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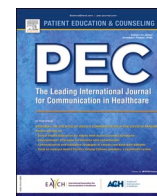
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Stigmatisation in medical encounters for persistent physical symptoms/functional disorders: Scoping review and thematic synthesis

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ABSTRACT

Objective: To conduct a scoping review of stigma in medical encounters for persistent physical symptoms and functional disorders (PPS/FD). Stigma is a social attribute that links a person to an undesirable characteristic. It has been extensively studied in relation to mental illness but less so in relation to PPS/FD.

Methods: We followed PRISMA-ScR reporting guidelines for scoping reviews. Searches for were designed using the SPIDER tool. We used descriptive and thematic analysis.

Results: The searches identified 68 articles, of which 32 were eligible for inclusion. 31 out of the 32 studies used a qualitative methodology. 8 studies used an explicit definition of stigma, of which 6 used the Goffman (1963) definition. Only 2 studies directly examined clinical consultations, the remainder relied on recalled accounts by patients or professionals.

Descriptive analysis identified the focus of the studies included: patient-physician interaction (n = 13); health care professionals' perceptions (n = 7); experiences of illness/stigma (n = 6); broader meaning of illness (n = 3); and patients' experiences of stigma in health care consultations (n = 3).

Conclusion: Patients experience stigmatisation in consultations for a wide range of PPS/FD. This suggests the presence of structural stigmatisation.

Practice Implications: There is a need for effective stigma reduction strategies in consultations about persistent physical symptoms.

1. Background

Persistent physical symptoms (PPS) are symptoms which are disproportionate to any underlying medical diagnosis and have lasted at least three months [1,2]. Notable examples include persistent abdominal pain, musculoskeletal pains, fatigue, headache and dizziness. Such symptoms currently do not have any single or consistent cause [3], but can be explained in terms of a complex interaction of biomedical, psychological and social factors [4]. Some PPS can meet the criteria for Functional disorders (FDs), for example fibromyalgia (FM) or irritable bowel syndrome (IBS). In general, PPS are associated with high morbidity and distress in patients and their families and high risk of loss of work capacity, have a high burden of disease and use a considerable amount of healthcare resources [5].

People with PPS commonly face negative attitudes both in society in a wider sense and in their encounters with medical professionals [6]. This can be understood from the perspective of stigma and stigmatisation. Stigma, broadly understood, is a form of social alienation

experienced as a result of different or discriminatory treatment [7]. Stigma can also be characterised as a social attribute that links a person to an undesirable characteristic [8]. Stigmatisation in a medical context is 'a social process or related personal experience characterised by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgement about a person or group identified with a particular health problem' [9]. It is a complex social phenomenon involving both social structures (including expectations and norms), and individual processes (such as labelling, stereotyping, separation, status loss, and discrimination) [10]. For stigmatisation to occur, power must be exercised [11] and it commonly becomes so entrenched in cultural norms and institutional policies it can be considered to be structural stigma [12].

The way stigma is communicated and perceived varies in different social settings and health conditions [13] as well as in different clinical contexts [14]. Addressing stigma within clinical encounters for conditions that are found to carry more stigma, has the potential to improve patients' experience and health outcome [15,16].

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We aimed to understand when and how stigma occurs within medical encounters about PPS/ FD. To do this we conducted a scoping review was to explore what is known on the topic of stigmatisation in medical encounters for PPS/FDs and considered the implications for clinical practice.

2. Methods

The scoping review was prospectively registered with OSF (<https://osf.io/g7azw>) and followed the steps of a scoping review process [17]. The study's protocol was drafted using the Preferred Reporting Items for Systematic Reviews and Meta-Analysis Protocols [18] and the reporting guidelines for scoping reviews [17]. The search strategy tool for qualitative/mixed methods research [19] called SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) was used to define key elements of the review question and search strategy. After the suitable articles were identified, a descriptive stage and a thematic synthesis were carried out followed by analytical synthesis.

2.1. Data sources

To identify potentially relevant data sources, the following bibliographic databases were searched: Ovid MEDLINE, PsychInfo and Epub. We searched from 1963 as this marked the publishing of Goffman [8] *Stigma: Notes on the Management of Spoiled Identity*, which paved the way for studying stigma in the social sciences. Initial searches were in December 2021 and were updated in June 2023. In addition, reference lists were reviewed for all studies that met the criteria of this scoping review to identify potentially relevant studies.

2.2. Search strategy

Search terms were developed by the research team to capture articles that might include the prevalence of the topic at hand. The search terms were refined using SPIDER (Sample, Phenomena of interest, Design, Evaluation, Research) [19]. The search terms according to SPIDER are found in Table A.1. We restricted the Sample to the medical setting and used keywords that reflected that. We defined the Phenomena of interest as PPS/FDs and related medical conditions. For Evaluation we put the construct of stigma and the synonyms related to that. As this is a scoping review we did not restrict either Design or Research.

2.3. Screening and data extraction

Following retrieval and removal of duplicates, initial screening by title alone was followed by a screening of abstracts to allow a two-stage process. The screening was carried out using an excel worksheet and macro written for the purpose.

The following data from the studies was extracted into an Excel sheet: Author; Title; Year published; Country in which the study took place; The study aim; medical condition; Research design; Research method; Study population; Whether the study defined stigma; Other stigma terminology used.

2.4. Analysis

Findings were analysed using Thematic Analysis (TA), which is a method that can be used to bring together and integrate the findings of multiple qualitative studies [20]. The resulting themes that emerged from TA were further developed using Thematic Synthesis (TS), to facilitate the interpretation of the themes uncovered in the light of additional interpretive constructs, explanations or hypotheses [21]. We first developed descriptive categories to characterise studies. The results from those descriptive themes were synthesised with a wider research context to create analytical themes. Finally, we related our findings to

two overarching concepts relating to stigma more generally: epistemic injustice [22] and structural stigmatisation [12].

3. Results

3.1. Search results

The literature search resulted in 368 titles published between 1963 and 2023. The search was initially run in December 2021 and updated in June 2023. The detection process is demonstrated in PRISMA Flowchart found in the appendix Fig A.1. All 368 abstracts were screened against the inclusion criteria. Of those 86 titles were assessed to be suitable to be assessed in full text. The selection included 32 first-hand studies. The literature search identified three narrative reviews. None of these were formally included into this scoping review as their focus did not match the inclusion criteria but they were used as a reference check to see if there were any studies that were missed in the literature search. In the revised search in June 2023 the search identified two reviews: a meta-analysis and an interpretive systematised review. The reference lists were reviewed to identify potentially missed studies. The overview of those secondary studies is described in Appendix Table A.2.

3.2. Description of studies

Most studies [23–46] (n = 24) used a qualitative research design. A mixed-methods approach was used in seven studies [47–53] (n = 7). Only one study [54] (n = 1) used solely a quantitative questionnaire method. A summary of individual primary studies is described in Appendix Table A.3.

The majority of the studies were conducted in countries with a high GDP. Most studies were carried out in the USA [24, 39, 44, 47, 51–53] (n = 7) and Scandinavia [25, 28, 32, 33, 38, 43, 48] (n = 7). Other studies took place in the UK [34, 37, 45] (n = 3); Spain [26, 36] (n = 2); Canada [41, 49] (n = 2); Netherlands [30, 42] (n = 2) there were two multi-country studies [23, 40]; and one study from each of those following countries: Germany [55], Japan [54], Mexico [50], Portugal [35], South Africa [29], Australia [27], New Zealand [46]. Detailed description of research methods used in the included studies is available in Appendix Table A.3 Summary of primary studies.

One study [43] directly observed consultations to assess stigma and stigmatisation. Rest of the studies (n = 31) relied on indirect reports (interviews or surveys). Two studies [39, 40] analysed the recordings of consultations to assess the effectiveness of explanations, of which one [40] was focusing on stigmatisation during the clinical consultation. Sixteen studies [24, 26–28, 31–33, 39–41, 44, 47, 48, 51–53] involved patients. Eight studies [23, 25, 30, 34, 42, 43, 49, 50] involved both patients and health professionals. And eight studies involved health professionals: four studies involved solely physicians [37, 38, 45, 54]; and four studies involved a mix of healthcare professionals [29, 35, 36, 46]. Six of the studies involving patients included only female participants [26–28, 32, 33, 39]. Five of those studies described purposive sampling of female patients for their experiences [26, 28, 32, 33, 39]. Detailed description of study sources of data used in the included studies is available in Appendix Table A.3 Summary of primary studies.

14 studies used umbrella terms for the medical condition, either chronic pain [25, 27, 33, 35, 43, 47, 49] (n = 7) or Medically Unexplained Symptoms (MUS) [30–32, 37, 42, 44, 45] (n = 7). The remainder used specific syndrome criteria: Psychogenic Non-Epileptic Seizures (PNES) [24, 29, 51] (n = 3); Fibromyalgia (FM): four studies included solely FM [36, 41, 50, 54] two studies combined FM with Chronic Fatigue Syndrome (CFS) [28, 38]; CFS (n = 1) [48]; Irritable Bowel Syndrome (IBS) (n = 2) [34, 53]; Functional Neurological Disorder (FND) (n = 1) [23]; Non-Epileptic Seizure (NES) (n = 1) [40]; Somatoform disorder (n = 1) [46]; Temporomandibular Pain and Dysfunction Syndrome (TMPDS) (n = 1) [52]; dyspareunia (n = 1) [39]; multiple chemical sensitivity (n = 1) [26].

3.3. Definition of stigma

The studies varied in the terminology they used when describing the phenomena of stigma. Out of 32 studies, only 8 explicitly defined stigma: 6 used Goffman 1953's definition of stigma [8] as the process of social devaluation, with two also referring to Link and Phelan [10]'s definition; one used Oxford English dictionary definition; and the other one used Chapple [56] et al. definition of social rejection - societal labelling of an individual as abnormal. Other studies used stigma-related terms such as: marginalisation; prejudice; negative attitudes; discrediting; othering; moral judgement; shaming; blaming; subordination (patient subordination to the will of physician); pejorative stereotypes/labelling; dismissal of patients; malingering; powerlessness; patronising; humiliating; negative interactions; maltreatment; overt rejection; dehumanisation; negative evaluation/impression of patients; and invalidation.

3.4. Descriptive categories

Five descriptive categories were developed from the studies identified to describe the approach of the research. These were: explicit analysis of stigma in health care consultations about PPS/FD ($n = 3$); clinical consultations with features suggestive of stigma ($n = 13$ studies); health care professionals' perceptions ($n = 7$); experiences of illness/stigma ($n = 6$); and broader meaning of illness ($n = 3$).

3.4.1. Stigma in health care consultations

Three studies were specifically framed in terms of stigma in clinical communication about PPS / FDs.

S Battin, Romsland and Christiansen [43] directly observed health care professional encounters with patients with an aim to understand stigma in chronic pain. They found that patients recognised the risk of being misinterpreted as "lazy or slackers". Thus they had to work to maintain their credibility against the prevailing stigma. This need to balance their own needs against how they appeared to others brought the additional challenge of interpreting the professionals' actions and whether they also reflected stigma.

Robson and Lian [40], in a study about stigmatising medical interactions among people with non-epileptic seizures, described how patients experience negative medical interactions in several different ways. They concluded that the overarching narrative depicts a poor, sometimes unethical and often detrimental medical encounters, which represents a fundamental breakdown in patient-provider relationships. Patients describe encountering health professionals who meet them with disbelief, suspicion, blame and judgement, and treat them with disdain and disrespect [40]. This was further broken down into four themes: (1) Identification of difference and labelling: patients were distinguished as not having a real illness. (2) Construction of stereotypes (with negative personal characteristics); (3) Loss of status as a legitimate patient; (4) Execution of disrespect. This echoes the previous work of Link and Phelan [10] who included in the stigmatisation process components of exclusion: separation and status loss. Here, Robson and Lian [40] found that the most defining feature of their study participants' narratives, was the maltreatment, the effort to prove them [patients] as "fake" – and unveil their moral character.

Braksmajer [39] studied women's experiences with dyspareunia and their struggles to seek medical legitimacy. In particular, they examined women's and their physicians' claims regarding bodily expertise and on women's perceptions of (gendered) invalidation by their physicians. While women sought a bodily explanation for their dyspareunia, with an aim to understand its origin, get treatment alternatives, and permission to avoid sexual activity, they experienced dismissal from their doctors when they pursued that. Patients also experienced physicians as reluctant to accept a negative answer when question about past sexual abuse. Another theme uncovered in this study was that in the absence of physical pathology, the physicians dismissed the complaints and denied

the legitimacy of women's pain. [39].

3.4.2. Clinical consultations with features suggestive of stigma

These studies examined the obstacles that both patients and physicians experienced when communicating about PPS/FDs without directly addressing stigma. Most of the studies (6 out of 10) in this category examined how patients experienced clinical encounters. Col [57] et al. found that there was a fundamental misalignment of communication goals between patients and physicians. They found that patients felt neither respected nor trusted by their providers and focused on transforming providers' negative attitudes towards them, whereas providers focused on gathering patient information. Similar findings were reported by Gilje [48] et al. who stressed that CFS patients said that lack of acknowledgement could be even worse than the symptoms. The patients wanted their doctors to ask questions, listen to them and take them seriously, instead of behaving degradingly. They also found that many participants felt that the doctors psychologised too much or trivialised the symptoms.

3.4.3. Professional perceptions of illnesses

Studies from the professionals' perspective examined health-care professionals' perceptions of PPS/FDs. The broad aim was to explore and understand the health-care professionals' illness perceptions of PPS/FDs and how it relates to their attitudes and reluctance of accepting patients with FDs. For example, Åsbring and Närvänen [38] examined the perceptions and strategies of how physicians in Sweden deal with patients with fibromyalgia/CFS. They found that there is a discrepancy between the ideal role of the physician and the reality. It was especially apparent with patients who have MUS as the physicians expressed frustration because patients were dissatisfied with the explanations given for their illness. The results illuminated how physicians had the tendency to describe patients in moralising terms, patients with MUS were regarded as "less serious" than those with medically explained symptoms. Physicians expressed scepticism regarding the seriousness of patients' situations and patients had negative attributes and stereotypes attributed to them.

3.4.4. Wider experience of illness/stigma

These studies focused on the lived experiences of patients who have been diagnosed with FDs. They included patients' experiences of interactions with health-care professionals and how negative interactions, stereotyping and labelling has affected their well-being and the trajectory of managing their conditions. For example, Naushad [47] et al. found that depression might play a role in the social experience of having chronic pain as individuals reported more perceived stigma when suffering both depression and chronic pain combined. Lennon [52] et al. found that having a FD puts a lot of strain on social relations. They found that the majority of their Temporomandibular Pain Disorder (TMPD) patients feel estranged from others in the society; they believe that others attribute patients' condition to personality problems; and therefore, many TMPD patients adapt two common stigma management strategies: disclosure and secrecy, which further isolates them from their support networks and society.

3.4.5. Broader meaning of illness

There were identified three studies, which observed the wider scene of stigma regarding PPS/FDs in the culture and examined how it affected patients and their experience of medical consultations. Studies in this category examined the perceptions of PPS/FDs from both the patients' and physicians' point of view and analysed the results in a broader cultural framework. For example, Canna and Seligman [24] looked at how cultural meaning co-determines the development of PNES and proposed a broader framework for how illnesses are culturally perceived. They proposed three main points: (1) Shared representations and beliefs about illnesses shape the manifestation of symptoms and the meanings of sensations; (2) The way individuals are socially primed to

come with trauma or chronic stress affects bodily symptoms; (3) Stigmatisation of symptoms impact patients' coping abilities.

3.5. Overarching themes

Across the different categories of studies and findings we found two over-arching and related themes: epistemic injustice and structural stigmatisation.

3.5.1. Epistemic injustice

In epistemic practice, such as medicine, members of a group propose, communicate, assess, and legitimise knowledge claims [58]. The notion of epistemic injustice describes an unfair treatment that takes place in the context of an epistemic practice, as in this case, in medical interaction [59]. It has two components, testimonial injustice and hermeneutical injustice. Testimonial injustice occurs when a patient is unfairly given a lower level of credibility as a result of prejudice of being a part of a negatively stereotyped group [22]. Hermeneutical injustice takes place when the conceptual resources for communication are, for some reason, lacking [22,59]. We found repeated examples of testimonial injustice as patients were not listened to / heard [38,43]. We also found instances of hermeneutical injustice. Therefore, the apparent absence of structured knowledge regarding PPS/FD, contributes to this culture where practitioners might see their patients as unreliable witnesses.

3.5.2. Structural stigmatisation of PPS/FDs

Structural stigma is defined as the "legitimation and perpetuation of a stigmatised status by society's institutions and ideological systems" [12,60]. We found evidence that stigmatisation in PPS/FDs is perceived, experienced and described in a similar way across multiple conditions and contexts. There are particular aspects of PPS/FD that increase stigma such as perceptions that there is nothing serious or that patients are exaggerating symptoms because a cause cannot be demonstrated on medical tests. This structural aspect means that stigma is a real or potential component of every consultation about PPS/FD. Particularly in the studies which explicitly studied consultations, patients were seen to be working to project the right balance of suffering (demonstrating that their symptoms were real), strength (to counter the idea that they may be less credible) and trust (that professionals were being genuine and that the patients were trustworthy in their presentation).

4. Discussion and conclusion

4.1. Discussion

The key finding of this scoping review was that while features of stigma were widely experienced in medical encounters about PPS / FD, they were rarely examined critically through the lens of stigma as a social and structural process. We argue that this makes it more likely that behaviours will persist within a narrow view of "poor communication" rather than a wider perspective of structural stigmatisation.

The strengths of this scoping review are that the study is constructed in a way that is replicable: the research team contributed to the development of the initial search terminology, conducting the scoping review we strived to adhere with well-established guidelines such as PRISMA ScR guidelines and SPIDER search strategy tool. In order to analyse the data, we used well-established guidelines and methods such as descriptive analysis, thematic analysis and thematic synthesis.

This scoping review has some limitations. Data was extracted by a

single reviewer (HT): this may have introduced some errors, for example internal researcher bias; however it is generally regarded as acceptable for a scoping review to have one reviewer, as the aim is to see the "big picture" [61]. This scoping review acted to mitigate this by having regular analysis meetings with a senior researcher (CB) and receiving feedback during regular research unit meetings.

4.2. Conclusion

In this scoping review, 32 studies were identified addressing stigma in clinical communication settings regarding PPS/FDs. Features indicative of stigmatisation were reported across multiple conditions and contexts suggesting it is a structural issue. Framing the problem as one of stigma is important to draw attention to the cultural and structural determinants of stigmatisation.

4.3. Practice implications

There are several implications for future research and practice development.

First the frequency and many ways in which stigmatisation of PPS occurs suggests this is a structural issue. Therefore, it is not sufficient to avoid practicing explicitly stigmatising forms of communication, but there is a need to explicitly destigmatise "ordinary" consultations. This need to destigmatise goes beyond clinicians' behaviour, to examine the structures that facilitate such harmful perceptions, whether it is the medical language we use, short consultation time windows, emphasis on individual responsibility or the remnants of a dualistic approach to medicine.

There is also a need for better tools to understand stigma in clinical interactions for PPS/FDs. We are currently developing a framework to help practitioners and clinical teachers and learners to recognise stigma and particularly to examine how new ways of understanding of PSS/FD may be translated into medical consultations [62]. Lastly, we need to put emphasis on developing interventions to reduce stigmatisation in PPS/FDs. Those interventions should be accessible, usable and adaptable for a wide array of health care professionals as patients' report facing stigmatisation in all levels of healthcare interactions.

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CRediT authorship contribution statement

Burton Chris: Validation, Supervision, Software, Resources, Methodology, Funding acquisition, Conceptualization. **Treufeldt Höbe:** Writing – review & editing, Writing – original draft, Project administration, Investigation, Formal analysis, Data curation.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix

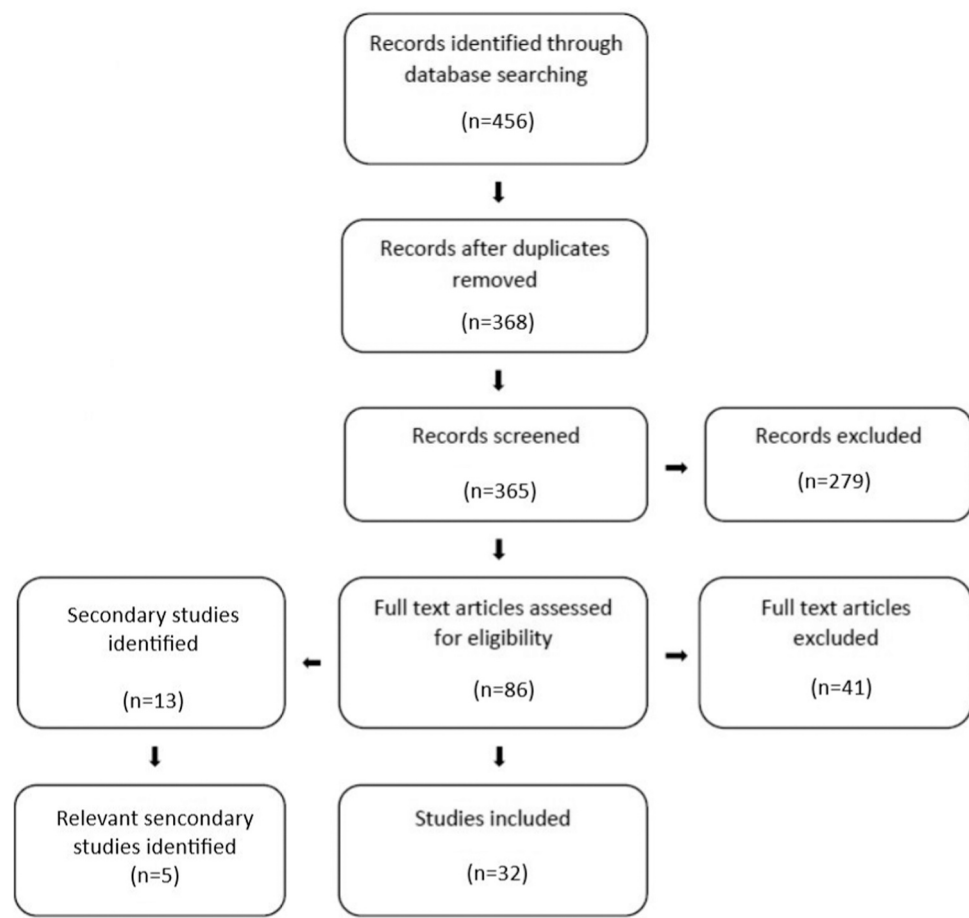


Fig. A.1. PRISMA Flowchart.

Table A.1
SPIDER mapping of search terminology used.

Sample	Phenomenon of interest	Design	Evaluation	Research
Medical setting	Persistent physical symptoms	All research designs	Stigma concept	All research designs
physician	Functional symptom\$		prejudi\$	
doctor	Functional syndrome\$		stereotyp\$	
patient	Functional disorder\$		stigma\$	
clinic\$	somatis\$		discriminat\$	
medical\$	medically unexplained		bias\$	
therap\$	somatoform			
communicat\$	psychosomatic			
consult\$	psychogenic			
interact\$	irritable bowel			
counsel\$	fibromyalgia			
encounter\$	chronic fatigue			
relation\$	non-epileptic			
interview\$	Chronic pain			
	somatic symptom disorder			
	bodily distress			

Table A.2
Summary of secondary studies.

Author	Title	Study aim
Macduffie[63] et al. (2020)	Stigma and functional neurological disorder: a research agenda targeting the clinical encounter.	To set forth a research agenda directed at better understanding the prevalence and context of stigma, clarifying its impact on patients and providers, and promoting best practices for stigma reduction.

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Table A.2 (continued)

Author	Title	Study aim
Buchman[64] et al. (2017)	Investigating Trust, Expertise, and Epistemic Injustice in Chronic Pain	To examine how a climate of distrust in pain management may facilitate what Fricker calls epistemic injustice
Cohen[65] et al. (2011)	Stigmatization of patients with chronic pain: the extinction of empathy	To address how health professionals' may inadvertently contribute to the stigmatization of patients with chronic pain
Barnett[66] et al. (2022)	The vicious cycle of functional neurological disorders: a synthesis of healthcare professionals' views on working with patients with functional neurological disorder	To synthesise studies which address the views of healthcare professionals (HCPs) towards patients with functional neurological disorder (FND).
Byrne[67] et al. (2022)	Communication interventions for medically unexplained symptom conditions in general practice: A systematic review and meta-analysis of randomised controlled trials	To evaluate the effectiveness of primary care based communication interventions at improving MUS patients' and/or clinician outcomes.

Table A.3

Summary of the studies included.

	AUTHOR AND YEAR	COUNTRY	CONDITION	PHENOMENA OF INTEREST	STUDY POPULATION (N)	RESEARCH DESIGN	RESEARCH METHOD	STIGMA DEFINED	STIGMA ALLUDED/ OTHER TERMINOLOGY USED
1	Kozłowska[23] et al. (2021)	Multiple countries	FND	Broader meaning of illness	Multidisciplinary team of experts; paediatric patients and their families	Qualitative	Case study: Clinical narrative vignettes	Oxford English dictionary	Yes/ negative emotional response from illness perceptions
2	Briones [26]-Vozmediano and Espinar-Ruiz (2021)-	Spain	Multiple Chemical Sensitivity	Experience of illness/stigma	Female patients (n = 22)	Qualitative	Open-ended in-depth interviews	No	Addressing the consequences of medical stigma
3	Canna and Seligman[24] (2020)	USA	PNES	Broader meaning of illness	-	Qualitative	Case study: Anthropological clinical narrative	No	Yes/ term used; moral judgment, moral appraisal, shame, pride, non-stigmatising
4	Diniz[35] et al. (2020)	Portugal	Chronic pain	Professional perceptions of illness	Female nurses (n = 50)	Qualitative	Sequential mixed methods including Similitude Analysis Thematic Analysis of free association task and clinical case completion	No	Yes/ dehumanisation
5	Tolchin[51] et al. (2020)	USA	PNES	Patient-physician communication	Patients (n = 60)	Mixed	Case study: Clinical vignette/ between-sub design MI before CBT treatment vs no MI	No	Yes/ term used; negative interactions; clinician based obstacles to treatment; clinician based stigma towards patient/ PNES
6	Fouché[29] et al. (2019)	South Africa	PNES	Patient-physician communication	Clinicians (n = 13)	Qualitative	Semi-structured interviews/ thematic analysis	No	Yes/negative attitudes, dismissal, malingering patients/ uncertainty
7	Naushad[47] et al. (2018)	USA	Chronic pain	Experience of illness	Four groups of patients (N = 236): depression only, chronic pain only, comorbid depression and chronic pain, and healthy controls.	Mixed	Demographics questionnaire; Structured Clinical Interview for DSM-IV-TR; Brief Pain Inventory; and completed a stigma measure that assessed general self-stigma, public stigma, treatment stigma, secrecy, and stigmatizing experiences	Goffman [8]	Stigma has been defined as "the situation of the individual who is disqualified from full social acceptance" (Goffman, 1963). A stigmatized trait "is deeply discrediting" to the bearer and degrades them "from a whole and usual person to a tainted discounted one" (Link & Phelan, 2001)

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Table A.3 (continued)

	AUTHOR AND YEAR	COUNTRY	CONDITION	PHENOMENA OF INTEREST	STUDY POPULATION (n)	RESEARCH DESIGN	RESEARCH METHOD	STIGMA DEFINED	STIGMA ALLUDED/ OTHER TERMINOLOGY USED
8	Briones-Vozmediano[36] et al. (2018)	Spain	Fibromyalgia	Professional perceptions of illness	Clinicians (n = 12)	Qualitative	Semi-structured interviews/a qualitative content analysis supported by Atlas.ti-7	No	Yes/ stigmatisation due to lack of social recognition of the disease/ Prejudice, negative attitude, perceptions, negative feelings
9	Braksmajer[39] (2018)	USA	Vulvodynia	Stigma in patient-physician communication	Female patients (n = 32)	Qualitative	Thematic analysis	No	Yes/ stigmatisation; invalidation, shame; prejudice/ feeling of shame that accompanied being “deviant” and the fear of being exposed to stigma from others
10	Robson and Lian [40](2017)	Across countries	NES	Stigma in patient-physician communication	Patients (n = 135)	Qualitative	Thematic discourse analysis	Goffman [8]	Yes
11	Houwen[30]et al. (2017)	Netherlands	MUS	Patient-physician communication	Patients (n = 43)	Qualitative	Semi-structure interviews	No	Prejudice
12	Lehti[25]et al. (2017)	Sweden	Chronic pain	Broader meaning of illness	GPs(n = 8); Patients(n = 10); Clinicians (n = 7)	Qualitative	Semi-structured interviews: Focus group interview with GPs; individual interviews with patients; interviews with health care providers in multimodal assessment teams	No	Yes/ process of othering; subordination; stereotyping; marginalisation
13	Colmenares-Roa [50]et al. (2016)	Mexico	Fibromyalgia	Patient-physician communication	Physicians (n = 4); Patients with Fibromyalgia (n = 8)	Mixed	Open-ended interviews: Anthropological ethnography; qualitative fieldwork;	No	Yes/Patient stigmatisation, overt rejection, and denial of the disease’s existence were identified as the disadvantageous position of the patient
14	Buchman[49] et al. (2016)	Canada	Chronic pain	Patient-physician communication	Patients (n = 27); re-contact interview patient-participants (n = 4); physicians (n = 6)	Mixed	Semi-structured interviews; Questionnaires; 2 feedback groups; Grounded theory data analysing	No	Yes/ Victims of Negative attitudes and assumptions/ Referenced Goffman, but not defined stigma
15	Homma[54]et al. (2016)	Japan	Fibromyalgia	Professional perceptions of illness	Physicians (n = 233)	Quantitative	Questionnaire DDPRQ-10	No	Yes/term used/ negative impression of patient characteristics; negative attitudes; negative emotions
16	Maatz[37]et al. (2016)	England	MUS	Professional perceptions of illness	Physicians (n = 17)	Qualitative	Semi-structured open-ended interviews	No	Yes/term used/ Negative evaluations; Negative attitudes
17	Burbaum[31]et al. (2010)	Germany	MUS	Patient-physician communication	Patients (n = 49); a control group (n = 42)	Qualitative	Recordings of consultations analysed using CA and positioning analysis	No	Yes/term used/ Negative attitude/ other positioning/ role ascription
18	Jones[53]et al. (2009)	USA	IBS	Experience of illness/stigma	Patients (n = 148)	Mixed	Semi-structured interviews; questionnaire	Chapple [56] et al.	Yes/Social rejection; societal labelling of an individual as

(continued on next page)

Table A.3 (continued)

	AUTHOR AND YEAR	COUNTRY	CONDITION	PHENOMENA OF INTEREST	STUDY POPULATION (N)	RESEARCH DESIGN	RESEARCH METHOD	STIGMA DEFINED	STIGMA ALLEUDED/ OTHER TERMINOLOGY USED
19	White and Seibold [27](2008)	Australia	Chronic pain	Experience of illness/stigma	Female patients (n = 5)	Qualitative	Open-ended interview; Narrative auto-ethnographic /thematic analysis	Goffman [8]	abnormal, is an important construct for a variety of chronic illness outcomes (Chapple et al., 2004) Yes/
20	Undeland and Malterud[32] (2008)	Norway	MUS	Patient-physician communication	Female patients (n = 2)	Qualitative	case study: Discourse analysis	No	Yes/term not used/ Stereotyping; patronising; humiliating
21	Gilje[48]et al. (2008)	Norway	CFS	Experience of illness/stigma	Patients (women n = 10; men n = 2); follow up meeting (women n = 5)	Mixed	Case study with data drawn from a group meeting; questionnaire; and a follow-up meeting	No	Yes/term used/ pejorative stereotypes/ trivialising symptoms/ maltreatment
22	Werner and Malterud[33] (2005)	Norway/ Denmark	Chronic pain	Patient-physician communication	Female patients (n = 10)	Qualitative	Semi-structured interviews	No	Yes/term not used/ stereotypes; labels 'hysteria'; blame, disempowerment, powerlessness; negative consultation experience; vulnerability
23	Åsbring and NÄrvänen[38] (2003)	Sweden	Fibromyalgia/ CFS	Professional perceptions of illness	Physicians (n = 26)	Qualitative	Semi-structured interviews; data analysis using the constant comparison method	No	Yes/term is used/ negative stereotypes; judgmental attitude
24	Åsbring and NÄrvänen[28] (2002)	Sweden	Fibromyalgia/ CFS	Patient-physician communication	Female patients with CFS (n = 12) and fibromyalgia (n = 13)	Qualitative	Semi-structured interview/ A systematic analysis of the interviews using the constant comparison method	Goffman [8]	Yes
25	Dixon-Woods and Critchley[34] (2000)	UK	IBS	Patient-physician communication	Female patients with IBS (n = 14) Physicians (GPs n = 6; gastroentologists (n = 6)	Qualitative	Semi-structured in-depth interviews were analysed using the constant comparative method	No	Yes/term used/ discredited; prejudice
26	Lennon[52]et al. (1989)	USA	TMPDS	Experience of illness/stigma	Patients (n = 151)	Mixed	Open-ended interviews; Stigma scale questionnaires	No	Yes/term used/ pejorative labelling; illness perception evokes fear and disgust; perceptions of deviance; malingering patients
27	Nishikawara[41] et al. (2023)	Canada	Fibromyalgia	Patient-physician communication	Patients (n = 14)	Qualitative	Interview; the enhanced critical incident technique (ECIT)	No	Yes/ term used: self stigmatisation; internalised stigma; invalidation; Examples included prejudicial beliefs like sexism and ageism; invalidation, minimising or dismissing symptoms

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Table A.3 (continued)

	AUTHOR AND YEAR	COUNTRY	CONDITION	PHENOMENA OF INTEREST	STUDY POPULATION (N)	RESEARCH DESIGN	RESEARCH METHOD	STIGMA DEFINED	STIGMA ALLUDED/ OTHER TERMINOLOGY USED
28	Stortenbeker[42] et al. (2022)	Netherlands	MUS	Patient-physician communication	BOTH We compared 41 MUS and 41 MES transcribed video-recorded general practice consultations.	Qualitative	Observation of recorder consultations: Content analysis (cross-sectional study)	No	Yes/ stigma, stereotypes, labelling
29	S Battin[43]et al. (2022)	Norway	Chronic pain	Stigma in patient-physician communication	BOTH 19 professionals and 26 patients	Qualitative	The use of participant observation combined with semi-structured interviews/ Thematic analysis	Link and Phelan [10], Goffman [8]	YesLink and Phelan (2001)Goffman (1963)
30	Bellman and Zolnikov[44] (2022)	USA	MUS	Patient-physician communication	Patients (n = 42)	Qualitative	A qualitative phenomenological study	No	Yes/implicit bias, stigmatisation, discrimination
31	Yon[45]et al. (2015)	UK	MUS	Professional perceptions of illness	Physicians (n = 22)	Qualitative	In-depth interviews analysed using the framework method	No	No/negative attitudes/views/ feelings
32	Dickson[46] (2009)	New Zealand	Somatoform disorder	Professional perceptions of illness	Multidisciplinary team of health care professionals (n = 6)	Qualitative	In-depth semi-structured interviews/ interpretative Phenomenological Analysis;	Goffman [8], Link and Phelan [10]	Yes

References

[1] Self-Efficacy for Pain Communication Moderates the Relation Between Ambivalence Over Emotional Expression and Pain Catastrophizing Among Patients With Osteoarthritis - The Journal of Pain.

[2] Aamlund A, Malterud K, Werner EL. Patients with persistent medically unexplained physical symptoms: a descriptive study from Norwegian general practice. *BMC Fam Pract* 2014;15(1):107.

[3] Burton C, Fink P, Henningsen P, Löwe B, Rief W. Functional somatic disorders: discussion paper for a new common classification for research and clinical use. *BMC Med* 2020;18(1).

[4] Henningsen P, Gündel H, Kop WJ, Löwe B, Martin A, Rief W, et al. Persistent physical symptoms as perceptual dysregulation: a neuropsychobehavioral model and its clinical implications. *Psychosom Med* 2018;80(5):422–31.

[5] Rask MT, Jakobsen PR, Clemensen J, Rosendal M, Frostholt L. Development of an eHealth programme for self-management of persistent physical symptoms: a qualitative study on user needs in general practice. *BMC Fam Pract* 2021;22(1).

[6] De Ruddere L, Craig KD. Understanding stigma and chronic pain: a state-of-the-art review. *Pain* 2016;157(8):1607–10.

[7] Major B, O'Brien LT. The social psychology of stigma. *Annu Rev Psychol* 2005;56(1):393–421.

[8] E. Goffman, *Stigma; Notes on the Management of Spoiled Identity*, Prentice-Hall 1963.

[9] Weiss MG, Ramakrishna J, Somma D. Health-related stigma: rethinking concepts and interventions. *Psychology. Health Med* 2006;11(3):277–87.

[10] Link BG, Phelan JC. Conceptualizing stigma. *Annu Rev Sociol* 2001;27(1):363–85.

[11] Link BG. Stigma: many mechanisms require multifaceted responses. *Epidemiol e Psychiatr Soc* 2001;10(1):8–11.

[12] Hatzenbuehler ML, Link BG. Introduction to the special issue on structural stigma and health. *Soc Sci Med* 2014;103:1–6.

[13] Stangl AL, Earnshaw VA, Logie CH, Van Brakel W, Simbayi LC, Barré I, et al. The health stigma and discrimination framework: a global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. *BMC Med* 2019;17(1).

[14] Dolezal L. Shame anxiety, stigma and clinical encounters. *J Eval Clin Pract* 2022;28(5):854–60.

[15] Nyblade L, Stockton MA, Giger K, Bond V, Ekstrand ML, Lean RM, et al. Stigma in health facilities: why it matters and how we can change it. *BMC Med* 2019;17(1).

[16] Feingold JH, Drossman DA. Deconstructing stigma as a barrier to treating DGBI: Lessons for clinicians. *Neurogastroenterol Motil* 2021;33(2).

[17] Munn Z, Peters MDJ, Stern C, Tufanaru C, McArthur A, Aromataris E. Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. *BMC Med Res Methodol* 2018;18(1).

[18] Moher D, Shamseer L, Clarke M, Ghera D, Liberati A, Petticrew M, et al. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Syst Rev* 2015;4(1):1–9. %@ 2046-4053.

[19] Cooke A, Smith D, Booth A. Beyond PICO. *Qual Health Res* 2012;22(10):1435–43.

[20] Alhojailan MI, Analysis-A Thematic. Critical review of its process and evaluation. *West East J Soc Sci* 2012.

[21] Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol* 2008;8(1):45.

[22] Fricker M. *Epistemic Injustice: Power and the Ethics of Knowing*. Oxford University Press; 2007.

[23] Kozłowska K, Sawchuk T, Waugh JL, Helgeland H, Baker J, Scher S, et al. Changing the culture of care for children and adolescents with functional neurological disorder. *Epilepsy Behav Rep* 2021;16:100486.

[24] Canna M, Seligman R. Dealing with the unknown. *Functional neurological disorder (FND) and the conversion of cultural meaning. Soc Sci Med* 2020;246:112725.

[25] Lehti A, Fjellman-Wiklund A, Stålnacke B-M, Hammarström A, Wiklund M. Walking down 'Via Dolorosa' from primary health care to the specialty pain clinic - patient and professional perceptions of inequity in rehabilitation of chronic pain. *Scand J Caring Sci* 2017;31(1):45–53.

[26] Briones-Vozmediano E, Espinar-Ruiz E. How do women suffering from multiple chemical sensitivity experience the medical encounter? A qualitative study in Spain. *Disabil Rehabil* 2021;43(8):1110–20.

[27] White S, Seibold C. Walk a mile in my shoes: an auto-ethnographic study. *Contemp Nurse* 2008;30(1):57–68.

[28] Åsbring P, Närvänen A-L. Women's experiences of stigma in relation to chronic fatigue syndrome and fibromyalgia. *Qual Health Res* 2002;12(2):148–60.

[29] Fouché M, Hartwig L, Pretorius C. Management of uncertainty in the diagnosis communication of psychogenic nonepileptic seizures in a South African context. *Epilepsy Behav* 2019;98:45–52.

[30] Houwen J, Lucassen PL, Stappers HW, Assendelft WJ, van Dulmen S, Olde Hartman TC. Improving GP communication in consultations on medically unexplained symptoms: a qualitative interview study with patients in primary care. *Br J Gen Pr* 2017;67(663):e716–23.

[31] Burbaum C, Stresing AM, Fritzsche K, Auer P, Wirsching M, Lucius-Hoene G. Medically unexplained symptoms as a threat to patients' identity? A conversation analysis of patients' reactions to psychosomatic attributions. *Patient Educ Couns* 2010;79(2):207–17.

[32] Undeland M, Malterud K. Diagnostic interaction: the patient as a source of knowledge? *Scand J Prim Health Care* 2008;26(4):222–7.

[33] Werner A, Malterud K. "The pain isn't as disabling as it used to be": How can the patient experience empowerment instead of vulnerability in the consultation? *Scand J Public Health* 2005;33(66 suppl):41–6.

[34] Dixon-Woods M, Critchley S. Medical and lay views of irritable bowel syndrome. *Fam Pract* 2000;17(2):108–13.

[35] Diniz E, Castro P, Bousfield A, Figueira Bernardes S. Classism and dehumanization in chronic pain: A qualitative study of nurses' inferences about women of different socio-economic status. *Br J Health Psychol* 2020;25(1):152–70.

[36] Briones-Vozmediano E, Ohman A, Goicolea I, Vives-Cases C. "The complaining women": health professionals' perceptions on patients with fibromyalgia in Spain. *Disabil Rehabil* 2018;40(14):1679–85.

- [37] Maatz A, Wainwright M, Russell AJ, Macnaughton J, Yiannakou Y. What's 'difficult'? A multi-stage qualitative analysis of secondary care specialists' experiences with medically unexplained symptoms. *J Psychosom Res* 2016;90:1–9.
- [38] Åsbring P, Närvenen A-L. Ideal versus reality: physicians perspectives on patients with chronic fatigue syndrome (CFS) and fibromyalgia. *Soc Sci Med* 2003;57(4): 711–20.
- [39] Braksmajer A. Struggles for medical legitimacy among women experiencing sexual pain: a qualitative study. *Women Health* 2018;58(4):419–33.
- [40] Robson C, Lian OS. "Blaming, shaming, humiliation": stigmatising medical interactions among people with non-epileptic seizures. *Wellcome Open Res* 2017;2: 55.
- [41] Nishikawara RK, Schultz IZ, Butterfield LD, Murray JW. "You have to believe the patient": What do people with fibromyalgia find helpful (and hindering) when accessing health care? *Can J Pain = Rev Can De la Douleur* 2023;7(2):2176745.
- [42] Stortenbeker I, Olde Hartman T, Kwerreveld A, Stommel W, Van Dulmen S, Das E. Unexplained versus explained symptoms: The difference is not in patients' language use. A quantitative analysis of linguistic markers. *J Psychosom Res* 2022; 152:110667.
- [43] Battin GS, Romsland GI, Christiansen B. Diminishing pain stigma: patient perceptions of encounters with interprofessional teams in biopsychosocial pain rehabilitation. *Ann Med* 2022;54(1):2562–73.
- [44] Bellman V, Zolnikov TR. Understanding patient-provider interaction, treatment acceptance, and outcomes in medically unexplained symptoms. *Cureus* 2022;14 (12):e32915.
- [45] Yon K, Nettleton S, Walters K, Lamaheewa K, Buszewicz M. Junior doctors' experiences of managing patients with medically unexplained symptoms: a qualitative study: Table 1. *BMJ Open* 2015;5(12):e009593.
- [46] B.E.H.-S. Dickson, E. Jean C.; Dean, J., et al. diagnosis the influence of stigma on interdisciplinary rehabilitation of somatoform disorder, *New Zealand Journal of Physiotherapy* (2009).
- [47] Naushad N, Dunn LB, Muñoz RF, Leykin Y. Depression increases subjective stigma of chronic pain. *J Affect Disord* 2018;229:456–62.
- [48] Gilje AM, Soderlund A, Malterud K. Obstructions for quality care experienced by patients with chronic fatigue syndrome (CFS)—a case study. *Patient Educ Couns* 2008;73(1):36–41.
- [49] Buchman DZ, Ho A, Illes J. You present like a drug addict: patient and clinician perspectives on trust and trustworthiness in chronic pain management: table 1. *Pain Med* 2016;17(8):1394–406.
- [50] Colmenares-Roa T, Huerta-Sil G, Infante-Castañeda C, Lino-Pérez L, Alvarez-Hernández E, Peláez-Ballesteros I. Doctor–patient relationship between individuals with fibromyalgia and rheumatologists in public and private health care in Mexico. *Qual Health Res* 2016;26(12):1674–88.
- [51] Tolchin B, Baslet G, Martino S, Suzuki J, Blumenfeld H, Hirsch LJ, et al. Motivational interviewing techniques to improve psychotherapy adherence and outcomes for patients with psychogenic nonepileptic seizures. *J Neuropsychiatry Clin Neurosci* 2020;32(2):125–31.
- [52] Lennon MC, Link BG, Marbeck J, Dohrenwend BP. The stigma of chronic facial pain and its impact on social relationships. *Soc Probl* 1989;36:117–34.
- [53] Jones MP, Keefer L, Bratten J, Taft TH, Crowell MD, Levy R, et al. Development and initial validation of a measure of perceived stigma in irritable bowel syndrome. *Psychol Health Med* 2009;14(3):367–74.
- [54] Homma M, Ishikawa H, Kiuchi T. Association of physicians' illness perception of fibromyalgia with frustration and resistance to accepting patients: a cross-sectional study. *Clin Rheumatol* 2016;35(4):1019–27.
- [55] Jutel A. Medically unexplained symptoms and the disease label. *Soc Theory Health* 2010;8(3):229–45.
- [56] Chapple A, Ziebland S, McPherson A. Stigma, shame, and blame experienced by patients with lung cancer: qualitative study. *Bmj* 2004;328(7454):0959–8138. 1470%@.
- [57] Col N, Hull S, Springmann V, Ngo L, Merritt E, Gold S, et al. Improving patient-provider communication about chronic pain: development and feasibility testing of a shared decision-making tool. *BMC Med Inform Decis Mak* 2020;20(1):267.
- [58] Kelly GJ, Licona P. Epistemic practices and science education. History, philosophy and science teaching. Springer.; 2018. p. 139–65.
- [59] Blease C, Caryl H, Geraghty K. Epistemic injustice in healthcare encounters: evidence from chronic fatigue syndrome. *J Med Ethics* 2017;43(8):549–57.
- [60] Bos AER, Pryor JB, Reeder GD, Stutterheim SE. Stigma: advances in theory and research. *Basic Appl Soc Psychol* 2013;35(1):1–9.
- [61] Campbell F, Tricco AC, Munn Z, Pollock D, Saran A, Sutton A, et al. Mapping reviews, scoping reviews, and evidence and gap maps (EGMs): the same but different- the "Big Picture" review family. *Syst Rev* 2023;12(1):45.
- [62] Fryer K, Sanders T, Greco M, Mooney C, Deary V, Burton C. Recognition, explanation, action, learning: Teaching and delivery of a consultation model for persistent physical symptoms. *Patient Educ Couns* 2023;115:107870.
- [63] Macduffie KE, Grubbs L, Best T, Laroche S, Mildon B, Myers L, et al. Stigma and functional neurological disorder: a research agenda targeting the clinical encounter. *CNS Spectr* 2020:1–6.
- [64] Buchman DZ, Ho A, Goldberg DS. Investigating trust, expertise, and epistemic injustice in chronic pain. *J Bioeth Inq* 2017;14(1):31–42.
- [65] Cohen M, Quintner J, Buchanan D, Nielsen M, Guy L. Stigmatization of patients with chronic pain: the extinction of empathy. *Pain Med* 2011;12(11):1637–43.
- [66] Barnett C, Davis R, Mitchell C, Tyson S. The vicious cycle of functional neurological disorders: A synthesis of healthcare professionals' views on working with patients with functional neurological disorder. *Disabil. Rehabil. Int. Multidiscip. J.* 2022;44 (10):1802–11.
- [67] Byrne AK, Scantlebury A, Jones K, Doherty L, Torgerson DJ. Communication interventions for medically unexplained symptom conditions in general practice: a systematic review and meta-analysis of randomised controlled trials. *PLoS One* 2022;17(11):e0277538.