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Systematic Review

Stigma perceptions and associated factors among caregivers of individuals with dementia: A systematic review of quantitative studies

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Abstract

Objectives: This systematic review aims to investigate studies on stigma perceptions and associated factors among caregivers of individuals diagnosed with dementia (IWD).

Methods: Studies published between January 2000 and July 2024 were searched in PubMed, Web of Science, Scopus, and EBSCO. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were followed for the search and review process. A total of 933 studies were identified through database searching, and 12 studies were included in this review, comprising 3,467 participants. A narrative synthesis was used to describe the included studies in terms of year, title, country, aim, participants, caregivers' relationship to the individual diagnosed with dementia, type of dementia, data collection methods, scales used, research design, analytical methods, and research findings.

Results: The findings indicated that stigma is associated with caregiver burden, emotional expressiveness, quality of life, anxiety, and psychological well-being. Regarding demographic variables, gender, age, education level, closeness to the individual diagnosed with dementia, and income level were found to be associated with stigma. For individuals with dementia, having frontotemporal dementia, a longer duration of dementia, and the presence of behavioral symptoms were associated with higher levels of stigma. It was also observed that caregivers taking breaks during caregiving had negative effects in terms of stigma.

Conclusion: These findings suggest that stigma is a multifaceted phenomenon influenced by both individual and contextual factors. Addressing stigma through targeted interventions, awareness campaigns, and culturally sensitive strategies is essential to improve caregivers' mental well-being and strengthen support systems. Future research would benefit from focusing on longitudinal and intervention studies to better understand the development of stigma over time and to design effective approaches to mitigate its impact.

Keywords: Dementia; family caregivers; stigma; systematic review

It is stated that there were 55 million individuals diagnosed with dementia (IWD) worldwide in 2020, and this number is estimated to double every 20 years.[1] Dementia is an umbrella term that includes many diseases affecting memory, thinking, and an individual's ability to perform daily activities. Although there are different types of dementia, such as vascular dementia, frontotemporal dementia, and dementia with Lewy bodies, Alzheimer's disease is reported to be the most common type.[2]

As stated, dementia is a disorder in which individuals experience difficulties in maintaining their daily lives.[2] These difficulties create a need for a caregiver for IWD.[3] Caregivers of IWD provide care both because of this need and because they perceive caregiving as their responsibility and wish to remain close to the individual diagnosed with dementia.[4] Caregiving is defined as experiences that include helping and supporting the care recipient in tasks they are unable to perform.[5] In addition

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to individuals who provide caregiving as a profession, there are also informal caregivers. Informal caregiving is defined as providing care to relatives in need within existing relationships, including family members, friends, or neighbors. It is stated that the majority of informal caregivers provide care without receiving any payment for this activity.[6] Informal caregivers are examined in three groups according to their degree of closeness: spouse/partner, adult child, and others. The "others" group includes siblings, friends, and children-in-law.[7] In the remainder of this study, the term caregiver refers to informal caregivers.

Caregivers provide many services to IWD, such as assisting with eating, dressing, bathing, and toileting,[8] accompanying them to medical appointments, and managing their personal and financial affairs.[9] As dementia progresses, the hours devoted to caregiving increase,[10] and caregivers may experience difficulties meeting even their own basic needs.[11] These challenges also cause caregivers to experience stress.[12] In addition to the practical difficulties of caregiving, having a relative diagnosed with dementia[13] and witnessing the gradual deterioration of their abilities pose significant emotional challenges for caregivers.[14] All of these factors can negatively affect caregivers. Studies have shown that caregivers of IWD experience various psychological problems, including depression, anxiety, and somatization.[15,16]

In addition to psychological distress, caregivers of IWD also report caregiver burden.[17] It has been stated that this burden increases further when IWD display rude, inappropriate, or unusual behaviors in the presence of people who are unaware of their illness. IWD may exhibit disruptive behaviors such as aggression and screaming.[18] When the cause of these behaviors is not recognized by others as dementia-related, such situations can be particularly challenging for caregivers and may lead them to feel stigmatized. Stigma is defined as "an attribute that is deeply discrediting," and it has been stated that stigma can be directed toward demographic characteristics (e.g., race, gender, age), physical or bodily characteristics, and individual flaws, such as mental disorders or criminal behavior.[19] Studies have shown that IWD report experiencing stigma and being treated negatively.[20] In fact, it has been reported that professionals working in this field may have difficulty disclosing the diagnosis because of stigma.[21]

When studies on stigma are examined, it is evident that stigma is not directed solely at individuals with the disorder. Negative societal attitudes toward people who are close to individuals with a disorder are referred to as courtesy stigma. In addition to courtesy stigma, individuals close to a person with a disorder may also experience associate stigma and affiliate stigma. Associate stigma reflects caregivers' perceptions of negative social attitudes, whereas affiliate stigma is defined as the internalization of these negative societal attitudes by caregivers.[22,23] In some studies, the terms stigma by association, associative stigma, and courtesy stigma are used interchangeably.[24,25]

What is presently known on this subject?

- It is known that the stigma associated with a disorder is not only perceived by individuals with the disorder themselves but also by those close to them. In other words, caregivers can also experience stigma, and this stigma is associated with various psychological problems.

What does this article add to the existing knowledge?

- Although there are studies addressing the stigma experienced by caregivers of individuals diagnosed with dementia, review studies in this area appear to be limited.

What are the implications for practice?

- Identifying variables associated with stigma can provide a foundation for the development of stigma-related interventions.

Studies conducted with caregivers of IWD have shown that caregivers experience both courtesy stigma[26] and affiliate stigma,[27] and that stigma is associated with various forms of distress, including caregiver burden, stress, depression, and anxiety.[27–29] It has also been stated that stigma reduces the likelihood that caregivers will participate in interventions aimed at reducing caregiver burden.[30] Moreover, stigma-related distress affects both the care provided and the interaction with the individual diagnosed with dementia. For example, distress associated with stigma has been shown to negatively influence caregiving practices.[31] In addition, negative emotions arising from stigma may alter caregivers' attitudes toward IWD, leading to reduced communication and social interaction.[22]

When recent review studies on stigma among caregivers are examined, it is observed that reviews have focused on stigma experienced by caregivers of individuals diagnosed with autism,[32] epilepsy,[33] psychological disorders,[34] and schizophrenia.[35] Although researching stigma in dementia has been identified as a priority in the context of caregivers of IWD,[36] studies in this area remain limited. This study aims to draw attention to this gap in the literature and to create a foundation for future research by reviewing existing studies. Accordingly, the purpose of this systematic review is to synthesize existing evidence on stigma perceived by caregivers of IWD and to identify associated factors. By examining these factors, the study aims to provide insights that can inform the development of targeted interventions, awareness campaigns, and culturally sensitive strategies. Ultimately, this knowledge may help improve caregivers' psychological well-being, enhance the quality of care provided to IWD, and reduce the negative impacts of stigma on both individuals with dementia and their families.

Materials and Method

Search Strategy

In this study, a systematic review was conducted to synthesize studies on stigma perceived by family caregivers of individuals with dementia (IWD). In July–August 2024, searches were conducted for studies published between 2000 and 2024 using the keywords "dementia caregiver" and "stigma". Searches were performed in the PubMed, Web of Science, Scopus, and EBSCO databases.

Inclusion and Exclusion Criteria

Studies published between January 2000 and July 2024 were screened. The inclusion criteria were:

1. **Language:** Articles written in English;
2. **Population:** Family caregivers of individuals diagnosed with dementia;
3. **Intervention, comparator, and outcome:** Studies that investigated stigma as a main variable;
4. **Study design:** Quantitative design.

The exclusion criteria were:

1. **Article types:** Non-research papers (dissertations, conference papers, reviews, scale adaptation studies);
2. **Population:** Studies in which participants were not family caregivers;
3. **Main topic:** Studies that did not consider stigma as a key variable.

Screening Procedure and Data Extraction

The author removed duplicates. Subsequently, the titles and abstracts of the retrieved studies were screened. Based on the title and abstract screening, studies eligible for full-text review were identified. Following full-text assessment, eligible papers were determined.

Data from each study were extracted by the author. Extracted data included the author(s), year, title, country, aim, participants, caregivers' relationship to the individual diagnosed with dementia, type of dementia, data collection methods, scales used, research design, analytical methods, and research results.

Statistical Analysis

Although only quantitative studies were included, substantial heterogeneity across studies was observed. Studies differed in several aspects, including the closeness of the caregiver to the IWD, the type of dementia, the scales used, and the variables examined. This heterogeneity made meta-analysis difficult; therefore, narrative synthesis was considered appropriate for examining stigma and associated variables.[37] Descriptive analyses of sample characteristics were performed using SPSS 24.0.

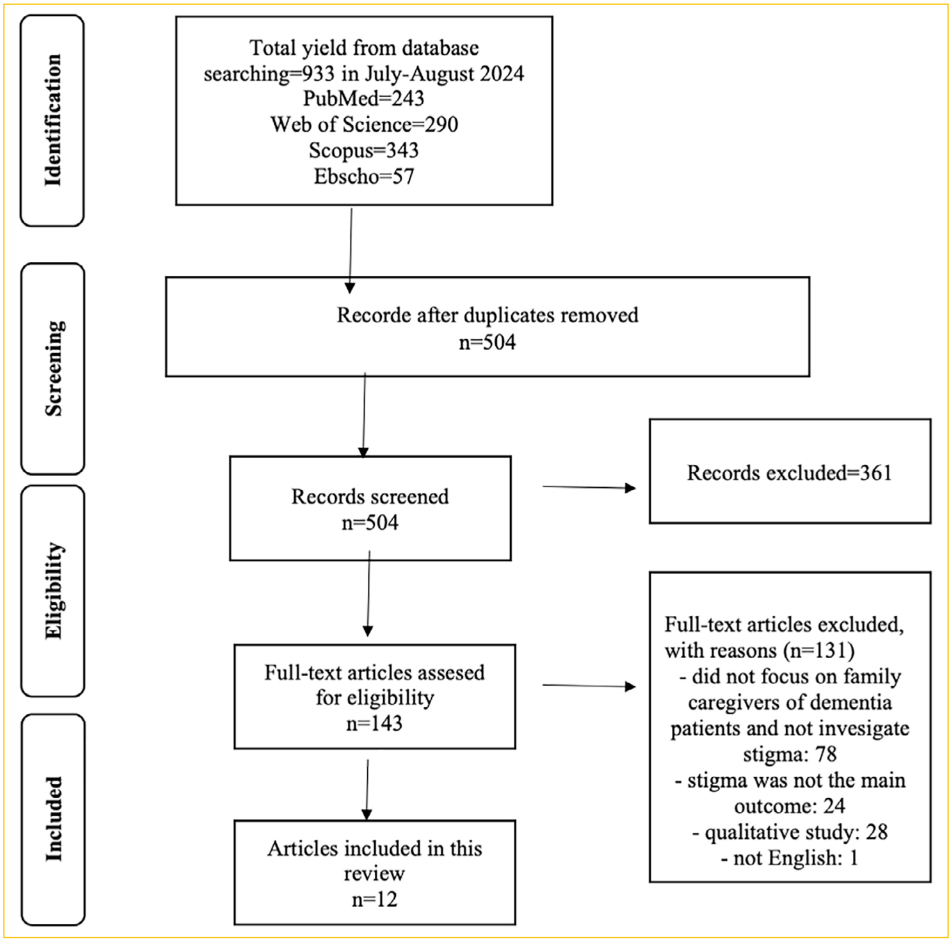

Figure 1. Inclusion PRISMA flow diagram.

Table 1. A summary of key features of incorporated studies

Country	n	Country	n
Israel	1	Patient's diagnosis	
United States	3	Dementia	7
Iran	1	Alzheimer	4
South Korea	1	Alzheimer's or other forms of dementia	1
Taiwan	2	Alzheimer's disease and related dementia	1
Belgium	1	Frontotemporal dementia	2
Colombia	1	Vascular dementia	1
China	1	Lewy body dementia	1
Malaysia	1	Mixed type dementia	1
Year		Sample size	
2012	1	<100	1
2016	1	101–200	4
2018	2	201–300	4
2020	2	301–400	1
2022	2	601–700	1
2023	3	701–800	1
2024	1	Data collection	
Study design		Online	3
Cross-sectional	11	Face to face	7
Longitudinal	1	Phone or mail	1
		Phone	1

Study Selection

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were followed for the search and review process.[38] The initial search yielded 933 articles, of which 429 duplicates were removed. The author screened the titles and abstracts of the remaining 504 articles according to the inclusion and exclusion criteria. After title and abstract screening, an additional 361 articles were excluded: 161 were non-research articles, 189 did not address stigma and did not include family caregivers of individuals with dementia, 2 were not written in English, 4 lacked author names and abstracts, and 5 were scale adaptation studies. The remaining 143 full-text articles were assessed for eligibility, and 12 articles met the inclusion criteria. These 12 articles were included in the review (Fig. 1).

Results

Twelve studies met the eligibility criteria and were included in this review. The characteristics and outcomes of these studies are presented in Tables 1, 2, and 3.

Characteristics of Included Studies

The 12 studies examined were conducted between 2012 and 2024 in Israel,[39] the United States,[40–42] Iran,[43] South Korea,[44] Taiwan,[27,45] Belgium,[24] Colombia,[46] Malaysia,[47] and China.[48]

Study Design and Methods

All twelve included studies were quantitative. Eleven studies used a cross-sectional design, and one study used a longitudinal design.

Sample Characteristics

The number of participants in the 12 included studies ranged from 82 to 727, with a total of 3,467 participants. Of these participants, 2,101 were female and 1,340 were male. The mean age of all participants was 48.39 years. When participants were evaluated in terms of their relationship to the care recipient, closeness information was unavailable in one study, whereas it was reported in 11 studies. Among these, 620 participants reported being the partner or spouse of the individual receiving care, and 2,082 reported being the children of individuals with dementia. In addition to spouses and children, caregivers also included siblings, grandchildren, children-in-law, nephews, friends, and neighbors. The diagnoses of individuals receiving care were also examined. Dementia was addressed in general terms in six of the twelve studies. One study focused exclusively on caregivers of individuals diagnosed with Alzheimer's disease, whereas the remaining studies included caregivers of individuals with various types of dementia.

Stigma Variables

All included studies addressed the concept of stigma; however, the way stigma was conceptualized varied. Of the twelve

Table 2. Features of incorporated studies

No	Author, year	Country	Aim of the study	Participants	Caregiver type	Dementia type
1	Werner et al., 2012[39]	Israel	To understand the predictor role of family stigma in caregiver burden	185 adult child caregivers of persons with Alzheimer's disease	Adult child caregiver	Alzheimer
2	Kahn et al., 2016[40]	USA	To investigate the caregiver stigma and burden in terms of caregiver type and gender	82 caregivers of persons with dementia	Spousal caregivers and adult child caregivers	Alzheimer, dementia, not diagnosed, or other, missing
3	Saffari et al., 2018[43]	Iran	To investigate the roles of spiritual coping and stigma related family stress on the relationship between patients' activities of daily living impairment and caregiver mental health	664 caregivers of persons with dementia	Spouse, child, others	Dementia
4	Weisman de Mamani et al., 2017[41]	USA	To investigate the mediator role of expressed emotion on the relationship between stigma and quality of life.	106 dementia caregivers	Adult children, spouses, grandchildren, nieces/nephews, children in law, siblings	Dementia
5	Jeong et al., 2020[44]	South Korea	To investigate the moderator role of family caregivers' affiliate stigma on information cross-checking, coping efficacy and coping outcomes.	226 family caregivers of patients with dementia	Spouses, children, related in some other way	Alzheimer's or other forms of dementia
6	Su & Chang, 2020[27]	Taiwan	To understand the relationship between caregiver burden and affiliate stigma and explore the factors associated with affiliate stigma	270 caregivers of people with dementia	Parent, spouse, child, and other	Dementia
7	Van den Bossche & Schoenmakers, 2022[24]	Belgium	To explore the effect of the affiliate stigma on caregivers' well-being	228 relatives caring for a person with dementia	Partner, sibling, parent, grandparent, aunt/uncle, friend/neighbor, no data	Dementia
8	Velilla et al., 2022[46]	Colombia	To explore the effect of family stigma and socioeconomic factors on psychological outcomes, quality of life and care burden	150 caregivers of patients with early-onset and late-onset Alzheimer's disease, and frontotemporal dementia	No information	Alzheimer's disease and frontotemporal dementia
9	Ellin et al., 2023[47]	Malaysia	To explore the association between affiliate stigma and psychological well-being.	178 caregivers of patients with dementia	Mother/father, spouse, and relative	Alzheimer's Disease, Vascular, Frontotemporal, Lewy Body dementia, Mixed type dementia, not identified
10	Hu et al., 2023[45]	Taiwan	To suggest a model showed the associations between affiliate stigma, caregiver burden, psychological distress and quality of life	275 family caregivers of people living with dementia	Spouse, children, others	Dementia
11	Schlag & Vangelisti, 2023[42]	USA	To investigate the effect of family stigma on the relationship between behavioral symptoms of patients and caregiver burden and the prediction of direct support in the relationship between caregiver burden and well-being.	375 family caregivers of patients with Alzheimer's disease and related dementias	Spouse, parent, other (e.g. grandparent, aunt, uncle), declined to respond	Alzheimer's disease and related dementias
12	Shi et al., 2024[48]	China	To investigate factors, affect the levels of perceived affiliate stigma	727 dementia family caregivers	Spouse, children, relatives	Dementia

Table 3. Methods and results of incorporated studies

No	Author, year	Data collection method	Instruments	Design	Analysis	Results
1	Werner et al., 2012[39]	Face to face	Zarit Burden Interview Short Form, Family Stigma in Alzheimer's Disease Scale, Problematic Behavior Scale	Cross-sectional	Descriptive statistics, Spearman correlations, Hierarchical multiple regression	Caregiver burden was found to be predicted by family stigma.
2	Kahn et al., 2016[40]	Phone or mail	Zarit Burden Inventory Short Form, Caregiver Section of the Family Stigma in Alzheimer's Disease Scale	Cross-sectional	Spearman's rank order correlation, independent t-tests, Pearson's chi-square tests, Fisher exact tests	Stigma was found to be correlated with caregiver burden. Female caregivers showed more stigma and burden as compared to male caregivers. Adult child caregivers presented to have more burden than spousal caregivers.
3	Saffari et al., 2018[43]	Face to face	Zarit Burden Interview, Spiritual Coping Strategies Scale, Lawton Instrumental Activities of Daily Living Scale, Short Form 12, Mini Mental State Examination, Hospital Anxiety and Depression Scale, and Family Stigma Stress Scale	Longitudinal	Descriptive statistics, Bivariate Pearson' correlations, Serial mediation analysis	The relationship between patient instrumental activities of daily living impairment and caregiver psychological health was mediated by spiritual coping and stigma-related stress
4	Weisman de Mamani et al., 2017[41]	Phone	The Clinical Dementia Rating Scale, 20-item Family Questionnaire, Quality of Life Inventory, Stigma Impact Scale	Cross-sectional	Pearson correlation coefficients, t-tests, ANOVA, PROCESS macro for mediation analysis	There is a positive relationship between caregiver stigma and emotional expressiveness, while caregiver stigma was negatively correlated with quality of life. Expressed emotion mediated the relationship between stigma and quality of life.
5	Jeong, Kim, & Kim, 2020[44]	Face to face	Information cross-checking with doctors, modified form of Emotion-focused coping scale, Affiliate stigma, modified form of Physical Coping Outcome Scale	Cross-sectional	Pearson's correlation, PROCESS macro for mediation and a moderated mediation	Low affiliate stigma was found to have moderator role in coping efficacy on the association between information cross-checking and dementia patients' health outcomes.
6	Su & Chang, 2020[27]	Face to face	Caregiver Burden Inventory, Affiliate Stigma Scale, Taiwanese Depressive Questionnaire, Beck Anxiety Inventory, Neuropsychiatric Inventory, Barthel Index, Clinical Dementia Rating, and Mini-Mental Status Examination	Cross-sectional	Hierarchical regression model	Age, dependence in daily activities, anxiety and care burden was found to be related with affiliate stigma.
7	Van den Bossche & Schoenmakers, 2022[24]	Online	The Affiliate Stigma Scale, the Patient Health Questionnaire – 9, 20-item Center for Epidemiologic Studies Depression Screening	Cross-sectional	Descriptive analyses, General Linear Model	Being women, having higher education, and being partner were found to affect affiliate stigma on mental well-being. Affiliate stigma was affected by the duration of dementia and the age of the caregiver.
8	Velilla et al., 2022[46]	Face to face	Interview for socioeconomic factors, Affiliate Stigma Scale, Functional Assessment Staging, The Frontal Behavioral Inventory, The Zarit Burden Interview, Center for Epidemiologic Studies Depression Scale, State-Trait Personal Inventory, QoL 36-Item Short Form	Cross-sectional	ANOVA, chi-squared tests, MANCOVA	Caregivers of early-onset dementia patients showed greater socioeconomic risk factors. Caregivers of patients with frontotemporal dementia were found to have higher levels of family stigma and higher prevalence of negative outcomes. Family stigma was most important risk factor for caregiver burden and quality of life.

Table 3. Cont.

No	Author, year	Data collection method	Instruments	Design	Analysis	Results
9	Ellin et al., 2023[47]	Face to face	21-item Affiliate Stigma Scale, Scale of Psychological Well-Being	Cross-sectional	T-test, ANOVA, Mann-Whitney U test, Kruskal-Wallis's Test, Hierarchical multiple linear regression	Income and gender were related to affiliate stigma was associated with psychological well-being. Affiliate stigma was found to be strongest predictor of psychological well-being.
10	Hu et al., 2023[45]	Face to face	Caregiver Burden Inventory, World Health Organization QoL Questionnaire-Brief, Affiliate Stigma Scale, an Beck Anxiety Inventory, and Taiwan Depression Questionnaire	Cross-sectional	Descriptive statistics, Pearson correlations, Structural Equation Model	Affiliate stigma was negatively related to quality of life, while affiliate stigma was positively related to caregiving burden. Caregiving burden and psychological distress sequentially mediated the relationship between affiliate stigma and quality of life.
11	Schlag & Vangelisti, 2023[42]	Online	Revised Memory and Behavior Problems Checklist, Items adapted from the Family Stigma in AD Scale, the Zarıt Burden Interview Short Form, Support Seeking, The Warwick-Edinburgh Mental Well-Being Scale	Cross-sectional	Path analysis	Caregiver and layperson stigma were predicted by behavioral symptoms. Caregiver burden and well-being relationship was mediated by direct support seeking.
12	Shi et al., 2024[48]	Online	Demographic questionnaire, Affiliate stigma scale, Caregiver burden inventory	Cross-sectional	Descriptive analysis, independent sample t-test, one way analysis of variance, Pearson correlation analysis, Multiple linear regression	Having regular breaks during patient care, time-dependent, developmental, physical and social burden were found to be associated with affiliate stigma.

studies, six examined affiliate stigma, three examined family stigma, one examined caregiver stigma, one examined stigma stress, and one examined perceived stigma. Affiliate stigma was measured using the Affiliate Stigma Scale,[22] while the Affiliate Stigma Scale (ASS) was used in one study examining family stigma. The remaining two studies examining family stigma used the Family Stigma–Alzheimer's Disease Scale (FS-ADS).[49] Caregiver stigma was measured using the Caregiver Section of the Family Stigma–Alzheimer's Disease Scale (FS-ADS-C).[49] Stigma stress was measured with the Family Stigma Stress Scale (FSSS),[50] and perceived stigma was measured using the Stigma Impact Scale.[51] Although the same instruments were used across multiple studies, the scales were applied in versions adapted to the countries in which the studies were conducted. Regarding administration methods, scales were administered face-to-face in seven studies, online in three studies, by telephone in one study, and via telephone or e-mail in one study.

Variables Addressed in Studies

When the variables examined alongside stigma in the reviewed studies are evaluated, it is observed that demographic variables, mental well-being, caregiver burden, behavioral problems, spiritual coping, functional status, health-related quality of life, cognitive functioning, anxiety, depression, dementia diagnosis and cognitive impairment, expressed emotion, quality of life, information cross-checking with doctors, coping efficacy, coping outcomes, psychological well-being, support seeking, well-being, relationship satisfaction, and help with care were investigated. A wide range of parametric and nonparametric analyses were used to examine these variables.

When the reviewed studies were evaluated in terms of caregiver gender, it was concluded that female caregivers reported higher levels of stigma.[24,40,47] However, it was also reported that male caregivers experienced higher levels of anxiety and care burden associated with affiliate stigma compared with female caregivers.[27] Regarding age, contradictory findings were observed. One study reported that older caregivers reported higher stigma,[24,40] whereas another study found that younger caregivers reported higher levels of affiliate stigma.[27] In terms of education level, it was reported that caregivers with higher educational attainment experienced higher stigma.[24,40] Additionally, having a middle income, compared with low or high income, was associated with affiliate stigma.[47] When findings related to caregiver closeness were examined, one study reported that partners experienced more stigma than spouses,[24] while another study found that adult children reported more stigma than spouses.[40] Furthermore, caregivers who took regular breaks during the caregiving process reported higher levels of affiliate stigma.[48]

When examined in terms of characteristics of individuals with dementia (IWD), caregivers of IWD who were less dependent in daily activities were found to report higher levels of stigma.[27] In another study, spiritual coping and stigma-related stress were found to have a mediating role in the relationships between impairment in daily activities of IWD and caregivers' anxiety, depression, care burden, and the mental health subdimension of quality of life.[43] In other words, impairment in daily activities predicted stigma-related stress, and stigma-related stress predicted caregivers' anxiety, depression, care burden, and the mental health subdimension of quality of life. In addition to functional dependency, it was reported that caregivers of individuals who had dementia for a longer duration experienced higher levels of stigma.[24,40] With respect to dementia type, caregivers of individuals with frontotemporal dementia reported higher levels of family stigma compared with caregivers of individuals with Alzheimer's-type dementia.[46] Regarding behavioral symptoms, it was reported that behavioral symptoms of the care recipient predicted stigma, and stigma had a mediating effect on the relationship between behavioral symptoms and caregiver burden.[42]

Moreover, stigma experienced by caregivers of IWD was found to be associated with caregiver burden[27,39,40] and psychological well-being.[47] In another study focusing on caregiver burden, affiliate stigma and psychological distress were associated with quality of life, whereas affiliate stigma was directly associated with caregiver burden. Additionally, caregiver burden and psychological distress had a sequential mediating effect on the relationship between affiliate stigma and quality of life.[45] Similarly, another study reported that family stigma was the most important factor associated with caregiver burden and quality of life among caregivers of individuals diagnosed with early-onset dementia, after controlling for dementia type, dementia stage, behavioral changes, and caregiver age and education.[46] In a study examining different dimensions of caregiver burden, individuals reporting high levels of time-dependent burden, developmental burden, and physical burden, as well as low levels of social burden, reported higher levels of affiliate stigma.[48]

Finally, in a study examining coping efficacy, coping efficacy was found to have a mediating role in the association between information cross-checking and care recipients' health outcomes. While coping efficacy mediated this relationship, low levels of affiliate stigma were reported to moderate coping efficacy.[44]

Discussion

The aim of this study is to systematically review studies on stigma perceived by caregivers of individuals with dementia (IWD). To achieve this aim, the PubMed, Web of Science, Scopus, and EBSCO databases were searched for studies conducted between 2000–2024, and the findings were examined in accordance with the PRISMA 2020 Statement.[38] As a result of this review, the characteristics and findings of 12 studies that met the inclusion and exclusion criteria were reported.

When the 12 studies were evaluated, it was observed that they were conducted between 2012 and 2024, with a noticeable increase in studies on stigma perceived by caregivers of IWD in recent years. Notably, 8 of the 12 studies were published between 2020 and 2024. In parallel with the global prevalence of dementia,[2] the studies were distributed across a wide geographical range. In this context, it is thought that the studies were conducted in countries that can be considered both individualistic and collectivist.[52] Although this diversity can be considered a strength, further studies are still needed, as the experience of dementia is known to vary across cultures. For example, in a study comparing stigma beliefs toward IWD among Israeli and Greek university students, Israeli students reported higher stigmatizing beliefs than Greek students.[53] In another cross-cultural study examining stigma experienced by IWD and individuals with mild cognitive impairment, participants in the United Kingdom reported higher stigma than those in Italy and Poland.[54] Although some studies have examined cultural influences on caregiving for IWD,[55] further research is required. Identifying cultural influences is also important for the development of effective interventions. In one study, it was reported that incorporating cultural and religious elements into interventions developed for caregivers of IWD may be beneficial.[56]

When the participants in the 12 included studies were evaluated, 2,101 were female and 1,340 were male. The predominance of female caregivers was consistent with previous caregiver research.[57] Most caregivers were partners or spouses and adult children of the individual receiving care, which is also consistent with the literature.[58] In addition, six of the reviewed studies differentiated between types of dementia. Considering that different types of dementia have distinct effects on caregivers,[59] making such distinctions is important, and many previous studies have also emphasized this issue.[58]

In studies examining stigma among caregivers of IWD, stigma was conceptualized as affiliate stigma, family stigma, caregiver stigma, stigma stress, and perceived stigma. Affiliate stigma has been defined as the internalization of stigma.[24] Family stigma has been conceptualized as stigmatizing experiences and perceptions of family members.[49] Caregiver stigma has been described as a subdimension of family stigma.[40] Another concept, family stigma stress, refers to stigma-related stress experienced by family caregivers.[43] Although different terms are used, there is considerable conceptual overlap across studies. For example, the Caregiver Stigma Impact Scale is used to measure perceived stigma and includes subdimensions such as social rejection, financial insecurity, internalized shame, and social isolation.[41] Thus, although perceived stigma is assessed, aspects of internalization are also evaluated. In terms of measurement tools, the Affiliate Stigma Scale[22] and the Family Stigma–Alzheimer Diseases Scale (FS-ADS)[49] were the most frequently used instruments. Although no review studies specifically addressing commonly used stigma scales among caregivers of IWD were identified, the Affiliate Stigma Scale has been used across multiple languages and caregiver populations, including dementia caregivers.[60–62]

When the methods of administering the scales were evaluated, it was observed that scales were administered face-to-face in seven studies, online in three studies, by telephone in one study, and via telephone or e-mail in one study. Studies involving caregivers of IWD have indicated that participation in research can be challenging for caregivers.[63] As dementia progresses, caregiving demands and time commitment increase,[10] which may further limit caregivers' ability to participate in research. Additionally, caregivers experiencing higher levels of stigma may isolate themselves from their social environment. To protect themselves and their relatives from negative social attitudes, they may limit social interactions and avoid public settings.[64] Consequently, individuals who experience higher levels of stigma may be underrepresented in research. For this reason, increasing the use of online research methods in future studies may be beneficial.

In addition to the consideration that conducting online studies in the future would be beneficial, it is also deemed necessary to implement awareness campaigns. As noted by participants, caregivers may refrain from going out, possibly due to feelings of stigma, which further highlights the importance of online studies.[48] While expanding online research constitutes one dimension, enabling caregivers to be outside without experiencing stigma represents another. Contrary to other studies conducted with caregivers of IWD,[65] one of the studies reviewed indicated that taking regular breaks from caregiving had negative effects. When assessed from the perspective of stigma, it is possible that caregivers use these breaks to socialize yet may be exposed to greater stigma during such interactions.[48] Furthermore, in contrast to previous research emphasizing that lower dependence is associated with more favorable outcomes,[66] one study reported that lower dependence of the care recipient was linked to greater stigma.[27] It is plausible that when people perceive the care recipient as highly dependent, they more readily recognize the condition as an illness, which may be associated with reduced stigma. However, it is also well established that higher dependence of the care recipient can lead caregivers to report negative outcomes.[66] Thus, while experiencing less stigma on one hand, caregivers may simultaneously feel overwhelmed by the burden of care. For these reasons, the implementation of awareness campaigns is of considerable importance. In this way, breaks taken by caregivers could yield more positive effects. Additionally, even if the care recipient is not highly dependent on the caregiver, it should be recognized that an underlying condition may still be present.

In this review, the examined studies reveal inconsistent findings regarding the relationship between demographic variables and stigma. While some studies found that female caregivers reported higher levels of stigma,[24,40,47] others indicated that male caregivers experienced greater anxiety and caregiving burden associated with stigma.[27] This suggests that there may be gender-based differences in stigma and that stigma may be internalized and expressed differently depending on gender. In terms of age, contradictory results were also reported. Some studies noted that older caregivers reported higher levels of stigma,[24,40] whereas another study found that younger caregivers reported greater stigma.[27] This may indicate that different stages of the life cycle, the meanings attributed to the caregiving role, and the availability of social support resources influence the experience of stigma.[67] Regarding educational level, caregivers with higher education were found to report greater stigma.[24,40] This finding may be explained by the possibility that individuals with higher education are more sensitive to societal perceptions[68] or engage more frequently in social comparison processes.[69]

From a clinical perspective, the findings that lower dependence in daily activities,[27] longer duration of illness,[24,40] and specific dementia types (e.g., frontotemporal dementia)[46] are associated with greater stigma indicate that stigma is not solely a function of disease severity but may be shaped by societal recognition and interpretation of symptoms. The mediating roles of spiritual coping, stigma-related stress, and stigma itself in the relationships between functional impairment, behavioral symptoms, and caregiver outcomes underscore the need to address both psychosocial and emotional processes in intervention strategies.[43] Collectively, these findings highlight that stigma among dementia caregivers is multifactorial, emerging from the interplay of personal attributes, relationship contexts, and care recipient characteristics. Future research should adopt an integrative approach to examine these factors simultaneously, allowing for more targeted and effective interventions to reduce stigma and its adverse consequences.

The findings underscore the complex interplay between stigma, caregiver burden,[27,39,40] psychological well-being,[47] and quality of life[45] among caregivers of IWD. Consistent with previous literature, the observed associations between affiliate stigma, caregiver burden, and psychological distress suggest that stigma not only exacerbates the emotional toll of caregiving but may also indirectly impair caregivers' quality of life through increased burden and distress. The identification of sequential mediating effects further indicates that stigma operates through multiple pathways, potentially triggering a cascade of psychological strain that ultimately diminishes well-being. Of particular interest is the finding that family stigma emerged as a key determinant of burden and quality of life in caregivers of individuals with early-onset dementia, even after controlling for disease-specific and demographic factors.[46] This emphasizes the salience of societal perceptions and social identity in shaping caregiving experiences, irrespective of clinical variables. Moreover, the association between specific burden types (e.g., time-dependent, developmental, physical) and higher levels of affiliate stigma suggests that the nature of caregiving demands may influence caregivers' internalization of stigma.[48] The moderating role of low affiliate stigma on coping efficacy provides a promising avenue for intervention, as reducing stigma may enhance caregivers' ability to cope effectively and, in turn, improve care recipients' health outcomes.[44] Taken together, these findings highlight the necessity of multifaceted intervention strategies that not only target the reduction of stigma but also address caregiver burden and coping mechanisms in an integrated manner.

Determining variables related to stigma may lead to the development of interventions targeting stigma. It has been stated that further research is still needed to identify effective approaches to reduce dementia-related stigma.[70] For example, while some studies indicate that a lack of knowledge plays an important role in stigma,[71] other studies suggest that lack of knowledge is not a determinant.[72] In other words, identifying variables related to stigma and translating them into intervention components is essential. In this context, it is thought that implementing psychoeducational and even social interventions related to dementia is important.[73]

When the limitations of the study are evaluated, the fact that the search was conducted using specific keywords in selected databases may constitute a limitation. In addition, although the characteristics of the included articles were examined, no assessment of study quality was performed. Considering that 11 of the included studies were cross-sectional, the findings primarily reflect correlations and do not allow for causal inferences.[74] Moreover, only quantitative studies were included in this review, and findings from qualitative research were not incorporated. In light of these limitations, there is a clear need for longitudinal studies on stigma among caregivers of individuals with dementia. Furthermore, evaluating study quality and including qualitative research in future systematic reviews are expected to provide more comprehensive insights.

Although dementia is a global condition,[2] research in this area remains limited. Addressing stigma experienced by caregivers of individuals with dementia in different countries is an important direction for future studies. Conducting research on stigma and identifying related variables may also facilitate the development of effective interventions. The availability of valid and reliable stigma-related measurement tools is crucial for identifying factors associated with stigma. However, the scales identified within the scope of this systematic review have not been adapted into many languages. Therefore, cultural adaptation of frequently used stigma scales in the literature is needed. Additionally, among the 12 studies reviewed, distinctions regarding dementia type and severity were limited. This is notable, as caregivers are known to experience different challenges depending on dementia type and severity.[59,75] The closeness of the caregiver to the individual diagnosed with dementia is also an important factor.[76] Accordingly, future stigma research should more clearly address dementia type, dementia severity, and caregiver–care recipient relationship characteristics.

Although there are studies examining stigma experienced by caregivers,[33,34] it is striking that no prior systematic review has specifically focused on dementia. This is noteworthy, as previous research has emphasized that stigma is a priority issue in dementia research.[36] Moreover, the increasing prevalence of dementia worldwide and its projected rise in the coming years further highlight the importance of dementia-related issues.[1] Given that healthcare systems are already considered insufficient under current conditions,[77] it is anticipated that systemic challenges will intensify as prevalence increases.[1] As a result of these systemic constraints, the need for care provided within the close social networks of individuals with dementia is expected to increase. This underscores the importance of caregiver well-being, as better caregiver well-being is associated with higher-quality care.[31] In addition to its negative effects on caregivers' psychological health,[27,28,29] stigma represents one of the most significant barriers to help-seeking.[78] In the context of a condition such as dementia, where early diagnosis is crucial,[79] investigating stigma is essential to overcoming help-seeking barriers and identifying factors related to caregivers' psychological health.

Conclusion

In conclusion, this systematic review addresses stigma perceived by caregivers of individuals with dementia and the factors associated with it. The reviewed studies indicate that stigma is influenced by cultural context, caregiver–care recipient relationships, and various dementia-related factors. Despite the significant impact of stigma on caregivers, the literature on this topic remains limited. There is a particular need for cross-cultural studies and research that distinguishes between different dementia types and stages. The findings highlight the importance of longitudinal and mixed-method research, cultural adaptation of stigma measurement tools, and the development of psychoeducational and social interventions aimed at reducing stigma. As the global prevalence of dementia continues to rise, addressing caregiver stigma is essential not only for improving mental health outcomes but also for enhancing the quality of care provided to individuals with dementia. Future research should adopt integrative approaches that simultaneously target stigma reduction, caregiver burden, and coping strategies, thereby fostering caregiver resilience and improving outcomes for care recipients.

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