 11 qualitative studies, all using non-random sampling. Caregivers included family members—children, spouses, and other relatives.

Qualitative studies primarily described caregiving experiences, revealing that many caregivers simultaneously experience multiple forms of stigma [30], including structural stigma from society, courtesy stigma, and self-stigma. Caregivers feel shame about patients' unconventional behaviors [31-32], perceive negative social attitudes [33], and often delay seeking help until crises occur due to fear of social judgment [32], desire to protect patients' dignity [34], or lack of dementia knowledge [35].

Quantitative studies explore mediating and moderating relationships between different stigma types and related variables such as social support (typically a mediator), caregiver burden (typically an outcome), and coping strategies (typically a moderator). Caregiver socioeconomic status (gender, age, education, relationship to patient) and patient characteristics (age, gender, cognitive level, behavioral problems) usually serve as independent or control variables. Research generally finds that social relationships can moderate the association between courtesy stigma and self-stigma [36], while higher perceived stigma correlates with heavier caregiver burden, poorer emotional states, and higher anxiety [37-38]. However, the role of different variables varies across studies, requiring further clarification.

3.2.4 Patient Studies

Ten articles examined patient stigma, including 2 cross-population scale validation studies, 4 qualitative studies, 3 quantitative studies, and 1 randomized controlled trial. Two articles validated the SIS scale among UK [40] and US [41] patient populations. All three quantitative studies used the SIS scale. A European study [42] compared stigma experiences among 180 dementia and mild cognitive impairment patients across three countries, finding UK patients experienced higher stigma levels than Italian and Polish patients. Patient stigma experiences negatively correlated with social support, quality of life, and emotional status.

Two qualitative studies explored patient stigma experiences in Chile [45], Northern Ireland [46], the Dominican Republic [47], and Pakistan [48]. Except for the Dominican study using case study methodology, the others used purposive sampling and interviews with 11-20 participants. Findings revealed Pakistani elders experienced more stigma at home than in community settings [48], with stigma experiences influenced by family [45] and culture (particularly religion) [48]. Stigma experiences, disease knowledge, and socioeconomic resources all affected help-seeking behaviors and time to service access. Support groups helped patients develop group identity, building confidence and reducing stigma' s negative impact [46].

4 Causal Inference in Dementia Stigma Research

Approximately 79% of studies used cross-sectional data or lacked temporal design. Only 17 studies (about 16%) considered time factors in data collection or analysis. The field lacks robust evidence for causal inference. Among 20 studies attempting causal inference, 10 were intervention studies and 10 were multi-factor vignette experiments, discussed below.

4.1 Multi-Factor Vignette Experiments Vignette experiments identify factors influencing stigma, focusing on: diagnostic labels (no diagnosis/normal aging, brain injury, Alzheimer' s dementia [AD] including mild, moderate, severe), disease progression (improvement, stable, deterioration), treatment options (presence/absence of disease-modifying therapy), symptoms (none, memory loss, behavioral-psychological symptoms), contact experience (knowing someone with dementia), risk status (not mentioned, possible risk, no risk), and patient age (50 vs. 80 years). Different studies employ various scenario combinations to compare stigma influences.

Findings on diagnostic labels are inconsistent. Some studies found no statistical differences in stigma levels among the general public [49-50] and nursing assistants [51] across different labels. However, one study found the general public showed less sympathy and more blame toward "normal aging" elders compared to "severe AD" patients, while showing greater social isolation tendencies toward "severe AD" patients [52].

When diagnostic labels indicate severity, they affect stigma differently. Two studies show heavier stigma with more severe labels. A French study found nursing assistants gave lower pain ratings and showed less compassionate behavior toward "severe" versus "mild" patients with otherwise identical profiles [51]. A US study found "mild AD" and "severe AD" labels elicited higher stigma levels than "no AD" scenarios [53].

Symptom disclosure shows inconsistent effects on stigma. A Hong Kong study found symptom information did not significantly affect public stigma levels [16], while another Hong Kong study found objects with "no symptoms or diagnosis" information elicited higher stigma than those with "symptoms" or "symptoms plus diagnosis" [5].

A US study found biomarker test results significantly influenced public stigma. Compared to negative results, positive biomarker results led to higher stigma levels. Specifically, when participants were told an elder' s brain scan confirmed memory problems were due to Alzheimer' s disease (simulating a PET scan), controlling for symptom severity and treatability, positive scan results increased stigma [53].

Regarding disease progression and treatment, studies show that "deteriorating" conditions elicit expectations of greater structural stigma and social exclusion compared to "improving" or "stable" conditions [49-50], while availability of disease-modifying treatment does not significantly affect stigma levels [53].

A Hong Kong study found people with relatives or friends with dementia showed lower stigma than those without such contact [5]. A Dutch study of breast cancer patients found that informing them chemotherapy might cause cognitive problems, with or without reassuring statements, increased stigma consciousness [54].

Patient age affects public stigma. Compared to younger patients, older patients elicit lower stigma levels from university students [36], contradicting the logic that the public more readily blames and shows less sympathy toward "normal aging" elders [52].

These findings reveal the complex effects of disease information disclosure (diagnosis, severity, symptoms, medical reports) and potential risks (deterioration, treatability, susceptibility) on stigma levels. This complexity reflects the challenging situation patients and families face when deciding whether to disclose information to the public or even professionals, often leading them to refuse disclosure, thereby reducing opportunities to seek timely services and support.

4.2 Intervention Studies Among 10 intervention studies, one described research design and one summarized a dementia documentary. Of the remaining 8 intervention studies, only one educational program for dementia staff showed no statistical significance [55]; the other 7 reported positive effects. Overall, increased social contact proved effective across countries and populations for reducing stigma. Social contact includes patient-to-patient interactions (e.g., support groups [46]) and contact between patients/families and the general public (e.g., intergenerational choirs [56]). Information dissemination also effectively promoted empathy and positive emotions while reducing negative emotions, including viewing dementia-related media (musicals [19], films [15], theater [57]) and awareness campaigns [58].

Notably, intervention groups (education only, social contact only, or combined) all showed improved dementia knowledge, with combined intervention effects persisting significantly three months post-intervention [59].

Despite positive findings, intervention research on dementia stigma has substantial room for development: (1) Evidence is insufficient—only 8 studies among 104 articles; (2) Study quality needs improvement—only one randomized controlled trial, with the other 7 lacking rigorous design and control for confounders, limiting internal validity; (3) Interventions lack clear theoretical frameworks. Although stigma theories appear rich, effective guidance for de-stigmatization practice remains scarce—an important direction for future research.

5 Characteristics and Significance of Dementia Stigma Research

Current dementia stigma research exhibits three main characteristics. First, definitions and measurement approaches need standardization. While researchers agree dementia stigma is multidimensional, no consensus exists on its constituent dimensions or measurement structure, demanding more sophisticated theoretical work.

Second, research concentrates in developed countries and urban areas, neglecting underdeveloped regions and rural populations. Most studies occur in developed nations; the few in underdeveloped regions (e.g., Africa) are typically led by developed-country teams. Moreover, most research focuses on urban or metropolitan populations, with rural-urban disparities rarely examined and rural patients largely ignored. Since stigma is heavily influenced by culture and social context [45,47-48], culturally grounded research is urgently needed.

Third, the field lacks evidence for causal inference and requires more intervention research. Studies on professional staff, informal caregivers, and patients particularly lack temporal considerations and control for confounders. Better causal evidence is needed to inform effective interventions and practice.

Beyond these research gaps, dementia stigma research holds special significance compared to other stigma domains. First, it offers an opportunity to transcend the binary subject perspective in traditional stigma research. In fields like HIV or mental illness, a rigid dichotomy exists between stigma perpetrators and victims. Dementia stigma research reveals a spectrum from public stigma to "being stigmatized" experiences. Among professionals, physicians are often viewed as perpetrators, while nurses and other staff experience stigma from superiors while also stigmatizing patients. Family caregivers simultaneously experience public, courtesy, and affiliate stigma [30]. Older adults may hold negative attitudes toward dementia before becoming patients themselves. In the context of dementia and aging, the perpetrator-victim boundary is easily blurred, especially given dementia' s unclear pathology and universal threat. This provides a rare chance to break the binary perspective and generate new insights into stigma mechanisms.

Second, while dementia stigma' s existence and negative consequences are well-documented, de-stigmatization programs remain limited in quality and quantity. Patients and caregivers continuously narrate their stigma experiences, yet some members of the public deny holding stigmatizing attitudes. For these individuals, sympathetic and accepting attitudes toward dementia may mask behavioral exclusion of patients and families, leading to denial of stigma' s existence and a "not my problem" mentality. This often results in refusing to learn about dementia and reducing contact with affected individuals to "avoid trouble," creating a form of "passive stigma." Unlike aggressive boundary-setting against infectious or mental illnesses, this subtle, everyday stigma and exclusion may have greater impacts on health and well-being.

As Goffman revealed, stigmatized individuals are advised to adopt "normal" perspectives—that everyone has troubles, so they need not feel pain, resentment, or self-pity, but should develop optimistic personalities and "appropriate adjustment" skills [60]. This means the injustice and suffering of stigma should never be displayed to "normals," who need not acknowledge how limited their decency and tolerance truly are [60]. This "unacknowledged stigma" silently exploits and emotionally ignores people with dementia and their families, while denying them legitimacy to speak for themselves. This not only affects population health outcomes but also challenges social solidarity and morality.

Finally, exploring factors and mechanisms underlying dementia stigma can deepen theoretical discussions of labeling and attribution theories. Inconsistent findings on how diagnostic labels and symptoms affect stigma among the public and some professionals challenge labeling theory' s assertion that "labels cause negative emotions, cognitions, and behaviors" [61]. Not all labels produce stigma. Why do individuals affected by dementia experience vastly different stigma levels? Does cognitive processing moderate the relationship between signs and stigma, as attribution theory suggests [39]? These questions require further exploration.

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