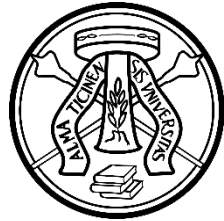


UNIVERSITY OF PAVIA – IUSS SCHOOL FOR ADVANCED STUDIES PAVIA

**Department of Brain and Behavioral Sciences (DBBS)
MSc in Psychology, Neuroscience, and Human Sciences**



**UNIVERSITÀ
DI PAVIA**



IUSS

**THE IMPACT OF CAREGIVER-AFFILIATE STIGMA ON PSYCHOSOCIAL
WELL-BEING IN CAREGIVERS OF INDIVIDUALS WITH
NEURODEGENERATIVE DISORDERS: A SCOPING REVIEW**

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1. Abstract

Caregiver-affiliated stigma in neurodegenerative disorders (NDDs) profoundly affects caregivers' well-being, though its full impact remains to be fully elucidated. This scoping review aims to consolidate current knowledge on caregiver-affiliated stigma in NDDs, explore its connection to caregiver psychosocial well-being, and pinpoint gaps in existing research. Adhering to PRISMA-ScR guidelines, a comprehensive search of five databases was conducted for peer-reviewed, English-language studies focusing on caregiver-affiliated stigma in NDDs. The initial search yielded 9,033 articles, with 19 meeting the inclusion criteria after rigorous screening. Bronfenbrenner's ecological systems theory was employed to analyze various stigma conceptualizations, encompassing public, courtesy, affiliate, and family stigma. Analysis revealed a correlation between elevated levels of affiliate stigma and increased caregiver burden, deteriorated mental health outcomes, and diminished quality of life. The internalization of stigma was found to vary across demographic groups, influenced by factors such as education level and social support. The review also highlighted the mediating role of coping strategies and the protective function of social support against stigma internalization. These findings underscore the necessity for targeted, culturally sensitive interventions that address caregiver-affiliated stigma across multiple ecological levels. This review contributes to a more nuanced understanding of caregiver-affiliated stigma in NDDs, laying the groundwork for future research and intervention development aimed at enhancing caregiver well-being in diverse cultural contexts.

2. Introduction

Global population demographics are shifting towards an aging population, with projections indicating that by 2050, individuals over 65 will become 16% of the worldwide population, doubling the number of children under the age of 5. This statement translates to an estimated growth from 771 million individuals above 65 in 2022 to 1.6 billion by 2050 (“World Population Prospects 2022,” 2022). The ongoing phenomenon is accompanied by an increasing prevalence of Neurodegenerative Disorders (NDDs) like Alzheimer's disease (AD), Parkinson's disease (PD), and motor neuron disease, which are the most prevalent (Mayeux, 2003; Sotoudeh et al., 2021). These disease are characterized by the progressive loss of neuronal functions and are becoming more prevalent with time (Zaib et al., 2023)

NDDs impact significantly different aspects of human functions, often limiting the ability to perform basic tasks. The nature of these disorders frequently prevents the possibility of remission (Lamprey et al., 2022). With over 55 million people worldwide currently living with dementia and the alarming annual increase of approximately 10 million cases every year, NDDs are a growing public health concern. This prevalence, together with the dependence associated with dementia, positions it as a significant contributor to the growing pressure on healthcare systems and the need for support for older adults (World Health Organization: WHO & World Health Organization: WHO, 2023).

The most common form of dementia is AD (World Health Organization: WHO & World Health Organization: WHO, 2023) which is characterized by the accumulation of specific protein deposits in the brain. AD's two main pathological hallmarks are the extracellular plaques composed of β -amyloid peptides and intracellular neurofibrillary tangles containing hyperphosphorylated tau protein (Selkoe & Hardy, 2016). These accumulations lead to a cognitive decline and impairment in reasoning, memory, and language skills (Selkoe, 2001; Selkoe & Hardy, 2016). These pathological changes are the result of altered processing of amyloid precursor protein, which leads to the formation of insoluble β -amyloid fibrils that disrupt synaptic signaling and promote neuroinflammation. The combination of synaptic dysfunction, neuroinflammation, and oxidative stress ultimately results in the degeneration and loss of neurons (Giri et al.,

2024; Hardy & Selkoe, 2002). Recent research has shown the complex interplay of genetic factors, environmental influences, and lifestyle choices in the onset and progression of Alzheimer's disease (Holtzman et al., 2011).

PD is a progressive neurological disorder characterized by tremors, muscle stiffness, and movement difficulties (Lampthey et al., 2022). It is the second most common NDD, with a complex etiology that involves genetic and environmental factors (Wirdefeldt et al., 2011). The motor deficit associated with PD is primarily due to the degeneration of the dopaminergic neurons in the substantia nigra, leading to the loss of dopamine in the striatum (Elbaz et al., 2016). Recent research suggests a more complex progression of the disease, potentially starting years before the motor symptoms appear (Logroscino et al., 2022).

Amyotrophic lateral sclerosis (ALS), is a progressive motor neuron disease that affects the motor neurons in the brain and spinal cord. This leads to the destruction of nerve cells and the degeneration of muscles (Morris, 2015). While most cases of ALS are sporadic, around 5-10% of them are inherited due to mutations in genes such as C90RF72 and SOD1 (Giri et al., 2024).

The impact of these disorders is far-reaching, contributing to the growing burden of NDDs on individuals, families, caregivers, and healthcare systems worldwide. The complexity of NDDs comes from the complex interaction between genetic, epigenetic, and environmental factors (Agnello & Ciaccio, 2022). Caregivers play a vital role in managing the daily lives of those affected by NDDs (Barello et al., 2019; Morelli et al., 2019). In this context, it is important to distinguish between formal and informal caregivers. This scoping review will focus on informal caregivers, who are typically unpaid individuals who assist with activities of daily living or instrumental activities of daily living of a person with chronic illness or disabilities, often family members or friends. In contrast, formal caregivers are paid for their service (Roth et al., 2015). Both of these roles come with significant stress. Research suggests that caregivers experience significant psychological stress, often exceeding the physical strain (Schulz & Sherwood, 2008). Factors like the caregiver's mental and physical health, personal resources, and social support significantly influence their ability to cope with these challenges (Aschieri et al., 2021; Huang et al., 2024; Schulz & Sherwood, 2008; Stajduhar et al., 2008).

While the Organization for Economic Cooperation and Development (OECD) countries typically offer support to informal caregivers following the line of providing information, counseling, training, and respite care, finding these resources can be challenging for caregivers. Additionally, countries often focus on providing information to the general public rather than offering counseling or training due to possible logistic difficulties in the implementation process. The common solution for this matter is collaborating with non-governmental organizations (NGOs). Respite care, or taking time away from caregiving responsibilities, is perceived as the most common and important support that is given to caregivers, as it directly addresses their burden. (Rocard & Llana-Nozal, 2022).

The specific challenges experienced by caregivers can vary depending on the nature of the disease and their individual situations. Depending on the nature of the stressor, there will be different levels of burden and depression symptoms (Roland & Chappell, 2019). For instance, research indicates that caregivers of individuals with NNDs are particularly vulnerable to depression (Kim, 2017; Lee et al., 2021; Roland & Chappell, 2019), with prevalence exceeding 30% in the case of AD. The most significant predictors for depressive symptoms were the caregiver's personal resources, poor health status, and low self-rated adequacy of performance as caregivers (Zanetti et al., 1998). Studies have also shown that an increase in problematic behaviors among individuals with dementia, especially those in long-term care settings, is strongly associated with worse mental and physical health for the caregiver (Hooker et al., 2002).

While being a caregiver presents a wide range of difficulties, it also has positive outcomes in the caregiver's life. Often, caregivers find meaning and purpose in their role, reporting feelings of being needed, useful, and personal growth (Lee et al., 2021; Zanetti et al., 1998). Caregiving can foster a deeper appreciation for life, a more positive outlook, and strengthened relationships (Cohen et al., 2002; Graffigna et al., 2021; Guida et al., 2019; Tarlow et al., 2004). A systematic review of studies using the Positive Aspects of Caregiving Scale (PACS) by Lee and Li (2022) further supports the notion that recognizing these positive aspects of their role is associated with better mental health outcomes, higher levels of well-being, and life satisfaction. Overall, it contributes to a lower caregiver burden.

Understanding the complex interaction between the challenges and rewards of caregiving is crucial for assessing their impact on well-being. In this matter, it is essential to highlight the concept of quality of life (QoL). Felce and Perry (1995) describe QoL as a concept that covers a broad spectrum, including objective descriptors and subjective valuations of physical, material, social, and emotional well-being, together with the extent of personal development and purposeful activity, all influenced by an individual set of values. These three elements are in a constant dynamic interaction with each other. For caregivers of people with NDDs, QoL can be significantly affected. Research has also shown a link between declining QoL in caregivers and increasing disease severity in the individuals they care for (Martinez-Martin et al., 2008). This suggests that as the condition of the person with NDD worsens, the caregiver's QoL often suffers as well.

A significant challenge inherent in the caregiving experience for individuals with NDDs is the phenomenon of stigma. Stigma, as defined by Andersen et al. (2022), is a social phenomenon characterized by labeling, negative stereotyping, linguistic separation, and power asymmetry. Building upon this concept, caregiver-affiliated stigma, a term that will be used throughout this review, refers to the process by which individuals closely associated with stigmatized persons, such as caregivers, internalize societal biases related to the NDD. This internalization can lead to feelings of unhappiness, helplessness, and self-perceived negativity, potentially resulting in social withdrawal, isolation, and ultimately, a decline in QoL (Mak & Cheung, 2008; Zhang et al., 2018).

The literature reveals diverse types of stigma relevant to NDD caregivers, defining them would help to understand the caregiver-affiliated stigma fully. Some of the main concepts are courtesy stigma or stigma by association, family stigma, self-stigma, and public stigma. Public stigma refers to the negative reactions from society directed at stigmatized individuals (Corrigan & Watson, 2002). Courtesy stigma, also known as stigma by association, involves prejudice and discrimination which is extended to individuals because of their connection to someone stigmatized (Goffman, 2009). Family stigma specifically addresses the stigma experienced by family members due to their association with a relative who has a stigmatized condition (Werner et al., 2012), and self-stigma is the internalization of the stigma within oneself (Hu et al., 2023).

Given the multifaceted nature of caregiver-affiliated stigma, researchers evaluating this concept have employed a combination of measurement tools. These include the Affiliate Stigma Scale (ASS) (Mak & Cheung, 2008) and variations of caregiver burden measurements such as the Caregiver Burden Inventory (CBI) (Novak & Guest, 2015) and the Zarit Burden Interview (ZBI) (Zarit et al., 1980). Finally, instruments designed to assess depressive and anxious symptomatology are frequently incorporated to provide a more comprehensive understanding of the psychological impact on caregivers and their QoL (Chang et al., 2015; Saffari et al., 2019).

Research on caregiver-affiliate stigma in NDDs has been growing in recent years, reflecting increased recognition of its importance. However, the field is still evolving, with several key areas requiring further investigation. Studies have shown that caregiver-affiliate stigma is associated with negative outcomes (Werner et al., 2012) and some measurements for this construct have seen some standardization with the development of scales like ASS (Mak & Cheung, 2008) and the Family Stigma in Alzheimer's Disease Scale (FS-ADS) (Werner et al., 2011).

Despite growing recognition of the caregiver-affiliate stigma in NDDs, its definition remains fragmented and the translation of research findings into policies and interventions is still developing. While some nations have incorporated caregiver support into their national dementia strategies, such as the World Health Organization's Global Action Plan on the Public Response to Dementia 2017-2025 which includes provisions for supporting caregivers against discrimination and burn-out (Dua et al., 2017), specific measures addressing stigma are often lacking. Research on interventions specifically targeting caregiver-affiliated stigma is limited, studies tend to describe general approaches for stigma such as psychoeducational programs, community awareness campaigns, and support groups (Milne et al., 2014).

The lack of a comprehensive understanding of how caregiver-affiliated stigma specifically influences well-being in caregivers of individuals with NDDs hinders the development of effective interventions and support systems tailored to address the needs of caregivers experiencing affiliated stigma. For these reasons, there is a need to systematically map the definitions of stigma to better measure and intervene to prevent this phenomenon.

2.1 Aims and Objectives

This scoping review aims to comprehensively map the existing literature on the impact of caregiver-affiliated stigma of caregivers for individuals with NDDs, on their psychosocial well-being. More specifically this review aimed to: (1) Examine the relationship between affiliated stigma and caregiver psychosocial well-being; (2) Identify and synthesize existing definitions and conceptualizations of caregiver-affiliated stigma and related concepts within the context of NDDs through the lenses of Bronfenbrenner's ecological systems theory and (3) Identify knowledge gaps in the existing literature, highlighting areas where further investigation is needed. Finally using Bronfenbrenner's ecological system theory, we discuss the review results to identify possible lines of interventions to prevent the caregiver-affiliated stigma phenomenon.

3. Methods

3.1 Study Design

A scoping review methodology was adopted guided by the methodological framework outlined by Arksey & O'Malley (2005) and further developed by Peters et al. (2022) in nine key stages: (1) Defining and aligning the objective/s and question/s; (2) Developing and aligning the inclusion criteria with the objective/s and question/s; (3) Describing the planned approach; (4) Searching for evidence; (5) Selecting the evidence; (6) Extracting the evidence; (7) Analysis of the evidence; (8) Presentation of the results, and (9) Summarizing the evidence. Moreover, this scoping review adhered to the PRISMA -ScR guidelines (Tricco et al., 2018) to ensure a systematic and comprehensive approach.

3.2. Eligibility Criteria

The review included peer-reviewed studies published in English, with no time limitations, that focused on primary caregivers of individuals diagnosed with any NDDs. Studies were required to be quantitative and to address caregiver-affiliate stigma in the context of NDDs and its impact on psychological well-being, including but not limited to the concepts of affiliate stigma, courtesy stigma or stigma by association, family stigma, and caregiver stigma. Inclusion criteria specified the use of validated measures of stigma

and psychosocial well-being, as well as reported quantitative outcomes related to the impact of stigma on caregiver well-being.

Studies were excluded if they did not specifically address caregiver-affiliate stigma or the related concepts mentioned in the inclusion above, focused solely on the stigma experienced by individuals with NDDs, or lacked outcomes related to psychosocial well-being.

3.3. Types of Sources

The search strategy included electronic databases (PubMed/MEDLINE, PsycINFO, Embase, CINAHL, Scopus), gray literature sources (Google Scholar, ProQuest Dissertations and Theses, and relevant organizational websites), and reference lists of included studies and relevant reviews.

3.4. Search Strategy

A comprehensive search was made across five electronic databases: Pubmed, Embase, CINAHL, PsycInfo, and Scopus. The search strategy incorporated keywords and MeSH terms related to caregiver-affiliated stigma, neurodegenerative disorders, and psycho-social well-being. Boolean operators were utilized to link search terms within and between concepts.

3.5. Source of Evidence Selection

Two independent reviewers screened titles and abstracts for relevance using Rayyan.ai, a web, and mobile app for systematic reviews. The platform's collaborative features allowed for efficient conflict resolution and progress tracking. Full-text articles were assessed against eligibility criteria. Any discrepancies were resolved through discussion between the two reviewers or, when necessary, through consultation with a third reviewer.

The study selection process, including the number of studies identified, screened, assessed for eligibility, and included in the final analysis, is illustrated in the PRISMA flow diagram (Figure 1).

3.6. Data Extraction

Data was extracted using a standardized form, including study characteristics (e.g., author, year, study design), participant characteristics, stigma measurement tools and definitions, outcomes related to caregiver psychosocial well-being, and key findings.

3.7. Data Synthesis and Analysis

Findings were synthesized with a narrative approach, guided by Bronfenbrenner's ecological system theory. Bronfenbrenner's model proposes four interconnected systems influencing human development and behavior: microsystem, mesosystem, exosystem, and macrosystem (Bronfenbrenner, 1979). This framework was applied to classify and analyze different types of stigma identified in the literature.

The synthesis focused on mapping the conceptualizations of stigma on these ecological levels, providing a structured understanding of caregiver-affiliated stigma in NDDs. This theoretical framework was chosen due to its capacity to elucidate the multiple levels at which stigma operated, from individual experiences to broader societal attitudes. This approach allows for a more nuanced understanding of how different forms of stigma interact and influence caregiver well-being, potentially informing more comprehensive and effective interventions.

4. Results

As presented in the PRISMA flow diagram (Figure 1), the initial database search resulted in 9,033 articles across the five databases (Scopus: 3,490; PubMed; 3,098; Embase: 1,182; CINAHL: 643; PsycInfo: 620). After the process of removing duplicated and screening titles and abstracts, 24 full-text articles were assessed for eligibility. In the

end, 19 studies met the inclusion criteria and were included in the final analysis.

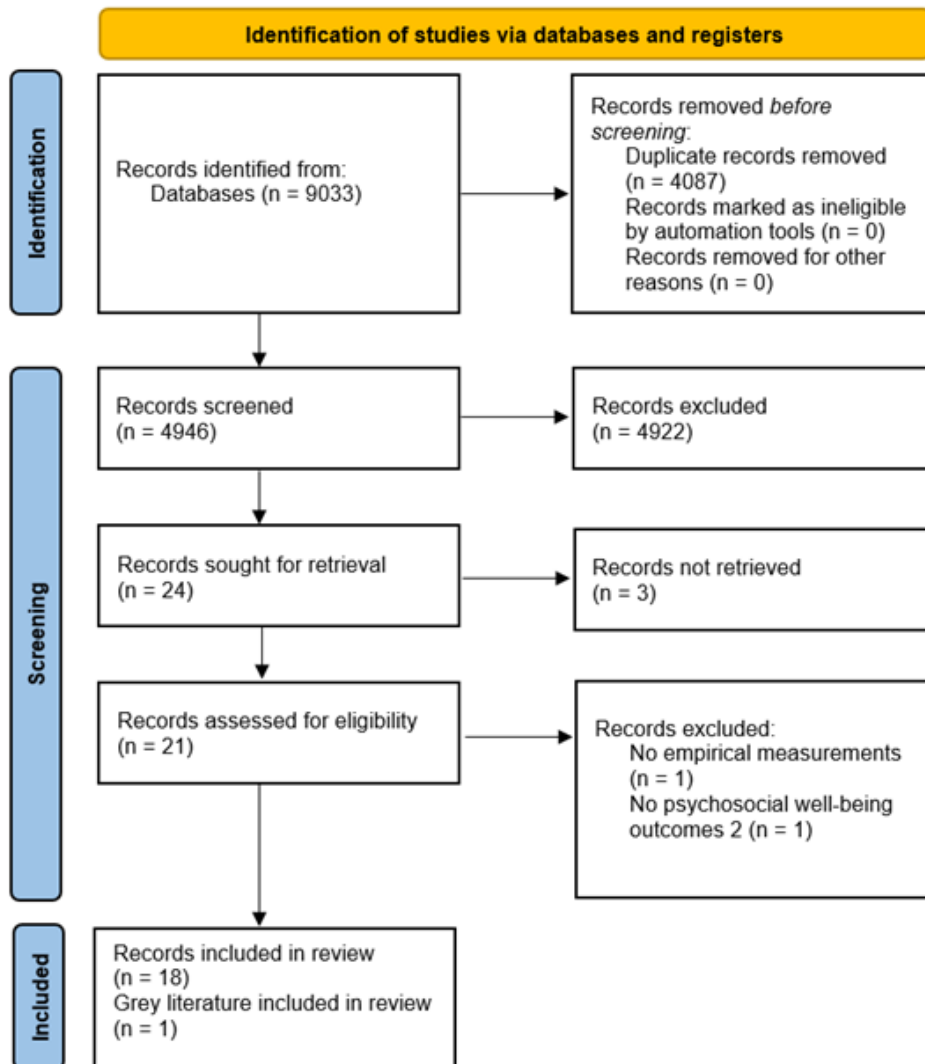


Figure 1. PRISMA Flow Diagram for Identification, Screening, Eligibility and Inclusion.

Table 1. *Characteristics of Included Studies on Caregiver-Affiliated Stigma in Neurodegenerative Disorders*

Author & year of publication	Country of study	Study population	Sample size	Aim of the study	Study design	Instruments used	Type of stigma & definition
Bhatt et al., 2022	United Kingdom	Family carers of individuals with primary progressive dementia.	70	To investigate the validity of the Family Stigma Instrument (FAMSI), and use it to explore the extent to which experiences of stigma are endorsed in family carers of people living with dementia.	Cross-sectional	FAMSI Rosenberg Self-Esteem Scale (RSES) Demographics Questionnaire	Stigma by association or Courtesy stigma: Refers to the stigma directed towards individuals because of their association with a stigmatized person. Affiliate stigma: Involves the internalization of stigma by association.
Brundige, 2022	United States	Husband/male long-term cohabitating life partner caregivers of	72	To examine whether high gender role conflict and stigma by association in husband/male life partner caregivers of women with	Cross-sectional	Geriatric Depression Scale (GDS) Bem Sex Role Inventory (BSRI)	Stigma by association: the prejudice and discrimination that is extended to people not because of some mark that they manifest, but rather because

women with
AD

Alzheimer's disease are
significantly related to
their vulnerability to self-
isolation

Family Stigma in
Alzheimer's
Disease Scale-
Caregiver section
(FS-ADS-C)

they are somehow linked to a
person with the stigmatized
mark

Marwit-Meuser
Caregiver Grief
Inventory Worry
and Felt Isolation
subscale (MMCGI-
WFI)

Multilevel
Assessment
Instrument – Social
Interaction subscale
(MAI-SI)

Chang et al., 2016	Taiwan	Caregivers of family members	271	To examine the psychometric properties of the ASS when used with	Cross-sectional	ASS	Structural stigma: the imbalances and injustices in social structures.
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diagnosed with dementia.

caregivers of family members diagnosed with dementia.

Taiwanese Depression Questionnaire (TDQ)

Public stigma: the negative reactions from the general population towards a stigmatized group

CBI

Self-stigma: internalization of the public stigma.

28-item World Health Organization Quality of Life Questionnaire (WHOQOL-BREF)

Courtesy stigma: prejudice and discrimination that are extended to people due to their relationship with a person with a stigmatized mark

Beck Anxiety Inventory (BAI)

Affiliate stigma: the internalization of courtesy stigma.

Chen et al., 2023

Taiwan

Dyads of people with

261

To investigate the mediating roles of

Cross-sectional

CBI

Affiliate stigma: for of internalized stigma.

ASS

dementia and their informal caregivers.	caregiver burden and affiliate stigma in the relationship between neuropsychiatric symptoms of people with dementia and the mental health outcomes (depression and anxiety) of their caregivers	TDQ BAI Neuropsychiatric Inventory (NPI).	Courtesy stigma: caregivers become stigmatized because of their family member's mental illness.
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Ellin et al., 2023	Malaysia	Caregivers of patients with dementia.	178	To assess the impact of affiliate stigma on the psychological well-being of caregivers of patients with dementia.	Cross-sectional	ASS Psychological Well-Being (PWB)	Caregiver stigma: negative perceptions and stigma among caregivers. It can be classified as associative or affiliate stigma. Associative stigma: stigmatization of a family member due to their association with the patient. Affiliate stigma: known as self-stigma.
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Hu et al., 2023	Taiwan	Family caregivers of individuals with dementia.	275	To explore the associations between affiliate stigma, caregiver burden, psychological distress, and QoL among family caregivers of people with dementia.	Cross-sectional	CBI WHOQOL-BREF ASS BAI TDQ	Affiliate stigma: type of stigma with features of courtesy stigma and self-stigma. Courtesy stigma: suffering from stigma due to the connection, association, or relationship with a stigmatized group. Self-stigma: endorsing and internalizing stigma within oneself.
Jeong et al., 2020	South Korea	Family caregivers of individuals with Alzheimer's or other forms of dementia.	226	To investigate the relationship between family caregivers, examining whether this relationship was mediated by the caregiver's enhanced coping efficacy	Cross-sectional	Information Cross-Checking Modified Coping Efficacy Scale ASS	Affiliate stigma: internalized stigma.

and moderated by the caregiver's affiliate stigma.

Modified Physical Coping Outcome Scale

Courtesy stigma: stigma from social association with a stigmatized individual

Liu et al., 2014	United States	Caregivers of persons with dementia in the early stages of the disease	51	To examine the relationship between perceived stigma and depressive symptoms among caregivers of persons with dementia.	Longitudinal	Mini-Mental State Examination (MMSE), Clinical Dementia Rating Scale (CDR), Knowledge of Alzheimer's Test Family Version (FKAT), Revised Memory and Behavior Problems Checklist (RMBPC),	Perceived stigma: the labeling behaviors of others which brings an internalization process and results in negative consequences Courtesy stigma: Family members experienced stigma due to their association with
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						Adapted Stigma Impact Scale (SIS)	persons with mental illness or dementia.
						Center for Epidemiologic Studies Depression Scale (CES-D)	
Saffari et al., 2018	Iran	Primary caregiver of older adults with dementia	664	To examine if and how spiritual coping and stigma-related family stress impacted the associations between the patient activities of daily living impairment and caregiver mental health	Longitudinal	ZBI Spiritual Coping Strategies (SCS) Lawton Instrumental Activities of Daily Living Scale (IADL) Short Form 12 (SF-12) MMSE	Social stigma: social stigmatization directed toward a person due to their neurological condition.

						Hospital Anxiety and Depression Scale (HADS)	Family stigma: Extension of the social stigma to the family.
						Family Stigma Stress Scale (FSSS)	
Saffari et al., 2019	Iran	Caregivers of older adults with dementia.	541	To establish the psychometric properties of the ASS among Iranian caregivers of people with dementia.	Cross-sectional	ASS ZBI HADS SF-12 RSES Multidimensional Scale of Perceived Social Support (MSPSS)	Courtesy stigma: the individual is affiliated with a stigmatized group. Public stigma: the negative reactions from society toward stigmatized people. Affiliate stigma: when the negative reactions are internalized Family stigma: when the caregiver is a family member

Sommers-Spijkerman et al., 2023	Netherlands	Caregivers of patients diagnosed with Amyotrophic Lateral Sclerosis (ALS) or Progressive Muscular Atrophy (PMA).	87	To investigate the experiences of stigma among ALS/PMA patients and their caregivers, and to identify potential associated factors of stigma.	Cross-sectional	Stigma Scale for Chronic Illness (SSCI), Amyotrophic Lateral Sclerosis Functional Rating Scale-Revised (ALS-FRS-R)	Enacted Stigma: it refers to the actual discrimination, prejudice, and negative behaviors that individuals with a disease and their caregivers experience from others.
						ASS	Felt Stigma: refers to the internalization of societal attitudes by the individuals with the disease and their caregivers, leading them to feel shame, embarrassment, or fear of discrimination.
	Taiwan		270		Cross-sectional	CBI	Affiliate stigma: felt stigma experienced by the caregiver due to their association with the stigmatized person.

Su & Chang, 2020	Caregivers of a family member aged older than 65 years with any type of dementia.	To investigate the relationship between caregiver burden in family caregivers of a person with dementia and affiliate stigma as well as the demographic and clinical factors contributing to this stigma type.	ASS TDQ BAI NPI Barthel Index (BI) Clinical Dementia Rating (CDR) MMSE	Affiliate Stigma: internalization of negative societal views. Courtesy stigma or stigma by association: involves the negative behaviors from the public toward, caregivers, relatives, and health professionals associated with the patient.	
Tudose et al., 2017	Romania Family members of patients admitted to a psychiatric hospital with	76	To investigate the relationship between perceived stigma, expressed emotion (EE), and QoL among caregivers of individuals with dementia.	Cross-sectional Patient and caregiver demographics questionnaire ASS FS-ADS	Structural stigma: the imbalances and injustices in social structures, political decisions, and legal regulations.

the diagnosis
of dementia.

Involvement
Evaluation
Questionnaire
(IEQ)

Affiliate stigma: internalized
public stigma.

Van den Bossche & Schoenmakers, 2022	Belgium	Relatives of patients with a formal diagnosis of dementia.	228	To determine the impact of the affiliate stigma on the mental well-being of relatives caring for a person with dementia	Cross-sectional	ASS Items of Patient Health Questionnaire-9 (PHQ-9) Items of the 20- item CES-D.	Courtesy stigma: discrimination and prejudice that people may experience because they are associated with individuals associated with a stigmatized group. Affiliate stigma: negative feelings that relatives of stigmatized individuals develop toward themselves because they perceive the associative stigma that prevails in society
Velilla et al., 2022	Colombi a	Caregivers of patients with	151	To assess the impact of family stigma	Cross-sectional	Structured interviews about	Self-stigma: when individuals accept and internalize the

<p>early-onset Alzheimer's disease due to E280A mutation in presenilin 1 (EOAD), frontotemporal dementia (FTD), and late-onset Alzheimer's Disease (LOAD).</p>	<p>and socioeconomic factors on psychological outcomes, QoL, and caregiver burden among caregivers of patients with early-onset AD</p>	<p>the socioeconomic factors</p> <p>ASS</p> <p>Functional Assessment Staging (FAST)</p> <p>Frontal Behavioral Inventory (FBI)</p> <p>ZBI</p> <p>CES-D,</p> <p>Spielberger State-Trait Personal Inventory (STPI),</p>	<p>stigma.</p> <p>Courtesy stigma: when prejudice and discrimination extend from stigmatized people to their friends or relatives who do not present marks of the stigmatized condition.</p> <p>Family stigma: the courtesy stigma is experienced by family caregivers.</p>
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36-Item Short Form Survey (SF-36).							
Weisman de Mamani et al., 2018	United States	Caregivers of individuals with Dementia.	106	To examine the relationship among stigma, EE, and QoL in caregivers of individuals with age-related dementia.	Cross-sectional	CDR, 20-item Family Questionnaire (FQ), Quality of Life Inventory (QOLI), Modified SIS	Perceived stigma: Caregiver's perception of negative attitudes and behaviors directed towards them by others due to their role in caring for individuals with dementia.
Werner & AboJabel, 2020	Israel	Israeli Arab family caregivers of persons with dementia.	175	To examine the characteristics of family caregivers of persons with dementia who internalize courtesy stigma, and to investigate the process of this internalization.	Cross-sectional	Authors-developed courtesy and affiliate stigma scale Activities of Daily Living Scale (ADL)	Courtesy stigma: caregiver's perceptions of public stereotypes about the person with the stigmatic condition.

						IADL Cognitive Status Scale	Affiliate stigma: self-stigma experienced by the caregivers of the stigmatized person.
						Problematic Behaviour Scale	
						MSPSS	
						Cope Multidimensional Coping Inventory- short scale (MCI)	Family stigma: associated with providing care for a relative.
						Zarit Burden Interview Short Form (ZBI-SF)	
Werner et al., 2011	Israel	Children of people with Alzheimer's Disease (AD).	185	To develop and examine the validity of a scale specifically designed to	Cross- Sectional	FS-ADS,	Structural stigma: the social aspect of stigma. Caregiver stigma: intrapersonal aspect of stigma by association.

measure family stigma
associated with AD

Public stigma: reactions of
people toward a stigmatized
individual or group.

ZBI-SF

Courtesy stigma / Stigma by
association: Emotions and
beliefs of those who surround
the stigmatized person.

Problematic
Behavior Scale

Family stigma: perception of
stigma that comes from being
associated with a relative with
AD.

Self-stigma: Internalization of
ideas and the reactions of the
people personally targeted by a
stigma.

Werner et al.,
2012

Israel

Adult child
caregivers of

185

To examine whether
family stigma is a

Cross-sectional

ZBI-SF

Public stigma: Involves
perceptions and reactions of the

elderly parents
diagnosed with
probable AD.

predictor of caregiver
burden in the context of
AD

FS-ADS,

general public towards both the
person targeted with stigma.

Self-stigma: internalization of
the ideas and reactions of those
personally targeted by stigma.

Problematic
Behavior Scale

Courtesy stigma: the emotions
and beliefs of those surrounding
the stigmatized person.

Table 2. *Key Findings from Studies on Caregiver-Affiliated Stigma in Neurodegenerative Disorders*

Author	Year of publication	Key findings
Bhatt et al.	2022	Guys who strongly identify with traditional male roles and feel judged for caregiving tend to isolate themselves more. Surprisingly, working men struggled more with this than retired ones. Men dealing with their own health issues or who were new to caregiving also tended to withdraw socially. Not knowing exactly what type of dementia their wife had seemed to make men more likely to isolate too.
Brundige	2022	Higher gender role conflict and social stigma significantly increased self-isolation risk. Contrary to expectations, employed caregivers, especially those working full-time and experiencing frequent stigma, were more vulnerable to isolation than retired ones. Caregivers in the early stages (up to 12 months) and those uncertain about their wives' specific diagnosis showed greater vulnerability. Qualitative data revealed that employment was perceived as an additional burden rather than a respite from caregiving.
Chang et al.	2016	The Affiliate Stigma Scale demonstrated strong internal consistency, good construct validity with a three-factor structure and significant concurrent validity with related measures. Rasch analysis showed good item fit, with

		<p>only one potentially problematic item. These findings support the Affiliate Stigma Scale as a valid and reliable tool for measuring affiliate stigma in dementia caregivers, aligning with previous research on the scale.</p>
Chen et al.	2023	<p>Caregiver burden and affiliate stigma significantly mediate the impact of neuropsychiatric symptoms in people with dementia on caregiver mental health, particularly affecting depression and anxiety levels. Mediation analysis indicated that these symptoms indirectly affect caregiver mental health through both burden and stigma. Additionally, a sequential mediation model suggested that caregiver burden might lead to affiliate stigma, subsequently impacting mental health. The models accounted for a substantial portion of the variance in depression (52.34%) and anxiety (37.72%) among caregivers.</p>
Ellin et al.	2023	<p>Most caregivers reported low affiliate stigma and moderate to high psychological well-being. A significant negative correlation was found between affiliate stigma and psychological well-being. Female gender and middle-income status were associated with higher affiliate stigma. Affiliate stigma emerged as the strongest predictor of caregivers' psychological well-being, explaining over half of the variance.</p>
Hu et al.	2023	<p>Results supported a theoretical model where affiliate stigma was negatively associated with quality of life both directly and indirectly through increased caregiving burden and psychological distress. Caregiving burden and psychological distress were found to be sequential mediators in the relationship between affiliate stigma and quality of life.</p>

Jeong et al.	2020	Results supported a moderated mediation model where coping efficacy mediated the relationship between information cross-checking and coping outcomes. Importantly, this mediation was moderated by affiliate stigma, such that the positive effects of information cross-checking and coping efficacy on outcomes were stronger for caregivers with low affiliate stigma compared to those with high affiliate stigma.
Liu et al.	2014	There was a significant positive association between perceived stigma and depressive symptoms, both at baseline and over time. This relationship remained significant after controlling for other factors like ethnicity, location, and severity of dementia symptoms. Additionally, perceived stigma partially mediated the relationship between caregivers' reactions to dementia-related behaviors and depressive symptoms.
Saffari et al.	2018	The results showed significant indirect effects, with spiritual coping and stigma stress sequentially mediating the associations between patient functioning and caregiver anxiety, depression, burden, and mental quality of life. The mediation models explained substantial variance in caregiver outcomes. Importantly, the order of mediators mattered, with spiritual coping preceding stigma stress in significant models.
Saffari et al.	2019	The results supported the original 3-factor structure (cognitive, affective, behavioral domains) and demonstrated good psychometric properties including internal consistency, and convergent and divergent validity. The ASS showed significant correlations with caregiver characteristics like quality of life, depression, anxiety, self-esteem, and social support. A notable finding was the significant negative correlation between affiliate stigma and social support.

Sommers-Spijkerman et al.	2023	Both patients and caregivers experience enacted stigma (e.g. social exclusion, staring) and felt stigma (e.g. shame, feeling judged). Patients and caregivers used both concealing and resisting responses to cope with stigma. Factors associated with higher stigma among patients included more bulbar symptoms, intermediate disease stage, younger age, and living without a partner. Common experiences for both patients and caregivers were being stared at and feeling left out.
Su & Chang	2020	High rates of depression (23.7%) and anxiety (37.4%) among caregivers. Male caregivers experienced higher levels of anxiety and care burden related to affiliate stigma compared to females. Caring for younger PWD with lower functional dependence was associated with increased affiliate stigma. The study found a significant positive relationship between caregiver burden and affiliate stigma severity. Caregiver anxiety and overall burden emerged as the strongest predictors of affiliate stigma when accounting for various factors.
Tudose et al.	2017	Affiliated stigma rates (10.4% to 22.6%) were comparable to international findings. Caregivers reported higher burden levels than in other European studies, particularly in tension and supervision areas. Non-dementia caregivers experienced more tension, while dementia caregivers faced higher supervision burdens. Male caregivers and those caring for younger, more independent patients reported higher affiliate stigma. While most respondents (99.3%) didn't perceive professionals' attitudes as stigmatizing, 43.7% found existing services inadequate for patient needs. Caregiver anxiety and overall burden emerged as the strongest predictors of affiliate stigma.

Van den Bossche & Schoenmakers	2022	Affiliate stigma significantly affected mental well-being, with women and partners experiencing greater impacts. The duration of dementia diagnosis and caregiver age were also significant factors, with longer duration and older age associated with higher affiliate stigma. Education level had some effect, though results were mixed.
Velilla et al.	2022	EOAD caregivers had more socioeconomic risk factors, while FTD caregivers experienced higher levels of family stigma and negative outcomes. Family stigma emerged as the strongest predictor of caregiver outcomes, even after adjusting for other factors. Specifically, higher family stigma was associated with increased caregiver burden and reduced quality of life in terms of energy/fatigue and emotional well-being.
Weisman de Mamani et al.	2017	Greater perceived stigma was associated with higher levels of expressed emotion in caregivers. Higher expressed emotion was linked to poorer quality of life for caregivers. The relationship between stigma and quality of life was partially mediated by expressed emotion. Caregivers who felt more stigma engaged in more critical and emotionally overinvolved behaviors, which negatively impacted their quality of life.
Werner & AboJabel	2020	About half of the caregivers experienced affiliate stigma. Lower education, higher courtesy stigma, and lower social support were the main predictors of affiliate stigma. Social support partially mediated the relationship between courtesy and affiliate stigma. Higher education, higher courtesy stigma, and lower social support were associated with greater affiliate stigma. Social support did not moderate the relationship between courtesy and affiliate stigma.

Werner et al.	2011	The scale encompasses three main dimensions: caregiver stigma, layperson stigma, and structural stigma. For caregiver and layperson stigma, the scale confirmed cognitive, emotional, and behavioral aspects. The structural stigma dimension revealed two factors related to caregiver burden and disease severity. Overall, the FS-ADS demonstrated good reliability and validity, explaining large portions of variance in each dimension and aligning closely with theoretical foundations.
<hr/>		
Werner et al.	2012	Caregiver stigma significantly improved the prediction of caregiver burden, with shame and decreased caregiving involvement being major contributors. Adult children reported lower stigma levels compared to mental illness caregivers. The lay public dimension of stigma was most important to caregivers.

4.1. Study Characteristics

The 19 studies represented a diverse geographical distribution, encompassing multiple countries Taiwan (n=4), Israel (=3), United States (n=3), Iran (n=2), and one study each from Malaysia, South Korea, Colombia, Netherlands, Belgium, Romania, and the United Kingdoms. This geographical diversity provides a broad perspective on caregiver-affiliate stigma across different cultural contexts.

Study designs were predominantly cross-sectional (n=17), with a minority of longitudinal studies (n=2). Sample sizes varied considerably, ranging from 51 to 664 participants, with a median sample size of 185.

The majority of articles (n=16) focused on caregivers of people with various types of dementia. A smaller number of studies specifically examined caregivers of those with AD only (n=2) and one study included caregivers of patients with ALS or PMA. Notably, despite Parkinson's disease being the second most common NDD (Wirdefeldt et al., 2011), none of the 19 studies included in this review specifically focused on caregivers of individuals with Parkinson's disease. This represents a significant gap in the current literature on caregiver-affiliated stigma in NDDs.

4.2. Impact of Caregiver-Affiliate Stigma in Well-being and Determinants

Table 2 presents a summary of the key findings from the included research, demonstrating the varied effects of stigma on the caregiver's well-being. Consistently across studies, higher levels of caregiver-affiliate stigma were associated with poorer outcomes for caregivers.

Specifically:

- Mental Health: multiple studies reported significant correlations between affiliate stigma and increased symptoms of depression and anxiety among caregivers (Chang et al., 2016; Chen et al., 2023).
- Quality of Life: higher levels of stigma were linked to lower scores of QoL (Hu et al., 2023).
- Caregiver burden: there is a positive association between affiliate stigma and caregiver burden (Su & Chang, 2020; Werner et al., 2012).

4.3. Factors Influencing Stigma Internalization

The internalization of stigma varied among demographic groups and was influenced by several factors:

- Educational level: Werner and Abojabel (2020) found that lower education was associated with higher levels of affiliate stigma.
- Social support: social support emerged as an important protective factor against stigma internalization (Werner & AboJabel, 2020).
- Gender: Van den Bossche and Schoenmakers (2022) reported that women experienced greater impacts of affiliate stigma on mental well-being. However, Su and Chang (2020) found that male caregivers experienced higher levels of anxiety and care burden related to affiliate stigma compared to females.
- Relationship to care recipient: Werner et al. (2012) reported that adult children experienced lower levels of stigma compared to other caregivers.
- Age and duration of caregiving: Van den Bossche and Schoenmakers (2022) found that longer duration of dementia diagnosis and older caregiver age were associated with higher affiliate stigma.

4.4. Conceptualization and Measurement of Stigma

The analysis revealed varied conceptualizations of stigma related to NDD caregivers. Eleven distinct constructs were identified across the studies: courtesy stigma or stigma by association (n=15), affiliate stigma (n=12), family stigma (n=4), public stigma (n=4), self-stigma (n=4), structural stigma (n=3), perceived stigma (n=2), caregiver stigma (n=2), social stigma (n=1), enacted stigma (n=1), and felt stigma (n=1).

Several validated instruments were used to measure these constructs, the ASS (n=11) was most frequently employed, demonstrating good psychometric properties across different cultural contexts (Saffari et al., 2019; Bhatt et al., 2022). Other commonly used instruments included BAI (n=4), CBI, (n=4), TDW (n=4), CES-D (n=3), FS-ADS (n=3), MMSE (=3), ZBI (n=3), and various versions of the ZBI (n=6).

4.5. Terminological Inconsistencies in Stigma Conceptualization

Analysis of the included studies revealed a notable lack of consensus in the terminology used to describe internalized stigma among caregivers of individuals with NDDs. The inconsistency highlights the complex nature of stigma in the caregiving context.

Affiliate stigma, employed by Chang et al. (2016), Su and Chang (2020), and Hu et al. (2023) were frequently used to describe the internalization of public stigma by caregivers. Chen et al. (2023) utilized the term self-stigma to refer to a similar process of internalizing negative stereotypes, while Sommers Spijkerman et al. (2023) used the term felt stigma. These concepts appear to overlap with affiliate stigma, though the authors used distinct terminology.

Werner et al. (2011) introduced the concept of family stigma, specifically addressing stigma experienced by family caregivers of individuals with Alzheimer's disease. This term aimed to capture the unique dynamics of stigma within the family context of NDD caregiving. Similarly, there is the term caregiver stigma used by Ellin et al. (2023), which encompasses both internalized and perceived stigma experienced by caregivers.

Courtesy stigma and stigma by association are used interchangeably across the included literature. For instance, Bhatt et al. (2022) and Brundige (2022) both used these terms to describe stigma directed towards individuals due to their association with a stigmatized person.

Other terms were used like public stigma, and structural stigma across studies to describe different aspects of the stigma experience (Tudose et al., 2017; Werner & AboJabel, 2020).

This variability in terminology underscores the need for a more standardized approach to conceptualization and measuring the caregiver-affiliate stigma of NDDs.

For a comprehensive overview of the terminology variations and conceptualizations of stigma across the reviewed studies, please refer to Table 1.

4.6. Ecological Systems Analysis of Stigma

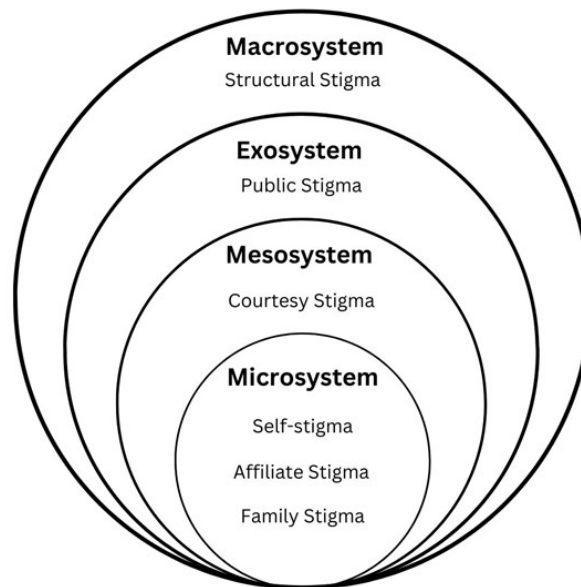


Figure 2. *Ecological Systems Classification of Stigma in Neurodegenerative Disorders Caregiving*

The use of Bronfenbrenner's ecological system theory (Bronfenbrenner, 1979) in the findings, as shown in Figure 2, reveals how caregiver-affiliated stigma operates across multiple social levels.

4.6.1. Microsystem

At the innermost level, there are the constructs that directly impact the self-perception and daily experiences of the caregivers. When talking about the internalization of stigma, four types of stigma were identified: self-stigma, affiliate stigma, family stigma, and caregiver stigma. Affiliate stigma, self-stigma, and family stigma were the most prominent concepts in the literature, warranting their inclusion at this level. While initially considered, the term caregiver stigma was ultimately excluded due to its ambiguous nature, potentially referring to both stigma directed towards caregivers and the internalization of such stigma (Ellin et al., 2023). This overgeneralization could perpetuate conceptual confusion and hinder precise analysis.

4.6.2. Mesosystem

The mesosystem refers to the interactions between different microsystems. The impact of the person being stigmatized due to their association is reflected in their isolation of other

groups by other individuals and/or themselves, this comes from their association with a stigmatized person, therefore the position of courtesy stigma in this section. Werner and Abojabel (2020) identified how factors such as family dynamics and social support networks influence the internalization of stigma. Having a strong social support network acts as a buffer against the negative effects of stigma.

4.6.3. Exosystem

At this broader level, public stigma is crucial. Van den Bossche and Schoenmakers (2022) revealed that the impact of affiliate stigma varies among demographic groups, with women and partners of those with dementia feeling more affected. These findings highlight how broader societal attitudes indirectly influence individual experiences of stigma.

4.6.4. Macrosystem

The macrosystem represents cultural attitudes and policies, therefore, the classification of structural stigma at this level. Tudose et al. (2017) talked about how societal-level factors contribute to caregiver burden and affect their QoL. Their results showed how cultural norms and healthcare policies shape the overall context in which caregivers experience and cope with stigma.

4.6.5. Interaction Across Systems

The classification of stigma types of stigma with Bronfenbrenner's framework becomes useful for understanding how stigma permeates from broad cultural norms to personal beliefs.

Starting at the macrosystem level, cultural values and societal beliefs about NDDs shape institutional practices and policies, influencing how healthcare systems and social services address the needs of individuals with NDDs and their caregivers. The exosystem serves as a conduit of these broad cultural attitudes into a more localized context. Here, public stigma is observed in community settings, workplaces, and healthcare systems, indirectly affecting caregivers even when they are not directly involved.

The mesosystem acts as a critical intermediary, where family dynamics, social networks, and immediate community interactions amplify the effects of broader stigma. The external attitudes previously directed towards the individual with NDDs, start to permeate to their caregivers. Finally, the microsystem level presents the culmination of these influences in the form of internalization of the stigmatizing attitudes they have encountered at the other levels.

The permeability between these systems is key to understanding the complex nature of stigma. Attitudes and beliefs do not simply flow top-down. There's a constant feedback loop where individuals' experiences can, over time, influence broader societal views.

4.7. Cultural Variations of Stigma Experiences.

Studies conducted in diverse cultural settings revealed both similarities and differences in stigma experiences. For example, Saffari et al. (2018) found that spiritual coping strategies played a significant role in mediating the relationship between stigma and caregiver outcomes in an Iranian context, highlighting the importance of culturally sensitive approaches to understanding the addressing of caregiver-affiliated stigma. In contrast, Jeong et al., (2020) focused on the information-seeking and efficacy beliefs as coping mechanisms when talking about the stronger outcomes for caregivers with low affiliate stigma. Taiwan presented a unique gender dynamic (Su & Chang, 2020) reporting higher levels of anxiety and care burden related to affiliate stigma among male caregivers, differing from Malaysia where Ellin et al. (2023) associated female gender with higher affiliate stigma. The Netherlands offered a broader perspective, with Sommers-Spijkerman et al. (2023) reporting on both enacted and felt stigma experienced by patients and caregivers alike, a distinction not prominently featured in studies from other countries. These findings illustrate the importance of considering cultural context in understanding and addressing caregiver-affiliated stigma in NDD

5. Discussion

This scoping review synthesized current knowledge on caregiver-affiliated stigma in the context of NDDs, providing valuable insights into its conceptualization, measurement, and impact on caregiver well-being. The analysis of 19 studies revealed significant variability in the terminology of measurement of stigma, highlighting the complex and multifaceted nature of this phenomenon.

Higher levels of caregiver-affiliated stigma were consistently associated with poorer outcomes for caregivers, including increased symptoms of depression and anxiety, lower QoL, and higher caregiver burden. These results align with broader literature on stigma in healthcare contexts, such as mental health caregiving (Corrigan et al., 2006), but also reveal unique challenges specific to NDD caregivers. For instance, the work of Werner and AboJabel (2020) with Israeli Arab caregivers emphasizes the importance of considering cultural nuances in understanding and addressing stigma. This cultural variability suggests that a one-size-fits-all

approach to stigma reduction may be insufficient, calling for culturally sensitive and context-specific interventions.

The review identified significant inconsistencies in the conceptualization and measurement of stigma across studies. The predominant use of the ASS in eleven out of nineteen studies suggests an emerging consensus around this construct. However, the use of diverse terms such as “caregiver stigma”, “family stigma”, and “self-stigma” indicates a lack of standardization in the field. This terminology inconsistency, while it reflects the complex nature of stigma, presents challenges for cross-study comparisons and meta-analyses. To address this issue, future research would benefit from efforts to harmonize the terminology. This review suggests adopting the term “caregiver-affiliate stigma” as a standardized term across future research. The use of this term would enhance conceptual clarity, improve comparisons across studies, and provide a more unified approach to understanding and addressing the stigma experienced by caregivers.

The application of Bronfenbrenner's ecological systems theory to classify stigma provides a useful framework for understanding how stigma operates at different societal levels, offering a pathway for targeted interventions:

1. **Macrosystem (Cultural Attitudes and Policies):** At this level, broader cultural beliefs and systemic policies shape the societal context in which caregivers experience stigma. Interventions at this level might focus on national or regional public awareness campaigns aimed at reducing the stigma associated with caregiving. Policy reforms could include advocacy for caregivers' mental health services and legal protections that recognize and mitigate the effects of stigma. Public health campaigns should aim to shift negative perceptions of caregivers and challenge the societal norms that reinforce stigma,

2. **Exosystem (Community and Healthcare Settings):** The exosystem level involves the indirect impact of stigma within community and healthcare environments. Interventions at this level could focus on creating stigma-reduction programs within healthcare settings, such as training for healthcare professionals to recognize and address stigma-related issues in caregiving. Community-level interventions, including peer support groups and caregiver-focused outreach programs, could help build supportive networks, reducing the isolation that often exacerbates stigma.

3. **Mesosystem (Family Dynamics and Social Networks):** The mesosystem represents the intersection of family and social networks, where family dynamics and social relationships may either buffer or exacerbate the effects of stigma. Interventions here could focus on family-based therapies and support groups that help caregivers and family members

navigate stigma together. Strengthening social networks through community engagement, providing respite care, and encouraging open communication within families could alleviate caregiver burden and reduce stigma.

4. **Microsystem (Individual Experiences and Internalized Stigma):** At the microsystem level, the focus is on the individual caregiver's internalized stigma and daily experiences. Interventions might include individual coping strategies, psychological counseling, and self-empowerment programs. Cognitive-behavioral therapy (CBT) and mindfulness training could help caregivers challenge negative self-perceptions and develop resilience against internalized stigma. Self-advocacy training could also empower caregivers to assert their needs within both family and community contexts.

This multilevel approach not only provides a comprehensive understanding of how different forms of stigma interact and influence caregiver well-being but also serves as a guide that informs targeted interventions addressing stigma at every level of society.

These findings suggest that interventions focused on enhancing coping skills and information literacy may be particularly beneficial for certain subgroups of caregivers.

While this review touched on cultural variations in stigma experiences, future research should deepen the exploration of how these differences shape caregivers' perceptions and coping strategies. Different cultural contexts may require distinct approaches to intervention. For instance, in collectivist cultures, where family reputation is central, family stigma may be more pronounced, necessitating interventions that focus on family dynamics. In contrast, individualistic societies may require interventions targeting self-stigma and personal coping mechanisms. Developing culturally sensitive tools and interventions is critical to effectively support caregivers from diverse backgrounds.

Several limitations of this review should be noted. First, the predominance of cross-sectional studies limits the ability to understand the causal relationships and long-term dynamics of stigma experience. A longitudinal perspective offers valuable insight into the evolution of the phenomena in time, as was illustrated by the study of Liu et al. (2014) which offers a view into the persistent nature of stigma's effect over time. Future research should prioritize longitudinal designs to further elucidate the temporal dynamics of stigma experiences and their impacts on caregiver outcomes. The focus on English-language publications may also have excluded valuable insights from studies published in other languages, limiting the cultural diversity of the findings. Future research should include a broader range of languages to enhance cultural inclusivity.

Additionally, despite PD being the second most common NDD (Wirdefeldt et al., 2011), none of the reviewed studies specifically addressed caregivers of individuals with Parkinson's. This represents a significant gap in the literature given the unique challenges faced by these caregivers. Future research should focus on this population to provide a more complete understanding of caregiver-affiliated stigma across NDDs.

Furthermore, while the application of Bronfenbrenner's framework offers a robust conceptual structure, future studies should expand on this by investigating how stigma intersects with other social determinants of health, such as socioeconomic status, race, and gender. Research into intersectionality could provide a more nuanced understanding of how different forms of disadvantage intensify the effects of caregiver-affiliated stigma.

The findings of this review have important implications for both practice and policy. Healthcare providers working with NDD patients and their caregivers should receive training to identify and address the stigma caregivers face. This could involve creating educational modules within healthcare training programs focused on recognizing stigma and developing supportive interventions for caregivers. Providers should also be equipped with resources to guide caregivers toward mental health support services.

From a policy perspective, the review highlights the need for comprehensive strategies that go beyond the medical management of NDDs to include the social and psychological challenges caregivers face. Policies should address caregiver well-being by funding mental health support, caregiver training, and community outreach programs. Legislative initiatives that offer financial assistance, legal protections, and healthcare benefits for caregivers would also help reduce stigma by validating their roles and experiences.

6. Conclusions

The analysis of 19 studies from diverse cultural contexts consistently revealed that higher levels of stigma are associated with increased mental health challenges, greater caregiver burden, and reduced quality of life. These findings highlight the profound negative effects that stigma can have on caregivers, emphasizing the need for targeted interventions to support this population.

A significant issue identified was the inconsistency in terminology and measurement of stigma across the studies. Terms such as "affiliate stigma", "self-stigma", and "courtesy stigma" were used interchangeably to refer to the same phenomenon, leading to confusion and hindering comparative analyses. Adopting a standardized term like "caregiver-affiliated

stigma" can enhance clarity, facilitate better communication among researchers, and improve the development of effective interventions.

Applying Bronfenbrenner's ecological systems theory provided valuable insights into how stigma operates on multiple societal levels. This multi-layered understanding suggests that interventions should not only focus on individual caregivers but also address family dynamics, community awareness, healthcare practices, and societal norms to effectively reduce stigma.

Despite these insights, there are still notable gaps in the literature. The insufficient amount of longitudinal studies limits understanding of how stigma and its effects on caregivers evolve over time. Additionally, the lack of research focusing on caregivers of individuals with Parkinson's disease, despite its prevalence among NDDs, indicates an area needing further exploration. Cultural variations in stigma experiences also underscore the necessity for culturally sensitive approaches in both research and intervention design.

These findings have important implications for practice and policy. Healthcare professionals should be trained to recognize signs of caregiver-affiliated stigma and equipped with strategies to offer appropriate support, such as counseling services and connections to support groups. Policies should acknowledge the vital role of caregivers and implement initiatives to reduce stigma, including public awareness campaigns and provisions for financial assistance or respite services.

In summary, caregiver-affiliated stigma significantly affects the well-being of those caring for individuals with NDDs. Addressing this stigma is crucial not only for improving caregivers' mental health and quality of life but also for enhancing the care they provide. The standardization of terminology and measurement approaches can improve the coherence and effectiveness of future research. Furthermore, culturally sensitive, multi-level interventions look promising for effectively reducing caregiver-affiliated stigma, ultimately leading to better health outcomes for caregivers and those they support.

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