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SYSTEMATIC REVIEW

STIGMA AND ALZHEIMER'S DISEASE AND RELATED DEMENTIAS: A SYSTEMATIC REVIEW OF RELATIVES' EXPERIENCES

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Abstract

Objective: This systematic review examines the multifaceted stigma experienced by relatives of individuals living with Alzheimer's Disease and related dementias (ADRD).

Methods: A comprehensive search of the PubMed and Scopus databases was conducted, resulting in the identification of eighteen relevant studies published within the last five years. These studies were then subjected to rigorous analysis.

Results: The findings reveal that family, cultural, social, and psychiatric stigma have a significant impact on caregivers, leading to increased burden, social isolation, delayed help-seeking, and psychological distress. The analysis further underscores the pivotal role of cultural beliefs and societal norms in shaping the manifestation and intensity of stigma across diverse contexts, including collectivist societies and immigrant communities. The review also explores the complex relationship between diagnostic disclosure, particularly with the advent of biomarkers, and the potential for increased stigma. Additionally, the review designates the need for further research on the experiences of LGBT+ caregivers, who often face a heightened level of stigma.

Conclustions: This study concludes with an emphasis on the necessity of interventions, including public education and culturally sensitive support systems, to mitigate the detrimental effects of stigma on ADRD caregivers.

Keywords: Alzheimer’s disease, dementia, stigma, caregivers, relatives.

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INTRODUCTION

Dementia is a degenerative disorder that affects nearly 50 million people worldwide and has been recognized by the World Health Organisation as a global health priority.[1] The largest proportion of people living with dementia come from low- and middle-income countries.[2]

Alzheimer's disease (AD) is a form of dementia that has become the most common form of dementia in recent years. Its main characteristic is memory loss and dependence of the patient on third parties.[3] Like other forms of dementia, Alzheimer's disease usually occurs after the age of 65. Although Alzheimer's disease and relative dementia (ADRD) have been studied extensively, and there are factors involved in the onset of the disease as well as its hereditary nature, the causes of the disease are not fully understood.[4] In a survey by Matthews et al. (2019)[3], 5.8 million Americans were diagnosed with Alzheimer's disease, and the number is expected to triple to up to 14 million patients by 2060. However, data from a survey conducted in Greece shows that the rates of patients with dementia and AD are lower compared to those in Europe.[5]

According to the World Health Organization (WHO), stigma is defined as "a mark of shame, disgrace, or disapproval that results in an individual being rejected, discriminated against, and excluded from participating in various aspects of society".[6] The concept of stigma is derived from the association of distinctive characteristics with preconceived notions or stereotypes, thereby establishing a divide between those who are considered to belong to the former group and those who are regarded as belonging to the latter group. This process inherently renders stigma an unpleasant experience, particularly for those who become its victims. A core dimension of stigma lies in the use of labels, which reinforce social separation and sustain practices of exclusion and marginalisation. The consequences of stigma can be profound, ultimately leading to loss of status and discrimination, thereby exacerbating social inequalities and reinforcing negative perceptions.[7] As a concept, stigma is closely associated with society's negative attitudes towards older individuals, which can hinder their productivity, mental well-being, and contribution to society. As a social construct, stigma is influenced by cultural factors that shape attitudes, beliefs, and values, which in turn determine its meaning and expression across diverse populations.[8]

People living with dementia can be stigmatised because of the cognitive changes caused by the disease itself due to the prejudices, discrimination and stereotypes that accompany it (1,9). The public stigma of AD – also termed AD stigma – refers to negative perceptions, attitudes, emotions, and reactions directed at individuals diagnosed with AD. The internalisation of these attitudes can have substantial negative effects on individuals. This internalisation, termed self-stigma, has been demonstrated to act as a barrier to seeking early diagnosis of AD

(10). One method of reducing the social stigma associated with individuals diagnosed with Alzheimer's disease (AD) is to implement an early diagnosis through biomarkers. This can be achieved even in cases where there are no observable symptoms.[11,12]

Duodu's study (2024)[13] demonstrates that dementia frequently correlates with functional impairments that curtail the independence of people living with the condition (PwD). Consequently, many PwD often require a higher level of support, which is provided by persons referred to as caregivers. The term 'caregiver' refers to an individual who assists and helps the person in need, ensuring their physical and psychological well-being.[13] It is an irrefutable fact that people living with ADRD are the victims of stigma, the effects of which include psychological stress and suffering for the individuals concerned, as well as their families and friends.[14]

The aim of the current study was to provide a comprehensive overview of the various forms and effects of stigma experienced by family members of people living with ADRD.

METHODOLOGY

This systematic review has been conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines, thereby ensuring optimal transparency and reproducibility of the review process.

Data sources and search strategy

Two major databases, PubMed and Scopus, were searched using keyword combinations related to Alzheimer's disease and the stigma experienced by patients' relatives. The search strategy employed was as follows: (Alzheimer's disease OR dementia) AND (stigma OR stigmatization OR discrimination) AND (relatives OR caregivers OR family OR spouses).

To ensure the timeliness of the data, only studies published within the past five years were included. Eligibility was further restricted to publications in English and to studies conducted in human populations.

Inclusion and exclusion criteria

The present systematic review encompasses all journal articles that meet the following criteria:

1. Primary studies on the experience of relatives of people with ADRD.
2. Published studies in peer-reviewed journals.
3. Studies describing findings from observational and qualitative or quantitative analysis.
4. Studies which were conducted in human populations.
5. Published studies in English within the last five years.

We excluded all publications that met the following criteria, to enhance the consistency of the selected articles for synthesis:

1. Studies that do not directly examine the experience of stigma in relatives of patients with ADRD.
2. Publications such as reviews, meta-analyses, and literature studies.
3. Studies that focus exclusively on patients and not their relatives.
4. Studies that do not provide the full text or could not be retrieved.
5. Studies that involve only medical interventions without reference to stigma.

Data extraction

The following items were extracted and studied in accordance with the PICO framework: a) Author, b) Year, c) Country, d) Aim of the Study, e) Study Design, f) Sample and g) Results (15) as it shows in Table 1.

RESULTS

During the initial search, a total of 1,349 articles were identified and retrieved from the PubMed and Scopus search databases, and only 18 were included in the survey. In particular, 25 duplicates and 1,172 for other reasons were removed. 112 articles were selected for retrieval, of which 2 could not be retrieved. Subsequently, articles meeting the eligibility criteria and were also available in full text were reviewed. Studies were excluded if they did not primarily focus on stigma, if they examined patients' relatives rather than patients themselves, or for other reasons. A detailed overview of the PRISMA flowchart for article search is shown in Figure 1.

Of the 18 studies encompassed in the present systematic review, 10 employed qualitative research methods, 4 utilized cross-sectional studies, one incorporated a mixture of methodologies, and one employed a non-randomized controlled trial design

Family stigma

The first type of stigma to be analyzed in this review is family stigma, which is defined as the stigma experienced by family members of a person living with ADRD.[16] One of the common reactions of the family members is hiding the diagnosis of their relative to avoid feelings of shame or fear because of the relative's disease.

Abojabel and Werner (2022)[16] tried to examine whether family stigma could be a predictor of caregiver burden experienced among family caregivers of patients living with AD. In addition, the interplay of family stigma and burden was investigated on coping mechanisms and the role of social support. The authors of this study recruited a sample of 175 family caregivers from the Israeli Arab community who provide care for elderly individuals diagnosed with AD. Structured face-to-face interviews were conducted with the caregivers with the assistance of Israeli Alzheimer's Association. Family stigma is found to be a substantial predictor of caregiver burden, even when demographic and clinical variables were considered. The findings indicate that social support functions as a mediating factor in this relationship, underscoring its protective role in mitigating caregiver burden. However, the mediating influence of coping strategies, particularly those focused on problem-solving, did not yield significant effects. This outcome may be attributed to an underestimation of culturally specific coping mechanisms, such as religious or spiritual adaptations.[16]

Another study of Velilla et al. (2022)[17] examined family stigma as a predictor of caregiver burden, among other variables, using Affiliate Stigma Scale. This study focused on 150 Colombian family members who were divided into three groups based on the diagnosis of their relatives (Early-onset AD, Frontotemporal Dementia and Late-onset AD). Their study adopted a cross-sectional and observational design. The study revealed that caregivers of patients with Early-onset AD reported a heightened sense of stigma compared to those with Late-onset AD. This disparity can be attributed to the stress that accompanies a diagnosis in the early stages of the disease. The study revealed that relatives of individuals with Early- onset AD reported a heightened sense of stigma compared to those with Late-onset AD. This disparity can be attributed to the stress that accompanies a diagnosis in the early stages of the disease. However, the sample that appeared to experience greater family stigma and, consequently, a diminished quality of life among relatives was the one with Frontotemporal Dementia. This study confirms that family stigma can lead to fatigue and a lack of energy. In summary, the findings of this study indicate that family stigma associated with conditions such as dementia can exacerbate the burden experienced by family caregivers, as they often serve as the primary caregivers for their relatives with dementia. This social pressure, stemming from the social stigmatization experienced by caregivers, has the potential to directly contribute to their psychological distress.[17]

The study by Parker et al. (2022)[18] examined the delay of diagnosis, regardless of the presence of symptoms or the concealment of diagnosis by the patient. The study's findings, based on interviews with 12 individuals from the UK, revealed that the stigma associated with dementia also affected healthcare professionals. The stigma encountered in clinical settings engendered a genuine conflict among caregivers, who, in their efforts to normalize the condition, had previously avoided discussing or seeking a diagnosis of dementia. However, in retrospect, these caregivers expressed a desire for healthcare providers to have seized the opportunity to make a diagnosis.[18]

Schlag and Vangelisti (2023)[19] examined whether family stigma influences the relationship between a care recipient’s behavioral symptoms and the perceived burden experienced by their family caregivers, as well as whether stigma and weight motivate them to seek support. To do so, they studied 375 caregivers from USA, using Family Stigma in AD Scale. In contrast to the studies mentioned above, this study did not find a statistically significant correlation between perceived familial stigma and the burden experienced by the caregiver.[19]

In the study by Oliveira et al. (2023)[1], the subject is family stigma, explored through the experiences of 15 family caregivers from Brazil. These family caregivers often depersonalize or infantilize people living with dementia, underestimate their capacities, and demand obedience. These behaviors, while often unintended, reflect the stigma present within the caregiving relationship. Furthermore, the study noted that caregivers also experience courtesy stigma, characterized by feelings of discrediting or social exclusion due to their association with the person living with dementia. The phenomenon of exclusion and social disengagement experienced by caregivers, particularly in the context of dementia, is further accentuated by societal stigma. It is noteworthy that this survey is the sole one to report positive social experiences concerning patient care, including respect, affection, and empathy.[1]

Cultural stigma

Cultural factors play a pivotal role in shaping the experiences of caregivers of individuals with ADRD. Stigma, misconceptions, and limited knowledge about ADRD contribute to delays in diagnosis and reluctance to seek help. The influence of cultural beliefs, such as fatalism and strong familial obligations, can give rise to internal conflicts within the family unit and lead to elevated levels of stress experienced by caregivers. Filial piety and social expectations can impose additional psychological burdens on caregivers, particularly when their efforts do not align with cultural norms. The challenges faced by caregivers are further compounded by language barriers, financial constraints, and a paucity of culturally competent healthcare services. This underscores the necessity for targeted interventions to support immigrant communities and other such groups.[20]

Wang et al. (2024)[21] conducted a study with 27 Korean and Chinese American caregivers of individuals living with ADRD. The study was conducted through focus groups in the participants' native languages as well as English. Not only did the Korean American participants express a reluctance to impose on others, but they also articulated challenges in seeking support due to the prevailing stigma and the fear of judgment or social exclusion stemming from the diagnosis and the challenges associated with dementia. In contrast, Chinese American participants who were more familiar with American culture exhibited a more open-minded approach to seeking social and family support. However, both groups noted that the prevailing stigma associated with mental health issues significantly hinders effective discussion and support.[21] A similar phenomenon is presented in the Hammad et al. (2024)[22] study conducted in Qatar. It points out that in the Arab world, families with an ADRD person change the way they interact with people in public spaces duo to shame, which in their culture is referred to as "the culture of aib".[22]

A similar phenomenon has been observed in Vietnam, where a survey conducted by Nguyen et al. (2021)[23] revealed that 12 caregivers expressed a lack of support and information programs concerning ADRD. This inadequacy leads to social isolation, exacerbated by the stigma surrounding the condition, which limits their ability to seek support from individuals beyond their immediate family. It is noteworthy that this phenomenon persists even in cases of migration to countries such as the USA and Australia.[23]

Social stigma

Another type of stigma that is frequently the focus of scholarly inquiry is social stigma. Several studies have indicated that the intensity of stigma is greater in Asian countries compared to developed Western countries. This phenomenon can be attributed, at least in part, to the fact that, in individualist cultures (e.g., Americans, Germans, and Australians), deviation from established norms is more readily tolerated compared to collectivist cultures (e.g., Asians, Africans, and Arabs). This difference can be attributed, at least in part, to the cultural diversity and libertine attitudes characteristic of collectivist cultures. Additionally, the dearth of studies and interventions in nations with low to moderate incomes could be a contributing factor to the observed variation in stigma levels across these countries.[24]

A study by Hammad et al. (2024)[22] in Qatar, which involved in-depth interviews with 32 caregivers and family members of elderly individuals living with ADRD, revealed that social stigma is influenced by socioeconomic characteristics, as well as cultural and behavioral influences. The study's findings indicate that social stigma was most strongly articulated by Qatari nationals who possessed both a well-established social network and a family name. The reputation of these individuals was also placed at risk. It was further noted that stigma is more pronounced in mental disorders than in pathological conditions, and this is because patients exhibit behavioral disorders and symptoms such as shouting in public places, inappropriate speech, and aggression. Additionally, it was observed that stigma also prevented most families from seeking help until they had reached advanced stages. This was attributed to the desire to preserve the dignity and well-being of their family members. Additionally, the impact on the social status of individuals with ADRD was noted, as many believe that having a family member with ADRD may increase the likelihood of developing the same condition.[22]

As substantiated by the findings of Duodu et al. (2024)[13], an investigative study conducted in Ghana, 30 subjects, comprising relatives and caregivers, attested to their encounter of stigma and shame stemming from the actions exhibited by their patients, with the awareness of a potential diminution in community esteem. This predicament, as highlighted, has the potential to engender further social isolation among caregivers, thereby exacerbating the complexity of the caregiving endeavor.[13]

Dadashi-Tonkaboni's et al. (2024)[25] research offers a divergent perspective on social stigma, aiming to explore the factors affecting the ability of family caregivers of Alzheimer's patients to persist in their caregiving roles. A total of 22 Iranian caregivers participated in the study through in-person interviews, during which they reported persisting in their caregiving duties despite encountering various challenges. These challenges included stigmatization, an unfavorable perception of nursing homes, apprehension regarding the home nurses' ability to maintain confidentiality concerning familial matters, and the concern of being held accountable and subjected to comparison with their peers. The analysis of the participants' accounts indicates that these challenges stem from their adherence to Muslim religious beliefs and the perceived fear of facing divine retribution.[25]

Chermahini et al. (2021)[26] sought to ascertain the impact of an educational program, centered on group discussions, on perceived stigma among AD family caregivers. Prior to the initiation of the educational sessions, participants completed the Stigma Impact Scale, a tool designed to assess the perceived stigma associated with caregiving for individuals with Alzheimer's disease. The intervention encompassed five weekly group discussion sessions, with a central focus on stigma. In the third and fourth sessions, caregivers delved into the intricacies of stigma, exploring its diverse manifestations and the ways it is expressed within the context of Alzheimer's care. The discussions also encompassed the discussion of practical strategies to reduce stigmatization and build coping skills for managing the emotional burden associated with it. The objective of fostering open dialogue in these sessions was to empower caregivers with the tools necessary to navigate and counteract stigma in their daily lives. At the conclusion of the program, caregivers were prompted to reflect on the efficacy of these strategies in assisting them in managing stigmatizing situations. Perceived stigma was reassessed immediately after the program and again one month later to evaluate any changes in the participants' experiences. As previously mentioned, in collectivist cultures such as Iran, caregivers may place a greater emphasis on their family's reputation and how others perceive them, which can further exacerbate their emotional and social burden.[26]

Analogous results have also been documented in the USA; however, these findings are predominantly confined to rural regions, as reported by Longstreth et al. (2022)[27] in their study. A survey was conducted, and 62 caregivers participated. One of the themes that emerged from the study was the stigma they face and how it affects them in their caregiving of relatives living with ADRD and in their interpersonal relationships with their community. Caregivers frequently described avoidant or distancing behaviors exhibited by others in the community, which they ascribed to fear and stigma. They also mentioned the pressure they face in caring for their relatives themselves rather than placing them in a care facility, a practice that would not be problematic in a large urban center.[27]

Lack of comprehension was frequently accompanied by misconceptions that contributed to stigma. Negative emotional responses, including fear and shame, were prevalent in the study by Theresia et al. (2023) (28), and appeared to be internalized from perceived public stigma. The study, conducted through focus group discussions with nineteen caregivers from Indonesia, revealed a prevalence of these adverse emotional responses. Their discourse revealed pervasive misconceptions about dementia, many of which reflected prevailing misunderstandings of the condition. These misconceptions included the belief that dementia is a natural part of aging or is caused by the consumption of betel nuts. A particularly stigmatizing misconception that emerged from the data was the belief that dementia is caused by malevolent spirits or witchcraft. Additionally, caregivers articulated apprehension concerning the potential reactions of others upon discovering a family member's dementia. Some caregivers expressed concerns that neighbors might respond with defensiveness due to the fear of being harmed. To mitigate such adverse reactions, caregivers described attempting to maintain transparency with both family members and neighbors. As reported in other studies cited earlier, caregivers also experienced feelings of shame associated with the behavior of the person with dementia, such as shouting or exhibiting childlike actions.[28]

Contrary to the findings of the above research, the study by Withers et al. (2021)[29] revealed that 27 caregivers of individuals with early-onset AD residing in the USA reported an absence of stigma or discrimination. Instead, these respondents indicated experiencing support from their social networks. However, the early age of onset presented challenges in convincing the community to accept the reality of the condition, which in turn hindered caregivers from leaving their homes with affected family members. This research underscores the potential efficacy of public education initiatives in reducing stigma associated with early- onset Alzheimer's disease.[29]

Psychiatric Stigma

The extant research has demonstrated an inverse relationship between the experience of contact with individuals suffering from mental illness and the endorsement of psychiatric stigma.[30]

In their study, Zhang et al. (2023)[31] reported that psychiatric stigma related to dementia significantly hinders positive attitudes toward the use of healthcare services among individuals diagnosed with the condition. This stigma has also been found to have adverse effects on family caregivers, who may encounter similar negative consequences. The study further identified that lower educational attainment, lower income levels, and unemployment were associated with heightened stigma toward dementia. Among the participants, who were Chinese, caregivers exhibited higher levels of psychiatric stigma compared to medical professionals. This discrepancy was attributed to cultural factors, including concerns regarding the hereditary nature of mental illness and the influence of "face" culture, which emphasizes maintaining family reputation and social image.[31]

Diagnostic Disclosure and Stigma

The progression of AD is characterized by a gradual deterioration of cognitive abilities, which can be categorized into three distinct stages. These stages are the early, middle, and advanced stages, respectively. However, recent research findings have indicated that the presence of biomarkers can precede the onset of symptoms by up to ten years. This stage is referred to as the pre-clinical stage.[32]

Bolsewig et al. (2024)[33] conducted a study with a sample of 107 Dutch informal AD caregivers, using online and focus group methods, to examine the relationship between blood- based biomarkers and diagnosis prior to symptom onset. The study found that diagnosis prior to symptom onset, often due to the absence of treatment for AD, can lead to AD-related stigma, potentially resulting in early incapacitation and negative feelings of helplessness, fear, and insecurity. Participants who were against BBBM testing or in doubt expressed attitudes that were even more pronounced. These participants stated that they would want to enjoy life without worries and that they would not see an added value of getting an early diagnosis without treatment availability.[33]

A similar pattern emerges in the study by Cui et al. (2024)[34], conducted in China with focus groups of 11 spouses of patients with young-onset dementia. The interviewees report that the stereotype that dementia is a disease affecting only older adults, combined with the stigma associated with young onset, made it challenging for them to accept the diagnosis of young-onset dementia. Notably, some spousal caregivers articulated concerns regarding the stigma associated with genetic susceptibility to YOD, apprehending its potential repercussions on their children's marital and professional trajectories. Furthermore, some caregivers disclosed their reluctance to utilize biomarkers for early diagnosis in their children, citing a desire to circumvent the psychological distress that might ensue from a positive diagnosis.[34]

Stigma in LGBT+ Caregivers

While informal caregiving for individuals with ADRD has been the focus of extensive research, the unique experiences of sexual and gender minority (SGM) caregivers remain understudied.[35] Despite the evidence suggesting that a significant proportion of SGM adults serve as caregivers, they often face elevated levels of stress, discrimination, and stigma compared to their heterosexual counterparts. The convergence of challenges, stemming from both their role as caregivers and their marginalized identity, may render SGM caregivers particularly vulnerable to adverse psychosocial consequences. In the context of ADRD, where caregiving demands are already considerable, the compounded effects of minority stress and stigma warrant focused attention to better understand and support this population.[3,36]

Anderson et al. (2021)[37] pursued this objective in a study comprising 286 caregivers, predominantly gay men, of patients with ADRD in the USA. Responses from the Ascertain Dementia 8-Item Informant Questionnaire, which was used revealed that higher levels of caregiver stigma were linked to greater distress related to neuropsychiatric symptoms. These findings indicate that the historical and contextual factors surrounding stigma—particularly those associated with the intersecting identities of SGM status and race—may contribute to an elevated risk of depression among this caregiver population.[37]

DISCUSSION

The findings of this systematic review, encompassing eighteen studies, highlight the multifaceted nature of stigma experienced by relatives of individuals living with Alzheimer's Disease and related dementias (ADRD). The review identified several key themes, including family stigma, cultural stigma, social stigma, psychiatric stigma, the impact of diagnostic disclosure, and the unique challenges faced by LGBT+ caregivers.

Family stigma has emerged as a significant predictor of caregiver burden in several studies.[16,17] The tendency for families to conceal the diagnosis due to shame or fear underscores the pervasive negative perceptions associated with ADRD in family contexts.[16] Notably, Velilla et al. (2022)[17] found that caregivers of individuals with early-onset AD reported higher levels of stigma than those with late-onset AD, possibly due to the unexpected and disruptive nature of an earlier diagnosis. The study by Oliveira et al (2023)[1] further illuminated the manifestations of family stigma in caregiving interactions, including depersonalization and infantilization of individuals with dementia. Interestingly, Schlag and Vangelisti's (2023)[19] study in the USA did not find a significant correlation between perceived family stigma and caregiver burden, suggesting that the relationship between these factors may be influenced by cultural or contextual variables.

Cultural stigma significantly shapes caregivers' experiences, particularly in collectivist societies and among immigrant communities.[20] Studies in Qatar[22], Vietnam[23], and among Korean and Chinese Americans[21] have shown how cultural beliefs such as the shame in Arab cultures and concerns about family reputation led to reluctance to seek support and increased social isolation. The contrast observed by Wang et al. (2024)[21] between Korean Americans, who were reluctant to burden others, and Chinese Americans, who were more familiar with Western norms, highlights the impact of acculturation on help-seeking behaviors in the context of ADRD-related stigma.

Social stigma was consistently reported across cultural contexts, often due to a lack of understanding and misconceptions about dementia.[28] Fear of negative judgment, social exclusion, and a perceived loss of community esteem due to the behaviors of people with ADRD were common concerns among caregivers in Ghana[13] and rural areas of the USA.[27] Dadashi-Tonkaboni et al.'s (2024)[25] study in Iran offered a unique perspective, suggesting that religious beliefs and concerns about divine retribution may influence caregivers' decisions to remain in their roles despite stigma and negative perceptions of alternative care options. Chermahini et al.'s (2021)[26] intervention study in Iran demonstrated the potential of educational programs and group discussions to reduce perceived stigma among family caregivers, highlighting the importance of addressing cultural sensitivities in stigma reduction efforts. However, the findings of Withers et al. (2021)[29] in the USA, reporting an absence of stigma among caregivers of individuals with early-onset AD who experienced strong social support, suggest that community understanding and support networks may play a critical role in buffering against stigma.

The review also highlighted the presence of psychiatric stigma associated with dementia, which can impede positive attitudes towards seeking health services. Cultural factors, such as concerns about the hereditary nature of mental illness and maintaining family reputation, contribute to this form of stigma, with caregivers reporting higher levels of psychiatric stigma than medical professionals.[31]

The impact of diagnostic disclosure, particularly at the preclinical stage facilitated by biomarkers, presents a complex interplay with stigma. Bolsewig et al. (2024) and Cui et al. (2024)[33,34] found that early diagnosis, in the absence of effective treatments, may paradoxically lead to increased AD-related stigma, early disability, and psychological distress in both at-risk individuals and their families. Concerns about the potential social and familial consequences of a genetic predisposition to early-onset dementia further complicate the decision-making process regarding biomarker testing.[34]

Finally, the review shed light on the understudied experiences of LGBT+ caregivers, who face compounded stigma stemming from both their caregiving roles and their marginalized identities. An association between higher levels of caregiver stigma and greater distress related to neuropsychiatric symptoms was found among predominantly gay male caregivers, highlighting the need for tailored support and interventions that address the intersectional nature of their experiences[37]

CONCLUSIONS

This systematic review offers a comprehensive overview of the diverse forms and impacts of stigma experienced by relatives of individuals living with ADRD. The findings consistently demonstrate that stigma, whether familial, cultural, social, or psychiatric, poses a significant challenge to caregivers, often leading to increased burden, social isolation, delayed help- seeking, and psychological distress. The role of cultural beliefs and societal norms in shaping the manifestation and intensity of stigma is crucial, underscoring the necessity for culturally sensitive interventions.

In conclusion, the reduction of stigma associated with ADRD is imperative to enhance the well-being of individuals living with the condition and their relatives. A comprehensive strategy that targets societal attitudes, cultural beliefs, and the specific needs of diverse caregiver populations is imperative to cultivate a more supportive and inclusive environment for those affected by this debilitating disease.

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ANNEX

FIGURE 1. PRISMA Flow Diagram of Literature Review.

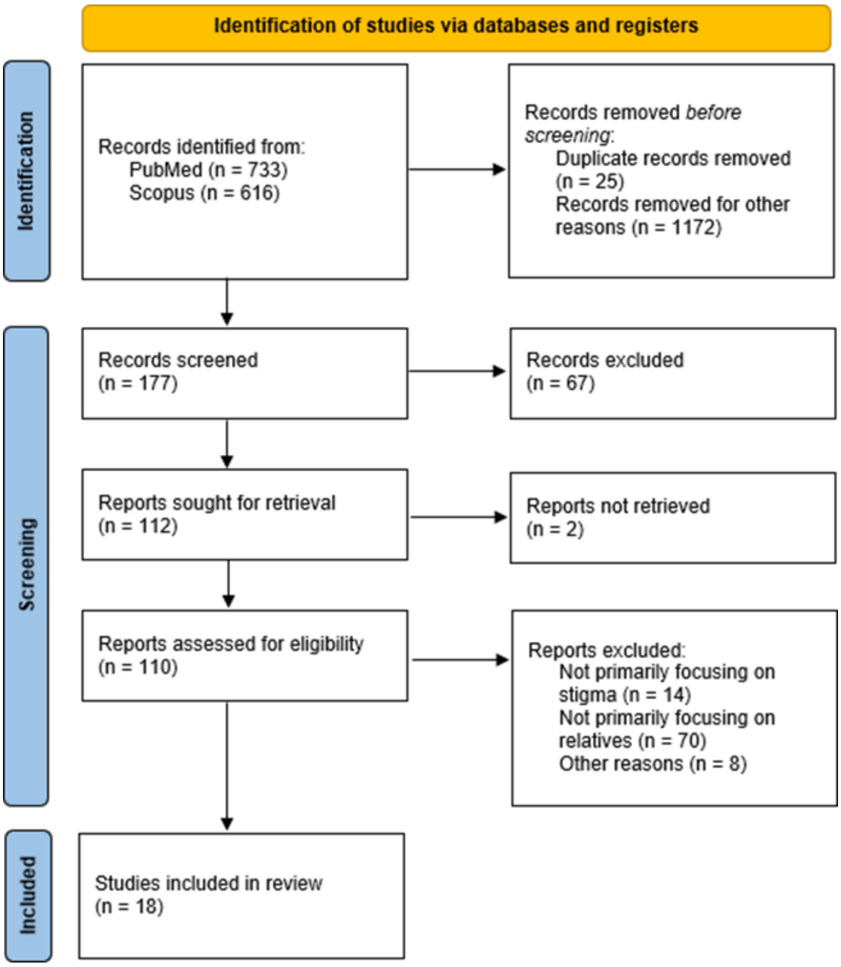

TABLE 1. Summary of the included studies.

Author (Year)	Country	Aim Study	Study design	Sample	Results
AboJabel & Werner (2022) (16)	Israel	To examine how family stigma predicts caregiver burden and its relation to coping and social support.	Structured face-to-face interviews	175 Israeli Arab family caregivers of elderly people with AD	Moderate levels of caregiver burden and family stigma were reported.
Duodu et al. (2024) (13)	Ghana	To explore primary caregivers' experiences of dementia care in Ghana.	Semi- structured face-to-face interviews	30 unpaid caregivers of PwD	Caregivers experienced stigma along with abuse, emotional stress, and social challenges.
Anderson et al. (2021) (37)	USA	To assess psychosocial factors among sexual and gender minority caregivers of people with Alzheimer's disease and related dementias.	Online survey and social media recruitment strategies	286 caregivers, with the majority being gay men	Caregiver stigma and microaggressions were linked to poorer mental health and quality of life.
Bolsewig et al. (2024) (33)	The Netherlands	To explore caregivers' attitudes toward blood- based biomarker testing for Alzheimer's Disease.	Mixed-method - survey and focus groups	107 informal AD caregivers	Stigma related to biomarker testing increased distress and hesitancy in caregivers.
Chermahini et al. (2021) (26)	Iran	To evaluate the impact of a group-based educational program on caregiver stigma.	Non- randomized controlled trial	66 caregivers	Group discussions effectively reduced perceived stigma among AD caregivers.
Cui et al. (2021) (34)	China	To explore the caregiving experiences of spouses of people with Young-onset dementia.	Semi- structured interviews	11 spousal caregivers	Young-Onset Dementia altered family dynamics and caregiving roles, contributing to stigma and isolation.

Dadashi- Tonkaboni et al. (2024) (25)	Iran	To identify factors influencing caregiver persistence in Alzheimer's care.	Semi- structured interviews	22 caregivers	Fear of societal stigma was a key reason caregivers continued their roles.
Hammad et al. (2024) (22)	Qatar	To examine how sociocultural and religious beliefs shape caregiving.	Semi- structured interviews	32 family caregivers	Stigma emerged as a socio- cultural factor shaping caregiving practices.
Longstreth et al. (2022) (27)	USA	To assess information and referral needs among dementia caregivers and stakeholders.	Questionnaire	62 caregivers	Stigma was identified as a key barrier to accessing dementia-related support and information.
Nguye et al. (2021) (23)	Vietnam	To explore caregiving experiences in a semi-rural Vietnamese setting.	Semi- structured interviews	12 family caregivers	Stigma was linked to misconceptions, emotional strain, and caregiving as a duty.
Oliverira et al. (2023) (1)	Brazil	To investigate stigma-related perceptions of dementia in Brazil.	Home-based semi- structured	15 family carers	Stigma led to exclusion, discrimination, and distorted perceptions of dementia and caregiving.
Parker et al. (2022) (18)	UK	To understand caregivers' experiences and stigma around hospital-based dementia care.	Semi- structured interviews	12 informal carers	Stigma prevented open discussions about dementia, delaying care- seeking.
Schlag et al. (2023) (19)	USA	To examine how stigma mediates the link between behavioral symptoms and caregiver burden.	Qualtrics survey	375 family caregivers	Stigma mediated the link between behavioral symptoms and caregiver burden.
Theresia et al. (2023) (28)	Indonesia	To explore caregiver experiences with dementia in Indonesia.	Focus group discussions	19 caregivers	Stigma influenced understanding, reactions, and delays in dementia diagnosis.

Velilla et al. (2022) (17)	Colombia	To assess how family stigma and socioeconomic factors impact burden and well-being in Early-Onset Alzheimer's Disease and Frontotemporal Tegeneration Dementia caregivers.	Cross- sectional and observational study	150 caregivers	Family stigma significantly worsened caregiver burden and reduced quality of life.
Wang et al. (2024) (21)	USA	To explore cultural influences and stigma in	Focus group discussions	27 caregivers (11 Korean	Stigma and cultural norms shaped caregiving
		Asian American dementia caregiving.		American & 16 Chinese American)	experiences in Asian American groups.
Withers et al. (2021) (29)	USA	To examine experiences and stigma among Latino caregivers of people with Early-Onset Dementia.	Focus group discussions	27 informal caregivers	Stigma and misconceptions about Early- Onset Alzheimer's Disease limited care-seeking in Latino communities.
Zhang et al. (2023) (31)	China	To investigate dementia knowledge and stigma among relatives of diagnosed patients in China.	Cross-sectional survey	51 relatives of diagnosed patients	Stronger psychiatric stigma was found in less educated or older relatives, affecting dementia knowledge.