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Stigmatisation in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) – a scoping review

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Abstract:

Objective: Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a severe chronic, multi-systemic disease characterised by post-exertional malaise (PEM), cognitive impairments and pain. There is no curative treatment yet. Stigmatisation is prevalent in several chronic illnesses, impacting patients' quality of life and health outcomes. This review aims to examine the types and effects of stigmatisation experienced by individuals with ME/CFS.

Methods: This scoping review followed the PRISMA-ScR guidelines. A systematic literature search was executed across six electronic databases, complemented by citation searching. The screening was performed independently by two researchers.

Results: We included 44 studies in this review. The most commonly assessed type of stigma was perceived stigma (n = 7); however, the majority of studies (n = 33) did not specify the type of stigma assessed. Our findings showed that not only individuals with ME/CFS can be affected by stigmatisation, but also people in their social circles such as friends and family members. Stigmatisation was reported in various areas of life, but the most frequently identified issue were stigmatising experiences by healthcare professionals such as physicians. Stigmatisation was found to contribute to poorer health outcomes, delays in diagnosis, and broader personal and societal consequences.

Conclusion: Individuals with ME/CFS can be profoundly affected by stigmatisation. Further research should investigate experiences of children and (very) severely ill patients. Research is also needed to develop strategies to reduce stigmatisation in healthcare and other settings and to improve the quality of care for individuals with ME/CFS.

Keywords:

ME/CFS; Myalgic encephalomyelitis; Chronic Fatigue Syndrome; Stigmatisation; Health care

1. Introduction

Myalgic Encephalomyelitis or Chronic Fatigue Syndrome (ME/CFS) is a debilitating and chronic multi-systemic disease characterized by the hallmark symptom of post-exertional malaise (PEM). PEM refers to an exacerbation of symptoms after even minimal physical or mental activity that can last for several days or longer (Carruthers et al., 2011; Keech et al., 2015). Individuals with ME/CFS experience additional symptoms including severe fatigue, cognitive impairments, sleep disorders, and pain (Carruthers et al., 2003; Centers for Disease Control and Prevention, 2024). Although ME/CFS was classified as a neurological disease by the World Health Organization (WHO) in 1969, its exact aetiology is still unknown. The disease needs to be differentiated from chronic fatigue, which can manifest as a symptom of a variety of other conditions. Due to a lack of diagnostic biomarkers, the diagnosis of ME/CFS is based on established international consensus criteria such as the Canadian Consensus Criteria (CCC) (Carruthers et al., 2003) and involves the exclusion of alternative diagnoses. Clinically, ME/CFS is defined by persistent fatigue lasting for at least six months in combination with the cardinal symptom PEM and the presence of further symptoms such as pain, sleep disturbances or orthostatic intolerance. To date, ME/CFS treatment is symptom-oriented, as there is no effective standard treatment or curative medication available (Carruthers et al., 2003; Collatz et al., 2016; Cortes Rivera et al., 2019; Scheibenbogen et al., 2023).

The disease is categorized into four levels of severity, ranging from mild to very severe. Even those who are mildly affected often must limit their daily activities and social interactions or reduce their work hours. In severe cases, ME/CFS can lead to bedriddenness and a permanent need for care. Consequently, ME/CFS is associated with increased rates of unemployment and disability pensions. Furthermore, the disease can severely affect quality of (Falk Hvidberg et al., 2015) (Institut für Qualität und Wirtschaftlichkeit im Gesundheitswesen, 2023). ME/CFS is estimated to affect 0.42% of the adult population in the United States, which corresponds to approximately 1.09 million adults (Jason & Mirin, 2021). As many Post-COVID patients meet the ME/CFS diagnostic criteria, prevalence can be assumed to increase as a result of the SARS-CoV-2 pandemic (Institut für Qualität und

Wirtschaftlichkeit im Gesundheitswesen, 2023; Kedor et al., 2022). The disease affects about three times as many women as men (Jason et al., 1999; Reyes et al., 2003).

This is particularly relevant, given that gender may influence societal and medical responses to chronic conditions as a contextual factor, including processes of stigmatisation (Samulowitz et al., 2018; van Alboom et al., 2023).

Stigmatisation is known to be associated with other chronic diseases such as migraine or multiple sclerosis (MS) (Pérez-Miralles et al., 2019; Young et al., 2013). While there are several definitions of stigmatisation in the literature, the term stigma usually refers to an "attribute that is deeply discrediting" (Goffman, 1963) and includes stereotyping (Link & Phelan, 2001). Stigmatisation can lead to discrimination and may negatively impact patients' quality of life and health (Corrigan, 1998; Goffman, 1963; Pérez-Miralles et al., 2019).

There are different types of stigmatisations, which are defined according to their mechanisms and effects on individuals. The most commonly reported types are public stigma, self-stigma, perceived stigma as well as experienced and enacted stigma. Public stigma includes social and psychological reactions of other people to someone with a stigmatised illness and can lead to negative behaviour towards the person, such as discrimination. Self-stigma results from the internalisation of public stigma and is therefore also referred to as internalised stigma. Perceived stigma, also known as felt stigma, consists of the assumption of negative perceptions from others or the expectation of stigmatisation by others. Experienced or enacted stigma refers to actual stigmatising experiences or behaviours (Bos et al., 2013; Brohan et al., 2010; National Alliance on Mental Illness, NAMI).

Stigmatisation in ME/CFS could further impair the already limited quality of life of those affected. Despite the global relevance of the disease, to our knowledge no reviews have examined stigmatisation in ME/CFS internationally. Therefore, the present review aims to answer the following questions: What types of stigmatisations do individuals with ME/CFS experience and how are individuals affected by them?

2. Methods

2.1 Protocol and eligibility criteria

We conducted a scoping review following the Preferred Reporting Items for Systematic review and Meta-Analysis extension for Scoping Reviews (PRISMA-ScR) guidelines (Tricco et al., 2018) and preregistered the protocol on the Open Science Framework (OSF) (https://doi.org/10.17605/OSF.IO/4FYCJ).

Eligible studies included all studies examining the stigmatisation attached to ME/CFS. In accordance with the nature of this scoping review, the results were allowed to include any study designs such as qualitative and quantitative studies as well as case reports or reviews. We limited the search to peer-reviewed full-text papers in English or German, but did not restrict the time period.

2.2 Search strategy and selection

Our search combined the constructs of stigmatisation and burden of disease to investigate whether there is a relationship between them, such as stigmatisation increasing the burden of disease. In order to ensure comprehensive coverage, keywords relating to ME/CFS were included combined with terms relating either to stigmatisation or disease burden. The two constructs were used as separate search terms rather than as intersecting criteria. This approach did not affect or limit the retrieval of studies focusing on either construct individually. However, the search results showed that existing publications examined either stigmatisation or the disease burden, but not both constructs within the same study. Consequently, we decided to report on the two topics in separate publications.

This review focuses exclusively on the stigmatisation of individuals with ME/CFS. We developed the search algorithm and the selection of databases in partnership with a librarian from the Central Medical Library of University Medical Centre Hamburg-Eppendorf (UKE) and one from the Business and Economics Library of the University of Hamburg to ensure that both the medical and economic perspectives were adequately considered. The search algorithm used in PubMed is presented in the Supplement S1. The final literature search was conducted on 6 March 2024, using the electronic

databases PubMed, Web of Science, Scopus, ABI Inform Complete, CINAHL and PsychInfo. Additionally, we conducted a snowball search based on the included studies.

All search results were extracted and duplicates were removed using Rayyan (Ouzzani et al., 2016). Two researchers (PV and SBW) independently performed the title and abstract screening, followed by a full-text screening. As there were no disagreements about the eligibility of studies, no third reviewer was consulted to reach a consensus. The search process is illustrated in Figure 1 (PRISMA flow diagram). The search was updated on 12 August 2025 using the same databases, and the corresponding screening was performed independently by two authors (PV and ND).

2.3 Data extraction & synthesis:

Two researchers (PV and CW) independently extracted data from five studies until consistency in the extracted data was achieved. Subsequent data extraction was conducted by one researcher (PV) and then cross-verified by a second researcher (CW). ND and PV extracted the additional results from the updated search. Excel was used throughout.

The collected data included authors, year of first publication, country, study design, sample size and characteristics, methods and key findings. The year refers to the year of the first publication date, including online publications of the work. In addition, we extracted the type of stigmatisation assessed and whether participants had a medical or a self-diagnosis. Moreover, we sorted all extracted data by type of construct and study design. We conducted the data synthesis following the JBI Manual for Evidence Synthesis (Peters et al., 2020) summarizing the study characteristics and findings and synthesizing them descriptively in both tables and texts.

3. Results

The search yielded 1,796 records from the databases. After removing duplicates, 832 records entered the title and abstract screening, of which 115 studies were included in the subsequent full-text screening. One full-text document could not be retrieved, and 57 records were excluded for not

meeting the eligibility criteria, resulting in 57 studies being included. Of these, 39 studies examined stigmatisation and 18 studies examined burden of disease and were therefore excluded from the present review. The subsequently conducted citation search did not identify any additional eligible stigma-related studies (Figure 1).

The search update yielded 148 additional stigmatisation-related results from the databases, including 74 duplicates. 74 studies were included in the title and abstract screening, of which 13 proceeded to full-text screening. Five of these studies remained after exclusions. As a result, a total of 44 studies were included in the present review (Figure 2).

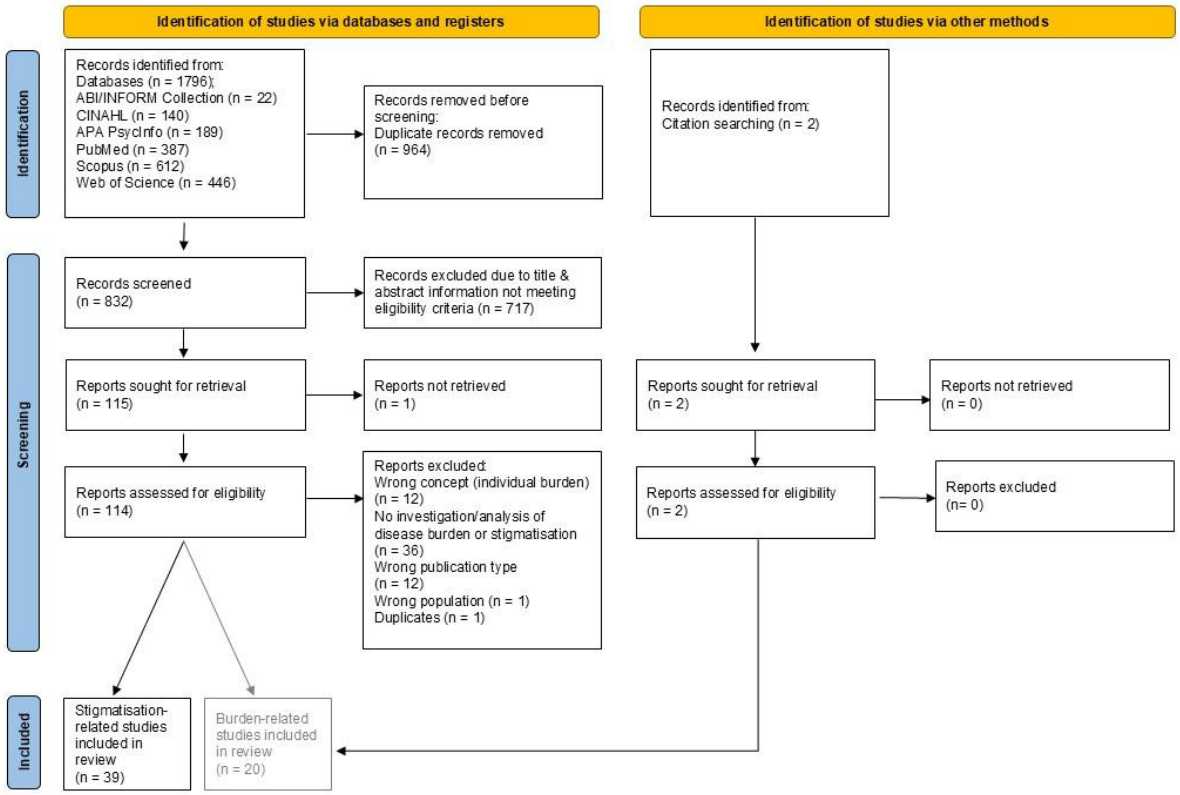

Figure 1: PRISMA flow diagram

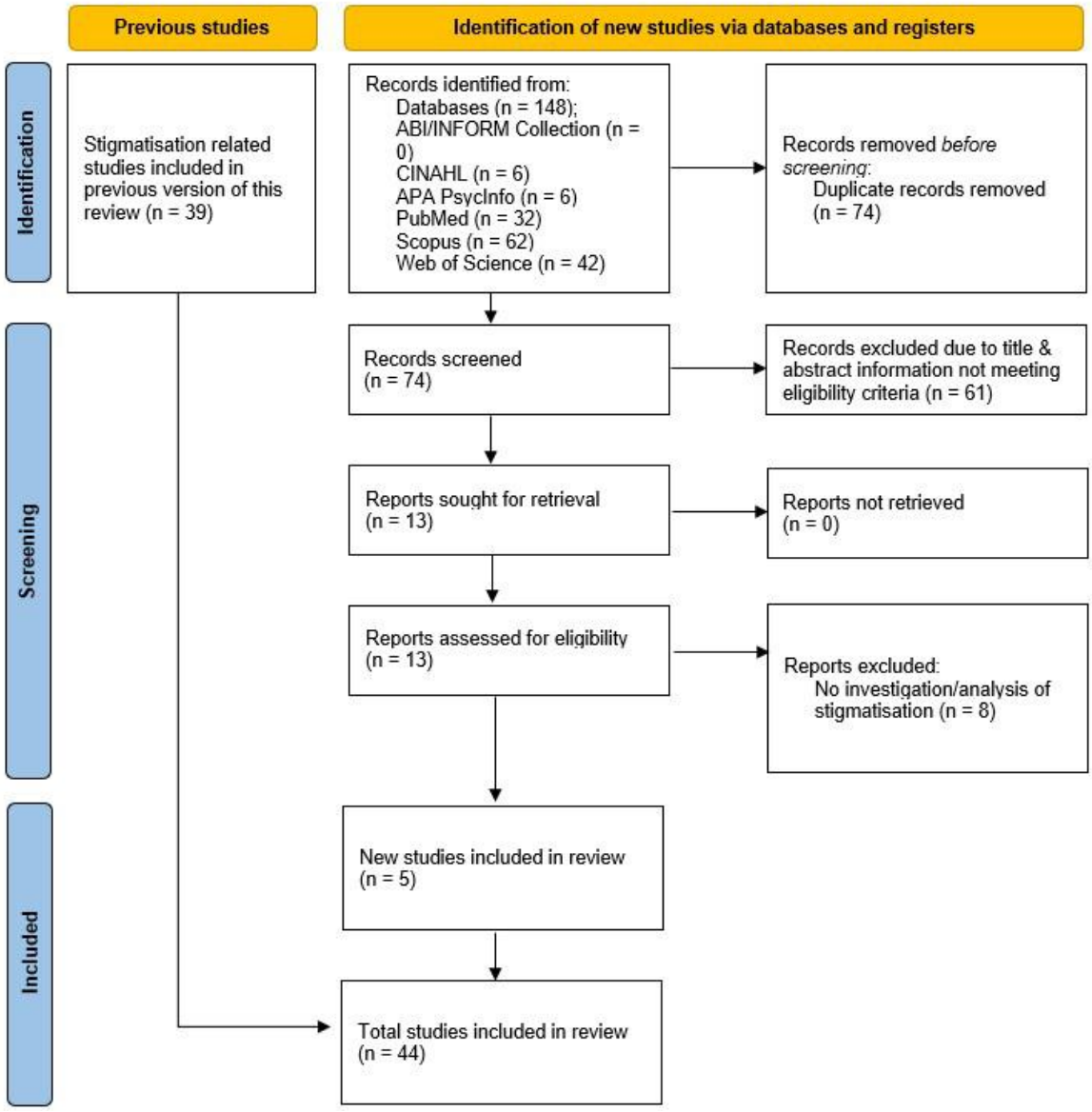

Figure 2: PRISMA flow diagram update

3.1 Characteristics of included studies

An overview of all 44 included studies can be found in Table 1. They date from 1992 to 2025 with a peak in 2021 in which six studies were published (Bartlett et al., 2022; Cheshire et al., 2021; Chu et al., 2021; Fennell et al., 2021; Froehlich et al., 2022; Waite & Elliot, 2021). This development aligns with the overall trend in ME/CFS publications on PubMed. Fifteen of the studies used a qualitative design (34%) (Alameda Cuesta et al., 2021; Arroll & Arroll, 2013; Åsbring & Närvänen, 2002; Bartlett et al., 2022; Bayliss et al., 2014; Cheshire et al., 2021; Dickson et al., 2007; Gilje et al., 2008; Hasan et al., 2024; Khalafbeigi et al., 2023; Lacerda et al., 2019; Taylor, 2005; Waite & Elliot, 2021; Ware, 1992;

Wolfe, 2012), followed by 13 studies with a quantitative design (30%) (Baken et al., 2018; Devendorf et al., 2020; Elliott & Jason, 2023; Friedberg et al., 2008; Froehlich et al., 2022; Godard et al., 2022; Green et al., 1999; König et al., 2024; Looper & Kirmayer, 2004; McManimen et al., 2018; Nehrke et al., 2017; Shlaes et al., 1999; Terman et al., 2020; Terman et al., 2019). In addition, eight studies using a mixed-methods design (18%) (Chu et al., 2021; Devendorf et al., 2020; Fennell et al., 2021; Hammond, 2002; McInnis et al., 2015; Picariello et al., 2015; Scoles & Nicodemo, 2022; Weinberg et al., 1994), seven reviews (16%) (Anderson et al., 2012; Hussein et al., 2024; Ko et al., 2022; Parslow et al., 2017; Shortland et al., 2024; Sirotiak & Thomas, 2025; Smith et al., 2014) and one viewpoint article (2%) (Bolton et al., 2025) were included. The most frequently used methods in the included studies were questionnaires, used in 20 studies (Baken et al., 2018; Devendorf et al., 2020; Elliott & Jason, 2023; Friedberg et al., 2008; Froehlich et al., 2022; Gilje et al., 2008; Godard et al., 2022; Green et al., 1999; Hammond, 2002; König et al., 2024; Looper & Kirmayer, 2004; McInnis et al., 2015; Nehrke et al., 2017; Picariello et al., 2015; Shlaes et al., 1999; Taylor, 2005; Terman et al., 2020; Terman et al., 2019; Weinberg et al., 1994) followed by interviews, used in 17 studies (Alameda Cuesta et al., 2021; Åsbring & Närvänen, 2002; Bartlett et al., 2022; Bayliss et al., 2014; Cheshire et al., 2021; Dickson et al., 2007; Gilje et al., 2008; Hammond, 2002; Khalafbeigi et al., 2023; Lacerda et al., 2019; Looper & Kirmayer, 2004; Taylor, 2005; Waite & Elliot, 2021; Ware, 1992; Weinberg et al., 1994; Wolfe, 2012). Further methods included systematic reviews, which were used in four our studies (Anderson et al., 2012; Ko et al., 2022; Parslow et al., 2017; Smith et al., 2014) case studies, which were used in three studies (Arroll & Arroll, 2013; Chu et al., 2021; Fennell et al., 2021), narrative reviews, which were used in three studies (Chu et al., 2021; Fennell et al., 2021; Sirotiak & Thomas, 2025), and scoping reviews, which were used in two studies (Hussein et al., 2024; Shortland et al., 2024). Furthermore, several approaches were used only once. These included secondary data analysis (Hammond, 2002), free text survey (Wolfe, 2012), machine learning techniques (Scoles & Nicodemo, 2022), and a viewpoint article (Bolton et al., 2025). For 15 studies, the country was not relevant as the study design was a review. Among the remaining studies, the majority were conducted in the US with seven studies (Devendorf

et al., 2020; Friedberg et al., 2008; Green et al., 1999; Nehrke et al., 2017; Shlaes et al., 1999; Taylor, 2005; Ware, 1992) and the UK (Bolton et al., 2025; Cheshire et al., 2021; Hammond, 2002; Lacerda et al., 2019; Picariello et al., 2015; Waite & Elliot, 2021; Wolfe, 2012), with seven studies each, plus one study which was a joint research effort between the US and the UK (Terman et al., 2019).

Furthermore, only 14 of the studies (31.8%) primarily focused on stigmatisation in ME/CFS (Åsbring & Närvänen, 2002; Baken et al., 2018; Dickson et al., 2007; Friedberg et al., 2008; Froehlich et al., 2022; Green et al., 1999; Ko et al., 2022; Looper & Kirmayer, 2004; McInnis et al., 2015; McManimen et al., 2018; Nehrke et al., 2017; Scoles & Nicodemo, 2022; Terman et al., 2020; Terman et al., 2019). The remaining studies (68.2%) only addressed it as a secondary or peripheral topic.

Seven of the studies with participants included only females (Arroll & Arroll, 2013; Åsbring & Närvänen, 2002; Bartlett et al., 2022; Chu et al., 2021; Fennell et al., 2021; Khalafbeigi et al., 2023; McInnis et al., 2015) and 26 included a higher proportion of females. The majority of participants in most studies were adults and only one study focused on children only (Parslow et al., 2017). In 23 of the included studies, it was reported whether the participants had a medical or a self-diagnosis: 18 studies included participants with a medical diagnosis (Åsbring & Närvänen, 2002; Baken et al., 2018; Bartlett et al., 2022; Cheshire et al., 2021; Dickson et al., 2007; Gilje et al., 2008; Green et al., 1999; Hasan et al., 2024; Khalafbeigi et al., 2023; Ko et al., 2022; Lacerda et al., 2019; Looper & Kirmayer, 2004; McInnis et al., 2015; Picariello et al., 2015; Terman et al., 2020; Terman et al., 2019; Waite & Elliot, 2021; Weinberg et al., 1994), three studies included self-diagnosed participants (Froehlich et al., 2022; McManimen et al., 2018; Shortland et al., 2024) and two studies included both (Hussein et al., 2024; König et al., 2024). The severity of the disease was not reported in 40 of the 44 studies. Only four studies provided information on disease severity: one study focused on patients with severe disease (Fennell et al., 2021), two included patients with mild to severe disease (Khalafbeigi et al., 2023; Lacerda et al., 2019) and one included patients with varying degrees of disease severity (Åsbring & Närvänen, 2002).

Author(s)	Year*	Country**	Study design	Methods	Sample size	Proportion female	Diagnosis ***	Focus on stigmatisation?	Type of stigma
Anderson et al.	2012	(USA)	review	systematic review & meta-analysis	n = 34 studies	/	/	no	/
Arroll & Arroll	2013	(England)	qualitative	case study	n = 1	100%	/	no	/
Asbring & Närvänen	2002	Sweden	qualitative	interviews	n = 25	100%	MD	yes	enacted stigma
Baken et al.	2018	New Zealand	quantitative	self-report questionnaires	n = 206	83%	MD	yes	/
Bartlett et al.	2021	Australia	qualitative	interviews	n = 5	100%	MD	no	/
Bayliss et al.	2014	England	qualitative	interviews	n = 36	/	/	no	/
Bolton et al.	2025	UK	viewpoint article	viewpoint article	/	/	/	no	/
Cheshire et al.	2021	UK	qualitative	interviews	n = 19	89%	MD	no	/
Chu et al.	2021	(USA)	mixed-methods	literature review	not specified	/	/	no	/
				case study	n = 1	100%			
Alameda Cuesta et al.	2019	Spain	qualitative	interviews	n = 13	92%	/	no	/
Devendorf et al.	2020	USA	mixed-methods	quantitative: questionnaire	n = 551	87%	/	no	/
				qualitative: questionnaire (open responses)	n = 29	79%			
Dickson et al.	2007	Scotland	qualitative	interviews	n = 14	57%	MD	yes	/
Elliott & Jason	2022	(USA)	quantitative	self-report questionnaires	n = 559	88%	/	no	perceived stigma
Fennell et al.	2021	(USA)		literature review	not specified	/	/	no	

			mixed-methods	case study	n = 1	100%			internalized & perceived stigma
Friedberg et al.	2009	USA	quantitative	self-report questionnaires	n = 45	51%	/	yes	/
Froehlich et al.	2021	Germany	quantitative	self-report questionnaires	n = 499	51%	SD	yes	perceived stigma
Gilje et al.	2008	Norway	qualitative	interview, (open-ended) questionnaire & follow-up meeting	n = 12	83%	MD	no	/
Godard et al.	2022	(Canada)	quantitative	study 1: self-report questionnaires	n = 117	61%	/	no	/
				study 2: experiment	n = 184	67%			
Green et al.	1999	USA	quantitative	self-report questionnaires	n = 44	89%	MD	yes	perceived stigma
Hammond	2002	UK	mixed-methods	quantitative: secondary data analysis	not specified	/	/	no	/
				qualitative: interviews & qualitative data from questionnaires	interviews n = 24, questionnaires n = 570				
Hasan et al.	2023	(Canada)	qualitative	interviews	n = 33	73%	MD	no	/
Hussein et al.	2024	Canada	review	scoping review	n = 21	/	MD or SD	no	/
Khalafbeigi et al.	2023	England	qualitative	interviews	n = 9	100%	MD	no	/
Ko et al.	2022	(Netherlands)	review	systematic review	n = 8 studies	/	MD	yes	perceived or experienced stigma

König et al.	2024	Switzerland	quantitative	self-report questionnaires	n = 169	72%	MD or SD	no	/
Lacerda et al.	2019	UK	qualitative	interviews	n = 28	57%	MD	no	/
Looper & Kirmayer	2004	Canada	quantitative	self-report questionnaires	n = 238	75%	MD	yes	perceived stigma
McInnis et al.	2015	Canada	mixed-methods	quantitative: questionnaires qualitative: narratives	n = 145	100%	MD	yes	perceived stigma
McManimen et al.	2018	(USA)	quantitative	self-report questionnaires	n = 551	87%	SD	yes	/
Nehrke et al.	2017	USA	quantitative	self-report questionnaires	n = 90	78%	/	yes	/
Parslow et al.	2017	(UK)	review	systematic review	n = 10 studies	/	/	no	/
Picariello et al.	2015	UK	mixed methods	quantitiative: self-report questionnaire qualitative: comments	n = 87	66%	MD	no	/
Scoles & Nicodemo	2022	(UK)	mixed-methods	machine learning & natural language processing tools	n = 11.128	/	/	yes	/
Shlaes et al.	1999	USA	quantitative	study 1: self-report questionnaires study 2: self-report questionnaires	sample 1 n = 240, sample 1a n = 42 n = 93	64% / (not specified)	/	no	/
Shortland et al.	2024	(UK)	review	scoping review	n = 19	/	SD	no	
Sirotiak & Thomas	2025	(USA)	review	literature overview +	/	/	/	no	/

				intersectional analysis					
Smith et al.	2014	(USA)	review	systematic review + meta-analysis	n = 71 studies	/	/	no	/
Taylor, R. R.	2005	USA	qualitative	interviews, (open-ended) questionnaires & progress notes	n = 47	96%	/	no	/
Terman et al.	2019	USA & UK	quantitative	self-report questionnaires	n = 317	87%	MD	yes	perceived stigma
Terman et al.	2020	(USA)	quantitative	self-report questionnaires	n = 554	88%	MD	yes	perceived stigma & stigma-related experiences
Waite & Elliot	2021	UK	qualitative	interviews	n = 8	88%	MD	no	/
Ware	1992	USA	qualitative	interviews (open-ended questions)	n = 50	80%	/	no	/
Weinberg et al.	1993	South Africa	mixed-methods	qualitative: interviews	n = 15	86%	MD	no	/
				quantitative: self-report questionnaires, rating-style repertory grid	n = 50	80%			
de Wolfe	2012	UK	qualitative	free text survey, interviews	n = 23	91%	/	no	/

*year of first (online) publication

**if the associated country not relevant due to the study design such as a review, then the country of the first author's affiliation is shown in brackets

***medical diagnosis (MD), self-diagnosed (SD) or not specified/applicable (/)

Table 1: Study overview

3.2 Key findings

In 33 of the studies the assessed type of stigma was not specified. In the remaining studies the most frequently assessed type was perceived stigma, identified in seven studies (Elliott & Jason, 2023; Froehlich et al., 2022; Green et al., 1999; König et al., 2024; Looper & Kirmayer, 2004; McInnis et al., 2015; Terman et al., 2019), followed by internalized and perceived stigma in one study (Fennell et al., 2021), perceived or experienced stigma in one study (Ko et al., 2022), perceived stigma or "stigma-related experiences" in one study (Terman et al., 2020), and enacted stigma in one study (Åsbring & Närvänen, 2002). As the majority of studies did not specify the type of stigma, the results have instead been grouped into overarching thematic categories derived from the results of the data synthesis.

The findings from all included studies could predominantly be assigned to four thematic categories: extent of stigmatisation, stigmatisation by healthcare professionals (HCPs), potential consequences of stigmatisation, and coping strategies. Additional findings that could not be allocated to one of these four categories were summarised under a fifth category entitled "further findings". An overview of all categorised findings is presented in table 2.

3.2.1 Extent of stigmatisation

ME/CFS was perceived as stigmatising and associated with high levels of stigmatisation for individuals with a diagnosis (Froehlich et al., 2022; Khalafbeigi et al., 2023; König et al., 2024; Smith et al., 2014; Terman et al., 2020; Waite & Elliot, 2021). Individuals with ME/CFS reported stigmatisation in many areas such as from friends, family, public authorities, in work environments, media and society (Anderson et al., 2012; Arroll & Arroll, 2013; Bayliss et al., 2014; Devendorf et al., 2020; Dickson et al., 2007; Fennell et al., 2021; Hammond, 2002; Khalafbeigi et al., 2023; Lacerda et al., 2019; Taylor, 2005). This was reflected, for example, in disbelief shown by family members and friends (Taylor, 2005) and by the media (Fennell et al., 2021), as well as in negative stereotyping within the community (Bayliss et al., 2014). Furthermore, perceived doubt and suspicion were reported in administrative settings during support seeking processes (Hammond, 2002) and in workplace contexts (Taylor, 2005).

ME/CFS was associated with higher levels of stigmatisation compared to many other diseases including MS, Parkinson's disease, paraplegia or depression. In general, stigma in ME/CFS was higher than in visible or more accepted illnesses (Baken et al., 2018; Godard et al., 2022; Ko et al., 2022; Looper & Kirmayer, 2004; McInnis et al., 2015; Scoles & Nicodemo, 2022). Moreover, not only individuals with ME/CFS were subject to stigmatisation, but also people around the affected person such as friends, family or physicians treating patients with ME/CFS experienced stigmatising behaviour (Fennell et al., 2021).

3.2.2 Stigmatisation by healthcare professionals

Across all studies, the most frequently reported theme was the stigmatisation of individuals with ME/CFS by those working in healthcare settings (n = 21). The vast majority of these healthcare professionals were physicians, such as general practitioners (GPs), who treated patients with ME/CFS (Alameda Cuesta et al., 2021; Anderson et al., 2012; Arroll & Arroll, 2013; Åsbring & Närvänen, 2002; Bayliss et al., 2014; Dickson et al., 2007; Fennell et al., 2021; Gilje et al., 2008; Green et al., 1999; Hasan et al., 2024; Khalafbeigi et al., 2023; Lacerda et al., 2019; Parslow et al., 2017). Although both men and women were affected, women reported experiencing greater stigmatisation by healthcare professionals than men (Anderson et al., 2012). In addition, male physicians were reported to show more stigmatising behaviours than female physicians (Green et al., 1999). The two most frequently reported stigmatising behaviours, predominantly displayed by healthcare professionals such as physicians, were disbelief regarding the existence of ME/CFS or the validity of its symptoms (n = 15) as well as psychologisation of the disease (n = 12). As part of the psychologisation of the disease, some physicians misdiagnosed the patients with depression (Dickson et al., 2007) or prescribed anti-depressants as a treatment for ME/CFS (Arroll & Arroll, 2013). In contrast to these findings concerning healthcare professionals, two studies from the United States reported fewer stigmatising attitudes among medical students and volunteers involved in ME/CFS research (Friedberg et al., 2008; Nehrke et al., 2017).

3.2.3 Potential consequences of stigmatisation

Due to their design, no causal links can be inferred from the included studies. The following section therefore focuses on events that may occur chronologically following stigmatisation. We refer to these as potential consequences without implying causality. Stigmatising behaviour by healthcare professionals, particularly physicians, was reported to contribute to diagnosis-related difficulties, including delays or problems in obtaining a correct diagnosis (Bayliss et al., 2014; Dickson et al., 2007; Green et al., 1999; Khalafbeigi et al., 2023; Lacerda et al., 2019; Parslow et al., 2017). Another potential consequence reported was that individuals with ME/CFS avoided contact with healthcare professionals or sought alternative treatments, primarily to prevent negative encounters and stigmatising experiences (Arroll & Arroll, 2013; Åsbring & Närvänen, 2002; Fennell et al., 2021; Hussein et al., 2024; Taylor, 2005).

Two studies indicated that stigmatisation by others may adversely affect the physical and mental health of individuals with ME/CFS (Baken et al., 2018; Ko et al., 2022) and could also increase the risk of trauma and suicide (Chu et al., 2021; Elliott & Jason, 2023; Fennell et al., 2021; König et al., 2024; McManimen et al., 2018). Some individuals reported pretending to be well or recovered to avoid the stigmatisation associated with the disease (Cheshire et al., 2021; Fennell et al., 2021). Consistent with these findings, one study found that some individuals with ME/CFS deliberately avoid obtaining a diagnosis to prevent exposure to such stigmatisation (Bayliss et al., 2014).

3.2.4 Coping strategies

Four strategies were reported that individuals used to cope with stigmatising experiences. The most frequently mentioned strategy (n = 3) was controlling information about the disease and keeping the illness a secret. In doing so, individuals sought to conceal their condition and associated symptoms to avoid the stigmatisation associated with it (Åsbring & Närvänen, 2002; Green et al., 1999; Waite & Elliot, 2021). A second strategy (n = 1) involved avoiding other people, including physicians, thereby reducing the risk of potential stigmatisation (Åsbring & Närvänen, 2002). A third strategy (n = 1) was

the opposite approach, involving disclosure of the illness with the aim of educating others about ME/CFS and protecting oneself from stigmatisation (Green et al., 1999). The fourth strategy (n = 1) consisted of engaging with other individuals with ME/CFS in online communities to provide mutual support and empowerment, for example through anonymous forums (Shortland et al., 2024).

3.2.5 Further findings

Two studies indicated that stigma in ME/CFS is associated with mental illness stigma as well as physically based illness stigma (Alameda Cuesta et al., 2021; Froehlich et al., 2022). Two other studies reported that psychiatric referrals as well as self-identification with public stereotypes may potentially reinforce stigmatisation (Terman et al., 2019; Weinberg et al., 1994). In contrast, two quantitative papers reported that exposure to facts about ME/CFS may increase positive attitudes towards ME/CFS patients (Friedberg et al., 2008; Nehrke et al., 2017).

Associations to stigmatisation were reported for further health-related factors such as duration of illness, mental health status or symptom severity as well as for personal factors such as gender, ethnicity, employment status, dissatisfaction with the partner or being a claimant of welfare benefits (Baken et al., 2018; Bolton et al., 2025; Green et al., 1999; Sirotiak & Thomas, 2025; Wolfe, 2012). Moreover, one study suggested that men may not fully disclose their symptoms due to stigmatisation (Sirotiak & Thomas, 2025).

A viewpoint article argues that stigmatisation in ME/CFS contributes to a lack of increased research funding for ME/CFS (Bolton et al., 2025).

In a methodological study, the CFS attitude test was found to be a moderately reliable tool to measure attitudes of others towards individuals with ME/CFS (Shlaes et al., 1999).

Identified Themes			Studies				
Major theme	**Category**	**Key findings**	**Qualitative studies**	**Quantitative studies**	**Mixed-methods studies**	**Reviews**	**Viewpoints**
Extent of the stigmatisation	Stigma in ME/CFS (n = 6)	ME/CFS is perceived as discrediting/stigmatic diagnosis	Waite & Elliot (2021); Khalafbeigi et al. (2023)	Froehlich et al. (2021)		Smith et al. (2014)	
		High levels of stigma for individuals with ME/CFS		König et al. (2024), Terman et al. (2020)			
	Stigmatisation by… (n = 11)	Administrative positions	Lacerda et al. (2019)		Hammond (2002)		
		Employers/co-workers	Taylor (2005); Lacerda et al. (2019)				
		Community/media/public	Bayliss et al. (2014); Khalafbeigi et al. (2023)		Devendorf et al. (2020); Fennell et al. (2021)		
		Friends/family	Taylor (2005); Dickson et al. (2007); Arroll & Arroll (2013); Lacerda et al. (2019)			Anderson et al. (2012)	
	Comparison to other diseases (n = 9)	Patients with ME/CFS experience more stigmatisation compared to other diseases (such as fibromylagia, MS, Parkinson's disease, adult epilepsy, TMPDS, neurological diseases, mental disorders, lymes disease, paraplegia or depression)		Green et al. (1999); Looper & Kirmayer (2004); Baken et al. (2018); Godard et al. (2022)	McInnis et al. (2015); Scoles & Nicodemo (2022)	Anderson et al. (2012); Ko et al. (2022)	
		Stigma in ME/CFS higher than in other visible, neurological or more accepted illnesses		Looper & Kirmayer (2004)	McInnis et al. (2015); Scoles & Nicodemo (2022)	Ko et al. (2022)	

	Who else experiences stigmatisation? (n = 10)	Family/friends/physicians treating ME/CFS patients experience stigmatisation			Fennell et al. (2021)	
Stigmatisating behaviour by HCPs	Gender specific aspects (n = 2)	Male physicians show stronger stigmatising behaviour than female		Green et al. (1999)		
		Women are more stigmatised by physicians than men				Anderson et al. (2012)
	Stigmatisation by HCPs (n = 21)	Stigmatisation by HCPs	Ware (1992); Åsbring & Närvänen (2002); Taylor (2005); Dickson et al. (2007); Gilje et al. (2008); Arroll & Arroll (2013); Bayliss et al. (2014); Lacerda et al. (2019); Alameda Cuesta et al. (2019); Bartlett et al. (2021); Khalafbeigi et al. (2023); Hasan et al. (2023)	Green et al. (1999), König et al (2024)	Devendorf et al. (2020); Fennell et al. (2021); Scoles & Nicodemo (2022)	Anderson et al. (2012); Smith et al. (2014); Parslow et al. (2017); Hussein et al. (2024)
	Typical stigmatising behaviours (n = 17)	Disbelief (by physicians/others)	Ware (1992); Åsbring & Närvänen (2002); Taylor (2005); Dickson et al. (2007); Gilje et al. (2008); Arroll & Arroll (2013); Lacerda et al. (2019); Alameda	Green et al. (1999), König et al (2024)	Devendorf et al. (2020); Fennell et al. (2021)	Parslow et al. (2017)

			Cuesta et al. (2019); Khalafbeigi et al. (2023); Hasan et al. (2023)			
		Psychologisation of the disease (by caregivers/physicians)	Ware (1992); Åsbring & Närvänen (2002); Taylor (2005); Dickson et al. (2007); Gilje et al. (2008); Lacerda et al. (2019); Khalafbeigi et al. (2023)	Green et al. (1999); Terman et al. (2020); König et al. (2024)	Picariello et al. (2015); Devendorf et al. (2020)	
	Contrary findings (n = 2)	Less/no stigmatic attitudes by medical students and volunteers working for ME/CFS research		Friedberg et al. (2009); Nehrke et al. (2017)		
Coping strategies	Coping strategies (n = 4)	Educating others		Green et al. (1999)		
		Avoiding others	Åsbring & Närvänen (2002)			
		Keeping illness a secret	Åsbring & Närvänen (2002); Waite & Elliot (2021)	Green et al. (1999)		
		Seeking online support				Shortland et al. (2024)
Potential consequences of the stigmatisation	Behavioural consequences (n = 7)	Avoiding contact with health care professionals	Åsbring & Närvänen (2002); Taylor (2005); Arroll & Arroll (2013)		Fennell et al. (2021)	Hussein et al. (2024)
		Patients pretend to be well/recovered (to avoid stigma)	Cheshire et al. (2021)		Fennell et al. (2021)	

		Avoiding diagnosis (to avoid stigma)	Bayliss et al. (2014)			
	Health effects (n = 7)	Negative health outcomes		Baken et al. (2018)		Ko et al. (2022)
		Increased suicide risk		McManimen et al. (2018); Elliott & Jason (2022); König et al. (2024)	Chu et al. (2021)	
		Increased risk for trauma			Fennell et al. (2021)	
	Diagnosis-related consequences (n = 6)	Stigma-related difficulties in obtaning a (correct) diagnosis	Dickson et al. (2007); Bayliss et al. (2014); Lacerda et al. (2019); Khalafbeigi et al. (2023)	Green et al. (1999)		Parslow et al. (2017)
Further findings	Factors associated to stigmatisation (n = 5)	Health related factors such as duration of illness, symptom severity, (mental) health status		Green et al. (1999); Baken et al. (2018)		
		Social & personal related factors such as gender, ethnitiy, unemployment, being a claimant of welfare benefits, dissatisfaction with spouse, missing legitimization of the illness		Green et al (1999); de Wolfe (2012); Baken et al (2018)		Sirotiak & Thomas (2025) Bolton et al. (2025)
	Factors influencing stigmatisation (n = 4)	Negative impact of psychiatric referral (patients who have been referred to a psychiatrist have greater levels of perceived stigma)		Terman et al. (2019)		
		(Segative impact of) Self-identification with perceived (negative) public stereotypes			Weinberg et al. (1993)	
		Positive impact of exposure to facts about ME/CFS (can lead to an increase in positive attitudes towards ME/CFS patients)		Friedberg et al. (2009); Nehrke et al. (2017)		
	Where does the stigma in ME/CFS come from? (n = 2)	Connected to mental-illness stigma	Alameda Cuesta et al. (2019)	Froehlich et al. (2021)		

		Connected to physically-based illness stigma	Froehlich et al. (2021)	
	Research funding (n = 1)	Stigmatisation hinders research funding		Bolton et al. (2025)
	Measuring stigma in ME/CFS (n = 1)	CFS attitude test is a moderately reliable measure	Shlaes et al. (1999)	
HCPs=healthcare professionals				

Table 2: Stigmatisation findings

4. Discussion

4.1 Sociodemographic and disease related influence factors on stigmatisation associated to ME/CFS

Region

The studies included in this review were conducted exclusively in middle to high-income countries, primarily in Europe and the United States. Research on other diseases such as mental illnesses show that region and culture may impact disease-related stigmatisation (Krendl & Pescosolido, 2020) (Zolezzi et al., 2018). Therefore, it is plausible to assume this to be the case in ME/CFS too. Further research would be needed to investigate stigmatisation in lower income countries and other regions with different cultures and differently equipped health systems.

Age

The fact that all but one study included only adult participants indicates a lack of research on stigmatisation in children with ME/CFS. This is particularly relevant as a peak prevalence of ME/CFS is in the 10-to-19-year age group (Bakken et al., 2014). As children's lives differ from those of adults, the types and effects of stigmatisation may likewise differ. For example, stigmatisation in school or other educational institutions could affect children's social development and identity formation with potentially long-term consequences such as lower educational attainment.

Gender

In addition, there was no study with exclusively or predominantly male participants, which is likely due to the higher prevalence in women (Cortes Rivera et al., 2019; Falk Hvidberg et al., 2015a). Nevertheless, some findings indicated gender-related differences such as higher levels of stigmatisation towards women (Anderson et al., 2012).The literature provides further indications of gender-specific differences in areas closely associated with stigmatisation, such as psychologisation: a 1996 study showed that 85% of the female patients with ME/CFS, but only 30% of the male patients, received a psychiatric diagnosis (Broom & Woodward, 1996).

The stigmatisation of individuals with ME/CFS may be partly related to the fact that women are disproportionately affected by the disease. In the past “women’s” diseases and symptoms were often psychologised and/or dismissed as hysteria. For example, a retrospective analysis of case records from

1970, examining an outbreak of likely ME/CFS cases in 1955, also referred to as the “Royal Free disease”, concluded that the outbreak was best explained by epidemic hysteria. This was based primarily on the high rate of women affected (McEvedy & Beard, 1970). Thoma et al. (2023) emphasised the historical connection between gender and the misclassification of ME/CFS as a psychosomatic disorder. They also pointed out that the term 'hysteria' carries explicit sexist connotations.

Even though society and medicine have changed a lot since those years, there still seem to be gender-specific differences in medical perception today. For instance, studies have shown that women’s pain is still taken less seriously than men's in clinical practice. Women receive slower and less analgesia, and their chronic pain is more likely to be attributed to psychological causes (E. H. Chen et al., 2008; Samulowitz et al., 2018). Recent research on diseases that primarily affect women, such as migraine or endometriosis, shows that these are also associated with stigmatisation (BARMER, 2024, June 28; European Migraine & Headache Alliance, 2024; Kocas et al., 2023; Sims et al., 2021). These findings underscore the necessity for future research to further investigate the mechanisms and consequences of gender-related stigmatisation.

Occupational status

The role of (un-)employment was rarely examined in the included papers. One paper found that unemployment duration was associated with stigmatisation through a perceived psychologisation of the disease, while two studies reported stigmatising behaviours by employers or co-workers (Green et al., 1999; Lacerda et al., 2019; Taylor, 2005). In addition, a study reported that welfare claimants with ME/CFS fear being stigmatised because of their claimant status (Wolfe, 2012). This could further exacerbate the stigma associated with their disease. Research on other diseases such as tuberculosis also reported an impact of employment status on stigmatisation (Vieira et al., 2025). As ME/CFS is related to high unemployment rates resulting in high productivity losses, work-related stigmatisation may not only have personal but also societal implications. Therefore, research is needed to further investigate the impact of occupational status on stigmatisation as well as its consequences for individuals with ME/CFS.

Disease severity

Only four studies provided information on the severity of ME/CFS in their participants, and none of these included very severely ill patients We assume that severely ill patients were not included or strongly underrepresented in the other studies as well, as participation can be restricted for this group due to the severity of their symptoms and barriers in study designs. While some studies included carers of patients with ME/CFS as proxies, the disease severity of the patients they cared for was either not very severe or not reported. A recent review reported low disease severity as a protective and high disease severity as a risk factor of tuberculosis-related stigmatisation (Vieira et al., 2025). Similar mechanisms may apply to ME/CFS related stigmatisation.

4.2 Type and extent of stigmatisation

This scoping review aimed to identify the types of stigmatisation individuals with ME/CFS experience and how the individuals are affected by them. Although the most commonly assessed type was perceived stigma, most studies did not specify the type of stigma assessed. This may be because stigmatisation of people with ME/CFS was not the focus of most of the included studies. Instead, they examined other topics such as illness experiences or suicidality. As there is still little research on ME/CFS, the associated types of stigmatisation have not yet been extensively studied. To the best of our knowledge, research into types of stigmatisation has primarily focused on HIV (Chen et al., 2020; Dessie & Zewotir, 2024; Kane et al., 2019; Picón-Jaimes et al., 2025) but is increasingly extending into further areas such mental health (Chen et al., 2020; Fox et al., 2018; Kane et al., 2019). Thus, the thematic categories identified in this review differ from established stigma types and underscore the need for clearer operationalisation of stigma types in future stigma-related ME/CFS research.

Our findings showed that individuals with ME/CFS reported high levels of stigmatisation which were also higher than in many other diseases and covered many areas of life including society and media.

We found that not only individuals with ME/CFS can be subject to stigmatisation, but also people around them such as friends, family or physicians. These findings are consistent with research about other diseases, which report, for example, stigmatising experiences by caregivers or family members

of individuals with autism spectrum disorder or mental illnesses (Meulien & Baghdadli, 2025; Yin et al., 2020).

4.3 Stigmatisation by HCPs

The most frequently reported issue was stigmatisation by healthcare professionals, particularly physicians. Similar patterns have been observed in other conditions, such as migraine or non-epileptic seizures (Robson & Lian, 2017; Young et al., 2013). Stigmatisation by healthcare professionals can severely compromise the quality of care for patients with ME/CFS. Delays or failures in diagnosis may result in negative consequences, including deterioration of health. Some patients even avoid contact with healthcare providers or turn to alternative treatments, which can increase the risk that diseases go undetected and untreated, exacerbate long-term health outcomes, and generate additional, avoidable individual and societal costs.

Our findings indicate that levels of stigmatisation vary across different healthcare-related groups. For instance, volunteers involved in ME/CFS research and medical students exhibited low levels of stigmatisation, whereas physicians demonstrated high levels. This suggests that aspects of medical practice itself may contribute to stigmatisation, potentially stemming from feelings of helplessness or powerlessness in the absence of clear biomarkers and effective therapeutic options.

Measures should be developed and implemented to reduce stigmatisation arising from healthcare professionals and its associated negative personal and societal consequences. Such measures could include incorporating (more) content on ME/CFS into medical and nursing curricula, as well as providing continuing professional development for healthcare professionals on ME/CFS, both in general and on diagnostic competencies in particular. The establishment and expansion of specialist ME/CFS outpatient clinics, similar to those for other chronic conditions such as MS or Parkinson's disease, would not only improve the quality of care for those affected but can also be expected to reduce stigmatisation.

4.4 Potential consequences of stigmatisation

The objective of this review was to gain a deeper understanding of stigmatisation in ME/CFS. As described, our initial search did not yield any publications that included information on both stigmatisation and burden of disease. However, our results suggest a potential link between the two concepts via delayed or missed diagnoses. Previous research on other diseases such as lung cancer or tuberculosis also indicate that stigmatisation can lead to delay in diagnosis (Scott et al., 2015; Storla et al., 2008). Delay in diagnosis, in turn, can have a negative impact on health outcomes and may lead to a higher economic and disease burden (Davis et al., 2004; DuBrock et al., 2024; Sulkanen et al., 2021). As our results show that stigmatisation can lead to a delay in or failure of diagnosis, stigmatisation may indirectly affect the burden of ME/CFS. Future research is needed to further investigate this potential association.

Avoiding a diagnosis or pretending to be healthy to escape stigmatisation can contribute to deterioration in health. Pretending to be well may lead to overexertion. Given that post-exertional malaise (PEM) can occur following mental or physical exertion and may result in short- or long-term worsening of symptoms, this represents a realistic risk for individuals with ME/CFS, with potential personal and societal consequences.

4.5 Coping strategies

Only four studies reported on coping strategies related to stigmatisation in ME/CFS. One strategy, educating others, appears to contrast with two other approaches, namely avoiding others or keeping the illness a secret. Educating others may be particularly beneficial, as our review also found that exposure to factual information about ME/CFS can foster more positive attitudes (Nehrke et al., 2017). In contrast, avoiding others or concealing the disease to escape stigmatisation may have negative consequences, as these strategies could prevent individuals from receiving emotional or practical support.

The fourth coping strategy involved online support and engagement with others individuals with ME/CFS. Given the physical limitations of the disease, people with ME/CFS are likely to seek social interaction through online forums and social networks. A study from 2012 reported that online forums

focused on ME/CFS exhibited higher levels of activity than forums on other diseases (Knudsen et al., 2012). Considering the international growth of social media since then, this trend likely continues among individuals with ME/CFS (Statista, 2025). However, as negative comments are also an integral part of social media, further research should examine the impact of social media networks on ME/CFS-related stigmatisation.

4.6 Further findings

Various health-related factors were reported to be associated with stigmatisation, including duration of illness, severity of symptoms, and mental health status. In addition, social and personal factors such as ethnicity, unemployment, and dissatisfaction with one's spouse were reported to be associated with stigmatisation in ME/CFS. Future research is needed to further investigate these associations and its consequences.

One of the reported impact factors that could contribute to reducing stigmatisation was an exposure to facts about ME/CFS (Friedberg et al., 2008; Nehrke et al., 2017). Therefore, providing more information about the illness might be an effective approach.

One publication argued that the stigmatisation could also have a negative impact on research funding (Bolton et al., 2025). This is supported by research from the US, as funding for ME/CFS does not reflect the economic impact of the disease and is lower than for similarly burdensome diseases (Dimmock et al., 2016; Mirin et al., 2020; Mirin et al., 2022)

The lack of funding may have contributed to the current absence of effective treatment options.

4.7 Methodological strengths and limitations

To enhance transparency and maintain high quality, our review was pre-registered on OSF and follows the PRISMA-ScR guidelines. A strength is that we developed the search algorithm and selected the databases with the support of a medical and an economic librarian to ensure a precise and exhaustive search strategy and a targeted selection of relevant databases. To enhance the explanatory approach of this scoping review, we did not exclude any publication dates or study types. We included only peer-

reviewed articles published in English or German, which may have led to the exclusion of some relevant articles. A limitation of our study is that we did not assess the quality of the included studies. While this aligns with PRISMA-ScR guidelines, it may affect the robustness of the findings. The included publications varied considerably in terms of study design and associated methodological rigor, ranging from meta- and secondary data analyses to viewpoint articles. For most of the findings, such as those concerning the extent of stigmatisation, or stigmatisation by HCPs, there is robust evidence supported by numerous studies of various designs. For a few findings, particularly 'further findings', the evidence is weaker. For instance, the finding that stigmatisation may hinder research funding is supported by only one viewpoint article.

5. Conclusion

This review examined studies on the stigmatisation of individuals with ME/CFS. Most included studies employed a qualitative design, and the majority did not specify the type of stigma assessed. Our findings indicate a high prevalence of stigmatisation, affecting not only individuals with ME/CFS but also those in their social circles, such as friends and family. Stigmatisation occurs across multiple areas of life, with the most frequently reported issue being stigmatisation by healthcare professionals. Such stigmatisation can lead to negative health outcomes, delays in diagnosis, and additional personal and societal consequences. Preliminary evidence suggests that increased awareness and information about the disease may help reduce stigmatisation. Future research should focus on stigmatisation in children and (very) severely ill individuals, as well as on developing and implementing interventions to mitigate stigma and thereby improve the quality of care for people with ME/CFS

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