STIGMA AND STIGMATISATION IN MEDICAL CONSULTATIONS FOR PERSISTENT PHYSICAL SYMPTOMS /FUNCTIONAL DISORDERS

Submitted in accordance with the requirements for the degree of

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Hõbe Treufeldt, MA, BA, BA

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Acknowledgements

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To my fellow PhD colleagues and friends from ETUDE, you have my deep gratitude, for the support and motivation you have provided. I am incredibly fortunate to have worked alongside such talented and supportive PhD colleagues, whose camaraderie and collaboration have truly been one of the most rewarding aspects of this PhD. Thank you for making this journey unforgettable.

Lastly, I would like to extend my gratitude for my friends and family for their unfaltering belief in my abilities and the support they have provided me.

1 Summary

1.1 Brief overview of the thesis

This thesis was designed to understand stigma in persistent physical symptoms (PPS) and to develop actionable ways of lessening the stigma and improving the care that people with PPS receive.

Aim

The series of studies presented in this thesis investigate the pervasive role of stigma in clinical encounters for Persistent Physical Symptoms (PPS) and Functional Disorders (FDs), as well as explore communication strategies that can mitigate negative patient experiences.

Methods

This thesis consists of five studies, that used complementary methods: scoping review, framework synthesis, conversation analysis, a qualitative focus group study and development of an actionable framework for interventions to reduce stigma.

Key findings

The collective findings across these five studies highlight the urgent need for stigma reduction strategies in consultations about PPS/FDs.

The first study: scoping review found that the stigma in PPS/FDs can be described as pervasive, ubiquitous, and structural. The second study was a best fit framework synthesis and proposed a framework to categorise and understand the patients' stigmatising experiences. The stigma framework consists of three stigma-carrying stereotypes and six stigmatising actions. The third study was a qualitative focus group study to understand patients' lived experiences. The findings further validated the stigma framework in study two and highlighted a relationship between experienced stigma and (re)traumatisation. The fourth study used conversation analysis to micro-analyse the difficulties that patients with PPS/FDs have described experiencing in the beginning of consultations. The findings show that a common consultation initiator 'How are you' is ambiguous and carries problems for patients with PPS/FDs. The fifth study was developing an actionable framework to provide clinicians the tools to use when wanting to promote therapeutic alliance and reduce stigma in consultations for PPS/FDs.

Conclusions and Implications

Stigma can exacerbate negative patient experiences, contributing to a cycle of trauma, and poor health outcomes. By employing clearer communication strategies and trauma-informed care, it is likely that clinicians can mitigate these effects and foster more positive patient-clinician interactions.

Keywords

Stigma, Persistent Physical Symptoms, Functional Disorders, Medical Consultation, Trauma, Communication, General Practice

1.2 Contributorship to multi-author publications

The research in this PhD is reported in five chapters each written in the format of a scientific paper. This follows the University of Sheffield “Publication Format” style. The first author of this thesis designed and carried out the research and is the first author for each of the studies. The following is the description of the contributorship of the author for the each of the studies.

1.2.1 Stigmatisation in medical encounters for persistent physical symptoms/functional disorders: A scoping review and a thematic synthesis

Authors: Hõbe Treufeldt, Prof Chris Burton

The author of this PhD thesis (HT) was the main contributor to the conceptualisation and design of the study, performed data collection and analysis, and drafted the manuscript. This study is co-authored by the primary supervisor (CB), who oversaw and supervised the research and manuscript revision process.

This has been published as a scientific article:

Treufeldt, H., & Burton, C. (2024). Stigmatisation in medical encounters for persistent physical symptoms/functional disorders: scoping review and thematic synthesis. *Patient Education and Counseling*, 108198. doi: 10.1016/j.jpsychores.2024.111828

1.2.2 Stigmatisation in clinical consultations for persistent physical symptoms/functional disorders: A best fit framework synthesis

Authors: Hõbe Treufeldt, Brodie McGhee Fraser, Prof Chris Burton

The author of this PhD thesis (HT) was the main contributor to the conceptualisation and design of the framework development, performed data collection and analysis, and drafted the manuscript. This study is co-authored by the primary supervisor (CB), who oversaw and supervised the research and manuscript revision process. As the framework synthesis and creating was an extensive process, that involved the whole authorship team discussions, to reach the consensus for the final framework (involved all authors HT, BMF and CB). The second author (BMF) contributed to the discussions, revisions of the framework and to the manuscript revision.

This has been published as a scientific article:

Treufeldt, H., Burton, C., & Fraser, B. M. (2024). Stigmatisation in clinical consultations for persistent physical symptoms/functional disorders: A best fit framework synthesis. *Journal of Psychosomatic Research*, *183*, 111828. doi: 10.1016/j.pec.2024.108198

1.2.3 Stigmatisation in medical encounters for patients with Fibromyalgia: A focus group study

Authors: Hõbe Treufeldt, Prof Chris Burton

The author of this PhD thesis (HT) was the main contributor to the conceptualisation and design of the study, performed data collection and analysis, and drafted the manuscript. The participants for the focus groups were recruited by HT and the focus groups were conducted by HT. This study is co-authored by the primary supervisor (CB), who oversaw and supervised the research analysis, and manuscript revision process.

This has been prepared for publication and is currently with the organisation Pain Alliance Europe, who contributed to recruitment to the study, prior to submission.

1.2.4 "How are you" ambiguity from the outset in consultations about persistent physical symptoms

Authors: Hõbe Treufeldt, Prof Chris Burton, Dr Traci Walker

The author of this PhD thesis (HT) contributed to the conceptualisation and design of the study. As the data was already collected and was owned by the University of Bristol, the primary supervisor (CB) dealt with the acquisition of the data, HT's role in this phase was to be the primary contributor to the writing of ethics applications and the paperwork regarding permissions. This study is co-authored by the secondary supervisor (TW), who oversaw and supervised the analysis methodology learning, the research conceptualisation for the analysis and manuscript revision process. HT was the main contributor to the research analysis direction, carried out the analysis, and was the primary contributor for the manuscript. The manuscript is being prepared for publication.

1.2.5 Stigmatisation in clinical consultations for persistent physical symptoms/functional disorders: A conceptual framework for reducing stigma and promoting alliance in consultations

Authors: Hõbe Treufeldt, Dr Peter Lucassen, Prof Chris Burton

The author of this PhD thesis (HT) was the main contributor to the conceptualisation and design of the study, performed data collection and analysis, and drafted the manuscript. This study is co-authored by the primary supervisor (CB), who oversaw and supervised the research and manuscript revision process. The second author (PL) contributed to the validity and reliability of the framework development by having discussions and sharing relevant research studies that were used to strengthen the framework and revised the manuscript. The manuscript is being prepared for publication.

1.3 Context of this PhD – the ETUDE programme

1.3.1 Description of ETUDE

This PhD has been a part of Encompassing Training in fUnctional Disorders across Europe (ETUDE) which in turn is a part of a Marie Skłodowska-Curie Innovation Training Network (ITN) and is funded by the European Commission, Horizon 2020 Program. ETUDE has been designed to train the next generation of researchers in Functional Disorders (https://etude-itn.eu/about-etude/). The network has provided PhD training to 15 Early-Stage Researchers (ESRs). This program aimed to identify underlying mechanisms, improve diagnosis and treatment, and reduce stigma of patients with FDs.

15 ESRs have been working in 9 European countries (the Netherlands, Germany, the United Kingdom, Denmark, Poland, Italy, Hungary, Belgium and Malta). In addition, 19 academic and non-academic partner organisations supported training and secondments for the ESRs. Participants in this program were strongly encouraged to collaborate with other researchers, academic institutions, and industry partners. A core part of ETUDE were the six compulsory week-long network-wide training schools, each involving an advanced scientific course on a specific topic related to functional disorders, a transferable skill course focusing on general academic skills, and an outreach activity. Secondments were also a compulsory part of ETUDE. There were academic and non-academic secondments to strengthen the relationships between industry and academia and to develop the skills to partner with non-academic entities.

1.3.2 Training within ETUDE

The training involved having to partake in one academic secondment and in two secondments with industry partners.

The first industry partner secondment was at the Pain Alliance Europe (PAE), Brussels, Belgium (Supervisor: Ms Deirdre Ryan). The aim was to learn about the patient perspective on acceptable and not acceptable explanations. This secondment was carried out part-time over 6 months.

The second industry partner secondment was at Grasshopper Films (GbR), Tübingen, Germany and was supervised by Mrs. Ross. The aim was to gain understanding regarding science communication using different tools that media can offer (presentations, podcasts, videos, voice overs, graphs) to be able to be more efficient communicating my research with the public and different stakeholders. The output of this secondment was to produce a video material to help clinicians to reduce stigma in consultations for PPS/FDs.

The academic secondment was carried out at the Radboud University Medical Centre Nijmegen (RUMC) in the Netherlands. I was stationed at the Radboud Institute for Health Sciences and supervised by Dr olde Hartman. The secondment's aim was to further develop the research dealing with stigma in consultations for PPS/FDs.

The ETUDE included five weeklong in-depth trainings on different topics related to the PPS/FDs. This was intended to give a thorough understanding of complex subject matter by world leading experts in the field and to give the early-stage researchers a good general foundation in this field.

1. Network-wide training event I: Kick-off. Online
2. Network-wide training event II: Diagnosis. Hosted by the Hamburg University
3. Network-wide training event III: Mechanisms. Hosted by the Károli Gáspár University of the Reformed Church in Hungary
4. Network-wide training event IV: Stigma. Hosted by the University of Florence
5. Network-wide training event V: Treatment. Hosted by the University of Aarhus

1.3.3 Additional outputs from this research through ETUDE

There have been two co-author papers:

1. Saunders, C., Treufeldt, H., Rask, M. T., Pedersen, H. F., Rask, C., Burton, C., & Frostholm, L. (2023). Explanations for functional somatic symptoms across European treatment settings: A mixed methods study. *Journal of Psychosomatic Research*, *166*, 111155. (Saunders et al., 2023)
2. McGhie-Fraser, B., Tattan, M., Cabreira, V., Chaabouni, A., Kustra-Mulder, A., Mamo, N., ... & Rosmalen, J. (2023). Quality assessment and stigmatising content of Wikipedia articles relating to functional disorders.(McGhie-Fraser et al., 2023)

The secondment with Pain Alliance Europe (PAE) resulted in connecting with local patients' advocacy organisations in different countries who would like to collaborate by using the findings presented in the Focus group study to write articles and promote awareness in their local languages and regions.

Contributing to the development of MOOC for health care practitioners. This consists of two videos. First video is about reducing stigma in PPS/FDs; the second video is about communication and stigma reducing explanations in PPS/FDs. This was done in co-operation with Grasshopper Films (GbR), Tübingen, Germany (Supervisor: Mrs. Ross), where I went on two secondments.

Developing a guide to be used to improve social cohesion and reduce stigma in PPS/FDs. This has been sent to the European Commission. Radboud University Medical Centre Nijmegen (RUMC), Radboud Institute for Health Sciences (Supervisor: Dr. olde Hartman), Nijmegen, Netherlands; Aim: develop training materials.

1.3.4 Dissemination

Stigma

Video about reducing stigma in PPS/FDs (in preparation)

Video is about communication and stigma reducing explanations in PPS/FDs (in preparation)

Writing a blog posts for persistent somatic symptoms

https://persistentsomaticsymptoms.com/ (in preparation)

podcast

1.3.5 Conference presentations featuring this research

1. 2022 EAPM Vienna poster presentation scoping review: Stigma and stigmatisation in clinical encounters for persistent physical symptoms: A scoping review and a best fit framework synthesis (Poster award).
2. 2022 SAPC North oral presentation: Stigma and stigmatisation in clinical encounters for persistent physical symptoms: A scoping review and a best fit framework synthesis.
3. 2023 EAPM Wroclaw oral presentation: Stigma and stigmatisation in clinical encounters for persistent physical symptoms: A new framework.

HYPERL

4. 2023 CBT conference in Estonia: Stigma and stigmatisation in clinical encounters for persistent physical symptoms: a new way of understanding consultations.
5. ETUDE stigma training week 2023 in Florence: Stigma and stigmatisation in clinical encounters for persistent physical symptoms.
6. SympCa Tromso 2023: Stigma and stigmatisation in clinical encounters for persistent physical symptoms: structural stigma.
7. 8th ELG Mental Health and Persistent Symptoms meeting in RUMC Radboud: Stigma and stigmatisation in clinical encounters for persistent physical symptoms: structural stigma.
8. 2024 EAPM Lausanne oral presentation: Stigma in medical communication for PPS/FDs: a new way of understanding and dealing with the difficulties both patients and clinicians face.
9. ETUDE international summer school lecture about stigma in PPS/FDs.
10. ETUDE international summer school: workshops in reducing stigma and improving clinical consultations.

1.3.6 Recognition

Member of the EAPM (European Association for Psychosomatic Medicine).

Awarded the EAPM junior fellow 2024.

Member for the scientific advisory board for the 24th World Congress of the International College of Psychosomatic Medicine.

2 INTRODUCTION

2.1 Thesis structure and Layout

This PhD thesis consists of a background, five research papers forming the body of the thesis and an overarching discussion based on the findings of the research.

The thesis begins with an overview of the background. The background introduces two key aspects of the thesis: Persistent Physical Symptoms and Stigma. This aims to give relevant overview regarding the different aspects of the knowledge that we currently have and introduce the complexity of the problems that the medical practice currently faces. The background aims to provide a context to the research questions and the studies that were carried out to be able to address those questions.

The main body of the thesis consists of five research papers that aim to form a cohesive account of stigma in consultations for persistent physical symptoms and propose ways of moving on from this.

The thesis has a short preface at the beginning of each study. The prefaces are designed to give a short personal commentary on the relationship of the following study to the rest of the thesis and to the PhD as a whole.

The first paper addresses the scope and the current knowledge of stigma in PPS/FDs and raises the general question of the current research gap and the knowledge we need to obtain.

The second paper is a further development of the themes identified in the first paper – using a best fit framework synthesis this paper proposes a novel way of understanding and categorising stigma in PPS/FDs. This is done with the synthesis of current models of stigma and the published experiences of both the patents and the clinicians to propose a new framework for stigma in PPS/FDs.

The third paper explores in an in-depth manner the Fibromyalgia patients' experiences of stigma in medical settings. This study uses both inductive and deductive approaches to exploring the rich data that was gathered. This study found that the experiences of stigmatisation can be very similar to trauma reactions. Therefore this proposes a link between stigmatisation and trauma. The framework developed in study two, was also tested to see if it can help to categorise the stigma experiences.

The fourth study takes an in-depth microanalysis approach of using conversation analysis to analyse video recordings of GP consultations about PPS/FDs. This study was inspired by the prior findings that minor changes in the way the clinicians ask questions, affect the way the patients respond and might contribute to their treatment trajectory. This study was designed to examine how the clinicians initiate the consultations with patients with PPS/FDs. The findings suggest that there is a simple way of rephrasing the initiation of the consultation that helps the patients.

The final study was about synthesising the knowledge gathered in the four previous studies and based on the developed stigma framework for PPS/FDs, develop a new framework that would promote therapeutic alliance and act anti stigmatising in consultations for PPS/FDs. This framework aimed to be able to be used as part of practical guidance for consultations.

The last part of the thesis is about the discussion of the findings of the five studies that formed this PhD. This involves the synthesis of main findings, the interpretations of those main findings, the strengths and limitations and the proposed next steps for the research directions.

The reference lists from the individual studies have been removed. The reference list for all of the used references in this thesis is found in the final bibliography, which is located at the end of the thesis Chapter 10: References.

2.2 The aim and three objectives of this PhD thesis

The main aim of this PhD is to examine and find ways to address stigma in consultations for PPS/FDs. In order to achieve that aim this thesis sets out to deepen the understanding of the reasons, different factors and possible perpetrators that contribute to stigma in PPS/FDs. Moreover, in order to address stigma in consultations, this thesis aims to use the knowledge and create training materials that seek to minimise stigma, which then could be used as part of training for medical students, clinicians and other allied professionals who come into contact in a medical setting regarding PPS/FDs. In particular, these will focus on finding acceptable patient-centred ways of approaching consultations and explanations regarding PPS/FDs which would help to reduce stigma and facilitate therapeutic alliance.

Three objectives to achieve the aim of this thesis are:

1. To understand how stigma in consultations for PPS/FDs happens.

2. To understand people’s experiences of stigma.
3. To develop materials to help to reduce the stigma in consultations for PPS/FDs.

2.3 Research questions for the PhD thesis

The previously outlined objectives were used as a foundation for forming the research questions that this PHD thesis is based on. The research questions are as following:

RQ1: What is currently known about stigma in healthcare consultations about persistent physical symptoms?

RQ2: How is stigma conveyed and perceived in consultations about persistent physical symptoms?

RQ3: How can consultations for persistent physical symptoms be modified to reduce or avoid stigma?

To answer the research questions, the following five studies were planned and completed:

1) Scoping review in order to understand the current state of published knowledge regarding stigma in medical consultations regarding PPS/FDs.
2) Stigmatisation in clinical consultations for persistent physical symptoms/functional disorders: A best fit framework synthesis.
3) Focus group study – to understand the lived experiences of patients with PPS/FDs and how they have experienced medical consultations and stigma.
4) Analysing recordings of medical consultations regarding PPS/FDs using Conversation analysis to understand how stigma is conveyed and perceived on an interaction level.
5) Stigmatisation in clinical consultations for persistent physical symptoms/functional disorders: a conceptual framework for reducing stigma and promoting alliance in consultations.

2.4 Methodological framework for the PhD thesis

2.4.1 Historical and Philosophical Roots of Understanding

This framework traces its philosophical roots to the classical debates about knowledge and understanding. Knowledge in this case can reflect the organisational principles of biomedical vocabularies and ontologies that are used in medical terminology. Some terminology can represent invariant features (classes, universals) of biomedical reality (i.e., they are a matter for ontology). Other uses of medical terminology convey also how this reality is perceived, measured, and understood by health professionals, therefore belonging to the domain of epistemology (Bodenreider et al., 2004). While traditional epistemology often focused on knowledge as justified true belief, contemporary thinkers emphasise the value of understanding, particularly in the empirical sciences. This thesis positions understanding as a higher-order cognitive achievement that has value in itself and is more than the sum of knowledge (Baumberger, 2009). Therefore, this thesis and the five research papers with in it, are guided by the importance of understanding and gathering the findings to reflect the wider picture, rather than just recording knowledge. The reason for that is because understanding is crucial for interpreting complex sociological phenomena like illness and stigma especially when the societal changes are fast and rapid (Kvanvig, 2009).

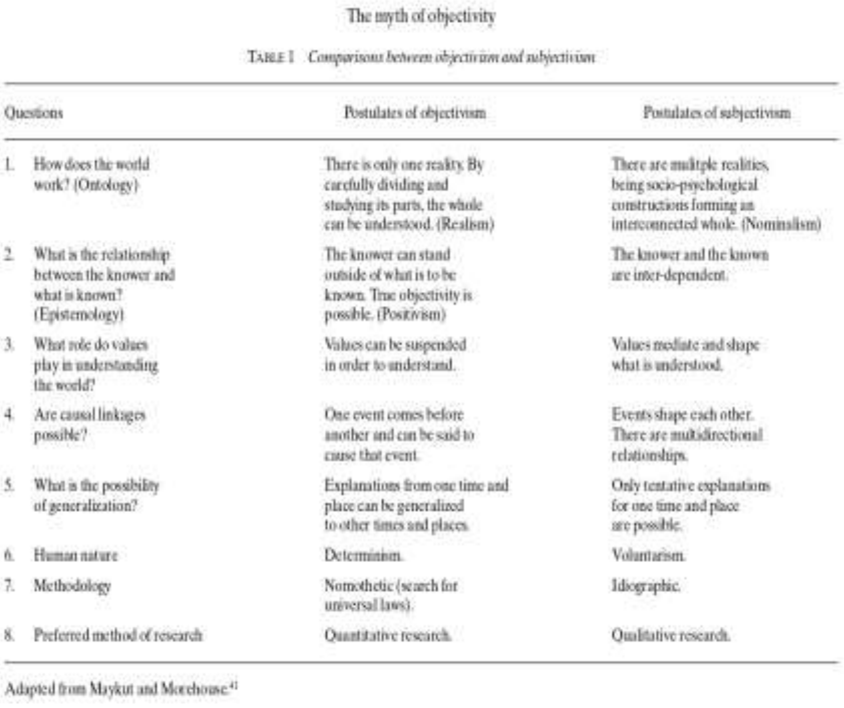
2.4.2 Epistemological and ontological positioning

In the context of the philosophy of science and epistemology this research draws on a constructivist framework. This learning framework states that people construct their own knowledge through their experiences and interactions with others (Dennick, 2016). Table 2.1provides a comparison between objectivism and subjectivism therefore providing a short overview for the ontological positioning for this thesis (Wilson, 2000). The constructivist framework asks us to consider the degree to which is the medical diagnosis that underpin the current system of healthcare, socially constructed versus inherently real. In this framework the illness is viewed as interplay of cultural, biological, and interpersonal factors. The doctor-patient relationship is central to the construction of illness experiences. Recovery is seen as influenced by cultural beliefs, social support systems, and therapeutic relationships. The constructivist framework uses qualitative methodologies, such as narrative and interview methods of research, in order to explore the complexity of medical decision-making and patient experiences.

Activities associated with knowledge production and use are called epistemic practices. And the way healthcare professionals come to know and use knowledge are central concerns of medical epistemology (Khushf, 2013). Therefore, this research is guided by the epistemological understanding of what is a ‘legitimate illness’. This epistemological understanding is shaped by historical approaches, social interactions and structures, and cultural environments.

Stigma, a core phenomenon in this thesis, can be understood generally as a social process that enforces unequal power relations. This aligns with the constructivist view that social interactions shape knowledge and experience. By examining illness experiences and their sociocultural underpinnings, the research acknowledges that knowledge of illness is both constructed and mediated by external social forces. In its essence, this thesis understands illness as both a personal experience and a social construct. This means that while illness has objective markers and identifiers, the knowledge about the illness is filtered through individual interpretations, rather than being purely objective.

Table 2.1 Comparison between objectivism and subjectivism (after Wilson, 2000)



The myth of objectivity

TABLE 1 *Comparisons between objectivism and subjectivism*

Questions	Postulates of objectivism	Postulates of subjectivism
1. How does the world work? (Ontology)	There is only one reality. By carefully dividing and studying its parts, the whole can be understood. (Realism)	There are multiple realities, being socio-psychological constructions forming an interconnected whole. (Nominalism)
2. What is the relationship between the knower and what is known? (Epistemology)	The knower can stand outside of what is to be known. True objectivity is possible. (Positivism)	The knower and the known are inter-dependent.
3. What role do values play in understanding the world?	Values can be suspended in order to understand.	Values mediate and shape what is understood.
4. Are causal linkages possible?	One event comes before another and can be said to cause that event.	Events shape each other. There are multidirectional relationships.
5. What is the possibility of generalization?	Explanations from one time and place can be generalized to other times and places.	Only tentative explanations for one time and place are possible.
6. Human nature	Determinism.	Voluntarism.
7. Methodology	Nomothetic (search for universal laws).	Idiographic.
8. Preferred method of research	Quantitative research.	Qualitative research.

Adapted from Maykut and Morehouse[41]

2.4.3 Epistemological Perspectives in Medicine

The dominant positivist orientation in biomedicine often prioritises objective, measurable phenomena while neglecting the subjective and interpersonal aspects of medical practice and peoples' lived realities. In contrast, this research adopts a constructivist approach, recognising that illness experiences are co-constructed through the patient-clinician interaction. This involves not only understanding the biological aspects of illness but also addressing the cultural, psychological, and social factors that shape how patients experience and report their conditions.

Contextual reflexivity acknowledges the setting of the epistemological phenomenon at hand —a complex clinical environment where larger rigid structures (such as diagnostic guidelines, healthcare systems, regulations around disability and sick leave, accrediting bodies, medical education, etc), the dualistic language, sociological hierarchical structures, personal biases, and cultural norms shape interactions. The research papers and this thesis aim to reflect on how the context influences both how we understand about the complex phenomenon and the way we research those processes, as well as how the research and clinical work itself needs to exercise more critical reflexivity to address the epistemic injustices.

2.5 The use of theories

In order to answer the research objectives and questions set out, this thesis uses several scientific theories to examine relevant phenomena. Scientific theory is a well-substantiated explanation of an aspect of the natural world that is based on a body of evidence and repeatedly tested through observation and/or experimentation. It integrates facts, laws, and hypotheses to provide a coherent understanding of a phenomenon and allows for predictions of future events or discoveries (Kuhn, 1970).

As this research handles the subject matter of complex sociological and psychological phenomenon, the use of theories is paramount. The starting point for this thesis was to understand the phenomenon of stigma and current knowledge of stigma theory approaches in PPS/FDs. The relevant theories of stigma are examined in the background and the shortcomings of those theories and the proposals for needed changes are going to discussed. It is important to note that stigma theory aims to explain a widely occurring and complex sociological phenomenon. As this research evolved, the complexity of the topic raised the need for including other theories. As a result this thesis lays out a background that focuses on the stigma theory, and as the research evolved, the new evidence pushed for the inclusion for other theories, such as epistemic injustice (Fricker, 2007) and will go on to propose a link between stigma and (re)traumatisation based on the mental health theories.

This is a reminder that the use of these theories is aimed at describing and explaining the observed patterns and findings to forward our understanding of a phenomenon. Moreover, when we are dealing with a complex sociological phenomenon, the theories themselves need to change in the light of new knowledge.

2.6 Personal role, lived experiences and the role of reflexivity

In qualitative research, reflexivity refers to the process by which researchers critically reflect on their own influence on the research process, including how their background, biases, values, and perspectives may shape the study's design, data collection, and interpretation (Finlay, 2002). My personal experience as a clinical psychologist treating patients with functional disorders, personality disorders, substance use disorders, chronic illness, trauma, and complex PTSD, has profoundly shaped both my clinical and research practices. My work within a multidisciplinary team, where I navigated the therapeutic space between physical and mental health, has deepened my understanding of how these dimensions are interconnected in patient care.

Moreover, living with chronic pain and a functional disorder has added a unique dimension to my professional lens, requiring me to consistently reflect on how my personal health experiences may influence my clinical approach and research interpretation.

In my research, I acknowledge that my personal experiences and clinical expertise have the potential to impact the way I engage with participants and interpret data. I am deeply aware of the need to manage potential biases stemming from my own lived experience and professional background. To address this, I have sought regular supervision, ensuring that my interpretations are grounded in the participants' experiences rather than my own assumptions. I have looked for guidance in published research on how to practice reflexivity (McCabe & Holmes, 2009) and sought out mentoring by senior researchers who have had to face and overcome a similar obstacle.

Practising reflexivity was particularly important in study 3 – the qualitative focus group study. For this study I sought guidance on how to design and conduct a qualitative study when my own personal experiences are similar to the topic of study. To make sure that the interpretation of the data was not guided by my own personal experiences and biases, the focus groups had a comprehensive topic guide and were video recorded. Therefore, my PI in the study had full access to those recordings. Moreover, the data analysis was supervised by my PI, with whom I was able to discuss and reflect on the themes and the findings. I also carried out a comprehensive theoretical background gathering on the topic, for to be able to refer to the current knowledge and research findings whenever I was doubtful. And lastly, my experience as a psychotherapist, well-versed in group therapy settings had prepared me for dealing with delicate topics that might echo my own experiences, which helped me to conduct the focus groups in a professional manner.

Additionally, I have employed triangulation methods in both designing my research and in practicing reflexivity to differentiate between my personal perspectives and the insights emerging from my research. Triangulation refers to the use of multiple methods, data sources, theories, or researchers to cross-check and validate findings, ensuring a more comprehensive and credible understanding of the research problem. It is used to increase the accuracy and reliability of results by examining the same phenomenon from different angles (Denzin, 2017). Reflexivity has been an ongoing practice in my work, guiding me to remain conscious of how my positionality—both as a clinician and as someone with lived experience—may shape the research process and its outcomes.

Through this reflective practice, I strived to ensure that my research remains balanced, ethical, and attuned to the complexities of the human experience, taking into account the broader social and political context. By engaging multiple perspectives and continuously reflecting on power dynamics and relationships within my research field, I aim to contribute meaningful, well-rounded knowledge to the study of functional disorders, the experienced inequalities, and mental health care.

2.7 Ethics

For all the studies involved in this PhD thesis, the relevant ethics permissions have been obtained, but more importantly, this research has been guided by the principles of the Helsinki Declaration (Shrestha & Dunn, 2019). This research deals with very sensitive personal subject matter, therefore the ethical considerations play a fundamental role, ensuring that the dignity, rights, and well-being of participants are prioritised throughout the research process. Given the personal, often sensitive nature of data collected and analysed in these studies—such as patient experiences, perceptions, and emotions—I acknowledge the need to navigate ethical concerns carefully to prevent harm and maintain trust. Ethical considerations ensure that the autonomy of participants is respected, informed consent is obtained, and confidentiality is upheld, fostering an environment where participants feel safe to share their personal stories.

3 BACKGROUND

3.1 Persistent physical symptoms and functional disorders

Persistent physical symptoms (PPS) are symptoms which are disproportionate to underlying pathology (Fryer et al., 2023) or not sufficiently explained by a medical condition after adequate examination and have lasted at least three months (Aamland et al., 2014; Löwe et al., 2024). Notable examples include persistent abdominal pain, musculoskeletal pains, fatigue, headache, and dizziness. These symptoms are often associated with impairment and distress among patients and increased healthcare costs (den Boeft et al., 2017).

PPS represent a spectrum of severity, ranging from mild symptoms to severe and chronic disorders (Rask et al., 2021). In some cases the PPS meet the criteria for functional disorders (FD). FDs is an umbrella term that describes several syndromes characterised by a specific combination of persistent somatic symptoms, rather than by structural bodily abnormalities (Guo et al., 2019). The three most prevalent functional syndromes in the general population are irritable bowel syndrome (IBS), fibromyalgia (FM) and chronic fatigue syndrome (CFS) (Ko et al., 2022).

PPS/FDs currently cannot be associated with any single consistent cause (Burton et al., 2020b) and the pathophysiological basis is either unknown or cannot be measured by current scientific means (Löwe et al., 2022) but these conditions appear to be associated with a complex interplay of biomedical, psychological and social factors (Henningsen et al., 2018).

In the next sections I will summarise current understanding about PPS in order to highlight ways in which PPS can be problematic for patients and clinicians.

The remainder of this section will give an overview of why this topic is relevant, and explain why there are problems in both understanding and treating these conditions. The next section will introduce the concept of stigma and will give an overview of why is this relevant for PPS/FDs.

3.1.1 The problem of terminology

In the published literature, the conditions described here as PPS have been variously referred to as: Conversion disorder (CD) Somatoform Disorders (SD) Functional Somatic Disorders (FSD), functional somatic syndromes (FSS); Medically Unexplained Symptoms (MUS), Bodily Distress Disorders (BDD) and Somatic Symptom Disorder (SSD) (Burton et al., 2020b; Czachowski, 2021; Ko et al., 2022). Some of these concepts have started to fall out of use (for example CD, SD, MUS) due to their conceptual and practical problems (Henningsen et al., 2018). In recent years, it has been proposed that using the term MUS can be itself a barrier to improved care. The term has received criticism for its ambiguity. This is because the term uses 'negative labelling', which is when the symptoms are described by what they are not, rather than by what they are, and this kind of medical label offers no insight into the cause, duration, severity or significance of symptoms. This line of medical diagnosis does not acknowledge the complex nature of the conditions. Moreover, it reinforces mind-body dualism – regarding symptoms as either "organic" or "non-organic"/"psychological" (Creed et al., 2010; Marks & Hunter, 2015) and it has been shown that patients find it unacceptable and distress inducing (Marks & Hunter, 2015; Picariello et al., 2015). Recently, research has also emphasised that the reliability of determining whether or not there is a pathophysiological explanation for certain symptoms is poor (Löwe et al., 2022). Moreover, people with ''MUS'' may very well show organic findings, such as normal variants, trivial findings, expression of underlying functional organ dysfunctions, or in the presence of comorbidity or differential diagnosis (Roenneberg et al., 2019). Therefore, the term MUS, is arguably misleading and unhelpful when applied to patients with PPS.

3.1.1.1 Terminology used in this research

More recently, a suggestion has been made to use the terms PPS or FDs, as these labels have shown to characterise the underlying mechanism in a more representative manner, while carrying less negative associations than other terminology used for those disorders (Ding & Kanaan, 2016).

PPS and FDs are closely related and sometimes overlapping but those two terms refer to distinctly different conditions. PPS can be regarded as more of an umbrella term for conditions that mainly involve persistent physical symptoms and the term is characterising the way the condition is experienced by the individuals (Picariello et al., 2015). Meanwhile, the term FDs is used to describe the underlying mechanisms(Marks & Hunter, 2015). One way to understand the relationship between the terms is that all FDs have PPS but not all PPS meet the criteria for FDs. PPS can also accompany other chronic symptoms that have medically established diagnosis, while FDs don’t have clearly established aetiology. Therefore, in this research both or either of those terms are used where appropriate and will use the abbreviation PPS/FD to cover both.

3.1.2 Epidemiology

Across Europe, PPS/FDs are found to be persistent in the general population and they are prevalent in both primary care and specialist care settings (Herzog et al., 2018; Kohlmann et al., 2013). Those conditions are common and associated with substantial individual and societal burdens. A pan-European review on disability burdens estimated a 12-month prevalence rate of approximately 5%, equating to 20 million affected individuals across the continent (Wittchen et al., 2011). A recent systematic review (Rometsch et al., 2024) found even higher point prevalence for FDs in the general population in Europe: 8.78% (95% CI from 7.61 to 10.10%). The highest overall point prevalence was found in Norway (17.68%, 95% CI from 9.56 to 30.38%) and the lowest in Denmark (3.68%, 95% CI from 2.08 to 6.43%). Overall point prevalence rates for specific FD diagnoses resulted in 20.27% (95% CI from 16.51 to 24.63%) for chronic pain, 9.08% (95% CI from 7.31 to 11.22%) for irritable bowel syndrome, and 8.45% (95% CI from 5.40 to 12.97%) for chronic widespread pain.

Prevalence estimates for FDs vary considerably due to differences in diagnostic criteria, assessment methods, and geographical factors. Some diagnoses, such as chronic fatigue syndrome (CFS) and fibromyalgia (FM), demonstrate greater consistency in prevalence estimates, whereas conditions like irritable bowel syndrome (IBS), chronic pain (CP), and chronic widespread pain (CWP) exhibit significant heterogeneity. This variability is primarily attributed to divergent diagnostic frameworks (ICD vs. DSM), assessment methodologies (validated vs. non-validated tools, inclusion of clinical interviews), and differing versions of classification systems (e.g., various iterations of the Rome criteria for IBS and ICHD for headaches), healthcare spending allocation, national guidelines, cultural and demographic variables and healthcare access for FDs in different countries (Rometsch et al., 2024).

There is a notable gap in research regarding the extent to which nosological inconsistencies influence epidemiological outcomes. The heterogeneity in prevalence rates across FDs diagnoses suggests that prevalence estimates are largely dependent on taxonomic and methodological differences. Findings indicate that self-administered questionnaires tend to overestimate prevalence compared to clinical interviews or physical examinations (Petersen et al., 2021). Furthermore, studies employing validated diagnostic tools report higher prevalence rates than those relying on non-validated instruments, reinforcing the necessity of robust assessment techniques.

The global FD prevalence is estimated at 12.9% (95% CI: 12.5–13.3%), based on the Somatic Symptom Disorder (SSD) criteria (Lowe et al., 2022). These findings underscore the urgent need for a unified scientific approach that implements validated assessment tools to enhance comparability and reliability in epidemiological research on functional disorders in order to tackle the well documented negative consequences of FDs, including psychosocial impairment, increased suicidality rates, and heightened healthcare expenditure, (Herzog et al., 2018).

3.1.2.1 *Population*

Epidemiological findings indicate that PPS and FDs are more prevalent among women, younger adults, and individuals from lower socioeconomic backgrounds (Kim & Chang, 2012; Kroenke, 1993). A systematic review about FDs and health outcomes (Ko et al., 2022) found that most prevalent FDs in the general population are irritable bowel syndrome (IBS) with a prevalence of 8.6%, fibromyalgia (FM) which has prevalence of 1.9% and chronic fatigue syndrome (CFS) with the prevalence of 0.8%. Conflicting evidence exists concerning whether prevalence increases or decreases with age. Some studies indicate that certain PPS, such as somatoform disorders, tend to decline with age, possibly due to adaptive coping mechanisms, reduced healthcare-seeking behaviour, or symptom reinterpretation over time (van Dessel et al., 2014). IBS is one of the most common FDs which was found to affect between 10% and 15% of the US and European populations. However, other studies suggest that FM prevalence increases with age among women, rising from 2% in those aged 30–39 years to 7% in those aged 60–69 years (Kim & Chang, 2012).

3.1.2.2 *Healthcare use*

PPS are very distressing for individuals to experience and for some people the symptoms can be severely disabling (Witthöft & Hiller, 2010). PPS have also been found to be a considerable burden for health care systems (Barsky et al., 2005; Bermingham, 2010; Kube et al., 2020), as they are very common. For instance, a German guideline group (Roenneberg et al., 2019) found that PPS affect around 10% of the general population.

In addition to distressing and sometimes severely impairing symptoms for the individual person (Witthöft & Hiller, 2010), PPS also represent a considerable burden for health care systems. Patients with PPS had more primary care visits; more specialty visits; more emergency department visits; more hospital admissions; higher inpatient cost; and higher outpatient costs. When these results were adjusted for the presence of comorbid anxiety and depressive disorders, major medical morbidity, and sociodemographic characteristics, patients with PPS still had more primary care visits, more specialist visits, more emergency department visits, more hospital admissions, more ambulatory procedures, higher inpatient costs, and higher outpatient costs (Barsky et al., 2005).

There are few studies about the estimated burden for health care. In USA an estimated $256 USD billion a year in medical care costs are attributable to PPS at the national level (Barsky et al., 2005). In England, Bermingham (2010) calculated the estimated annual cost of healthcare use and productivity loss based on the existing literature, estimates of prevalence, healthcare use and disability. They found that the health care cost incurred by patients with PPS was estimated to be £3 billion. That finding represented approximately 10% of total NHS expenditure on these services for the working-age population in 2008–2009. By their calculations, the cost of sickness absence and decreased quality of life associated with these patients amounted to over £14 billion.

3.1.2.3 Primary care

PPS, are very common in primary care: about 25–30% of doctor visits in primary care are due to PPS (Van Hemert et al., 1993) in some studies this number is even as high as 20%-50% (Roenneberg et al., 2019). Moreover, it has been found that about 25% of primary care patients have clinically relevant PPS (Fink et al., 2007; Natalie Steinbrecher, 2011). It has been reported that PPS account for over half of all outpatient medical appointments, of which 33% are left as medically unexplained, and are chronic in 25% of patients (Kroenke, 2003).

A recent cross-sectional survey (Chaabouni et al., 2024) looked at patients with persistent symptom diagnosis (who have had this diagnosis for over a year) and compared their symptom burden with other primary care patients. Approximately one-third of primary care patients previously diagnosed with persistent symptoms no longer reported experiencing these symptoms at the time of survey completion. However, among those whose symptoms remained persistent, significantly higher levels of somatic symptom severity were observed in comparison to other primary care patients. Furthermore, individuals with persistent symptom diagnoses exhibited elevated levels of depression and anxiety. Notably, general health utility and physical functioning were significantly lower in this group, whereas mental functioning and social well-being did not differ significantly from that of other primary care patients.

Approximately one-third of patients who had previously consulted their general practitioner for persistent symptom diagnoses no longer experienced these symptoms at the time of follow-up. This may be attributed to the fluctuating nature of persistent symptoms, as previous research indicates that symptom trajectories fluctuate in 80% of cases (Claassen-van Dessel, van der Wouden, Hoekstra, et al., 2018). Findings from prior studies on medically unexplained symptoms and somatoform disorders align with these results. Patients in primary care settings with persistent symptoms consistently report moderate to severe somatic symptom severity in 40–50% of cases (Claassen-van Dessel, van der Wouden, Twisk, et al., 2018; den Boeft et al., 2017), compared to 9–15% (Hinz et al., 2017; Kocalevent et al., 2013) in the general population. Additionally, previous research has demonstrated that individuals with persistent symptoms experience higher levels of depression and anxiety, greater impairment in physical functioning, and reduced quality of life when compared to other primary care patients.

The similarities in illness burden between patients with persistent symptoms and those diagnosed with other conditions suggest substantial overlap in the functional and psychological consequences of these disorders. This underscores the need for a more integrative clinical approach to address the shared impact of persistent symptoms across different diagnostic categories

3.1.2.4 Specialist care

A German guideline group (Roenneberg et al., 2019) found that PPS account for 25%-66% in specialist care. A cross-sectional survey conducted by Nimnuan et al. (2001) looked at seven different specialist care areas to see how PPS are represented in different specialist care settings. They found that patients with symptoms of PPS were common: Dental care: 37%; Chest 41%; Rheumatology 45%; Cardiology 53%; Gastroenterology 58%; Neurology 62%; Gynaecology 66%; Overall 52%. A study based in secondary care indicated that about 50% of patients had no clear diagnosis at 3 months (Chew-Graham et al., 2017).

3.1.3 Impact on patients

3.1.3.1 Persistence of symptoms

The prevalence of PPS is vastly common. It has been found that 80% of the general population experience one or more symptoms within 1 month. Moreover, in clinical populations, 20-25% of individuals with acute symptoms develop PSS and remain affected 1 year after their first consultation (Kroenke, 2003; Löwe et al., 2022).

A German guideline group carried out a systematic review of the literature with the aim to formulate a practice guide for the treatment of PPS/FDs in Germany (Roenneberg et al., 2019). They found that in at least 20%, to 50%, of patients who have multiple somatic symptoms fulfil the criteria of BDD (Body dysmorphic disorder: ICD-11). Over the course of time 50% -75% of patients report improvement, while for 10% to 30% of patients, the symptoms worsen.

3.1.3.2 Quality of life

A recent systematic review of FDs and health outcomes (Ko et al., 2022) found that patients with PPS experience higher levels of negative health outcomes compared to patients with comparable, but organically explained physical complaints. For instance, they found that CFS patients had significantly lower overall health related quality of life (HRQoL) scores than in other explained chronic illness groups. FM patients had similar or significantly worse physical and mental health status scores, HRQoL scores and functional disabilities compared to those with rheumatoid arthritis, Parkinson’s disease and pain conditions. Significantly lower HRQoL scores were also found in patients with IBS as compared to inflammatory bowel disease, diabetes mellitus, dialysis-dependent end-stage renal disease and panic disorder.

Those findings are in line with previous reports of the HRQoL of patients with PPS/FDs compared to other patient groups. Zonneveld et al. (2013) found the quality-of-life values of patients with PPS were among the poorest and their health-care costs were among the highest of all patient groups. Similar findings are reported in another recent review conducted by Guo et al. (2019). They emphasised that people with PPS are more likely to experience impairments in HRQoL, long-term occupational functioning, and self-rated health.

3.1.4 Mechanisms

Currently, the mechanisms that cause PPS are still not known for certain but there is evidence for multiple mechanisms involving the body and the brain (Czachowski, 2021; Löwe et al., 2022). Various classifications and frameworks, including ICD-10 and DSM-5, describe these conditions differently and emphasise different mechanisms. There are still controversies and disagreements due to the lack of an unambiguous explanatory theory. Nevertheless, there are several current theories classifications and frameworks. While the research in this thesis did not attempt to examine these mechanisms, it is important to describe them to emphasise what is currently known and contrast that with patients' experiences of having their condition dismissed which does feature throughout this thesis. In this section, there is an overview of several current theories, classifications and frameworks.

3.1.4.1 Mechanisms primarily involving communication between the brain and the body

The following is an introduction of the mechanisms that are found to be involved in the communication between the brain and the body in PPS/FDs.

3.1.4.1.1 Autonomic nervous system

A meta-analysis and systematic review of cardiac autonomic nervous system (ANS) dysfunction in FDs conducted by Tak et al. (2009) found some evidence that dysfunction of the ANS could be influenced by intense, acute, repetitive and chronic psychosocial stress. They hypothesised that this process could act as a potential mechanism through which psychosocial stress influences the onset or maintaining of PPS. Particularly relevant finding was that ANS dysfunction may develop when one of the following conditions is met: when the load of stressors in an individual is too much; when the ANS activation is chronic; or when the capacity of the ANS to adjust is diminished. The systematic review concluded that the potential mechanism through which this specific dysfunction may contribute to experience of PPS is through a misinterpretation of generated peripheral physiological arousals and sensations.

A recent study (Santonocito et al., 2024)investigated the role of the gut-brain axis in IBS, focusing on how probiotics can stabilise gut microbiota and alleviate stress-induced gastrointestinal issues. It highlighted the interaction between stress, gut microbiota, and brain function, providing insight into the gut-brain axis's role in IBS.

3.1.4.1.2 Hypothalamic–pituitary–adrenal (HPA) axis

Stress and the activation of the hypothalamic–pituitary–adrenal (HPA) axis has been studied since Selye (1936) first noted the connection. Since then stress has been associated with an increased release of cortisol from the adrenal glands. In recent years, a paradoxical phenomenon has been described: a hyporesponsiveness on different levels of the HPA axis in a number of stress-related states. Moreover, low cortisol levels have been reported in 20–25% of patients with stress-related disorders such as CFS, FM, IBS (Fries et al., 2005). Fries et al. (2005) proposed that the phenomenon of hypocortisolism may occur after a prolonged period of hyperactivity of the HPA axis due to chronic condition.

Heim and colleagues (Heim, 2000) proposed in their review article that PPS/FDs can be characterised by a dysregulation of the HPA axis. They found evidence that factors such as genetic vulnerability, previous stress experience, coping and personality styles may determine the manifestation of this neuroendocrine abnormality. They postulated that the persistent lack of cortisol availability in chronically stressed individuals may promote an increased vulnerability for the development of stress-related bodily disorders.

3.1.4.1.3 Immune system

The role of the immune system in PPS and chronic pain states has been found to play a major role. Recent findings show that the interactions of the endocrine, immune and central nervous systems are very important in both pain perception and in sickness behaviour (Dantzer, 2005). Moreover, the pain perception might be modified to hypo-as well as hyperalgesia when those interactions are dysfunctional (Rief & Broadbent, 2007). A review article (Kim & Chang, 2012) proposed that the immune system might play a pathophysiologic role in some patients with PPS/FDs. Common immune markers of interest, according to their findings, were mast cells and pro-inflammatory cytokines such as TNF-a, IL-1 and IL-6.

Another review article (Bjurstrom et al., 2016) identified cytokines and neurotrophic factors as key mediators involved in neuroimmune activation pathways in chronic pain models. Those findings are supporting the clear association of a mechanistic role of altered central cytokines and neurotrophic factors in a number of chronic pain states

Fries et al. (2005) found that alterations in HPA axis function may have long-lasting immune effects due to the modulating role of glucocorticoids on the immune system. They proposed that impaired suppressive effects of low cortisol levels increased the inflammatory responses.

Therefore, a hypocortisolemic stress response, which has been found in FDs such as CFS, and FM, may result as an over activity of the immune system (Heim, 2000; Rohleder et al., 2004).

3.1.4.1.4 Prior illness/injury

The patients' history could involve a physical injury in the past, from which a perceptual system receives disconformity information. Despite the potential adaptivity of this perceptual system, it may no longer best correspond to structural injury (Kube et al., 2020). A study of functional neurological disorders (Fobian & Elliott, 2019) found that peripheral injury was present in the majority of patients with functional dystonia, while 20% of patients with functional weakness had experienced physical injury to the affected limb near symptom onset. This link has been consistently observed, suggesting that physical trauma may play a significant role in FNSD (functional neurological symptom disorder) onset.

3.1.4.2 Mechanisms primarily involving the brain responding to the body

It has been established in neuroscientific research, that central brain mechanisms can evoke the experience of pain even in the absence of any external sensory stimuli (Derbyshire et al., 2004; Landgrebe et al., 2008; Raij et al., 2005).

Kirmayer et al. (2004) argued in their review article that PPS is characterised by a network of interacting systems. They proposed that the central nervous system (CNS) modulates the experience of physical symptoms in PPS. This can be understood as a network of interacting systems which has a bidirectional communication with the CNS.

In another review article (Kim & Chang, 2012) the researchers emphasised that brain imaging can aid the understanding of the role of CNS alterations in PPS. They found that although studies have used different methodology and neuroimaging modalities, the brain regions that were responsive to painful stimuli, were similar in different functional pain syndromes. Those commonalities were found in sensory processing regions (i.e., thalamus, insula), and both in cognitive and affective processing regions (i.e., ACC- anterior cingulate cortex). The review concluded that in the networks involved, there are shared alterations in the way the perceptions of painful stimuli are processed.

Those review articles have highlighted the evidence that the symptom experience may be modulated by the CNS and may mediate the effects of psychosocial factors on the development of PPS. Those findings are challenging the simplistic models of symptom origins. Similar CNS alterations have been observed in chronic pain and in other PPS, such as in dizziness, fatigue, or in gastrointestinal complaints (Kirmayer et al., 2004).

3.1.4.2.1 Central sensitisation

Central sensitisation has been a widely studied concept in PPS. Central sensitisation can be defined as a highly reactive state of the nervous system which results in the perpetuation of chronic pain (Guo et al., 2019; Löwe et al., 2022). It is well established that central sensitisation is present in chronic pain (Löwe et al., 2022) and there is some evidence that central sensitisation can be a factor in PPS/FDs for example in: IBS, FM, myofascial pain syndrome, tension headache, multiple chemical syndrome, migraine, temporomandibular joint dysfunction, restless legs syndrome and primary dysmenorrhoea (Guo et al., 2019).

Löwe and colleagues from SOMACROSS group (Löwe et al., 2022) proposed that neuroinflammation might be a likely process through which central sensitisation happens. It is hypothesised that neuroinflammation occurs in the central and peripheral nervous systems and is indicated by higher serum levels of interleukin 6 (IL-6) and tumour necrosis factor (TNF). This process can be seen as the contributing force in the transition from acute to chronic pain. One of the key factors modulating this process, has been the changed function of the glia in different pathological states. A review of glia's role in chronic pain (Ji et al., 2013)postulated that chronic pain could be a result of "gliopathy,". This would be a dysregulation of glial functions in the central and peripheral nervous system. In their comprehensive review Bjurstrom et al. (2016), argued that the normal function of glia is to carry out a protective role but in pathological states, it is found that glia can directly or indirectly magnify the pain transmission properties of neurons. They proposed that this process is shaping the synaptic plasticity in a dysfunctional way.

3.1.4.2.2 Predictive processing

According to the current neuroscientific understanding, the brain does not ''passively" process the incoming sensory data (Kube et al., 2020). A review article about conceptual integration of psychological expectation models and predictive processing in PPS (Kube et al., 2020) emphasised that the brain ''actively" generates top-down predictions about expected sensory input. The predictive processing theory states that the sensory data gathered by the brain is matched with prior predictions (priors) and any deviations from priors (i.e. prediction errors) are used to provide corrective feedback in order to update predictions.

SOMACROSS research unit (Löwe et al., 2022) has several studies underway in order to gain more insight into the mechanisms of PPS. Their findings so far have suggested that in PPS the symptom perception arises through an integrative process that consists of sensory input, prior experience and contextual cues (for example emotional state). This framework of predictive processing model suggests that the relationship between subjective symptoms and pathophysiological dysfunction is highly variable. The article stressed that symptom experience can be highly influenced by both somatic input and by priors and can vary between and within individuals.

3.1.4.2.3 Interoception

Currently the research about the neural correlates of PPS is sparse. There are findings that indicate an increased activation of ACC and the insula (Browning et al., 2011; Kube et al., 2020). These regions have also been involved in the experience of unpleasant symptoms in the absence of sensory stimuli and have been shown to alter their neural activity in response to experimental interventions (Kube et al., 2020; Landgrebe et al., 2008).

It has been demonstrated that the brain reacts differently to information that is consistent with prior expectations. In their review article Kube et al. (2020) hypothesised that the lack of expectation updating in people with PPS might involve prefrontal regions, such as ACC and the inferior frontal gyrus, which have a pivotal role in higher-order modulation of perception and cognition. An especially relevant hypothesis, that they proposed, is that those regions might supress the neural crosstalk with lower-order regions, which under normal conditions deal with prediction errors. Therefore, this suppression might allow strong priors to override prediction errors and as a result, perception continues to be biased towards strong and inaccurate priors.

3.1.4.2.4 Psychological processes

A review of symptom models and mechanisms in PPS (Rief & Broadbent, 2007) found that many psychological models propose that misinterpreting physical sensations and cognitive abnormalities in patients with PPS are thought to play a crucial role in symptom development. Abnormal or dysfunctional cognitive factors include: symptom attention, symptom attributions, illness beliefs, illness perception, expectations, prior experience, memory, and health anxiety (Guo et al., 2019; Rief & Broadbent, 2007).

Rief and Broadbent (2007) argued that these factors might contribute to PPS by perpetuating negative illness perceptions and attentional biases towards physical threats. Another review emphasised similar findings (Witthöft & Hiller, 2010). They put forward that patients' frequent checking of their symptoms, interpreting normal sensations in a dysfunctional way and heightened expectations for negative consequences, were associated with both the maintaining and severity of PPS/FDs.

Moreover, there is evidence that emotion regulation styles, attachment styles, personality and traumatic experiences might contribute to the development of PPS (Rief & Broadbent, 2007). And it has been found that negative illness perceptions may lead to higher symptom reports and future disability due to the impairments in physical, social, and emotional functioning (Guo et al., 2019).

3.1.4.3 *Integrative models*

Over the last decade or so, the emphasis has been shifting from determining the causes of PPS, to understanding the interplay of various complex mechanisms through which PPS develops. Most of the current explanatory models for PPS, base their models on integrating different approaches.

Integrative models of PPS aim to explain both how PPS develops and how PPS is being maintained. As opposed to traditional models, which focus more on determining the causes of PPS. Most current models are considered to be integrative models.

The most widely regarded are:

- The perception-filter model of somatoform disorders (Rief & Broadbent, 2007)
- The expanded CBT model of MUS (Deary et al., 2007)
- The Violation of Expectations Model (Kube et al., 2020)
- Risk factors and mechanisms for PPS: SOMACROSS research unit (Löwe et al., 2022)

3.1.4.3.1 The biopsychosocial model

A growing body of research provides evidence that expectations play a crucial role in clinical outcomes. Schmitz et al. (2019) found that expectations tend to predict symptom course, treatment benefit and negative side effects of treatments. These effects have been demonstrated for a wide range of medical and psychological conditions. Those effects have been observed in both PPS, as well as in conditions with a well-established pathology.

Moreover, a review of the commonalities across PPS (Guo et al., 2019) stressed the importance of biopsychosocial factors in the symptom burden and treatment outcomes. Such as: social factors, early life stressors, prior experience, belief of symptoms, peripheral sensory input processing, central sensitisation, cognitive processing, interpretation of symptoms, focus on symptoms and subsequent illness-related behaviours.

The SOMACROSS group (Löwe et al., 2022) has highlighted the patients' expectations of symptoms as playing a central role in symptom processing. They emphasised that the factors that play a role in the development of PPS are connected to both expectations and biological, psychosocial and medical treatments. Particularly relevant is the emphasis of a common denominator for risk factors for PPS, such as dysfunctional psychological processes (for example catastrophising, dysfunctional illness perceptions and health anxiety). They concluded that those processes can be regarded as a core feature of current aetiological models for PSS.

3.1.5 Relationship of PPS to mental health difficulties

3.1.5.1 Common cause/mechanisms

The comorbidity of PPS with psychiatric disorders has been widely studied. PPS/FDs are found to be associated with coexisting depressive and anxiety disorders. Other predictors of psychiatric co-morbidity include recent stress, lower self-rated health and higher somatic symptom severity, as well as high healthcare utilisation, difficult patient encounters as perceived by the physician, and chronic medical disorders (Kroenke, 2003). It has been also found that, in addition to the underlying pathophysiology, psychosocial factors play a relevant role in the development and persistence of symptoms in somatic diseases (Löwe et al., 2022).

A meta-analytic review (Henningsen et al., 2003) looking at the relationship between IBS, FM and CFS to depression and anxiety found that these syndromes were related to psychiatric disorders but not fully dependent on them. A particularly relevant finding was a significantly higher rate of lifetime generalised anxiety disorder, panic disorder and major depressive disorder. They concluded that there is strong evidence that this association goes beyond the rate observed in healthy controls or in patients with similar diseases of known organic pathology. They also found that there is limited meta-analytic evidence for three further effects: a linear dose-effect-like relationship between the number of experienced persistent physical symptoms and psychiatric disorders.

However, the causal and temporal relationship of psychiatric disorders and the development of PPS is still unclear and is being investigated. A review of commonalities across PPS (Guo et al., 2019) concluded that mental health disorders can be both contributors and consequences of PPS. They found that shared pathology could contribute to the onset of both physical and depressive symptoms and suggested that this might be due to the underlying epigenetic processes. For example, such as early childhood trauma affecting the immune system and thus impacting neuronal plasticity through inflammatory pathways. Additionally, symptom burden, the subjective view of symptom severity and associated physiological burden, is commonly adversely associated with several psycho-behavioural and functional characteristics for patients who experience a variety of symptoms of different aetiologies. The level of symptom-related distress is recognised as a predictor of PPS prognosis.

3.1.5.2 Anxiety

PPS are shown to be accompanied by comorbid depression, anxiety and other psychiatric comorbidities. There is an increased risk for suicidal ideation and suicidal attempts particularly in more severe cases (Kim & Chang, 2012; Löwe et al., 2022). Furthermore, stress and other psychosocial factors appear to play a role in the development or the symptom exacerbations of these conditions.

For the general population, the lifetime prevalence rate of the most common anxiety diagnosis are as follows: specific phobia: 18.4; social phobia: 13.0; post-traumatic stress disorder: 10.1; generalised anxiety disorder: 9.0. Whereas the 12-month prevalence is estimated to be as follows: 12.1%; social phobia; 7.4%; post-traumatic stress disorder 3.7%; generalised anxiety disorder: 2.0% (Kessler et al., 2012)

A review of FDs and their underlying mechanisms (Kim & Chang, 2012) noted that it has been reported that 28.5% patients with FDs also had a co-existent anxiety disorder and 30% IBS patients had anxiety symptoms. For patients with FM, the prevalence of an anxiety disorder ranged between 13% to 63.8% and the risk of lifetime anxiety disorders, particularly obsessive-compulsive disorder and PTSD, has been estimated to be 5 times higher among women with FM than without (Fietta & 2007). Furthermore, the same study (Fietta & 2007) has indicated that more than 50% of individuals with FM reported symptoms of post-traumatic stress disorder (PTSD). The association between PTSD and FM has been observed in both community-based samples and clinical populations, with over half of FM patients demonstrating symptoms of PTSD. This prevalence is markedly higher than that found in the general population, where PTSD affects approximately 6%, and is comparable to rates observed among Vietnam War veterans, as well as survivors of natural disasters and motor vehicle accidents (Fietta & 2007). Moreover, the prevalence of depression and anxiety in a CFS population in the United Kingdom were both 14%, with coexistent depression and anxiety in 18%. They also found that based in a large community sample of patients with interstitial cystitis/painful bladder syndrome, the probable diagnosis of depression was 34.8% and panic attacks were experienced by 52%.

3.1.5.3 Depression

Kim and Chang (2012) also reviewed studies for depression prevalence in FDs. They found that 22% of IBS patients had depression symptoms while another study evaluating patients with FDs, at a tertiary outpatient clinic, found that 30.4% had a comorbid depression disorder. One of the most important findings of the review was the prevalence of depression, which ranged between 20% and 80% (Fietta & 2007). A lifetime prevalence of having a diagnosis of depression in a CFS population in a large United States survey study was as high as 57%. An US study demonstrated that the lifetime prevalence of a depressive disorder for TMD patients, was 41%. In a study of IC/PBS female patients at a tertiary urology clinic setting, 5% had a diagnosis of depression, 11% had positive depression symptoms, and 14% had a panic disorder. For comparison the lifetime prevalence estimates in the general population for major depressive episode is 29.9%, whereas the 12-month prevalence is 8.6% (Kessler et al., 2012).

3.1.6 Specific challenges for patients and clinicians relating to PPS/FD

3.1.6.1 The epistemic gap

In PPS, an epistemic gap has been observed. Åsbring and Närvänen (2003) studied the discrepancy between the ideal role of the physician from the reality in the everyday work with patients with PPS/FDs. They found that the physicians used moralising terms and expressed scepticism when describing patients with FDs. Moreover, the status of illness was regarded as less serious than those with well-established pathology. The study concluded that there is a disparity from the learnt role of a doctor in a medical school, where the emphasis is on diagnosable and curable diseases, from everyday practice, where PPS are common. In their dealings with FDs physicians tended to gravitate towards the knowledge and roles obtained in their training and not acknowledge fully the lived experience and suffering of patients.

A study on physicians perspectives on patients with CFS and FM (Åsbring & Närvänen, 2003) found that the physicians' used moralising language for their interpretations of patients. CFS and FM illness status were regarded as less serious than those with an established medical disease status, regardless of the impairments patients suffered for their QoL. The study concluded how the patient groups with PPS/FDs do not always gain full access to the sick-role, in part as a consequence of the conditions not being recognised as diseases.

Johansen and Risor (Johansen & Risor, 2017) conducted a meta-ethnographic study about the experience of PPS. They found that almost all papers mention the incongruence between patients' symptom presentations and the explanatory models for biomedical disease. They observed parallel negative experiences, i.e. both medical professionals and patients experienced consultations about PPS in a negative way. They hypothesised that those parallel negative experiences are related to the epistemological incongruences of disease models that many physicians used. Moreover, they argued that PPS/FDs are reflecting the incompatibility of symptom understanding through biological explanatory models and frameworks for treatment. One of the most prevalent findings is that for the medical professionals, the issue of PPS/FDs is the epistemological incongruence between dominant disease models and the reality of meeting patients suffering from persistent illness (Johansen & Risor, 2017). Therefore, both patients and medical professionals have had experiences of being stuck, untrustworthy and helpless.

3.1.6.1.1 Impact of a diagnosis

A review explored the topic of discursive construction of 'MUS' diagnosis (Jutel, 2010). This review argued that the function of a diagnosis is to explain conditions of deviance in terms of disease rather than in terms of moral failing and it situates those deviances under the jurisdiction of medicine. A positive diagnosis provides a trajectory of treatment and a social identity, creating a sense of order from uncertainty. Moreover, they showed evidence that medical labels control the allocation of resources (Dumit, 2006; Swaan, 1989), styles of expressions (Munro, 2002) and stigmatisation (Raz & Vizner, 2008). Diagnosis also affects clinical outcomes, for example different disease labels may result in different prognosis and different social outcomes. The review concluded that the role of a medical diagnosis is to explain, legitimise and normalise. Diagnosis has power to frame social reality and instances when patient complaints cannot be diagnosed, challenge both medicine and society in general.

A recent cross sectional study (Tattan et al., 2024) found that having previously received a FD diagnosis (FM, CFS, IBS) was strongly associated with female sex, negative illness perception, with poor health related quality of life. Weaker associations were found with lower SES (socio-economic status), higher anxiety, and adverse life events. No associations were found with health anxiety, depression, kinesiophobia or physical activity.

3.1.6.1.2 Healthcare professionals

PPS can be confusing for both doctors and patients. A qualitative analysis of explanatory model of MUS (Ravenzwaaij, 2010) found that many general practitioners feel powerless and irritated when patients repeatedly visit their practice with PPS. They pointed out that patients often feel disbelieved and not taken seriously by their doctors. Especially relevant finding is that contrary to what is often suggested, patients with PPS request somatic interventions less often than physicians offer them. Moreover, they emphasised that patients seek emotional support and a legitimate and a convincing explanation for their symptoms. They concluded that although GPs recognise the importance of explaining the diagnosis of PPS, they often face difficulties in explaining the nature of the symptoms of PPS during clinical encounters.

Another review looked at what kind of strategies clinicians have developed to deflect the threat to medical competence that posed by the complexity and ambiguity of PPS/FDs. Kirmayer et al. (2004) found in their review of how ‘MUS’ conditions are explained that strategies used can involve shifting the blame from the limits of medicine to some characteristic of the patient. They hypothesised that using these kinds of strategies helps the medical professionals to give meaning to distress, locate the responsibility for care within the system of medical specialisation, and neutralise the threat to professional competence posed by the ambiguity or resistance to treatment of PPS.

3.2 Stigma

Stigma is a social attribute that links a person to an undesirable characteristic. Stigmatisation 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 judgment about a person or group identified with a particular health problem" (Weiss et al., 2006b). Moreover, stigmatisation can be understood with the reference to adverse and exclusionary social processes and for stigmatisation to occur, power must be exercised (Link & Phelan, 2001). The components of stigma are: labelling, stereotyping, separation, status loss, and discrimination (Link & Phelan, 2001).

We can understand the concept of stigmatisation by describing the psychological factors that are essential to this process. The most important factor in the generation of stigma is the perception of difference. A tendency or a predisposition to notice difference is innate in all human groups, since they depend on the predictable behaviour of their members for their functioning and safety (Smith, 2002). There are categories of characteristics that are regarded differently by the nature of these differences that they impose. Some characteristics can be described as representative of 'natural' or objective differences, such as age, gender or skin colour. In order for stigmatisation to occur, such differences must be linked to undesirable traits. For example, part of the stigma of mental illness lies in the association of illness with stereotypes of potential violence, communication problems and unpredictability. These individuals are characterised as a 'them', who are different from 'us' (Smith, 2002).

3.2.1 The concept of stigma

The term stigma comes from the ancient Greek *stizein* that means to tattoo or brand with a sharp stick (a "stig"). This term described a distinguishing mark that was burned, cut, or tattooed into the flesh of slaves or criminals. This was done so that others would know who were the less-valued members of society and then act accordingly by not socialising with them (Arboleda-Flórez & Stuart, 2012).

The stigma construct is used to describe a complex phenomenon. One of the ways to understand better what stigma stands for, is to examine the existing stigma definitions and how our understanding of stigma has evolved and changed over time. One of the most important aspects of stigma are the social elements. Goffman (1963), in his well-regarded classic formulation, defines stigma as "an attribute that is deeply discrediting" and proposes that the stigmatised person is reduced “from a whole and usual person to a tainted, discounted one” (Yang et al., 2007). A particularly influential and widely used definition is that of Jones (1984) who used Goffman (1963) observation that stigma can be seen as a relationship between an “attribute and a stereotype” to produce a definition of stigma. They put forward the definition of stigma as a “mark” (attribute) that links a person to undesirable characteristics (stereotypes). Link and Phelan (2001) have added the component of discrimination to the Jones (1984) definition of stigma. Another layer to the stigma definition has been added by Weiss et al. (2006b). They researched health related stigma and put forward that stigmatisation is ‘’a social process or a related personal experience characterised by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular health problem”.

3.2.2 Stigma in a wider social context

Stigma and the enactment of stigmatisation is a deeply social phenomenon and as already shown, stigmatisation requires a social context and the interaction of attributions and prejudices. This has led stigma researchers to put more emphasis on the need to conceptualise and measure stigma as a social phenomenon with roots in social structures (Hatzenbuehler & Link, 2014). In order to better understand the relationships between stigmatisation, social structures and individual experiences, it is beneficial to understand what structural stigma is and how it is affecting vulnerable populations. Structures have been defined as “organising principles on which sets of social relations are systematically patterned” (Bonilla-Silva, 1997). Drawing on prior conceptualisations, Hatzenbuehler and Link (2014) defined structural stigma as a set of societal-level conditions, cultural norms, and institutional policies that constrain the opportunities, resources, and wellbeing of the stigmatised.

3.2.3 Epistemic injustice

Stigma and stigmatisation is part of a wider social structure and can be regarded as part of epistemic practices, more precisely the act of stigmatisation can be described as part of epistemic injustice. Epistemic practice is a term that describes the socially organised and internationally accomplished ways that members of a group propose, communicate, assess, and legitimise knowledge claims (Kelly & Licona, 2018). For example, medicine and communication about medical conditions are epistemic practices. The notion of epistemic injustice describes an unfair treatment that takes place in the context of distinctively epistemic practices and activities (Blease et al., 2017).

Fricker (2007) puts forward two foundational kinds of discriminative epistemic injustice: testimonial and hermeneutical.

3.2.3.1 Testimonial injustice

Testimonial injustice occurs when a speaker is unfairly given a lower level of credibility as a result of prejudice. This prejudice is due to their membership of a negatively stereotyped group. A growing body of work has suggested that individuals suffering from ill health are more vulnerable to testimonial injustice (Carel & Kidd, 2014; Wardrope, 2015). There is a risk of testimonial injustice when the (non-)intentional negative stereotyping of an illness or disability (on the part of a healthcare professional) constrains the patient's epistemic contribution to consultations, and wider conversations, about their condition (Blease et al., 2017).

3.2.3.2 Hermeneutical injustice

Fricker (2007) defines hermeneutical injustice as a collective shortfall in our shared conceptual resources. Hermeneutical injustice can be described as a structural problem and testimonial injustice is executed by individuals. Hermeneutic practice can be understood as making sense of our own and others' social experiences and are fundamental to our social life (Blease et al., 2017). Hermeneutical injustice takes place when those resources are for some reason lacking: it can be characterised as a failure by the members of one or more social groups to use the shared hermeneutical resources necessary for mutual understanding of some set of distinctive social experiences (Blease et al., 2017; Fricker, 2007).

Recent research has begun to describe a set of findings concerning the role of structural stigma in the production of negative outcomes for members of stigmatised groups (Hatzenbuehler & Link, 2014) and people with FDs/PPS have been demonstrated to be stigmatised against (De Ruddere & Craig, 2016).

3.2.4 Stigma approaches in different fields

There is no generally accepted unitary theory of stigma as the stigma concept is a complex interaction between social science, politics, history, psychology, medicine and anthropology

(Smith, 2002). Examining stigmatisation in different fields often requires an emphasis on different facets of stigma.

To understand how the concept of stigma might differ in different health- research related fields of research, it is beneficial to examine how stigma has been conceptualised and where the emphasis has been.

In sociology, researchers have looked at how people construct cognitive categories and link those categories to stereotyped beliefs (Scambler, 2006). In psychology, the focus has been on studying the conceptual model of stigma and how to understand the function of stigma in intra-and interpersonal relations (Phelan et al., 2008). In social psychology, researchers have focused on how to better understand and address the psychological mechanisms and the effects of social stigma on a larger scale (Major & O'Brien, 2005). Anthropology has focused on understanding the unique social and cultural processes that create stigma in order to better understand the lived experiences of the stigmatised (Kleinman & Hall-Clifford, 2009). Recent research in medical anthropology has looked at structural stigma and the extent to which structural stigma represents a risk indicator for adverse health outcomes among stigmatised patients.

As Link and Phelan (2001) have argued that because of the complexity of the stigma phenomenon, it seems wise to continue to allow variation in definitions so long as investigators are clear as to what is meant by stigma when the term is used.

3.2.5 Stigma in medicine

De Ruddere and Craig (2016) conducted a review on stigma in chronic pain and found abundant evidence highlighting the prevalence of stigma in the lives of individuals with chronic pain (Åsbring & Närvänen, 2002; Dewar et al., 2003; Goldberg, 2010; Holloway et al., 2007; Newton et al., 2013; Nguyen et al., 2013; Schaller & Neuberg, 2012; Toye & Barker, 2010, 2012; Werner & Malterud, 2003). They concluded that qualitative evidence indicates that people with chronic pain do not feel believed by romantic partners, relatives and friends. Moreover, they found that people with chronic pain believe that practitioners think their pain is exaggerated or imagined. And they also feel blamed, misled and even report being dismissed by healthcare providers.

Certain medical conditions have been found to carry negative social connotations and therefore can be more stigmatising. It has been proposed that FDs can be experienced as more stigmatising, than medical conditions, which have a direct physical explanation or a cause (Eger Aydogmus, 2020; Kirmayer et al., 2004). Fox et al. (2018) looked at how stigma was related to mental health illness perception and found that stigma perception may differ across health conditions as people who have well documented physical reasons for their illness, were found to experience less stigmatisation, than people whose condition is described by PPS. Findings indicate that patients who have experienced higher levels of stigma are less likely to adhere to treatment or show improvements in FD symptoms, depression, or anxiety after treatment (Feingold & Drossman, 2021).

Similar findings are reported by a survey conducted by the functional neurological disorder advocacy organisation (FND Hope), which found that 85% of patients reported feeling disbelieved and disrespected when visiting a medical professional and stigma is believed to be a salient negative influence in clinical interactions (Macduffie et al., 2020).

Both medical professionals and general lay people tend to react with uncertainty and confusion to patients whose pain does not have a clear medical explanation. It has been noted (De Ruddere & Craig, 2016) both medical professionals and lay persons tend to attribute lower pain to patients if their pain does not have a clear basis in tissue pathology. Those attitudes been found in the general population (Chibnall & Tait, 1995; De Ruddere et al., 2013; De Ruddere et al., 2014; Tait & Chibnall, 1994), medical students (Chibnall et al., 1997), nursing students (Halfens et al., 1990), nurses (Taylor et al., 1984), internal medicine physicians (Tait & Chibnall, 1994), physiotherapists and general practitioners (De Ruddere et al., 2014). Moreover the attribution of stigma to these patient groups has been found to lead to acting on those stigmatising beliefs. De Ruddere and Craig (2016) reported that people in the general population and healthcare practitioners are less inclined to help (Taylor et al., 1984) and feel less sympathy (De Ruddere et al., 2013; De Ruddere et al., 2014). It has been found that health care practitioners tend to dislike patients with PPS/FDs more and suspect deception when there is no clear medical explanation for the pain (De Ruddere et al., 2013; De Ruddere et al., 2014). It has also been recorded that nurses attribute lower pain to patients when the pain is chronic compared to acute (Taylor et al., 1984) and the discrepancy between nurses' and patients' pain ratings are larger with patients with chronic pain than with patients with acute pain (Teske et al., 1983).

There is abundant evidence that both medical professionals and general public typically discount chronic pain reports, take patients less seriously and express doubt about credibility when the pain cannot be 'justified' by clear medical evidence and/or when the patients experience PPS or FDs (De Ruddere & Craig, 2016). As there has been a steady increase in interest in the topic of stigma in health-related fields, the negative consequences of stigmatisation have become better understood. Stigmatisation has been found to have adverse consequences for patients: including emotional distress, medication non-adherence, barriers to accessing care and increased symptoms (Feingold & Drossman, 2021).

3.2.6 Structural and systemic issues that affect stigma in medicine for PPS/FDs

Structural and systemic factors significantly contribute to the stigmatisation of PPS/FDs. Within many healthcare systems, these conditions are met with scepticism due to diagnostic uncertainty and the absence of clear biomedical markers, fostering an environment where patients' experiences are often dismissed (Kroenke, 2003). Insufficient emphasis on these conditions in medical education often results in diagnostic uncertainty and reinforces a narrow biomedical model (Wessely et al., 1999). Moreover, limited healthcare allocation and fragmented care pathways, which are characterised by short consultation times and inadequate disability resources exacerbate these challenges, leaving patients marginalised and their symptoms frequently dismissed (Hatzenbuehler et al., 2013). Inconsistent diagnostic criteria across healthcare settings further compound these issues, contributing to disparities in care and perpetuating stigmatising attitudes. This biomedical paradigm not only reinforces negative stereotypes but also perpetuates stigmatising attitudes among healthcare professionals, ultimately affecting patient care and access to appropriate services (Blease et al., 2017; Henningsen et al., 2007). These structural challenges underscore the need for integrative models of care that recognise both the biomedical and psychosocial dimensions of these disorders.

3.3 Summary

In this background I have demonstrated that PPS/FDs have had a problematic history which is reflected even today by the way the medical community diagnoses, communicates, teaches and treats patients with PPS/FDs. More importantly PPS/FDs are complex conditions involving bio-psycho-social aspects, that require medical care. Moreover, those conditions are stigmatised, which reflects in the denial of patients' experiences, healthcare personal negative attitudes, comorbidity, and treatment trajectories. The rest of this thesis examines stigma in PPS/FDs using different methods and covering different perspectives.

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

Authors

Hõbe Treufeldt [a]

Christopher Burton [a]

[a] Division of Population Health, University of Sheffield, Samuel Fox House, Northern General Hospital, Sheffield, S5 7AU, UK

Corresponding Author: Hõbe Treufeldt. h.treufeldt@sheffield.ac.uk

4.1 Preface

This first study in this PhD thesis asks what is currently known about stigma in medical consultations for PPS/FDs? I chose to conduct a scoping review as preliminary searches indicated that that the studies in the field were highly heterogeneous. Therefore, it was not possible to conduct a systemic review and it was decided that currently there is a need to record and understand the scope of the knowledge in this field.

The overall aim was to understand how stigma has been defined in medical consultations for PPS/FDs, what kind of methods did the research use and to look for commonalities emerging from the findings of the studies that could help to paint the wider picture and help with the framing of and the interpretation of the analysis of the subsequent studies.

4.2 Highlights

- 32 studies were identified addressing stigma in clinical communication settings regarding PPS/FDs, however few used clear definitions of stigma.
- Stigma was reported across multiple conditions and contexts suggesting it is a structural issue.
- Patients with these conditions have to work hard in consultations to maintain their credibility.
- Only one study observed consultations to see how stigma is being communicated.

4.3 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.

Keywords

Stigma, medical consultation, persistent physical symptoms, functional disorders, medically unexplained symptoms, scoping review

4.4 Background

Persistent physical symptoms (PPS) are symptoms which are disproportionate to any underlying medical diagnosis and have lasted at least three months (Aamland et al., 2014). Notable examples include persistent abdominal pain, musculoskeletal pains, fatigue, headache and dizziness. Such symptoms currently do not have any single or consistent cause (Burton et al., 2020a), but can be explained in terms of a complex interaction of biomedical, psychological and social factors (Henningsen et al., 2018). 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 (Rask et al., 2021).

People with PPS commonly face negative attitudes both in society in a wider sense and in their encounters with medical professionals (De Ruddere & Craig, 2016). 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 (Major & O'Brien, 2005). Stigma can also be characterised as a social attribute that links a person to an undesirable characteristic (Goffman, 1963). 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' (Weiss et al., 2006a). 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) (Link & Phelan, 2001). For stigmatisation to occur, power must be exercised (Link, 2001) and it commonly becomes so entrenched in cultural norms and institutional policies it can be considered to be structural stigma (Hatzenbuehler & Link, 2014).

The way stigma is communicated and perceived varies in different social settings and health conditions (Stangl et al., 2019) as well as in different clinical contexts (Dolezal, 2022). Addressing stigma within clinical encounters for conditions that are found to carry more stigma, has the potential to improve patients' experience and health outcome (Nyblade et al., 2019) (Feingold & Drossman, 2021).

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

4.5 Methods

The scoping review was prospectively registered with OSF (https://osf.io/g7azw) and followed the steps of a scoping review process (Munn et al., 2018). The study's protocol was drafted using the Preferred Reporting Items for Systematic Reviews and Meta-Analysis Protocols (Moher et al., 2015) and the reporting guidelines for scoping reviews (Munn et al., 2018). The search strategy tool for qualitative/mixed methods research (Cooke et al., 2012) 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.

4.5.1 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 (Goffman, 1963) *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.

4.5.2 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) (Cooke et al., 2012). The search terms according to SPIDER are found in Table 4.1. 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.

Table 4.1 SPIDER mapping of search terminology

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			

4.5.3 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.

4.5.4 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 (Alhojailan, 2012). 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 (Thomas & Harden, 2008). 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 (Fricker, 2007) and structural stigmatisation (Hatzenbuehler & Link, 2014).

4.6 Results

4.6.1 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 Figure 4.1 PRISMA flowchart.

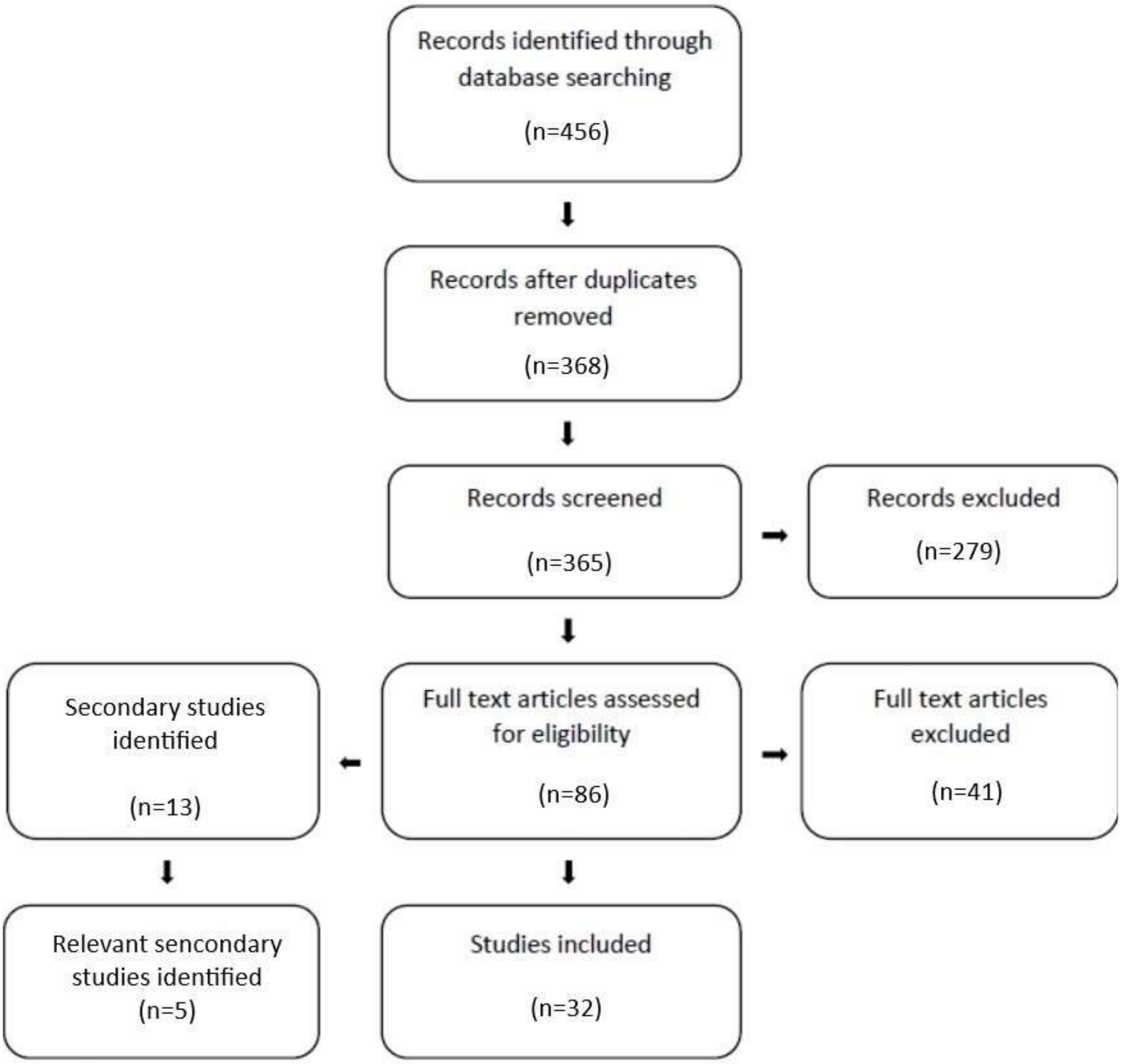


Figure 4.1 PRISMA flowchart

All 368 abstracts were screened against the inclusion criteria. Of those 86 titles were assessed to be suitable to be assessed in full text. From the identified 41 full-text titles, 9 were excluded, primary reasons were that those articles did not match the inclusion criteria (such as full text article in English language, did not include a component of stigma/medical setting/PPS or FD). 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 Table 4.2.

Table 4.2 Overview of those secondary studies

Author	Title	Study aim
Macduffie (Macduffie et al., 2020)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.
Buchman (Buchman et al., 2017)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 (Cohen et al., 2011)et al. (2011)	Stigmatisation of patients with chronic pain: the extinction of empathy	To address how health professionals' may inadvertently contribute to the stigmatisation of patients with chronic pain
Barnett (Barnett et al., 2022)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 (Byrne et al., 2022)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.

4.6.1.1 Description of studies

Most studies (Åsbring & Närvänen, 2002, 2003; Bellman & Zolnikov, 2022; Braksmajer, 2018; Briones-Vozmediano & Espinar-Ruiz, 2021; Briones-Vozmediano et al., 2018; Burbaum et al., 2010; Canna & Seligman, 2020; Dickson, 2009; Diniz et al., 2020; Dixon-Woods & Critchley, 2000; Fouché et al., 2019; Houwen et al., 2017; Kozlowska et al., 2021; Lehti et al., 2017; Maatz et al., 2016; Nishikawara et al., 2023; Robson & Lian, 2017; S Battin et al., 2022; Stortenbeker et al., 2022; Undeland & Malterud, 2008; Werner &

Malterud, 2005; White & Seibold, 2008; Yon et al., 2015) (n=24) used a qualitative research design. A mixed-methods approach was used in seven studies (Buchman et al., 2016; Colmenares-Roa et al., 2016; Gilje et al., 2008; Jones et al., 2009; Lennon et al., 1989; Naushad et al., 2018; Tolchin et al., 2020) (n= 7). Only one study (Homma et al., 2016) (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 (Bellman & Zolnikov, 2022; Braksmajer, 2018; Canna & Seligman, 2020; Jones et al., 2009; Lennon et al., 1989; Naushad et al., 2018; Tolchin et al., 2020)(n=7) and Scandinavia (Åsbring & Närvänen, 2002, 2003; Gilje et al., 2008; Lehti et al., 2017; S Battin et al., 2022; Undeland & Malterud, 2008; Werner & Malterud, 2005) (n=7). Other studies took place in the UK (Dixon-Woods & Critchley, 2000; Maatz et al., 2016; Yon et al., 2015)(n=3); Spain (Briones-Vozmediano & Espinar-Ruiz, 2021; Briones-Vozmediano et al., 2018) (n=2); Canada (Buchman et al., 2016; Nishikawara et al., 2023) (n=2); Netherlands (Houwen et al., 2017; Stortenbeker et al., 2022) (n=2) there were two multi-country studies (Kozlowska et al., 2021; Robson & Lian, 2017); and one study from each of those following countries: Germany (Jutel, 2010), Japan (Homma et al., 2016), Mexico (Colmenares-Roa et al., 2016), Portugal (Diniz et al., 2020), South Africa (Fouché et al., 2019), Australia (White & Seibold, 2008), New Zealand (Dickson, 2009). Detailed description of research methods used in the included studies is available in Table 4.3.

Table 4.3 Summary of primary studies

	Author and year	Country	Condition	Phenomena of interest	Study population (n)	Research design	Research method	Stigma defined	Stigma alluded/other terminology used
1	Kozlowska 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-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 (2020)	USA	Psychogenic Nonepileptic Seizures (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 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 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 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 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 (1963)	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)
8	Briones-Vozmediano 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 (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 (2017)	Across countries	Nonepileptic seizures (NES)	Stigma in patient-physician communication	Patients (n=135)	Qualitative	Thematic discourse analysis	Goffman (1963)	Yes
11	Houwen et al. (2017)	Netherlands	MUS	Patient-physician communication	Patients (n=43)	Qualitative	Semi-structure interviews	No	Prejudice
12	Lehti 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 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 et al. (2016)	Canada	Chronic pain	Patient-physician communication	Patients (n=27); re-contact interview patient-	Mixed	Semi-structured interviews; Questionnaires; 2 feedback groups;	No	Yes/ Victims of Negative attitudes and assumptions/

					participants (n=4); physicians (n=6)		Grounded theory data analysing		Referenced Goffman, but not defined stigma
15	Homma 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 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 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 et al. (2009)	USA	IBS	Experience of illness/stigma	Patients (n=148)	Mixed	Semi-structured interviews; questionnaire	Chapple et al. (2004)	Yes/Social rejection; societal labelling of an individual as abnormal, is an important construct for a variety of chronic illness outcomes (Chapple et al., 2004)
19	White and Seibold (2008)	Australia	Chronic pain	Experience of illness/stigma	Female patients (n=5)	Qualitative	Open-ended interview; Narrative auto-ethnographic /thematic analysis	Goffman (1963)	Yes/

20	Undeland and Malterud (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 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 (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 (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 (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 (1963)	Yes

25	Dixon-Woods and Critchley (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 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 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
28	Stortenbeker et al. (2022)	Netherlands	MUS	Patient-physician communication	BOTH We compared 41 MUS and 41 MES transcribed video-recorded general	Qualitative	Observation of recorder consultations: Content analysis (cross-sectional study)	No	Yes/ stigma, stereotypes, labelling

					practice consultations.				
29	S Battin 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 (2001), Goffman (1963)	Yes/Link and Phelan (2001)Goffman (1963)
30	Bellman and Zolnikov (2022)	USA	MUS	Patient-physician communication	Patients (n=42)	Qualitative	A qualitative phenomenological study	No	Yes/implicit bias, stigmatisation, discrimination
31	Yon 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 (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 (1963), Link and Phelan (2001)	Yes

One study (S Battin et al., 2022) directly observed consultations to assess stigma and stigmatisation. The rest of the studies (n=31) relied on indirect reports (interviews or surveys). Two studies (Braksmajer, 2018; Robson & Lian, 2017) analysed the recordings of consultations to assess the effectiveness of explanations, of which one (Robson & Lian, 2017) was focusing on stigmatisation during the clinical consultation. Sixteen studies (Åsbring & Närvänen, 2002; Bellman & Zolnikov, 2022; Braksmajer, 2018; Briones-Vozmediano & Espinar-Ruiz, 2021; Burbaum et al., 2010; Canna & Seligman, 2020; Gilje et al., 2008; Jones et al., 2009; Lennon et al., 1989; Naushad et al., 2018; Nishikawara et al., 2023; Robson & Lian, 2017; Tolchin et al., 2020; Undeland & Malterud, 2008; Werner & Malterud, 2005; White & Seibold, 2008) involved patients. Eight studies (Buchman et al., 2016; Colmenares-Roa et al., 2016; Dixon-Woods & Critchley, 2000; Houwen et al., 2017; Kozlowska et al., 2021; Lehti et al., 2017; S Battin et al., 2022; Stortenbeker et al., 2022) involved both patients and health professionals. Moreover, eight studies involved health professionals. Of those four studies involved solely physicians (Åsbring & Närvänen, 2003; Homma et al., 2016; Maatz et al., 2016; Yon et al., 2015); and four studies involved a mix of healthcare professionals (Briones-Vozmediano et al., 2018; Dickson, 2009; Diniz et al., 2020; Fouché et al., 2019). Six of the studies involving patients included only female participants (Åsbring & Närvänen, 2002; Braksmajer, 2018; Briones-Vozmediano & Espinar-Ruiz, 2021; Undeland & Malterud, 2008; Werner & Malterud, 2005; White & Seibold, 2008). Five of those studies described purposive sampling of female patients for their experiences (Åsbring & Närvänen, 2002; Braksmajer, 2018; Briones-Vozmediano & Espinar-Ruiz, 2021; Undeland & Malterud, 2008; Werner & Malterud, 2005).

Fourteen studies used umbrella terms for the medical condition, either chronic pain (Buchman et al., 2016; Diniz et al., 2020; Lehti et al., 2017; Naushad et al., 2018; S Battin et al., 2022; Werner & Malterud, 2005; White & Seibold, 2008) (n=7) or Medically Unexplained Symptoms (MUS) (Bellman & Zolnikov, 2022; Burbaum et al., 2010; Houwen et al., 2017; Maatz et al., 2016; Stortenbeker et al., 2022; Undeland & Malterud, 2008; Yon et al., 2015) (n=7). The remainder used specific syndrome criteria: Psychogenic Non-Epileptic Seizures (PNES) (Canna & Seligman, 2020; Fouché et al., 2019; Tolchin et al., 2020) (n=3); Fibromyalgia (FM): four studies included solely FM (Briones-Vozmediano et al., 2018; Colmenares-Roa et al., 2016; Homma et al., 2016;

Nishikawara et al., 2023) two studies combined FM with Chronic Fatigue Syndrome (CFS) (Åsbring & Närvänen, 2002, 2003); CFS (n=1) (Gilje et al., 2008); Irritable Bowel Syndrome (IBS) (n=2) (Dixon-Woods & Critchley, 2000; Jones et al., 2009); Functional Neurological Disorder (FND) (n=1) (Kozlowska et al., 2021); Non-Epileptic Seizure (NES) (n=1) (Robson & Lian, 2017); Somatoform disorder (n=1) (Dickson, 2009); Temporomandibular Pain and Dysfunction Syndrome (TMPDS) (n=1) (Lennon et al., 1989); dysparenuia (n=1) (Braksmajer, 2018); multiple chemical sensitivity (n=1) (Briones-Vozmediano & Espinar-Ruiz, 2021).

4.6.1.2 Definition of stigma

The studies varied in the terminology they used when describing the phenomena of stigma. Out of 32 studies, only eight explicitly defined stigma: six used Goffman 1953's definition of stigma (Goffman, 1963) as the process of social devaluation, with two also referring to Link and Phelan (2001)'s definition; one used Oxford English dictionary definition; and the other one used Chapple et al. (2004) 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.

4.6.1.3 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);

4.6.1.3.1 Stigma in health care consultations

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

S Battin et al. (2022) 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 (Robson & Lian, 2017), 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 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 (Robson & Lian, 2017). This was further broken down into four themes: (1) Identification of differentness 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 (Link & Phelan, 2001) who included in the stigmatisation process components of exclusion: separation and status loss. Here, Robson and Lian (Robson & Lian, 2017) 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 (Braksmajer, 2018) 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 questioned 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. (Braksmajer, 2018).

4.6.1.3.2 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 (Col et al., 2020) 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 (Gilje et al., 2008)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.

4.6.1.3.3 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 (Åsbring & Närvänen, 2003) 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.

4.6.1.3.4 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

(Naushad et al., 2018)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 (Lennon et al., 1989) 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.

4.6.1.3.5 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 (Canna & Seligman, 2020) 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 cope with trauma or chronic stress affects bodily symptoms; (3) Stigmatisation of symptoms impact patients' coping abilities.

4.6.1.4 Overarching themes

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

4.6.1.4.1 Epistemic injustice

In epistemic practice, such as medicine, members of a group propose, communicate, assess, and legitimise knowledge claims (Kelly & Licona, 2018). 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 (Blease et al., 2017). 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 (Fricker, 2007). Hermeneutical injustice takes place when the conceptual resources for communication are, for some reason, lacking (Blease et al., 2017; Fricker, 2007). We found repeated examples of testimonial injustice as patients were not listened to / heard (Åsbring & Närvänen, 2003; S Battin et al., 2022). 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.

4.6.1.4.2 Structural stigmatisation of PPS/FDs

Structural stigma is defined as the "legitimisation and perpetuation of a stigmatised status by society's institutions and ideological systems' (Bos et al., 2013; Hatzenbuehler & Link, 2014). 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).

4.7 Discussion and conclusion

4.7.1 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 in 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" (Campbell et al., 2023). 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.

4.7.2 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.

4.7.3 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 (Fryer et al., 2023). 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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5 Stigmatisation in clinical consultations for persistent physical symptoms/functional disorders: A best fit framework synthesis

Authors

Hõbe Treufeldt a

Brodie McGhie Fraser b

Christopher Burton a

a Division of Population Health, University of Sheffield, Samuel Fox House, Northern General Hospital, Sheffield, S5 7AU, UK

b Department of Primary and Community Care, Research Institute for Medical Innovation, Radboud University Medical Center, Nijmegen, Netherlands.

Corresponding Author: Hõbe Treufeldt. h.treufeldt@sheffield.ac.uk

5.1 Preface

This best fit framework synthesis drew from the results of the previous scoping review and thematic synthesis. Creating the framework was not a part of the original thesis plan. This framework development began in discussion with my primary supervisor that there might be some common themes emerging from the data. Indeed, when I started to systematically look for ways to describe, categorise and understand the data and the findings of the thematic synthesis, it became apparent that the themes formed categories and those categories themselves shared certain core characteristics. This began a long process of constructing the novel framework that this study presents.

5.2 Introduction

Persistent physical symptoms (PPS) is an umbrella term for symptoms lasting at least three months and which are disproportionate to underlying organ-system disease (Aamland et al., 2014; Löwe et al., 2022). These symptoms may exist on their own (for example dizziness) or as part of a syndrome. Currently those syndromes are referred to as functional disorders (FDs), the most prevalent being irritable bowel syndrome and fibromyalgia (Burton et al., 2020a; Henningsen et al., 2018). PPS/ FDs represent a spectrum of severity, ranging from mild symptoms to severe and chronic disorders (Rask et al., 2021). PPS currently cannot be described by any single consistent cause (Burton et al., 2020a) but they can be understood as arising from a complex interaction of biomedical, psychological and social factors (Henningsen et al., 2018).

PPS are common; approximately one in six patients with persistent symptoms had at least 1 symptom diagnosis persistent more than a year (Chaabouni et al., 2023; Kroenke, 2003; Löwe et al., 2022). In 2010, a Europe-wide review on disability burdens found that the 12-month prevalence rate is estimated to be around 5% (i.e., 20 million individuals in Europe) (Wittchen et al., 2011).

Stigma is a social attribute that links a person to an undesirable characteristic (Link & Phelan, 2001). Stigmatisation, in its essence, is the process of increasing social distance between individuals. This is a social process that starts with an identification of a difference that is then connected to a culturally present negative stereotype. Therefore, the labelled persons are placed in distinct categories so as to accomplish some degree of separation of "us" from "them" (Link & Phelan, 2001). This is a process of increasing social distance which then leads to the labelled persons' experiencing differential treatment and discrimination that lead to unequal outcomes.

It is important to note that stigmatisation is contingent on access to social, economic, and political power. This allows the identification of differentness, the construction of stereotypes, the separation of labelled persons into distinct categories, and the full execution of disapproval, rejection, exclusion, and discrimination. Those processes affect stigmatised people's everyday functioning and well-being (Hatzenbuehler & Link, 2014; Link & Phelan, 2001).

Stigmatisation related to medical conditions 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 judgment about a person identified with a particular health problem" (Weiss et al., 2006b). Certain medical conditions have been found to carry negative social connotations and therefore can be more stigmatising. There is evidence that PPS/FDs can be experienced as more stigmatising, than medical conditions, which have an established medical diagnosis or cause (Eger Aydogmus, 2020; Fox et al., 2018; Kirmayer et al., 2004). Moreover, it has been found that patients who have experienced higher levels of stigma, are less likely to adhere to treatment or show improvements in symptoms, depression, or anxiety after treatment (Feingold & Drossman, 2021). A survey conducted by the functional neurological disorder advocacy organisation (FND Hope) found that 85% of FND patients reported feeling disbelieved and disrespected when visiting a medical professional and stigma was believed to be a salient negative influence in clinical interactions (Macduffie et al., 2020).

We have recently conducted a scoping review of stigma in medical consultations for PPS/FDs (Treufeldt & Burton, 2024). In this, we found that stigmatisation was present across the spectrum of PPS/FDs in a variety of medical specialties, in different medical settings and across countries and cultures. The findings suggest that there are widespread societal-level conditions, cultural norms, and institutional practices present, which negatively effect the treatment of patients who are affected by PPS/FDs. Together these can be considered as form of structural stigmatisation (Hatzenbuehler & Link, 2014). We also found that there was no consistent framework or definition of stigma in consultations for PPS/FDs.

As stigmatisation is a social process, the way stigma is communicated and perceived is dependent on prevalent social, cultural and medical contexts (Koschorke et al., 2017; Weiss et al., 2006b). In order to be able to improve consultations regarding PPS/FDs we first need to understand what specifically in the communication process causes the stigma that patients experience. For that end, the general models and frameworks about stigma are useful as they help us to understand the wider picture and societal shifts of attitudes and prejudices. Unfortunately, general frameworks are not very useful in a practical sense, particularly in a clinical consultation setting. One of the reasons for the development of a new framework for PPS/FDs, is that for example models for mental health stigma don't always represent PPS/FDs patients' lived experiences, especially considering people's experiences of physical symptoms. In that context the use of models of psychological attribution can be stigmatising as those models tend to attribute psychological causes to the patient's physical symptoms. Secondly, social distance models are often not relevant to the context of PPS/FDs as they have focused more on the visible markers of differences and infectious diseases. Moreover, sociological models are overall all-encompassing and describe wider societal and general processes and therefore are abstract. Consequently, those models are not well suited for medical interactions as they are not designed to provide specific guidance on how to evaluate individual experiences or encounters, especially in a medical setting.

Therefore, there is a need for a practical framework with specific examples of what is stigmatising in consultations for PPS/FDs as both patients and clinicians report difficulties and experiences of stigma in those interactions.

This paper aims to address this identified gap in both research and in clinical practice. We describe the development of an actionable framework to aid understanding of how stigmatisation most commonly happens in clinical interactions for PPS/FD.

5.3 Methods

5.3.1 Overview

The current study is part of the innovative training network ETUDE (Encompassing Training in fUnctional Disorders across Europe) (Rosmalen et al., 2021).

This framework synthesis used the Best Fit Framework (BFF) synthesis approach (Carroll et al., 2013). The BFF method offers a means to test, reinforce and build on an existing published model. This method is suited for producing context-specific conceptual models for describing or explaining the decision-making and health behaviours of patients and other groups. The BFF can also be used to adopt a model or a framework for a potentially different but relevant population. The process uses several steps: (1) identifying candidate frameworks and choosing an *a priori* framework (2) initial mapping of data to the *a priori* framework (3) identification of new themes to extend the framework if necessary (4) an iterative process of fitting data to the newly formed framework and revising this framework (5) testing of this evolved framework to reach the final conceptual model. The analysis was carried out by HT (PhD student) with regular supervisory input from CB (general practitioner) and additional input and discussion by BMF (PhD student).

5.3.2 Identifying candidate frameworks and choosing the *a priori* framework.

In order to find stigma frameworks and models that describe in the most representative manner the stigma in clinical consultations for PPS/FDs we first looked for current psychological models of stigma. The reason is that stigma is widely researched in the field of psychology and mental health disorders. The search strategy followed the BFF method (Carroll et al., 2013) but as there are no stigma frameworks in PPS/FDs we followed the first stage of the process, which was to combine free text and database searches in the relevant identified fields (psychology, mental health, sociology, stigma, healthcare). We aimed to incorporate key papers for commonly used stigma models in psychology and related mental health fields, therefore we searched Google Scholar and looked for stigma frameworks and models that were considered influential. As stigmatisation is widely recognised as a social process, we also looked for more generic sociological stigma models using the same search strategy. As no single model appeared to be a good fit, therefore we tabulated key components from the identified relevant models and from these derived an *a priori* framework. In this process, existing models of stigma were discussed with three authors (HT, CB and BMF) until those discussions resulted in consensus. At the stage of choosing the *a priori* framework we focused on one with a few high-level and inclusive concepts rather than seeking to produce a more granular *a priori* framework with multiple fields.

5.3.3 Mapping data to the *a priori* framework

Data for analysis consisted of verbatim quotations from the participants of the qualitative studies included in the previously published scoping review (Treufeldt & Burton, 2024). This analysis included 253 quotations from 32 studies. Those quotes involved both the perspectives of patients with PPS/FDs but also healthcare professionals working with PPS/FDs. The search strategy and selection of these articles are previously described in our scoping review (Treufeldt & Burton, 2024). From the results sections of these articles, we extracted all quotations that were used to illustrate the themes of the individual papers. We used these as the raw data for the mapping process. Mapping refers to a process of applying data to a framework to see what fits (and what does not fit). During this mapping it became apparent that the *a priori* framework, which was aimed to describe high-level structures, provided insufficient detail for the purpose of describing individual experiences. This analysis was carried out by two of the researchers (HT and CB). The summary of the primary studies used to extract quotations is found in Table 5.1

Table 5.1 Summary of primary studies used to extract quotations

	Author	Country	Condition	Phenomena of interest	Study population (n)	Research design	Research method	Stigma defined	Stigma alluded/other terminology used
1	Kozlowska 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	Yes	Yes/ negative emotional response from illness perceptions
2	Briones-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 (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 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 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 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 et al. (2018)	USA	Chronic pain	Experience of illnes	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	Yes; (Goffman, 1963)	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)

8	Briones-Vozmediano 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 (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 (2017)	Across countries	NES	Stigma in patient-physician communication	Patients (n=135)	Qualitative	Thematic discourse analysis	Yes; (Goffman, 1963)	Yes
11	Houwen et al. (2017)	Netherlands	MUS	Patient-physician communication	Patients (n=43)	Qualitative	Semi-structure interviews	No	Prejudice
12	Lehti 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	No	Yes/ process of othering; subordination; stereotyping; marginalisation

							assessment teams		
13	Colmenares-Roa 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 stigmatization, overt rejection, and denial of the disease's existence were identified as the disadvantageous position of the patient
14	Buchman 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 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 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 et al. (2010)	Germany	MUS	Patient-physician communication	patients (n = 49); a control group (n = 42)	Qualitative	Recordings of consultations analysed using CA and	No	Yes/term used/ Negative attitude/other positioning/role ascription

							positioning analysis		
18	Jones et al. (2009)	USA	IBS	Experience of illness/stigma	Patients (n=148)	Mixed	Semi-structured interviews; questionnaire	Yes; (Chapple et al., 2004)	Yes/Social rejection; societal labelling of an individual as abnormal, is an important construct for a variety of chronic illness outcomes (Chapple et al., 2004)
19	White and Seibold (2008)	Australia	Chronic pain	Experience of illness/stigma	Female patients (n=5)	Qualitative	Open-ended interview; Narrative auto-ethnographic /thematic analysis	Yes; Goffman (1963)	Yes/
20	Undeland and Malterud (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 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 (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 (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 (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	Yes; Goffman (1963)	Yes
25	Dixon-Woods and Critchley (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 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

5.3.4 Adding new themes

We thus coded data from the quotations into new conceptual categories, or themes, as described in the BFF (Carroll et al., 2013). Coding represents a process of generating new concepts (or themes) from the data (particularly that which did not fit in the mapping exercise). This led to a more detailed framework in which the major conceptual categories were subdivided into meaningful conceptual units. At this stage of initial framework development, we generated a set of descriptors for the conceptual categories being formed.

5.3.5 Iterative fitting of data and revising of framework

We then repeated the mapping of all data to the revised initial framework. HT and CB carried this out independently and disagreements were resolved by discussion. A further step was that a third reviewer BMF (PhD candidate) independently mapped all text data to the revised framework. Any differences were again resolved by discussion.

5.3.6 Testing of the final conceptual framework

As a final step, we identified the themes in the quote data that did not fit the revised initial framework. These themes and the data supporting them were then considered and discussed by the entire review team. A final consolidated list of modified conceptual categories and definitions led to the slight revision of the new conceptual framework. At this stage, we finalised the new conceptual framework definitions.

5.4 Results

5.4.1 Identifying candidate frameworks and choosing the *a priori* framework.

We identified five potentially relevant models of stigma in mental health: (1) Measuring Mental Illness Stigma (Link, 2004); (2) Mental Illness Stigma Framework (Fox et al., 2018); (3) The Health Stigma and Discrimination Framework (Stangl et al., 2019); (4) Social Categories and Stereotypes Communication Framework (Beukeboom & Burgers, 2019); (5) A Framework for Assessing Structural Stigma in Health-Care Contexts for People with Mental Health and Substance Use Issues (Livingston, 2020). We also identified four more generic stigma models: (1) Sociological model of stigma (Link &

Phelan, 2001); (2) Psychological mechanisms of stigmatisation (Major & O'Brien, 2005); (3) Health related stigma model (Weiss et al., 2006b); and (4) Model for attitude and behaviour in stigma (Fiske, 2000), From these models we derived five components of stigma that could be observed in each. This is summarised in Table 5.2. While power differences are explicit in stigma, we accepted that these are implicitly present in clinical encounters and did not expand on them further. The remaining four components are described below.

Table 5.2: Derivation of the priori framework from candidate models

	Aim of the model	Power differences	Prejudice	Stereotypes	Actions	Outcomes
Link & Phelan (2001) [9]	Sociological model of stigma	Stigma as a way of exercising power	Dominant belief about undesirable characteristics	Used to construct categories of difference	Reduce status; produce unequal outcomes	Separation, status loss, and discrimination
Fiske (2000) [26]	Model for attitude and behaviour in stigma	Interpersonal level of one person responding to another\ based on that person's perceived social category	Present	Present	Present	Prejudice predicts behaviour more strongly than stereotypes
Major & O'Brien (2005) [25]	Psychological mechanisms of social stigmatisation	Members of high-status and low-status groups are likely to respond in dramatically different ways to being the target of stigma, even though the immediate situation seems the same	Present	Present and automatically activated	Negative treatment; Expectancy of same; Act to threaten identity	Situational cues, collective representations of one's stigma status, and personal beliefs and motives impact on well-being

Weiss et al, (2006) [11]	Health related stigma model	Present; social disqualification	Present	Discriminatory/ adverse social judgement	Cultural epidemiology of stigma and practical actions to implement to counter undesirable effects of stigma	Stigma as disqualification from full social acceptance

5.4.2 Preconceived judgements or prejudices

Prejudice reflects an evaluative or emotional component of social bias (Amodio, 2014). In The Nature of Prejudice, Allport (Allport et al., 1954) argued that an adequate definition of prejudice must include two essential elements. Firstly, there must be an attitude of favour or disfavour. Secondly, there must be an overgeneralised, erroneous belief (Kite & Bryant-Lees, 2016). These can be characterised as preconceived judgements that are culturally relevant, widespread, and often invisible, as it is in the case of implicit bias. The quote data evidenced the prejudiced beliefs, which perceived the objectively measurable "organic" disorders to be categorically different from other disorders. Therefore, this prejudice carries the implicit belief that objective organic disorders are more "real" and carry less implications of moral responsibility. It is then perceived that disorders not fitting this rigid definition may be either mental (in the mind) or not actually medical disorders at all. Prejudices are typically hidden from cognitive processes, are more of an emotional response and are more difficult to access but set the stage for the activation of negative stereotypes.

5.4.3 Activation of a negative stereotype

Link and Phelan (Link & Phelan, 2001) described two components: labelling and stereotyping, however we found it difficult, particularly considering the nature of the quote data, to differentiate between them. Therefore, we chose to use the terminology of 'negative stereotype', which aims to include in itself the activated negative labels. The reason for this decision was that at this stage we had no access to the cognitive and emotive processes that differentiate the labelling between stereotype activation.

5.4.4 Actions to stigmatise

In the stigmatisation process, Link and Phelan (Link & Phelan, 2001) described components of exclusion: separation and status loss. In this framework we have regarded it as the things that clinicians do or say to create or increase the social distance between 'them' and 'us', or between 'deserving' and 'undeserving' patients. This process can be seen as the exercise of unequal power in the consultation by attributing a lower status to the patient and enforcing epistemic injustice. The notion of epistemic injustice describes an unfair treatment that takes place in the context of giving, sharing and receiving knowledge, as in this case, it is in the context of medical interaction (Blease et al., 2017).

5.4.5 Discriminatory outcomes

Stigmatisation results in discrimination, a way of unfair treatment that is based on negative stereotyping and results in a person not getting the medical treatment that they need and otherwise would receive. Discriminatory actions have been evidences to have negative effects for multiple levels of micro-, meso- and macro- social interactions (Stangl et al., 2019). Not all quotes described the discriminatory outcomes and where it was reported it appeared to be highly context dependent.

5.4.6 Mapping data to the *a priori* framework and adding new themes

During the mapping we found that while prejudice was apparent in the data, it was not well differentiated. Rather it could be summed up by a common prejudice that PPS/FDs did not have the same status as "organic" disorders. While there may have been different prejudices that are relevant, these were not readily apparent in the qualitative quote data.

We also found that discriminatory actions or outcomes that followed from stigmatisation were not easily classified and often left implied. This left us with a three-part model of stigmatisation in clinical encounters. The three parts were (1) prejudice, (2) stereotype and (3) action to stigmatise. The themes developed were then used to create meaningful categories within the stereotype and action components as described below.

5.4.6.1 Prejudice

Hidden or implicit beliefs regarding the inferior status of PPS/FDs compared to "organic disorders" that is prevalent in the wider context of the society. By "organic disorders" we mean the cluster of symptoms with a clearer or more structural explanation or being able to apply a medically established diagnosis.

5.4.6.2 Negative stereotypes

These represented the focus of stigmatisation. There are three sub-categories of this: (1) Condition (stereotypes referring to the nature of the symptom or condition itself); (2) Person (perceived personal characteristics of the individual with PPS/FDs, or people with PPS/FDs in general) ;(3) Behaviour (the perceived actions of a person or group of people with PPS/FDs during the clinical consultation, or referring to the general behaviour of people with PPS/FDs). These are described further in Table 5.3.

Table 5.3 Classifications of Stereotype / focus of the stigma

Location of stereotype	Description	Example
Medical condition	The stereotype location is in the condition itself, with emphasis on the nature of the condition itself (rather than a particular patient or patient group). Typically separates the condition from other conditions, and places negative values on the condition: it is substantively different and less legitimate than other medical conditions. Labelling could be used as a way to stigmatise the condition, but applying a label is part of the stigmatisation of the condition. Language use: quotes here will typically take the perspective of the condition, using pronouns: 'it', 'this condition', ''it''.	"I have been discouraged from even mentioning this issue with most doctors and nurses that I deal with, being told that if it's not epileptic it's not a "real" seizure and should not be even brought up ever. And yet, when I find myself on the floor, it sure feels real to me! This is not in any way something that I would want to invent, fake or choose to have if there were an option" [Table 5.1, source 10] *(Patient with non-epileptic seizures - current acceptable terminology Functional (dissociative) seizures)*
The behaviour	The stereotype location is in the behaviour of a person with the condition. The emphasis is on the behaviour of the person during interaction with healthcare professionals or when seeking help (e.g. during a consultation, or receiving a diagnosis). Typically, generalises about the behaviour and actions of people, in a negative way. This emphasises that the behaviour and actions of people is different from how other people behave or are expected to behave. Language use: the comment is typically focussed on actions of people (using verbs).	"A lot of them give the impression that they are steering the diagnosis towards this end, when they find out what the disease entails. It's as if they want their symptoms to fit –and if they fit into something that's already been done, defined, even better– because that's easy. All these diagnoses that don't have a precise definition are clung to like a life vest, a salvation." [Table 5.1, source 8] *(Physiotherapist perspective on patients with Fibromyalgia)*
The person	The stereotype location is in the people with the condition, with emphasis on the attributes and motivations of an individual person. Typically, generalises about the person (they are grouped with other people) and places negative values onto the person. This creates the impression that	"I'm reluctant as far as this sort of thing is concerned, but I have to admit that it comes down to my own prejudice. I hold it against this sort of patient to a certain degree, they're soft, you have to put pressure on them so that they will liven up their act/…/I think that in cases of women with fibromyalgia you're conditioned to think twice about granting them work

	they are inherently different to other patients (in terms of characteristics and attributes, motivations for health-seeking, and aspirations). Language use: quotes here will typically focus on the individual person: ‘you’, ‘me’, ‘them’.	leave.” [Table 5.1, source 8] *(General Practitioner perspective on patients with Fibromyalgia)*

5.4.6.3 Actions used to stigmatise

These represent the behaviour by the clinician within the consultation. We identified six categories: (1) Othering – the person is not perceived as a legitimate patient and therefore it is perceived to be justifiable to treat the patient in a way that in other circumstances would be socially completely unacceptable; (2) Denial- the person's complaints are perceived not to be medically valid and therefore it is perceived to be justifiable to refuse to engage with the patient further; (3) Non-explanation – It is communicated that there are no medically valid ways of understanding and explaining the person's complaints and therefore blocking the person the access to further care and leaving the person isolated; (4) Minimising - It is communicated that the person's complaints or symptoms are not at a severity that warrants clinical interventions, therefore putting the disproportionate amount responsibility for managing their symptoms on the patient; (5) Norm-breaking – the clinical practitioner acts in a way which typically is perceived as inappropriate; (6) Psychologising – The clinical practitioner explicitly or implicitly communicates that the person's bodily symptoms or their cause is purely psychological and therefore the physical symptoms are not addressed. These are described in more detail in Table 5.4.

It is important to recognise that while some of these actions are likely to always be stigmatising (e.g. othering and denial); others are only stigmatising in some contexts. For instance, breaking the norms of a consultation can be a positive disruption in a situation of mutual trust. Similarly, explaining the role of psychological factors when the patient wishes to know about them is not stigmatising.

1.

Table 5.4 Actions used to sitgmatise

Action to stigmatise	Description	Example
Othering	The person is not perceived as a ‘proper’ patient. There is something about this person that separates them from a typical legitimate patient. They do not warrant normal engagement	“If you have ever had an alcohol or drug issue no matter how far in the past it was and how much you dealt with it, if you mention that to any doctor that is dealing with your chronic pain, and your painkillers, they will forever brand you an addict or an alcoholic and in doing so, will completely change the way they approach you with the medicine and their whole attitude and outlook. ” [Table 5.1, source 14] *(Patient with Chronic pain)*
Denial	Saying or implying that the underlying condition is not valid, that there is no medically valid reason for their complaints. Or outright denying that there is a condition that matches the patient’s account	“…doctor in the hospital said that because there were no abnormalities in my brain waves that it could be nothing else but voluntary”[2] [Table 5.1, source 10] *(Patient with non-epileptic seizures - current acceptable terminology Functional (dissociative) seizures)*
Non-explanation	Implying or saying that the condition is not understood and therefore not appropriate for a medical consultation. Requests for explanation are blocked	“My GP does not seem to understand what is going on and every time I go and ask for help or advice I get nothing from her” [Table 5.1, source 2] *(Patient with Multiple Chemical Sensitivity)*
Minimising	It is implied that this person’s symptoms are not of a severity which needs medical solutions. Minimal or no solutions or explanations are offered. Therefore, putting the disproportionate amount responsibility for managing their symptoms on the patient	“The neurologist was more interested in my migraines than what was troubling me. He dismissed my concerns and just said they were “funny turns” and would go away eventually by themselves” [Table 5.1, source 10] *(Patient with non-epileptic seizures - current acceptable terminology Functional (dissociative) seizures)*
Norm-breaking	Practitioner speaks or acts in ways which would typically be perceived as inappropriate.	“Three women noted that their physician told them to get drunk before having intercourse, as this would aid in their relaxation. As Maya (34 years old) recalled, “I did go to my gynaecologist,

		and I said, you know, 'I'm having a really hard time having sex.' And she was just saying, "You're just nervous. You're tensing up. Get drunk." [Table 5.1, source 9] *(Patients with Psychosomatic attribution to experiencing sexual pain)*
Psychologising	Practitioner explicitly or implicitly implies that this person's symptoms are of psychological origin. There is no evidence provided to explain the psychological causes or the reasoning for attributing this cause. It is implied that the way to deal with their physical symptoms is using psychological treatments.	"The neurologist did not give me a diagnosis. Instead, he suggested that my mother organize an appointment to see Dr. X. When we rang to make the appointment, we realized that Dr. X was a psychologist. It was then that I realized that the neurologist thought that it was all in my head" [Table 5.1, source 10] *(Patient with non-epileptic seizures - current acceptable terminology Functional (dissociative) seizures)*

5.5 Discussion

5.5.1 Summary of main findings

We used an established BFF method to create a new actionable framework which can be used to characterise the stigmatisation which commonly occurs in medical consultations about PPS/FDs. It comprises an underlying prejudice about PPS/FDs, the negative stereotypes regarding the condition or the behaviour the or the person with PPS/FDs and lastly the actions used by the clinicians to stigmatise.

5.5.2 Discussion of the knowledge domain in stigma frameworks

Stigma is conceptualised in various ways across disciplines, with some models explicitly incorporating knowledge as a key component, while others focus on social, psychological, and structural aspects. The current framework aligns more closely with models that do not explicitly include knowledge as a defining feature of stigma. This omission raises important theoretical and practical considerations, including why knowledge was excluded, the potential benefits and drawbacks of its inclusion, and whether it should be integrated into future stigma models.

The framework used in this study is closely aligned with Link and Phelan (2001)'s model of stigma, which defines stigma as a social process involving: distinguishing and labelling human differences; associating labels with negative stereotypes; placing labelled individuals in a separate category; and discriminating against or disadvantaging the stigmatised group. This model does not explicitly prioritise knowledge but rather focuses on social categorisation, stereotyping, and power dynamics in shaping stigma. Similarly, Goffman (1963)'s theory of stigma views it as a relational process in which certain individuals are socially discredited, without necessarily requiring differences in knowledge levels between groups. In contrast, some models, such as Weiss et al. (2006b) and the WHO framework on stigma (Organization, 2015) explicitly include knowledge (or lack thereof) as a key domain of stigma, arguing that misinformation and limited awareness contribute to stigmatising beliefs and actions. Thus, by excluding knowledge, this framework aligns with sociological and interactionist models of stigma rather than cognitive or information-based approaches.

Moreover, this framework is designed to categorise and describe stigmatising experiences in medical consultations, focusing on what patients' experience rather than what causes stigma. Therefore, including knowledge gaps as a factor would shift the model from being descriptive (what happens) to explanatory (why it happens), which may require a different conceptual approach. Unfortunately, healthcare professionals are often highly knowledgeable about conditions such as fibromyalgia, yet stigma still occurs. This suggests that stigma is not always caused by a lack of knowledge but can be influenced by biases, institutional norms, and power structures. Including knowledge as a component might oversimplify the problem, implying that better education alone would reduce stigma, when in reality stigma is also shaped by societal and systemic factors. Some research suggests that increasing knowledge does not always lead to reduced stigma, particularly in medical settings (Corrigan et al., 2001). Healthcare professionals may be aware of the biomedical basis of PPS/FDs and fibromyalgia but still exhibit stigmatising behaviours due to their own attitudes, emotional responses, or institutional pressures.

Therefore, the exclusion of knowledge from this framework may reflect a deliberate focus on enacted stigma rather than its cognitive origins.

5.5.3 Stigma framework and possible modifications

The omission of knowledge as a core component in this framework is theoretically justified, as it aligns with interactionist and power-based models of stigma rather than cognitive or education-based frameworks. However, incorporating knowledge as an additional domain in some models may provide useful insights into when stigma is driven by ignorance versus when it is driven by bias or institutional norms.

Despite these benefits, there are also potential drawbacks to incorporating knowledge as a stigma domain. One of the potential risks might be the risk of oversimplification. The reasoning for that is that if knowledge is framed as a primary cause of stigma, there is a risk of reducing the issue to an "educational deficit", when in reality stigma is often linked to social power and discrimination rather than just lack of understanding.

Another risk might be the difficulty in measuring knowledge-related stigma in medical interactions. Unlike stigmatising actions (which can be reported in patient narratives), knowledge levels are harder to assess in real-world medical encounters. Moreover, patients may perceive their clinician as uninformed when, in fact, the clinician holds medical knowledge but still engages in stigmatising behaviours. Finally, the issue of limited applicability in interpersonal stigma on medical encounters. In one-on-one medical encounters, stigmatising behaviour may be more about attitudes, emotions, or institutional pressures than purely about knowledge gaps. This is particularly relevant PPS/FDs, where stigma persists even among specialists who are knowledgeable about these conditions.

A potential modification could involve expanding stigma models to include knowledge as a moderating factor rather than a core component. This would acknowledge that while lack of knowledge can contribute to stigma, it is not always the primary driver, particularly in medical settings where stigma can persist despite knowledge.

Therefore, while the current framework effectively describes stigma as it is enacted, future iterations might benefit from examining the interplay between knowledge, stigma, and clinical decision-making.

5.5.4 Strengths and limitations

The main strength of this work is the use of a structured approach to developing the framework. The BFF method has been recognised as valuable for qualitative evidence synthesis to address “policy-urgent” questions (Carroll et al., 2013; Dixon-Woods, 2011). We considered an extensive range of potential models in the first stage and in the later fitting stages, and the mapping of data to frameworks was carried out independently by three researchers at different stages.

This framework has several limitations. Firstly, the quotes were extracted from already published studies which may have had a selection bias towards more polarised quotes. Secondly the quotes from the studies were very varied and studies used may have used different levels of rigour in selecting the quotes. On the other hand, it could be considered a strength that despite the different qualitative approaches and the array of study methods used, types of PPS/FD and different countries where the studies were set, we found that the conceptual model remained relevant in all those contexts. However, further validation is needed to know if the framework still applies in other cultural and healthcare contexts, other than the populations identified in the scoping review.

There are myriad of factors that might influence the stigma perception in a consultation. As stigma is a very complex social phenomenon, it is likely that there are aspects of stigmatisation that the framework does not and cannot capture. The framework aims to describe and categorise common experiences of patients that they have reported to be stigmatising. With this work we aim to draw attention to the finding that there are certain patterns that emerge from the experiences of patients that can have a very negative impact on those patients. Moreover, in the scoping study [17] only two studies directly observed the consultations, the remainder relied on recalled accounts by patients or professionals. This might be a limitation as there might be a recall bias. However, since stigma is also a subjective ongoing or a cumulative process, a third objective party might not be in tune to understand that this interaction was stigmatising, as the meaning communicated could be understood by the stigmatised or marginalised party.

In developing this framework, patient advocacy groups were not directly involved during the developmental stages. We consulted a patient advocacy group, Pain Alliance Europe, to understand if such a framework would be useful for patients. Moreover, we have conducted focus groups and have collaborated with a patient advocacy group in the further development and the validation of the framework.

Lastly, for future research it would be useful to have a wider perspective on cultural and other healthcare contexts.

5.5.5 Implications for practice, policy, and research

Stigma is mistakenly often thought of as most prevalently occurring between individuals, therefore neglecting the role of intersectionality (Turan et al., 2019). Although the setting for stigmatisation is often on the level of an individual interaction, we all are affected by the dominant societal norms, beliefs, and prejudices. Therefore, when designing communication interventions for PPS/FDs in order to reduce stigmatisation in the clinical consultation settings, we should also address the underlying social processes and structures. If we are failing to adequately consider the established societal-level conditions, cultural norms, and institutional policies that constrain the opportunities, resources, and wellbeing of the stigmatised, we mistakenly put the burden of responsibility and change on the most affected and vulnerable groups.

This risks further stigmatising and constraining the opportunities and wellbeing of the affected persons.

This framework is currently being tested in a focus group study of patients. That study is the first step in validating the framework in different contexts and to gauge the potential usefulness for the framework to act as a tool in better understanding the experiences of patients.

There are several more implications for future research and practice development. Firstly, the future research is needed to better understand the effects of stigmatisation in PPS/FDs on the individual. That includes both the psychological and social processes and also the consequences of stigmatisation on self-perception and social perception of self.

Future research could also explore the relation of this developed framework of stigma in PPS/FDs to other stigma frameworks. Currently we know that stigma is a very complex social process, which can depend on several aspects whether the person perceives themselves to be stigmatised or not. For example, the prior experience of stigmatisation has been found to perpetuate stigma in addiction services [32].

There have been, to our knowledge, few studies focusing on frameworks of stigma in healthcare settings. One recent study applied the Health Stigma Discrimination Framework to the clinicians working with HIV patients. They found that stigma manifested highest through the endorsement of stereotypes and in the use of unnecessary precautions when treating people with HIV [33]. This finding is a testament to the idea that while stigmatisation has some common denominators, the way stigma is being acted out or communicated varies from the setting and the medical condition at hand. Future research would benefit by understanding stigma as not just an isolated process, but to address the wider and underlying sociological processes that perpetuate stigmatisation in medical settings.

5.5.6 Implications for the use of the framework

The framework should make it easier and more accessible to recognise stigma when it is present by identifying specific actions and ways of communicating therefore making it a useful tool for understanding the reasons that certain patterns of communication are stigmatising. Secondly, it shows that potentially well-intentioned clinical approaches, such as exploring psychological factors, might carry the unintended connotation of stigma, so that clinicians can be aware and potentially modify their approaches to avoid that happening. Third, it provides a framework which can be used to develop and train focused interventions to reduce stigma. For instance, by finding appropriate language or by introducing psychological factors in a way that is not stigmatising.

This framework provides practical and specific examples of how stigmatisation is being communicated in the clinical consultations for PPS/FDs. This can then be used to design specific communication and intervention strategies to address each identified action for stigmatisation. It is important to note that the stigma in PPS/FDs can be described as structural in nature – that it is embedded in the way care is structured and delivered (Treufeldt & Burton, 2024). Strategies that might be successful in the medical communication for other healthcare conditions may carry increased potential for stigmatisation in PPS/FDs. But these social distance strategies are only stigmatising depending on the individual context. For example, when done in a collaboration with the patient, exploring psychosocial factors carries a huge benefit for the continuous management of a chronic condition and might contribute to the increased quality of life for the patient.

Moreover, it is important to recognise that the way of improving the consultations for PPS/FDs is to address the structural stigma patients affected by those conditions face. Therefore, clinicians need to learn not simply how not to stigmatise, but how to actively destigmatise. This framework aims to provide a starting point for that.

5.5.7 Conclusion

We have developed a new actionable framework to categorise stigma in clinical healthcare consultations for PPS/FDs. In contrast with previous, more broad conceptual approaches, this new framework can be used to understand individual consultations and experiences.

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6 Stigmatisation in medical encounters for patients with Fibromyalgia: A focus group study

Authors

Hõbe Treufeldt [a]

Christopher Burton [a]

TBC *Deidre Ryan*

[a] Division of Population Health, School of Medicine and Population Health

University of Sheffield, Regent Court, 30 Regent Street, S1 4DA Sheffield, UK

Corresponding Author: Hõbe Treufeldt. h.treufeldt@sheffield.ac.uk

6.1 Preface

From the scoping review it became apparent that the stigma in PPS/FDs seemed to be widespread, yet the studies lacked in-depth analysis and synthesis to understand what was stigmatising and how did the stigmatising experience affect the patients. The scoping review presented in study 1 found that while there were studies in PPS/FDs that had identified stigma, only few studies specifically focused on stigma. This focus group study was planned to investigate those stigma experiences in depth and additionally it provided an opportunity to indirectly test the validity of the framework developed in study 2.

I (HT) had a secondment with the Pain Alliance Europe (PAE), which is a patient advocacy organisation mostly aimed to advocate for patients' rights and their fair representation in research and policy. I used this opportunity to better understand the patients' perspectives and together with my primary supervisor (CB) and colleagues from the University of Groningen, we started to plan in-depth studies that focused on the patients' experiences. The colleagues from University of Groningen looked at how the label of a diagnosis affected the patients using interviews, and we designed a focus group study trying to understand the stigmatising experiences. PAE helped to promote the studies and because they had patients across Europe, we were able to design the study accordingly. Fibromyalgia was chosen as the diagnosis of interest, because it is one of the most common diagnoses and we anticipated that the patient recruitment for the study might have some obstacles.

The analysis of this study comprised of two different but complementary approaches. First I validated the stigma framework from the previous study. Second, I aimed to analyse peoples' lived experiences using an inductive approach. This enabled me to explore the patterns emerging across the focus groups and uncover powerful themes.

For me, as a person with related lived experience, this study was important on different levels and I took extra care to be aware of my own bias and experiences influencing the research. When meeting with participants and conducting the focus groups, my decision was to disclose my own background, this involved both my clinical background and my lived experience. This decision was made together with my supervisors, senior researchers who have had more experience with disclosing lived experiences and also with the patient advocacy organisation PAE. The reasons for that were that as these focus groups touch upon a very delicate topic that has possibly caused a lot of hurt and alienation for the participants, therefore it might help them to know that this won't be another stigmatising experience where they could experience rejection and dismissal. Therefore, creating a more trusting environment where it is possible to share their experiences.

Highlights

- We can understand experiences of stigma using the stigma framework for clinical interactions regarding PPS/FDs
- Patients report being stigmatised regarding their condition, but most negative consequences are when patients experience stigmatisation regarding their personhood.
- Stigmatising consultations can be traumatising or retraumatising in its nature.
- More focus has to be directed at reducing stigma and treating patients with PPS/FDs and using trauma informed care principles.

6.2 Abstract

Objective

The aim of this study is to better understand and explore the accounts of stigma that patients with fibromyalgia have experienced in their medical consultations.

Methods

Qualitative focus group study with 6 focus groups comprising 20 participants from 8 different European countries. The study used framework analysis with a recently developed framework for stigma in medical encounters and inductive analysis methods to synthesise the focus group results.

Results

Framework analysis showed that participants reported different forms of condition related stigmatisation. But the patients gave an account for their experiences of the stigmatising action of othering of their personhood as most saliently traumatising.

Inductive analysis found repeated patterns of traumatisation and retraumatisation through stigmatising actions. This was experienced saliently and had a long-lasting effect on participants' health care trajectory.

Conclusion

Stigmatisation in medical interactions regarding PPS/FDs can contribute to experiencing trauma and can be part of medical (re)traumatisation.

Practice Implications

Clinicians would benefit to take into account that patients with fibromyalgia/PPS/FDs are experiencing ongoing adverse consultations and stigmatisation and therefore should take active role in trauma informed and anti-stigmatising approach to their interactions with this patient group.

Keywords

Stigma, medical consultation, persistent physical symptoms, functional disorders, medical trauma

6.3 Background

Fibromyalgia (fibromyalgia) is a chronic and often highly debilitating condition. It affects 2-4% of people, and is more common in women [American College Rheumatology; (Galvez-Sánchez & Reyes Del Paso, 2020). The disorder is characterised by multiple somatic symptoms, including widespread musculoskeletal pain, persistent fatigue, and headaches (Clauw, 2014). The lack of objective markers of the illness has been a persistent problem in fibromyalgia research, clinical management, and social recognition of the disease. Because of the lack of currently detectable biomarkers and an individual illness profile, of the condition fibromyalgia can be thought of as belonging under the umbrella of Persistent Physical Symptoms (PPS) or classified as a functional disorder (FD) (Burton et al., 2020b).

The experience of people living with fibromyalgia has been reported as more distress-inducing than a comparable chronic pain condition (Van Alboom et al., 2021). Moreover, the consultation experiences with clinicians can be distressing and characterised by uncertainty and unpredictability. This can contribute to the experience of invalidation and the inability to receive answers or helpful treatments. (Byrne et al., 2023). The social recognition of the condition seems to play a role on not only the medical management of the condition, but patients have reported that their physical, mental and social health has been compromised (Lempp et al., 2009; Thornicroft et al., 2022). Moreover, the patients' experience of living with FM has been reported as stigmatising on multiple levels from individual to the structural obstacles that they face(Armentor, 2017).

Stigmatisation in medicine is "a social process or a personal experience characterised by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgement about a person identified with a particular health problem" (Weiss et al., 2006b). Stigmatisation, in its essence, is the process of increasing social distance between individuals. This process is contingent on power and starts with an identification of a difference of the individual who has less power, that is then connected to a culturally present negative stereotype (Link & Phelan, 2001). This then leads to the labelled persons' experiencing differential treatment and discrimination that lead to unequal outcomes. It is important to note that stigmatisation is contingent on access to social, cultural, economic, and political power. This allows the identification of differentness, the construction of stereotypes, the separation of labelled persons into distinct categories, and the full execution of disapproval, rejection, exclusion, and discrimination. We have recently developed a framework for describing stigma in clinical consultations for PPS/FD (Treufeldt & Burton, 2024; Treufeldt et al., 2024).

Certain medical conditions have been found to carry negative social connotations and therefore can be more stigmatising. It has been found that PPS/FDs can be experienced as more stigmatising, than medical conditions, which have an established medical diagnosis or cause(Eger Aydogmus, 2020; Fox et al., 2018; Kirmayer et al., 2004; Treufeldt & Burton, 2024). Moreover, it has been found that patients who have experienced higher levels of stigma, are less likely to adhere to treatment or show improvements in symptoms, depression, or anxiety after treatment (Feingold & Drossman, 2021). Stigma has been reported in relation to medical conditions among people with fibromyalgia (Åsbring & Närvänen, 2002; Briones-Vozmediano et al., 2018; Nishikawara et al., 2023; Silverwood et al., 2017), however there has been no attempt to categorise it systematically.

This study aimed to understand the range of experiences of stigmatisation in medical encounters among people who have fibromyalgia and consider the implications for consultations.

6.4 Methods

6.4.1 Design

A qualitative design with the focus group technique was used to explore people's lived experience with stigmatisation in medical interactions. Focus group interviews have the advantage of group dynamics for accessing rich information to explore different viewpoints in depth (Freeman, 2006). Theoretical insights were inductively derived from focus group interviews with patients and were then deductively compared to the stigma framework for PPS/FDs (Treufeldt & Burton, 2024).

6.4.2 Setting

We aimed to include participants with fibromyalgia from multiple European countries. This pan-European design was chosen on purpose to have a more comprehensive overview of patients' experience in different cultural settings and healthcare contexts. Therefore, we reached out to chronic pain patient advocacy and support groups affiliated to Pain Alliance Europe (PAE) and to other fibromyalgia patient advocacy groups that were prior identified as possibly interested in taking part in research. PAE is a Europe-wide non-profit organisation based in Belgium, aiming to promote awareness for chronic pain and to reduce the impact of chronic pain across Europe. We also included participants from patient advocacy groups from South Yorkshire and Estonia.

6.4.3 Participant selection and recruitment

The participants were invited to take part in the study if they met the following criteria: (1) Adults aged over 18 with fibromyalgia or chronic widespread pain; (2) Moreover due to the complex nature of fibromyalgia and the co-morbidity of other conditions, participants were not excluded if they had additional medical conditions or other persistent physical symptoms (e.g. dizziness) or FDs (e.g. irritable bowel syndrome). (3) For the participants to be able to fully participate in the focus groups, it was necessary for them to be sufficiently fluent in the language of the focus group. Therefore, we offered focus groups in the following languages: in English, Estonian or German. Those languages were chosen because the focus group facilitator could facilitate a focus group in those languages. There were no participants who preferred German, and one focus group was carried out in Estonian. (4) Finally, the participants needed to have the technical resources and ability to undertake a video call interview and to communicate consent by email.

Invitations to take part in the study were sent by Pain Alliance Europe to its members and to members of its partner organisations. Patient advocate organisations from South Yorkshire and Estonia were invited to partake.

Invitations included study information and a link to an online reply form (Google Forms, University of Sheffield), which collected respondents' nationality, languages spoken, main chronic pain condition(s), and email address. The form included consent to be contacted further about participation in the study.

6.4.4 Data collection

Six focus groups took place using the Google Meet video-conferencing platform between November 2022 and May 2023. Each group consisted of 3–5 participants, which represented the ideal size of a focus group regarding emotionally difficult topics. Smaller group size is recommended where participants need more time and space to voice and explore their experiences and regarding topics that might be emotionally difficult. A participant information sheet and a focus group topic guide were developed and sent out to participants beforehand. Participant information sheet included information regarding the aims of the study, data governance and informed consent. The Focus group topic guide aimed to ensure that the participants had time to reflect on what experiences they wished to share and it was aimed to reduced the anxiety that comes with opening up in unfamiliar surroundings regarding distressing events. The mean duration of group interviews was one hour and fifteen minutes. One moderator (HT), who is a clinical psychologist and an experienced group therapist, led the focus group interviews by using a script. The script helped to increase the reliability of the results by ensuring that each focus group interview was conducted in a similar way.

After a short introduction of purpose and method of the focus group interview, three main topics were discussed: (1) an experience(-s) in a medical consultation when the participant felt excluded, rejected, blamed, or devalued; (2) Experiences comparing consultations regarding fibromyalgia to other consultations; (3) Positive experience, addressing participants needs and asking for guidance how to better communicate to reduce stigmatising experiences. Participants were encouraged to use the raise hand function to indicate their turn to speak. After posing a topic to discuss the moderator aimed to create an open discussion, therefore minimal structure was provided by the moderator. Focus groups were video-recorded and transcribed verbatim. During weekly supervisory meetings, the quantity and quality of data from each group was discussed and evaluated. There was consensus that within-group and across-group data saturation about stigmatising experiences in medical interactions for fibromyalgia, was reached after six focus groups as no new information seemed to emerge.

6.4.5 Analysis strategy

The analysis strategy comprised two main elements. First step was to review the results of the analysis through the recently developed framework for describing common forms of stigmatising actions and stigma targets in consultations for PPS/FDs (Treufeldt & Burton, 2024). The second step was to carry out an additional, inductive analysis in order to capture any emerging themes and evidence that was not accurately represented in the framework analysis.

6.4.6 Framework analysis

The first step involved analysing the data using the already developed stigma framework for PPS/FDs in clinical encounters (Treufeldt & Burton, 2024). This step of the analysis explored how applying the framework can provide insights into the stigmatising actions that patients have experienced and therefore could be used to understand what actions taken by the health care professionals patients experience or report more often.

The framework (shown in Figure 1) was used to analyse the stigmatising medical interactions that the participants reported. The framework analysis is designed to help to categorise different stigmatising experiences by helping to show and describe what exactly what negative stereotype is being activated and therefore the target of stigmatisation (the individual, the condition, or the behaviour) and then what type of action is used to act on that stigmatisation (othering, denial, norm breaking, non-explanation, minimising, psychologising).

Using the framework, it is possible to categorise those stigmatising experiences by stereotype-action combinations. Therefore, the three stereotypes can be combined with the 6 actions creating 18 possible combinations. The current analysis consisted of categorising the participants' experiences by first identifying the activated negative stereotype and second categorising the action taken to stigmatise. We coded each instance of described experience once by first identifying the negative activated stereotype (e.g. the target of stigma) and then categorising the action taken by the medical professional. The important part in that process was to focus on the participants' description of their lived experience. For example, what kind of language the participant used, what was the message that they remember was communicated, how they were made to feel and what were the consequences. As stigma is a social process that is difficult to pinpoint, the context, social cues and consequences become more relevant to understand stigma in interaction.

6.4.7 Inductive analysis

In the second step, the focus of analysis was on inductive coding, which included group dynamics in verbatim transcripts in order to gain an in-depth understanding of stigmatising experiences in medical interaction that patients have and are experiencing. We explored the data to look for emerging themes. Initial open coding was conducted by HT using the NVivo 12 software program was used to identify themes, to derive codes from transcripts. These were then grouped into conceptual categories using a constant comparative method with increasing levels of abstraction.

6.4.8 Methodological quality

To enhance the study quality, context and researcher triangulation was used. Participants from different European countries with different duration of symptoms were included. Before the focus group started, the researcher (HT) introduced themselves, explained the focus group goal and described the research project. Observational notes, the summary, verbatim transcripts and were used as a starting point for data analysis. An experienced supervisor (CB) was involved in all steps of data analysis. Both researchers had previous experience with qualitative research and have clinical experience (CB – a general practitioner and HT a clinical psychologist). Regular critical self-reflection and in-team discussions about key attributes helped to foster an open attitude and to interpret participants' views. The study adhered to the consolidated criteria for reporting qualitative research guidelines.

6.4.9 Ethical considerations

Ethics committees of the University of Sheffield provided approval to conduct the focus groups between May 2022 and June 2023. Ethics application number 046641 (06.05.22, amendments on 08.12.22; 30.03.23). Informed consent was obtained from all participants prior to data collection. Participants were provided with detailed information about the study and were informed that focus groups would be audio recorded, that their anonymity would be assured and that they could withdraw from the study at any time without further explanation.

6.5 Results

6.5.1 Characteristics

In total, 20 people with lived experiences participated in the focus groups of which the demographic characteristics are described in Table 6.1.

Table 6.1 Study participants' characteristics

Age	Under 35	5
	35-50	8
	51-65	5
	66-75	1
	Over 75	1
Education	Secondary school	4
	College	4
	University degree	12
Diagnosis	Fibromyalgia	9
	Fibromyalgia +Chronic pain	2
	Fibromyalgia (diagnosis not official)+ Chronic pain	9
Gender	Male	1
	Female	17
	Nonbinary	2
Country of Residence	Sweden	3
	Denmark	3
	England	3
	Scotland	1
	Ireland	1
	Belgium	1
	Estonia	7
	Malta	1

Symptom duration	1 - 3 years	1
	3 - 10 years	6
	10 - 20 years	6
	More than 20 years	7

6.5.2 Similarities and differences between countries and regions

The common experiences of stigmatisation included lack of validation. Many patients experienced a lack of validation from healthcare professionals, often evidenced by practices of othering, denial, or the psychologisation of their symptoms. Another common theme was the experienced cumulative stigmatisation, which included repeated episodes of stigmatisation that resulted in anticipatory anxiety and the development of avoidant healthcare-seeking behaviours. The final overall common thread was the frustration with medical inconsistencies, where participants expressed frustration over inconsistent medical responses, particularly concerning diagnostic uncertainty and the scarcity of effective treatment options.

Regional variations in healthcare experiences were also present. For example, diagnostic delays and access to specialist care in Northern and Western European countries (e.g., the UK, Sweden, Denmark). Some participants reported significant delays in diagnosis, often involving multiple referrals before receiving a fibromyalgia diagnosis. Conversely, participants from Southern and Eastern European nations (e.g., Malta, Estonia) reported limited access to specialist care, which frequently resulted in misdiagnoses or the early dismissal of symptoms. This suggests that healthcare infrastructure and the availability of specialists may determine the point at which stigmatisation is encountered during the patient journey.

Another regional variation seemed to be the psychologisation of symptoms. In healthcare systems where mental health stigmatisation remains prevalent, patients were more commonly informed that their symptoms were "all in their head" and were advised to prioritise psychological interventions over medical treatments. In contrast, those in countries with robust social welfare systems (notably Scandinavian nations) enjoyed greater access to multidisciplinary pain management; however, scepticism regarding the legitimacy of their condition persisted.

Differences in communication styles between clinicians and patients were also noted. Participants from countries such as Sweden and Denmark described clinician interactions as formal and distant, which they perceived as dismissive or lacking in empathy. Whereas in Southern European settings (e.g., Malta), interactions were generally more conversational and personal; nevertheless, patients still experienced stigmatisation, for example, through the minimisation of their symptoms by being told they were "not serious" rather than receiving an appropriate care plan.

The role of patient advocacy organisations also varied by region. In countries such as the UK and Sweden, these organisations have been instrumental in educating both healthcare professionals and the public about fibromyalgia, potentially alleviating certain forms of stigmatisation.

6.5.3 Framework analysis

6.5.3.1 Introduction of the framework

We previously developed a framework to categorise and describe patients' experiences of stigma in medical encounters for PPS/FDs (Treufeldt & Burton, 2024). The framework consists of underlying prejudices that are commonly held in society, in this specific context regarding the validity/credibility of medically less established conditions with no clear underlying pathology, such as PPS/FDs and fibromyalgia. Those underlying prejudices inform the identified commonly held stereotypes that patients face: regarding the condition, the patients' behaviour or the patient as a person. These become the target of stigma (found in Table 6.2). Lastly there are the actions that communicate the stigmatisation or deliver the stigmatisation process: othering, denial, norm breaking, non-explanation, minimising and psychologising (Found in Table 6.3).

Table 6.2 Location of negative stereotype

Location of stereotype	Description
Medical condition	The stereotype location is in the condition itself, with emphasis on the nature of the condition itself (rather than a particular patient or patient group).

	Typically separates the condition from other conditions, and places negative values on the condition: it is substantively different and less legitimate than other medical conditions. Language use: quotes here will typically take the perspective of the condition, using pronouns: ‘it’, ‘this condition’, ‘’it’’.
The behaviour	The stereotype location is in the behaviour of a person with the condition. The emphasis is on the behaviour of the person during interaction with healthcare professionals or when seeking help (e.g. during a consultation or receiving a diagnosis). Typically, generalises about the behaviour and actions of people, in a negative way. This emphasises that the behaviour and actions of people is different from how other people behave or are expected to behave. Language use: the comment is typically focussed on actions of people (using verbs).
The person	The stereotype location is in the people with the condition, with emphasis on the attributes and motivations of an individual person. Typically, generalises about the person (they are grouped with other people) and places negative values onto the person. This creates the impression that they are inherently different to other patients (in terms of characteristics and attributes, motivations for health-seeking, and aspirations). Language use: quotes here will typically focus on the individual person: ‘you’, ‘me’, ‘them’.

Table 6.3 Actions used to stigmatise

Action to stigmatise	Description
Othering	The person is not perceived as a ‘proper’ patient. There is something about this person that separates them from a typical legitimate patient. They do not warrant normal engagement
Denial	Saying or implying that the underlying condition is not valid, that there is no medically valid reason for their complaints. Or outright denying that there is a condition that matches the patient’s account
Non-explanation	Implying or saying that the condition is not understood and therefore not appropriate for a medical consultation. Requests for explanation are blocked
Minimising	It is implied that this person’s symptoms are not of a severity which needs medical solutions. Minimal or no solutions or explanations are offered.

	Therefore putting the disproportionate amount responsibility for managing their symptoms on the patient
Norm-breaking	Practitioner speaks or acts in ways which would typically be perceived as inappropriate.
Psychologising	Practitioner explicitly or implicitly implies that this person's symptoms or their cause are psychological. There is no evidence to explain why this i. are not in their body, the solution in their mind not their body or reflects trauma or other untreated psychological conditions

6.5.3.2 Stigmatising stereotype-action combinations

The results of applying the framework analysis to the focus group data (found in Table 6.4) showed that certain types of stereotype-action combinations were more commonly experienced than others. Most often the combination of Individual-Othering occurred, which participants reported to be salient, negatively affecting them and had long-lasting consequences. Thereafter commonly experienced stereotype was regarding the condition with the combination of different stigmatising actions.

The interesting case is the negative stigma location for Behaviour as from the research we have done prior [14] we found that when medical professionals stigmatise, they can use the patients' behaviour as a feature to stigmatise (eg 'they don't act in a way that makes the clinician believe that the patient is in pain'). Therefore, while the behaviour is useful concept to have when observing the location of stigma, it does not reflect as much in the patients' recollections. This might be due to the way people recall and make sense of their experiences, as the behaviour is not thought of as being separate either from the personhood the individual experience or the condition.

The key finding from the framework analysis is that stigma takes many forms and can be communicated in myriad of ways. There is not one simple way of understanding and categorising peoples' lived experiences of stigmatisation. When categorising stigmatising actions, one action can carry several stigmas with it and can be interpreted differently depending on the context, other intersectional vulnerabilities, prior experiences, non-verbal communication, feasibility of getting helpful treatments and so forth.

Table 6.4 Overview of frequency of Stereotype- stigmatising action combinations

Number of occurrences	Type of stigmatising stereotype-action combinations	Example
24	Individual- Othering	After that he [clinician] called me a drug addict and he told me that nothing was wrong with me and he sent me on my way. (FG1)
17	Condition- Norm breaking	[Doctor] was reading an article about fibromyalgia in a magazine when he was waiting in line at a pharmacy. And it was about a lady who was diagnosed with fibromyalgia […] and she met a man and she started having sex with this man and she was magically healed […] But he figured if I could just have more sex I would be fine. (FG1)
8	Condition- Othering	I felt that I was a waste of time now I have a multiple health issues, for me fibromyalgia ... But the fibromyalgia, is always kind of like ''yeaahh, your fibromyalgia''.
8	Condition- Denial	I am generally quite desperate, but that was the thing everybody was saying at the start of it all, that it is all in my head and in reality nothing is aching. then it was my task to prove that something was going on. I cannot believe how long I had to go to different doctors and say the same thing all over again and wait until I started to get some answers.
8	Condition- Minimising	You don't need just a one off [pain management course] and then, oh you are better you can manage yourself. Which was really the attitude that they gave off and that is what is my unfortunately my work though this happened. So you had this course now so you are fine you can manage yourself so.
7	Condition- Non-explanation	I think it was lack of knowledge, I simply think they did not know what to do with someone like me… And I tried to explain them that this didn't help and I needed some answers and they couldn't give it to me so they just send me back to my GP or referred me to another one or let's take another blood sample, let's do this. So they were like fumbling in the dark trying to do something without knowing exactly what to do.
5	Individual- Norm breaking	I kept going and seeing him and all I did was cry for an hour and he asked questions and then he just sat there and looking at me. After a few times my husband told me there is no point of me going there.

4	Behaviour- Othering	My parents were worried like every parent would of course and they were taking me to the doctors and at the time they were looking into my parents' eyes and saying that she is imagining the pain and she is seeking of attention these are growing up pains
3	Condition- Psychologising	I just kept crying when I came in so when you are supposed to narrow your life down to a doctor it sort of comes over you you realise how terrible things are you just sort of start crying and he gave me this pills for psychic and he gave me these pills for depression and he was quite happy with himself.
3	Individual- Minimising	I had doctor say to me why are you taking these, you know he didn't understand me he didn't understand even why I was on the medication. That in itself can be really isolating because you think I am just managing this condition on my own there is nobody else seeing it and you sit down with the doctor
2	Behaviour- Norm breaking	I remember when I went to get the diagnosis of fibromyalgia. The consultation was very short, around 30 mins. and you try to say everything in that time. and at one point the doctor said, just shut up, why do you talk so much. And later I looked in the digital consult notes that the doc wrote that the patient talks too much. I tried to fit everything into that 30 minutes and then when I left, the doctor told me in an arrogant tone, I hope not to see you again.
2	Behaviour- Non-explanation	I was told ''you have said this before and I couldn't help you the last time so I don't know what I can do for you''. The end.
2	Behaviour- Minimising	They don't believe me they question me, they have a sceptical approach ''You are well dressed I can see you showered today, it can't be that bad''. It is that bad but it is only thing I have left. So that consciously struggling every day not to have a mental break down almost, is that has been I think that has been the hardest struggle in all the years because it wears you down.
2	Individual- Non-explanation	I felt discouraged I didn't know what was happening to me. I had no answers, so I had to work part-time in the last couple of years of my career as a teacher.
1	Individual- Psychologising	A very particular occasion I was trying to find a right treatment for my psoriasis, the consultants, you know one of questions there is automatically is about fibromyalgia being present and he was you know telling me like I have fibromyalgia because I have the personality and I worry too much or I over analyse things

1	Behaviour-Psychologising	But what shocked me was that if other times I had great difficulties to describe my condition then this time around I put everything on paper, so when I took out my notes so that I would be heard, as it is just so difficult otherwise. and then when I took out my papers, he looked at me in a very disapproving way, that I am too thorough, and exhibit health anxiety but I was just concerned that I am not able to convey everything that I need to. That experience really affected me awfully, I felt broken.
1	Individual- Denial	I remember going to the doctor when I was younger a child for different reasons for my head aches for my heart for my I don't know any other reason that I had to go to the doctors, I always sort of got the answer that there is nothing wrong with me so obviously I learned to live with some kind of life quality which wasn't really you know amazing
0	Behaviour- Denial	

6.5.3.3 Inductive analysis

One of the prevailing themes in all focus groups was the consequences of the repetition of stigmatising experiences. This included the lack of knowledge of fibromyalgia by multiple clinicians. For example the poor way of communicating the causal-and contributing factors and possible treatments were experienced as alienating and deeply stigmatising, as the patients left with the feeling that they were causing their own distressing symptoms and therefore they felt unheard, blamed and disbelieved and received little help on helpful treatments. Patients described instances where their own bodily knowledge and experiences were not deemed as valid, and this resulted in the dismissal of their symptoms and their complaints not being taken seriously.

The main feature was the repeated nature of the different experiences of stigmatisation.

> *I have had that several times and I think it is not just because I am a woman but it is this, um, this the feeling of being considered a hypochondriac. It is because you keep saying this and you keep saying that you have this pain and that pain and this and now it is there and last time you were here it was in another place and now you have this and It was like. You must be making this up. And they didn't say it in so many words but it was like looking down in the papers and writing a few notes and just saying ''hmm, hmm, hmm, yeah, hmm, yeah well, you have said this before and I couldn't help you the last time so I don't know what I can do for you". The end. (FG2).*

There were instances where the participants recalled a stigmatising consultation experience very vividly and that experience stuck with them.

> *And he actually laughed at my face that it is such a minor thing. But it was a horrific experience for me. That was so awful the way he just laughed at me, I still cannot cope with that. (FG 6)*

The repetition of experiences that were perceived as traumatic had a salient negative effect on how the participants further related to health care, sought treatment and what expected in future encounters.

> *Fortunately, as my fibromyalgia was undiagnosed for 8 years, so the previous interactions had prepared me for that traumatic one and to expect from every consultation only worse and worse interactions. and then I went 3-4 times to the same specialist and I had to be like a broken record, I had to assert myself to be able to say the things that were needed to get the diagnosis and by the time I went to the surgeon's appointment I had already received the preparation from all of the previous consultations where I they had been minimising my pain and try to contest me, my experience (FG6)*

These kinds of repeated interactions left participants with anticipatory anxiety, fear of communicating their symptoms, having intrusive memories of the consultations.

> *I still go need to talk about those doctors' visits with my psychologist in therapy. It was a couple of years ago and I still feel emotionally disturbed by it and at unease, I just cannot shake it off the way he [doctor] laughed at me, I am afraid to go back. (FG 6)*
>
> *I had to be like a broken record, I had to assert myself to be able to say the things that were needed to get the diagnosis and by the time I went to the surgeon's appointment I had already received the preparation from all of the previous consultations where I they had been minimising my pain and try to contest me, my experience. (FG 5)*

This experience of stigmatisation, for some participants, led them to use of dysfunctional coping mechanisms that were harmful in the long term for their healthcare trajectory (eg avoidant coping behaviour).

> *I think I tend to not bother going to the doctors which is probably an assumption that I have made that they are just going to put it up to fibromyalgia, so I have just kind of put it down to fibromyalgia which isn't their fault maybe they should all say, but it is quite hard to speak to a doc at the moment certainly. Yeah. I don't really don't have good examples because yeah I just don't bother trying. (FG1)*

The unacknowledged struggle of opening up old wounds, the act of reliving the most painful moments in a brief medical consultation was experienced as traumatic in itself. Moreover, what felt as enforcing that trauma was the repeated nature of doing that again and again and with very little support and payoff.

Well, it's trauma in itself, isn't it? You know, you tell your story and then you have to tell your story again, and you have to tell your story again. (FG5)

In summary, participants described repeated, vividly recalled, negative experiences. Those salient negative experiences have led to current health care behaviour, including avoidance, and can be understood as representing traumatisation.

6.6 Discussion and conclusion

6.6.1 Summary of main findings

People with fibromyalgia experience many forms of stigma in medical consultations. These experiences include stigma targeted at the condition, the person and their behaviour. Experiences of stigma were repeated, recalled vividly, distressing, and associated with avoidance of and anticipatory anxiety about further healthcare contacts. We conclude that stigma in consultations has many features of (re)traumatisation.

6.6.2 Stigmatising consultation experiences and the possible recall bias

Stigma is a social process and can be highly context-dependent. The inductive analysis did not focus solely on what was said in consultations, but rather on how patients interpreted and internalised their (repeated) experiences. The study acknowledges that perceived stigma is significant in itself, even if an intention to stigmatise was not explicitly present in the medical professionals' words or actions.

In qualitative research on patient experiences, particularly within the context of stigmatisation in medical consultations, it is essential to recognise that what is said during a GP consultation and what is remembered by the patient may not always align. This discrepancy can be influenced by cognitive biases, prior experiences, and emotional states, especially in individuals who have experienced trauma and/or anticipate stigmatisation. In this study, several methodological steps were taken to mitigate recall bias and ensure analytical rigour. Firstly, the study utilised a structured stigma framework (Treufeldt et al., 2024) to systematically categorise patients' accounts of stigma. This approach ensured that narratives were contextualised within an established theoretical structure, reducing the risk of over-interpretation based on emotional recall. Secondly, the focus group methodology allowed for a comparative approach, where individual accounts were cross-referenced with those of other participants. Patterns in responses provided credibility to commonly shared experiences while reducing the likelihood that findings were overly shaped by individual biases or extreme cases. Moreover, the study employed a dual analytical strategy, combining deductive coding (applying the stigma framework) with inductive thematic analysis to capture emergent themes. This ensured that subjective experiences were validated against recurring patterns, reinforcing consistent themes rather than isolated perceptions.

The study does not claim to provide an objective transcript of consultations, but rather an analysis of how patients experience and interpret medical interactions—which is fundamental to understanding the long-term impact of stigma and retraumatisation in healthcare settings. While it is possible that traumatised patients may recall consultations differently from how they occurred, this study implemented multiple methodological safeguards to ensure the validity of findings. The research team engaged in regular reflexivity discussions to ensure that personal biases did not unduly shape interpretations. This was particularly relevant given the clinician-researcher backgrounds of the authors, who remained mindful of how clinician-patient power dynamics could influence both patient recall and researcher interpretation. By employing a structured framework, triangulating responses, applying dual analysis methods, and considering emotional salience, the research accounted for the complex interplay between memory, trauma, and stigma perception.

6.6.3 Focus group findings and Stigma framework for PPS/FDs

The Stigma Framework (Treufeldt et al., 2024) provided a structured approach to categorising stigmatising experiences in medical consultations for patients with fibromyalgia and other PPS/FDs. However, the qualitative analysis revealed certain experiences that were not fully captured by the existing model. This might suggest that modifications may be needed, or that the stigma framework in PPS/FDs might not be appropriate to apply outside of the consultation.

One of the most striking themes in the inductive analysis was the repeated and cumulative nature of stigmatising encounters. Participants described not just isolated experiences but a pattern of retraumatisation over multiple consultations. The current framework categorises stigma based on specific stereotype-action combinations, but it does not fully account for how repeated exposure to stigma compounds emotional distress and influences long-term healthcare engagement. Potential modification might be to introduce a temporal dimension to the framework, recognising that stigma in healthcare is often a chronic, cumulative process rather than a one-time event.

While the framework effectively categorises how stigma is enacted (othering, denial, minimising, non-explanation, norm breaking, psychologising), it does not explicitly address the psychological consequences of stigma on help-seeking behaviour, coping mechanisms, and engagement with healthcare. The inductive analysis highlighted that many participants developed avoidant coping strategies—delaying or avoiding medical care due to fear of further stigma, which may worsen health outcomes. Potential modification might include considering expanding the framework to include patient behavioural responses to stigma, such as avoidance, hyper-vigilance, and emotional distress, which align with established trauma models (Dallam, 2010).

Some participants described heightened sensitivity to perceived stigma due to previous traumatic healthcare experiences. The framework does not currently distinguish between first-time experiences of stigma and experiences that re-activate prior trauma. One way to include that in the framework might be to incorporate an additional layer that differentiates acute stigma experiences from re-traumatisation due to past encounters, as this distinction may inform trauma-informed clinical practices.

Some participants recalled non-verbal forms of stigmatisation, such as dismissive body language, lack of eye contact, or tone of voice. These subtle yet impactful interactions do not always fit neatly into the existing stereotype-action combinations but were reported as key sources of distress. For future studies it might be important to introduce a category for implicit, non-verbal stigma within the framework, recognising that stigmatising messages are often conveyed through more than just verbal interactions.

Although the study focused on stigmatising experiences, some participants provided examples of positive medical interactions where clinicians validated their experiences and engaged in patient-centred care. The original framework is deficit-focused, mapping stigma but not highlighting potential solutions. The modification that we have done is to develop a "Reversed Stigma Framework"(Chapter 8:Stigmatisation in clinical consultations for persistent physical symptoms/functional disorders: A conceptual framework for reducing stigma and promoting alliance in consultations), which could guide proactive strategies for clinicians to counteract stigma in consultations.

In the Stigma Framework (Treufeldt et al., 2024), stigma-targeted behaviour was well documented, as healthcare professionals frequently referred to patients' behaviour as problematic or indicative of their condition. However, in the focus groups, behaviour as a stigma target was rarely mentioned by patients themselves. This discrepancy may be explained by recall bias and self-perception differences. For example, the recall effect tends to happen when people tend to recall life events through internalisation—that is, they focus on how they felt and how they were treated rather than on their own behaviours during the interaction (Conway & Pleydell-Pearce, 2000; Fivush et al., 1996; Ross & Sicoly, 1979). Patients may remember the emotional impact of being dismissed or invalidated but may not explicitly link this to their own behaviour.

The role of narrative focus might play a role. When patients recall stigma experiences, their framing is self-focused—they discuss what happened to them, rather than how they behaved. This aligns with psychological theories suggesting that individuals attribute negative experiences externally (e.g., discrimination, bias) and the framing of these experiences in personal narratives reflects a tendency to emphasise the impact of external social forces, rather than focusing on their own responses (Major & O'Brien, 2005).

In contrast, healthcare professionals tend to discuss patients' behaviours, likely because their training emphasises observable actions. This external focus aligns with medical discourse, where symptoms, patient compliance, and behavioural cues are crucial for diagnosis and treatment (Hafferty, 1998).

Therefore, the evidence suggests that stigma as experienced by patients often centres around how they were treated, while professionals may discuss stigma in terms of how patients present and behave. This contrast suggests that while behaviour may be a key component of how stigma is enacted, it is not always how it is internally experienced or recalled by patients.

6.6.4 Discussion of patients' experiences in different regions and their similarities and differences

While the study revealed remarkable similarities in the stigmatisation experiences of fibromyalgia patients across various European countries, it remains important to investigate whether regional differences also emerge. The considerable variation in healthcare systems, cultural attitudes towards chronic illness, and societal perceptions of fibromyalgia suggests that national contexts may shape both the experience and interpretation of stigma. These findings also suggest that both detached and overly casual communication styles can contribute to patients feeling invalidated, albeit through different mechanisms.

In regions where advocacy for chronic pain is less developed, patients reported greater difficulties in accessing reliable information, leading to a heavier reliance on self-education. This underscores the importance of institutional support and public awareness initiatives in mitigating stigmatisation.

These findings indicate that stigmatisation is a systemic issue in the management of fibromyalgia and related persistent physical symptoms across diverse European healthcare settings.

6.6.5 Discussion of different levels of stigma

As already demonstrated in the in the background section 3.2.6, stigma in healthcare occurs at multiple levels, ranging from individual clinician-patient interactions to broader systemic and policy-driven influences. While the focus group participants primarily described experiences of stigma at the interpersonal level, their narratives also reflected underlying structural and institutional factors that shape GP behaviour and contribute to the persistence of stigma in PPS/FDs.

This study looked at how stigma is perceived to be communicated during direct interactions between patients and healthcare professionals and was focusing on the impact of those stigmatising interactions had for the patients. While the study's focus was not on understanding how the participants saw the systematic and structural factors affecting their experiences, there were similar themes emerging from the discussions.

Findings from the focus groups indicated that participants often perceived stigmatisation as a personal failing of individual doctors, for example physicians who dismissed symptoms, questioned the legitimacy of fibromyalgia, or implied that symptoms were psychological rather than biomedical. The participants all were aware of that these clinician behaviours may be shaped by systemic pressures, rather than purely individual attitudes. However, all of the participants also had non-stigmatising interactions with medical professionals, some regarding their PPS/FD diagnosis. The participants were in agreement that exhibiting stigmatising attitudes towards a patient was not an appropriate way of communicating in a medical setting. Moreover, this rarely happened regarding other consultations (notable exceptions were consultations for weight related problems, psychiatric problems and gynaecological problems), therefore the participants justifiably attributed the responsibility of not causing iatrogenic harm towards the medical professionals, who did not have to communicate in a stigmatising way.

The participants generally acknowledged that the structure of healthcare delivery and clinical guidelines can reinforce stigma by limiting diagnostic clarity, restricting referral pathways, and underfunding PPS/FDs research and treatment. They also understood that the GPs often act as gatekeepers to specialist services, but without clear referral pathways for fibromyalgia, patients may experience repeated dismissals and delayed diagnoses. The lack of standardised diagnostic criteria and specialist treatment options in many countries means that GPs alongside with other healthcare professionals may not feel equipped to manage these conditions, leading them to minimise symptoms or attribute them to psychological causes.

The participants were also aware that the health policy and resource allocation play a critical role in shaping health care professionals' responses to fibromyalgia. The underfunding of PPS/FDs services, combined with long waiting times for specialist care, may lead medical professionals to downplay the condition, normalise patient suffering, or over-rely on psychologisation due to lack of viable medical interventions. While most patient narratives focused on interpersonal interactions, there were instances where participants explicitly acknowledged structural barriers in their experiences. Some recognised that GPs were constrained by time pressures, lack of referral options, or systemic scepticism toward fibromyalgia, suggesting that stigma is not just a matter of individual prejudice but also a reflection of healthcare system failures.

Additionally, some participants also were aware that the healthcare funding models may influence GP behaviour. In some systems, short consultation times and lack of reimbursement for complex chronic illness management create conditions where GPs have neither the time nor the incentive to engage deeply with patients with PPS/FDs.

Benefits and social welfare policies also intersect with stigma, as patients with fibromyalgia often struggle to access disability support.

The focus groups participants also shared that the public attitudes toward conditions like fibromyalgia might influence how healthcare professionals view these conditions. The participants acknowledged that because of the lack of clear biomedical markers for PPS/FDs means that fibromyalgia is often not seen as a ‘real’ illness in the same way as conditions with established biomarkers (e.g., rheumatoid arthritis, multiple sclerosis), but then again noted that while they understand why they were

However, because stigma is often experienced in direct interactions, many participants framed their experiences in personalised terms, attributing their distress to the attitudes of specific doctors rather than recognising the systemic issues that shape those attitudes. The participants shared that their painful lived experiences were exacerbated by the individual actions and attitudes of medical professionals, therefore the trauma that they had experienced was during a direct interaction with a medical professional rather than on a structural level, although that had contributed to the experience of suffering as well.

This distinction is critical because interventions to reduce stigma must operate at multiple levels. Educating individual clinicians about fibromyalgia is insufficient if the structural barriers (e.g., lack of referral pathways, inadequate funding, short consultation times) remain unchanged.

The study findings underscore the need for a multi-level approach to tackling stigma in fibromyalgia care. While individual clinician attitudes undeniably contribute to patient distress, these attitudes are shaped by larger structural factors such as funding constraints, diagnostic uncertainty, and medical education gaps. Addressing stigma requires restructuring consultation models to allow more time for complex chronic illness management. Moreover, there is a need to incorporate PPS/FDs (including fibromyalgia) into medical education to reduce implicit bias. It is also important to challenge welfare policies that force medical professionals into a gatekeeping role for disability benefits, which can exacerbate scepticism toward patient-reported symptoms.

By recognising stigma as a systemic issue rather than purely an individual failing, we can develop more effective interventions that reduce both interpersonal and institutional stigma in fibromyalgia care.

6.6.6 Strengths and limitations

This study involved participants from eight different European countries. Although there are differences in the cultures, histories, languages, medical systems etc, we found remarkable similarities in experiences regarding stigmatising interactions in medical encounters.

This study has several limitations. The selection of participants was limited by access to technology and language limitations. As the recruitment was through patient advocacy organisations, potential participants had to contact the research team themselves and follow several steps (filling out a form, signing a consent form, reading information sheets, scheduling a practice call and then scheduling a focus group). Those limit the accessibility of the study reach as for participants whose health condition poses more limitations or would need more support with the steps or documentation, would be excluded. It is important to find ways for future research to make studies like this more accessible.

By allocating each statement of stigma to only one target-behaviour combination it was inevitable that some data was lost. As with usual real-life experiences, it is almost impossible to neatly categorise lived experiences. However, the fact that all but one combination in the framework was present, therefore hopefully the developed framework can act as one way of making sense of the experiences.

The participant sample, although sufficient was small and representative of European countries that although historically and culturally very different, still have advanced medical systems. The future directions of the research should aim to include a wider range of participants from more diverse backgrounds.

6.6.7 Relationship to trauma models

In analysing the stigmatisation experiences of patients with fibromyalgia, we carefully considered various conceptual frameworks to explain their psychological and behavioural responses. The decision to frame the findings in terms of traumatisation and re-traumatisation rather than alternative models such as internalised stigma or stress-coping theories was guided by several factors. The participants' experiences demonstrated patterns of emotional distress, hyper-vigilance, anticipatory fear, avoidance behaviours, and intrusive memories, which are consistent with trauma models. According to Dallam (2010) and Ronksley-Pavia (2022), traumatisation occurs when an individual is exposed to a series of emotionally harmful events, leading to lasting psychological and physiological responses. The repetitive stigmatising experiences in medical consultations described by participants align with the core components of trauma exposure outlined by the three E's of trauma from Substance Abuse and Mental Health Services Administration (Services, 2014): Event – Stigmatising medical interactions in which patients feel dismissed, disbelieved, or blamed; Experience – The perceived harm, humiliation, or distress resulting from these encounters; .Effect – Long-term emotional and behavioural responses, including hyper-vigilance, healthcare avoidance, and emotional distress.

Moreover, re-traumatisation emerged as a dominant theme, as participants described repeated medical encounters that mirrored prior distressing experiences, leading to cumulative psychological harm. This aligns with established trauma research, which suggests that repetitive exposure to similar distressing events exacerbates emotional dysregulation and avoidance behaviours (Dallam, 2010).

Therefore, trauma frameworks provided the most comprehensive explanation for: the vivid recall of past stigmatising interactions; the escalating emotional impact over time; and the avoidance of future healthcare interactions due to fear of further harm.

From prior research we know that experiencing stigmatisation has been demonstrated to be a common among people with fibromyalgia (Åsbring & Närvänen, 2002; Briones-Vozmediano et al., 2018; Nishikawara et al., 2023; Silverwood et al., 2017). Moreover, the research has demonstrated that there might be a link between traumatic adverse life events and the development of fibromyalgia (Gardoki-Souto et al., 2022; Kaleycheva et al., 2021). A recent cross-sectional study (Gardoki-Souto et al., 2022) of people with fibromyalgia found that the majority of participants (72%) met the diagnostic criteria for current post-traumatic stress disorder (PTSD). Participants reported having suffered traumatic events throughout their lifespan, especially in childhood and early adolescence.

The results of this focus group study propose that there might be a relationship between not only the experienced trauma before the onset of fibromyalgia but the repeated nature of stigmatisation that has been experienced in medical interactions, may have created a trauma in its own right. This would be crucial information for clinicians to know when treating patients with FM, as there are clear practice implications for treating any patient who has traumatic adverse lived experiences – if there is a likelihood for the patient to be retraumatised before medical interaction, the clinician has to take a trauma aware approach for this clinical interaction.

In the light of these findings, we can understand how a medically complex, individually varied, and poorly understood condition, such as FM, and trauma can intersect in complex and potentially re-traumatising ways (Ronksley-Pavia, 2022). Trauma, whether physical or psychosocial, has profound effects on health, and influences how people engage with their healthcare (Grossman et al., 2021).

6.6.8 Considerations of other models

Generally internalised stigma (self-stigma) occurs when individuals accept and internalise negative societal stereotypes about their condition, leading to self-devaluation, shame, and reduced self-efficacy (Corrigan & Watson, 2002a, 2002b). While elements of internalised stigma were evident in some patient narratives, this model alone did not fully capture the external social processes that shaped participants' experiences, as stigma was actively enacted by clinicians rather than being purely self-directed. Moreover, considering the repetitive nature of distressing encounters, which had a progressive impact rather than a one-time cognitive shift. Also taking into account the avoidance of healthcare settings due to anticipated harm, which is more aligned with trauma-avoidance responses than with self-stigma processes.

Although internalised stigma can certainly compound the psychological distress of patients, it was not the dominant mechanism observed in the study's qualitative findings. Instead, participants' distress was primarily linked to repeated external invalidation, making trauma models more appropriate for explaining their experiences.

The stress-coping framework (Folkman, 1984) suggests that individuals appraise stressful events and respond through adaptive or maladaptive coping mechanisms. While this model is widely applied to chronic illness management, it was insufficient to explain the deep emotional scars left by stigmatising encounters, which resembled traumatic imprints rather than general stress reactions. The intensity of negative healthcare expectations developed over time, which aligns more with avoidant trauma responses than with coping strategies. The profound impact of medical retraumatisation, which exacerbated distress rather than being buffered by individual coping mechanisms. While stress-coping theories are valuable in understanding day-to-day symptom management, they do not fully account for the severe psychological and behavioural consequences observed in these participants.

Given the long-lasting psychological effects, repetitive exposure to harm, and avoidant behaviours observed in participants, the trauma model—specifically re-traumatisation—provided the most accurate conceptual framework. While internalised stigma and stress-coping theories offer useful insights, they do not sufficiently explain the escalating distress, persistent avoidance, and intense emotional impact described by patients. Future research could explore how these frameworks interact, particularly in relation to how prior stigma contributes to both trauma and internalised stigma over time.

6.7 Conclusion

Patients with fibromyalgia experience stigmatisation in medical encounters which takes many forms and can have sustained consequences in keeping with repeated traumatisation.

6.7.1 Practice implications

There are several implications for future research and practice development.

Firstly, how to use the developed framework to be able to understand what types of stigmatisation happens, how to communicate and disseminate the knowledge about the stigmatising stereotypes and actions. Currently we are working on ‘reversed stigma framework’ that could provide with an actionable way of approaching potential stigmatisation. As we have demonstrated patients have come to except to be stigmatised or to experience communication difficulties, so it is up to the health care professionals to actively de-stigmatise.

Secondly, the notion of different types of trauma or traumatisation that FM patients might experience. One of the ways to help patients to not be (re-)traumatised is to be more conscious about trauma informed care approaches when dealing with FM patients.

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7 "How are you" ambiguity from the outset in consultations about persistent physical symptoms

Authors

Hõbe Treufeldt a

Christopher Burton a

Traci Walker b

a Division of Population Health, School of Medicine and Population Health University of Sheffield, Regent Court, 30 Regent Street, S1 4DA Sheffield, UK

b School of Allied Health Professions, Nursing & Midwifery 362 Mushroom Lane
Sheffield S10 2TS The University of Sheffield

Corresponding Author: Hõbe Treufeldt. h.treufeldt@sheffield.ac.uk

7.1 Preface

This study aimed to use conversation analysis to gain in-depth understanding of the possible obstacles that might contribute to the difficulties commonly experienced by both patients and clinicians in consultations for PPS/FDs.

The original plan for this PhD was to include direct observation of consultations to examine stigma as the consultations unfold. However, following the Covid19 restrictions the plan had to be revised as carrying out direct observations in clinical settings was not feasible. Therefore, the observational part of the PhD took the shape of an in-depth analysis of existing video recorded dataset. We obtained the video recorded data from the One in a Million database held by the University of Bristol. I (HT) had to undertake training in the conversation analysis approach to be able to conduct this study. This was a very different level of an approach, as the previous studies focused on understanding the issue of experienced stigma both on more of a general level (as in a scoping review) and on an intrapersonal level (the focus groups).

In this study the focus was on micro-analysis of usual GP consultations that were about presumed PPS/FDs. It took a long time of familiarising myself with the video data to be able to identify the elements that are of most interest in this context. The final decision was made to analyse the consultation initiation by the GPs. One of the reasons for this the finding from the focus group study that participants could sometimes ‘’tell that the consultation will be difficult when the clinician greets you’’ but they weren’t able to articulate what exactly gave them this impression. The theme of anticipatory anxiety experienced by the patients with PPS/FDs has been mentioned in previous qualitative studies exploring the patients’ experiences. Therefore, looking at that from an observational angle and using video recorded data, seemed like a good next step to explore those uncovered themes.

Another research finding that influenced the decision to look at the opening sequence was the subtle changes of the way the GPs phrase ‘do you have anything else to ask’ vs ‘something else’(Welch, 2010).

7.2 Abstract

Introduction

Persistent physical symptoms (PPS) and functional disorders (FDs) are common in primary care: different studies estimate around 15-50% of patients meet the criteria for PPS. PPS are also found to carry stigma and often are difficult to communicate about and treat, therefore contributing to more perceived difficulty and negative consultation experiences and poor treatment outcomes. It has been found previously that minor in the way the clinicians ask questions can have a substantial effect on the consultation experience. This study aims to understand if the way the GPs initiate the consultation has an affect on the way patients respond.

Method

We obtained video recordings of GP consultations from One in a Million Database from the University of Bristol. We selected the 10 consultations that were about PPS/FDs and included the different variations of 'How are you' (HAY). We used the established We methodology of Conversation analysis to analyse the consultations.

Results

The analysis found that when the GPs initiate the consultation by using HAY, that this can be problematic, as it is ambiguous and can be interpreted very differently by the patients either to be an extended greeting or a problem elicitation. The consultations where the GPs were using HAY+ a specifier (now/doing/been), were treated to act as a problem elicitation.

Practitioner Points

- HAY can be ambiguous as it can be treated as an extended greeting or a problem elicitation, therefore being ambiguous.
- For patients who are of increased risk of experiencing stigma, ambiguity in a consultation needs to be minimised.
- HAY+ seems to be treated as more straightforward and does not carry the ambiguity of just using HAY

Keywords:

Persistent physical symptoms, conversation analysis, general practice, medical communication, consultation initiation

7.3 Introduction

Persistent physical symptoms (PPS) is an umbrella term for symptoms lasting at least three months and which are disproportionate to underlying organ-system disease (Aamland et al., 2014; Burton et al., 2020b; Löwe et al., 2022). These symptoms may exist on their own (for example dizziness) or as part of a syndrome. Currently those syndromes are referred to as functional disorders (FDs). PPS/ FDs represent a spectrum of severity, ranging from mild symptoms to severe and chronic disorders (Rask et al., 2021). PPS currently cannot be described by any single consistent cause (Burton et al., 2020b) but they can be understood as arising from a complex interaction of biomedical, psychological, and social factors (Henningsen et al., 2018).

PPS are common a recent meta analyses found that an overall point prevalence for FDs in population was 8.78% (95% CI from 7.61 to 10.10%) across Europe (Rometsch et al., 2024). Moreover approximately 1 in 6 patients with persistent symptoms had at least 1 symptom diagnosis persistent more than a year (Chaabouni et al., 2023; Kroenke, 2003; Löwe et al., 2022). In 2010, a Europe-wide review on disability burdens found that the 12-month prevalence rate is estimated to be around 5% (i.e., 20 million individuals in Europe) (Wittchen et al., 2011).

Stigma is common in healthcare, particularly in people with PPS/FDs. Stigma is commonly defined as a social attribute that links a person to an undesirable characteristic and leads to actions that increase the social distance from that person. This also includes different or discriminatory treatment in health care. There is evidence that PPS/FDs can be experienced as more stigmatising, than comparable medical conditions, which have an established medical diagnosis or cause (Eger Aydogmus, 2020; Fox et al., 2018; Kirmayer et al., 2004). PPS/FDs have been found to be associated with negative stereotypes, and therefore the people experiencing those conditions face more stigmatising prejudices, attitudes, and obstacles in their healthcare than with other comparable conditions. Moreover, it has been found that patients who have experienced higher levels of stigma, are less likely to adhere to treatment or show improvements in symptoms, depression, or anxiety after treatment (Feingold & Drossman, 2021; Macduffie et al., 2020). This stigmatisation of PPS/FDs seems to be structural and omnipresent in different cultural and medical contexts (Treufeldt & Burton, 2024).

In the literature of medical consultations, it has been proposed that the underlying theme for the medical consultations is negotiating legitimacy. That means that the patient's visit to seek medical care should be properly motivated by an appropriate medical problem. Heritage and Robinson (Heritage & Robinson, 2006) in their influential research proposed two underpinning reasonings from the patient's perspective for the medical consultation: (a) the existence of a concern or problem that they lack the knowledge, skill or other forms of expertise to manage on their own, and (b) project the concern or problem as one that is properly handled through the exercise of medical expertise.

Therefore, a significant part of the patient's project during the visit can concern the justification of the visit itself. Thus, from the outset of the medical visit, patients can face a *doctorability* issue. For patients, a doctorable problem is one that is "worthy of medical attention, worthy of evaluation as a potentially significant medical condition, and worthy of advice and, where necessary, medical treatment" (Heritage & Robinson, 2006). This might be especially relevant for the patients with PPS/FDs as they are faced with the negotiating legitimacy and being seen as a credible patients (Treufeldt & Burton, 2024).

Part of the experienced stigma in PPS is the epistemic incongruence that the patients face. Epistemic incongruence refers to the discrepancy between patients' symptom presentations and the explanatory models for biomedical disease that are used by the clinicians (Åsbring & Närvänen, 2003; Johansen & Risor, 2017) This also translates to the attitudes and discrimination that those patients experience on individual to structural levels and can be understood as epistemic injustice, where the person's lived experiences are dismissed by the medical profession when those experiences are not supported by hard evidence.

In order to be able to provide more equal and better health care for patients with PPS, there needs to be more knowledge of how the interactions between the patient with PPS and the clinician unfold and what might be contributing to the stigma and the epistemic injustice to be able to enact change. This paper uses the methodology of Conversation analysis (CA) in medical interactions to look at the interactions between the general practitioner (GP) and the patient (PT).

7.3.1 Relevant findings in medical consultations by using CA

CA has established that the interactional practices through which persons conduct themselves elsewhere are transported from the everyday world into the doctor's office. For example, practices for describing a problem or trouble, or for telling good or bad news are carried across the threshold of the doctor's office and affect how doctors and patients go about addressing particular interactional tasks. Secondly, the organisation of interaction is fundamentally geared to the joint management of self–other relations (Maynard & Heritage, 2005).

The issue of the opening sequence in doctor–patient interaction has been a topic of research for a long time as it carries many real-world implications. The GPs have to navigate the multitude of expectations of the medical consultation, for example the time constraints for the consultations makes it unfeasible to use the normative stepwise progression of introducing topics (Lynch, 1993). Therefore, the way the GPs are taught to open the consultation is to use the topic initial elicitors such as ‘How are you’, ‘What can I do for you?’, ‘What’s the problem?’, ‘How are you feeling?’ (Button, 1985). At first glance, the commonly used phrase how are you (HAY) might seem to be a good choice for opening a consultation, as HAY could be classified as an open-ended question, which one might assume would help the PT to talk uninterrupted (Robinson, 2003). However, on a closer look the use of HAY introduces certain ambiguities that might impose communication barriers right at the start of the consultation and put pressure on both the patient and the clinician to repair the communication barrier. When using the HAY approach, there are a number of things that are being unknowingly communicated. The problem encountered by the patient is deciding which domain the HAY is targeting, and therefore whether they should treat it as part of the greeting sequence, or as the opening of the problem presentation phase of the consultation (Gafaranga & Britten, 2003).

One of the key motivations for investigating the opening sequence of GP consultations in this study was the growing body of research demonstrating that small linguistic variations in clinicians’ phrasing can substantially influence patient responses, consultation dynamics, and overall healthcare experiences. A particularly relevant study by Welch (2010) examined the implications of subtle wording changes in the way GPs phrase questions towards the end of the consultation, specifically comparing "Do you have anything else to ask?" versus "Is there something else?" They found that even minimal linguistic adjustments in closing questions could change the scope of patient responses, with significant consequences for consultation effectiveness. The research demonstrated that: "Do you have anything else to ask?" This broader, more open-ended phrasing suggests a final opportunity for the patient to raise concerns. It is often associated with longer consultation times, as it can lead to additional topics being introduced. Patients may perceive it as an invitation to elaborate, particularly when spoken with rising intonation (suggesting openness). However, in some cases patients may hesitate to bring up further concerns, especially if they feel their initial concerns were not adequately addressed. "Is there something else?" This more constrained formulation suggests a limited scope, subtly implying that the GP expects a specific additional issue rather than a general inquiry. Patients may feel less encouraged to introduce broader or unrelated concerns, perceiving the phrase as a cue to wrap up rather than an opportunity to expand. The phrasing is often associated with shorter consultation lengths, as it subtly signals an expectation of one more issue, rather than an open-ended invitation. If spoken with falling intonation, it can further reinforce a sense of finality. Those findings underscore the impact of subtle conversational choices in medical encounters, raising important questions about how other phrases—such as "How are you?" (HAY)—may similarly shape consultation outcomes. While Welch (2010) focused on closing sequences, the same principles could potentially be applied to opening interactions, where ambiguity in GP phrasing may impact whether patients feel encouraged or discouraged to elaborate on their concerns, and to the extent to which stigma, epistemic injustice, and credibility issues emerge in early interactions.

Several other studies support the broader implications of question framing in GP-patient interactions. Robinson (2003) explored how patients interpret different types of doctor-patient inquiries, demonstrating that even slight variations in question format can alter patients' willingness to disclose information. Heritage and Robinson (2006) examined how doctors' question design shapes the way patients explain their visits and present their problems. Maynard and Heritage (2005) found that conversation structure in medical encounters directly influences treatment adherence, showing that patients who feel their concerns were elicited and acknowledged early on are more likely to engage in follow-up care.

There is evidence that both patients with PPS/FDs and physicians who treat them, find medical encounters regarding PPS/FDs challenging (Hahn, 2001). Moreover, it has been found that patients with PPS/FDs experience structural stigma and epistemic injustice in medical systems (Treufeldt & Burton, 2024). Therefore, the overall goal of this study was to identify and examine a potential source of difficulty for the patients with PPS/FDs who present at the GP consultations and to lay the groundwork for practice implications and further research directions. In order to achieve this, this study used an in-depth analysis of the usage of HAY by GPs and the ways the PTs treated the HAY in consultations regarding PPS/FDs. This was done by micro-analysing a set of consultations and comparing different ways the HAY was treated.

7.4 Methods

7.4.1 Overview

The current study is part of the innovative training network ETUDE (Encompassing Training in fUnctional Disorders across Europe) (Rosmalen et al., 2021).

The study takes a qualitative approach to studying medical consultations and will use the methodology of conversation analysis (CA) in order to analyse the interactions recorded in clinical consultations about PPS. CA is an established method of studying interaction in a social setting as it identifies and describes the practices that interactants use in social interaction and uses these results to understand and describe the underlying structural organisation of social interaction (Stivers, 2015). CA is characterised by a co-constructive and collaborative analytic approach. This means that CA emphasises the conduct of both parties as they interact with each other in real time (Monzoni et al., 2011) . Analysing the co-construction of talk is a direct research embodiment of patient-centredness and it facilitates the biopsychosocial approach to the interview, as well as a more recent emphasis on relationship-centred care (Maynard & Heritage, 2005).

CA is generally concerned with how people create, maintain, and negotiate meaning. Two of CA's core assumptions are as follows. First, CA assumes that people produce and understand communication primarily in terms of the social action(s) it accomplishes

(Schegloff, 1995). Second, CA assumes that the production and understanding of action are not only influenced by traditional forms of context (e.g., sex, race/ethnicity, self-monitoring), but also by interactional forms of context (Goffman, 1983).

The production and understanding of an utterance as an action derives from *features of the social context*, most especially an utterance's place in an organised sequence of talk. Any participant's communicative action is doubly contextual. Firstly, the action is *context-shaped.* Its contribution to a mutual understanding derives in part from the immediately preceding utterance or set of activities in which it occurs. In the medical interview, the phase of the encounter in which a sequence appears helps to configure its meaning (Maynard & Heritage, 2005; Robinson & Heritage, 2014).

One of the underlying concepts in CA is the idea of the adjacency pair, whose central characteristic is the rule that a current action (a "first pair part" such as a greeting or a question) requires the production of a reciprocal action (or "second pair part") at the first possible opportunity after the completion of the first. This sequence is normatively organised (Goodwin & Heritage, 1990). In CA the terminology of ‘turns’ is used to analyse the interaction, and the treatment of a turn is used as evidence for how it’s understood (Goodwin & Heritage, 1990).

7.4.2 Data sources

The data for this study were obtained from the One in a Million dataset, a collection of video-recorded GP consultations held at the University of Bristol. The dataset consists of recorded consultations from 12 GP practices across the UK, covering a range of urban, suburban, and rural settings to reflect the diversity of primary care. The consultations were recorded between 2014 and 2015 as part of a larger study aiming to understand communication in general practice. The name "One in a Million" refers to the goal of capturing a representative sample of everyday GP consultations, reflecting the wide variety of issues presented in routine primary care. The dataset was ethically approved, with all patients and GPs providing consent for their consultations to be recorded and used for research purposes.

The consultations in the dataset were classified using the International Classification for Primary Care (ICPC) scheme. A list of codes is included in Table 7.1. The Syndromes excluded from the search because they are not present within the database is found in

Table 7.2. The dataset for the study comprised of the consultations in the One in a million dataset which include either (a) one or more syndromes or symptoms typically associated with persistent physical symptoms / functional disorders or (b) clinical test results.

Table 7.1 List of ICPC codes to be searched within the One in a Million database

Code	Descriptor
A01	Pain general / multiple sites
A04	Fatigue
D01	Abdominal pain general
D02	Abdominal pain (epigastric)
D07	Dyspepsia
D09	Nausea
D87	Stomach function disorder
D29	Digestive symptom / other
D93	Irritable Bowel Syndrome
K04	Palpitation / aware of heart
K24	Fear of heart disease
L02	Back symptom / complaint
L03	Low back symptom / complaint
L04	Chest symptom / complaint
L18	Muscle pain
L20	Joint symptom / complaint
L84	Back syndrome without radiating
N01	Headache
N03	Pain in face
N05	Tingling fingers / feet / toes

N06	Sensation disturbance (other)
N17	Vertigo / dizziness
N18	Paralysis / weakness
N99	Neuro disease (other)
R02	Shortness of breath / dyspnoea
R04	Breathing problem (other)
R23	Voice symptom / complaint
X01	Genital pain female
X17	Pelvis symptom / complaint female
Y02	Pain in testis / scrotum
Y06	Prostate symptom / complaint

Table 7.2 Syndromes excluded from the search because they are not present within the database

P75	Somatisation
R98	Hyperventilation
N95	Tension headache
Y06	Prostate symptom / complaint

7.4.3 Inclusion criteria

From the full One in a Million dataset, we initially identified 24 consultations that involved discussions of PPS/FDs. These were selected based on ICPC (International Classification for Primary Care) codes, which were used to classify the consultations in the dataset. The specific ICPC codes relevant to PPS/FDs are listed in Table 7.1 List of ICPC codes to be searched within the One in a Million database.

To refine the dataset further, only consultations in which the GP used "How are you?" (HAY) as part of the opening sequence were included. This resulted in a final set of 10 consultations that were suitable for analysis.

7.4.4 Exclusions and Considerations

Out of the 27 consultations initially identified as relevant to PPS/FDs, 14 consultations were excluded for the following reasons: Ten consultations did not contain HAY in the opening sequence, making them incompatible with the study's research focus on the role of HAY in shaping consultations. Additionally, four consultations were excluded due to poor audio or video quality, which made detailed conversational analysis difficult.

While the exclusion of non-HAY consultations means that some relevant PPS/FD interactions were not included, this was an intentional methodological decision. The study was specifically designed to examine the interactional role of HAY and its variations. Excluding non-HAY consultations does not suggest that different opening strategies (e.g., "What can I do for you today?") would not be of interest in future research, but rather that they fall outside the scope of this specific analysis. Future studies could investigate comparative differences between consultations initiated with HAY versus other formats.

7.4.5 Analysis approach

Conversation analysis was being used to analyse the data. The focus is on the opening phase of the consultations where the GP and the PT are orienting the talk towards the problem presentation. Specifically, we narrow our focus to the use - or non-use – of 'how are you' sequences.

The analysis approach for these recordings focused on the opening part of the consultation that was relevant for the medical consultation setting. Therefore, any talk relating to the recording setup was left out of the analysis.

7.4.6 Reporting style

This paper uses the abbreviation style to refer both to the patient (PT) and to the general practitioner (GP). This has a deliberate choice to keep the PT and the GP representation symmetrical and concise.

7.5 Results

In total, 10 video recordings were analysed. Six contained HAY And four consultations contained modified HAY (HAY+) as a part of the opening sequence.

7.5.1 How are you

When using the HAY in a medical setting, patients can experience ambiguity as to what kind of response the clinician expects - whether the normative extended greeting or a problem presentation.

Firstly, is the possibility of the PT treating the HAY as a form of extended greeting and producing the unmarked response (''I'm good, HAY") (Mondada et al., 2020). This normative expectation presents an obstacle for the PT to overcome. The PT could treat HAY as initiating an extended greeting sequence that has no consequences for the issue of doctorability, therefore treating it as standing apart from the medical consultation. In CA research it has been found that what appear to be quite minor, detailed aspects of wording or phrasing in the design of a turn in the medical consultation, have consequences for the sequential uptake by the next speaker (Drew et al., 2001). This could mean that there might be a dissonance that the PT has to overcome, especially for PTs with PPS/FDs who experience epistemic injustice – would it affect the doctorability of the reason for their visit if they treat the HAY as an extended greeting and responding accordingly (''I'm good '')? How would the PT navigate the incongruence between the ''I'm good" statement and the problem presentation?

The Second possibility is for the PT to treat the HAY is a request for problem presentation. This way of treating the HAY might carry the risk of not responding in a socially normative way, with an extended greeting. In CA, it has been demonstrated that interaction can be understood as intuitionally normative. Therefore, if the person responds for a socially normative sequence in a norm breaking way, there might be trouble and both parties might need do more work to repair the interaction(Heritage, 1989). This problem of treating the HAY ‘’incorrectly’’ might affect the relationship between the PT and the GP.

The problem encountered by the patient is exactly this - deciding which domain the HAY is targeting, and therefore whether they should treat it as an extended greeting, or as the opening of the problem presentation phase of the consultation.

Next there are examples of different ways from the recordings that the patients have treated the HAY.

Example 1: HAY is treated as a social greeting

GP: Great, thank you. How are you?
PT: Not too bad, you?
GP: Yes, fine. How can I help?
PT: Actually I’ve got this tender pain in the neck.

The GP initiates the consultation by using HAY. In CA the treatment of a turn is used as evidence for how it’s understood (Sacks et al., 1974). The reason for that is we cannot know what the GP’s intention for using the HAY was, therefore, we look for evidence how the turn is treated. Therefore, we can say that here, the PT displays an understanding of the HAY as part of the greeting sequence because they deliver a ‘no news’ response and reciprocate the question. The GP is then subject to the normative expectation set up by this new first pair part, which they respond to with “yes fine”, before more clearly moving the consultation into the problem presentation phase by asking “how can I help”.

Moreover, the use of ‘’not too bad” by the PT is significant in this case. It has been found that using anything other than a positive (‘’fine’’, good, well etc”) serves a function in a conversation (Jefferson, 1980). In this instance ‘’Not too bad” seems to foreshadow the PT’s next turn in which they bring up a complaint.

This extract has shown how the PT can both navigate the normative expectations of HAY and also present themselves as a credible patient, with a doctorable problem. This short interaction highlights the treatment of HAY as a part of an extended greeting, where the PT chooses to use the non-normative way of responding to HAY. This treatment of HAY foreshadows or implies that there is a problem. This is further evidenced by using 'actually' to start the next turn and go into the doctorable problem. 'Actually' in this context serves a bridge between the answer to the HAY as 'not too bad' and the doctorable problem presentation. This can be understood as the PT trying to maintain credibility and being taken as a PT who is there with a serious symptom.

Example 2: HAY as a request for problem presentation

GP: I'm Dr NAME. How are you?

PT: Oh, I'm not too bad. It's just that I've had this pain on the right side of my head. It started when I woke up in the early hours of Saturday morning.

GP: Yes.

In this example the GP initiates the consultation by using a formal introduction of themselves, which seems to indicate that there is no or very little prior relationship. The GP then extends their turn with HAY. At this point the HAY could be treated as either an extended greeting or a request for information. PT starts their turn with 'Oh', which in CA has been shown to indicate that the following might be unexpected (Stivers, 2015). The PT then continues, 'I'm not too bad'.

This way of answering might be used to accomplish several tasks.

As noted above, anything other than the standard 'fine/okay' response is designed to accomplish something (Jefferson, 1980). This might therefore also foreshadow a problem presentation that is not straightforward. This response serves an extended greeting function as the PT does not directly go into the problem presentation but rather gives a general evaluation of their situation. It also might be a way of navigating the ambiguity of HAY but recognising the HAY's function as an extended greeting but protecting the credibility of the PT but not claiming to be 'fine', which might contradict a later message, therefore remaining congruent and a credible witness to their experience. This can be evidenced by the PT using the rest of their turn to state the symptom presentation.

There are similarities with the previous example (Example 1) where the HAY was also met with a non-normative answer that foreshadowed a problem presentation. The difference from the Example 1, is that here the PT treats the HAY as one directional, which is evidenced by not reciprocating with the HAY. Whereas in the Example 1 the PT treated the HAY as an extended greeting by reciprocating it, but still responded in a way that remains congruent with the further problem presentation, here the PT treated the HAY as an extended greeting but does not reciprocate it, instead going immediately into the problem presentation.

This together with the Example 1 shows the different ways the PT can treat the HAY. The PTs display the awareness that the HAY can be problematic by doing the following– (a) they mark their response as unusual; (b) they don't say they are 'fine'; (c) they may not reciprocate the greeting; (d) they balance how they 'are' with immediately introducing a doctorable problem.

Example 3: HAY treated as not appropriate for the setting

GP: How are you?

PT: [I wouldn’t be here if I was fine 0:00:13]. (laughter) I have these pains again in my stomach.

GP: Right.

PT: It started, probably, about last Sunday week

The GP initiates the consultation by using HAY. The PT uses their turn to respond in a way that acknowledges the ambiguity of the HAY being used in this context. The ‘’I wouldn’t be here if I was fine” followed by laughter accomplishes several things. This first part of the PT’s turn treats the HAY as being a normative extended greeting which has only one way of answering. This can be evidenced by the PT using the word ‘fine’ but prefacing it with ‘I wouldn’t be here if I was...’ It this way the PT acknowledges the normative way of responding to the HAY as being ‘fine’ without the GP saying anything about the PT being fine, feeling better or asking why they are there. This utterance also serves a function of foreshadowing a doctorable problem by stating that the PT is there for a reason, otherwise they would not be there. For the PPS/FD PTs this might serve another function which has to do with the epistemic injustice and wanting to remain a credible PT. It has been found that the PTs with PPS/FDs feel disbelieved and have to work more to present themselves as credible witnesses to their own illness experiences when the biomedical tests come back clear but their symptoms persist (Mik-Meyer, 2015). This navigating of the desire to present themselves as a reliable witness to their illness experience is done by altering the response from the normative expectation of responding to the HAY. In this way, the PT rejects the normative 'fine' label to maintain the credibility of their illness interpretation and foreshadow the seriousness of their symptoms.

Moreover, laughter is shown to be used in a consultation setting as a tool to navigate a delicate situation (Haakana, 2001). This implies that the PT is treating the utterance as not a normative way of responding and is trying to mitigate the possible trouble and ease the tension that comes when breaking normative expectations. The PT then continues to demonstrate that they understood the GP's turn design could be also interpreted as a request for problem presentation by going into the doctorable problem and stating the main symptoms presentation. But the symptom presentation is worded in a way that implies a continuous relationship, by using the words *these* and *again.*

This example highlights additional problems when opening a consultation with HAY that might come up for PTs with PPS/FDs. This might impose additional struggle for the PT to navigate as it may be treated by them as a question of why they are not yet 'fine' and therefore having to explain or justify their status as a credible and legitimate PT returning with a doctorable problem to the GP.

Example 4: HAY is used to delay the problem presentation

GP: Come on through.
PT 1: Hello.
GP: Hi NAME, how are you?
PT 1: I'm alright, how are you?
GP: Hi NAME. Lovely to see you.
PT 1: You got us being filmed, have you?
GP: I haven't seen you in a long time.

Thank you very much for agreeing to this.

PT 1: That’s alright, we’re still filing the forms out so I don’t know whether you want to, do you want to know?

GP: No, I don’t want the form. I just want the number off the top, 11 and 12.

PT 1: 11 and 12.

GP: Shall we start with NAME first NAME?

PT 1: Yes, I’m the nearest to you. I’m still off work.

The GP initiates the consultation by using HAY, which the PT treats as an extended greeting by replying with ‘’I’m alright, HAY”. The GP does not acknowledge this question during their turn and instead responds with ‘’Hi NAME. Lovely to see you” which is addressed towards the other PT in the room. This lack of response is treated not as breaking a normative expectation, but as a way of opening the consultation, which is evidenced by the way the PT1 uses their turn to further ask about the recording of the consultation ‘’You got us being filmed, have you?”. The GP starts their next turn by stating that ‘’I haven’t seen you in a long time” and then uses the rest of their turn to acknowledge the filming part by saying ‘’Thank you very much for agreeing to this.” The PT starts their turn by acknowledging the thank you by saying ‘’that’s alright” and then continues to ask a question about the forms.

Example 5: HAY without the opportunity for response

GP: How are you? Because I came out to visit you not long ago, and you were at the hairdresser, but I spoke to your husband. I don't know if you know that I popped out.

PT: Well, he doesn't tell me everything. No, I can't remember.

GP: Your memory is not that good nowadays, anyway, is it?

PT: No, it's one of my bad days, isn't it?

The GP initiates the consultation with HAY but doesn’t leave room for the PT to respond, as is evidenced by the turn design which continues with a description of coming by the PT’s house. After the utterance of HAY, GP continues the turn with a ‘because’. This is a problematic formulation of the turn as ‘because' doesn't fit grammatically or semantically as an extension of HAY. Rather, the ‘because’ begins an account by the GP of what they have done for the PT. Therefore, the GP has closed down the space for the PT to respond to the HAY. This treatment of the HAY by the GP displays an awareness that the HAY is ambiguous (i.e. can be either an extended greeting or a problem elicitation) and this is supported by how the GP themselves treat the HAY: the GP has closed down the opportunity for the PT to respond to HAY in any way. The GP uses the rest of their turn to bring up new information that the PT needs to respond to. This is further evidenced by the PT’s treatment of the GP’s turn, which does not address the HAY but addresses the latter part of the GP’s turn.

This example shows that the initiation of the consultation by the GP using HAY can be acknowledged as ambiguous by not allowing room to respond, and instead initiate another sequence.

Example 6: HAY is treated as a problem elicitation

GP: Okay=How are you?
Male: She’s getting a lot of –
PT: Pain in my head.
Male: Pains in her head.
GP: Yes, yes.

In this final example of HAY, the GP initiates the consultation by using ‘’okay” as a marker of orienting towards the PT and following up with the use of HAY. The use of ‘’okay” serves as a boundary between one section of the interaction and the next.

The PT’s companion then uses their turn to get right into the PT’s complaint, thus treating the HAY as a problem elicitation and not part of a greeting.

Unlike any of the other examples none of the participants attempt to treat the HAY as a greeting.

7.5.2 How are you+

So far, we have seen some of the different ways that PTs treat HAY thus showing how it can introduce ambiguity right at the beginning of the consultation. Knowing how important individual words can be in GP consultations (Heritage & Robinson, 2011), we examined how the use of HAY and HAY+ specifier might elicit different responses.

HAY+ specifiers are mainly time specifications, which make a treatment of the HAY as a problem presentation more relevant and easily recognisable. For example, ‘’HAY now” elicits a request for self-evaluation comparing the present state with the previous state. Therefore, it is a clear reference to problem presentation, rather than an extended greeting.

The following examples show a treatment of HAY+ not as an extended greeting but as a request for problem presentation.

Example 7 Examples of HAY+ elicits self-evaluation and PT treats is as an opening of the problem presentation phase

GP: Lovely. How are you=how’s it been?

PT: Yes, okay. Still, sort of, up and down with the toilet, basically.

GP: Last time you came, there were several issues, weren’t there?

PT: Yes, we had the chest X-ray for this cough.. It’s been ongoing..

Example 8

GP: So how are you doing now, NAME?

PT: Yes, not too bad at the moment. I've have a date back for my MRI scan for my back. That's, I think, the 6th, the 7th of March. So physio are holding back at the moment to see what the results are from the scan and go from there, I suppose.

The following Examples 8 and 7 are being treating in a similar way by the PT, as eliciting self-evaluation and problem presentation.

In the example 7, the GP initiates the consultation by using the HAY but then adding a specifier ‘how’s it been’ to their turn. This indicates an ongoing relationship and that the turn seems to be designed to let the PT know that GP is aware of the medical issues of the PT. This is accomplished by using the verb form "has been" which describes an action that began in the past and is still ongoing in the present. Therefore, it serves as a continuer from the last consultation and serves to elicit a general self-evaluation of health since the last consultation. This evidenced by the way that the PT starts their turn by giving a general self-evaluation of ‘okay’, which then is elaborated with the symptoms that have been still ongoing. The GP uses their next turn to refer to the previous consultation and ‘several issues’. This turn seems to be designed to assess what might be the PT’s take and if there are several issues what is the most prevalent for the PT to address.

This is further evidenced by how the PT uses their turn to recapture last consultation and describe the ongoing issues and brings up the ongoing bothersome symptoms.

In the Example 8, the GP initiates the consultation by using HAY+ with the additional verb and adverb ‘’doing now ‘’. In this example the GP uses a verb form that describes things that are happening right now, or around now. In order to be able to talk about ‘’now” this design claims prior knowledge of an issue that the PT has seen the GP about before. Moreover, the ‘’now” acts as a way to narrow down the ‘’how are you doing” to elicit a self-evaluation regarding the issue that the PT was presenting with previously. the PT orients to this by ending their first TCU with ‘’at the moment”. This ‘’at the moment” stakes a claim that despite the PT being better now, this state might still change, therefore there is still a ‘’doctorable problem” here.

Those two examples show how altering verb forms within HAY that indicates a continues relationship or claims prior knowledge can be interpreted as unambiguously requesting self-evaluation.

Example 9: HAY+ is treated as a request for self-evaluation

GP: Right. How are things today then?
PT: It’s coming. It’s coming. Definitely.
GP: Yes.
PT: My [gestures towards face/cheeks/sinus area] changed.
GP: Oh, good. How do you mean?
PT: Oh, I’m more myself.
GP: Okay. [token of acknowledgment]
PT: Not 100%.

Here the GP initiates the consultation by adding a specifier ‘ ’today, then” to the HAY , which narrows down the possibilities of how the PT would be able to use their turn to answer. The usage of ''today then'' could be acting as a comparator that implies a continuous relationship. This usage of two additions to the HAY can be treated as an indicator that the GP remembers the PT's problem presentation from the last consultation and therefore, this turn is design to elicit self-evaluation and a problem presentation.–PT replies with ' It's coming. It's coming'. The 'it's coming' is in the present progressive, indicating ongoing action, which is important here because it marks out the patient's problem as not solved, improving but not better. The ''it'' pronoun usage here might refer to the condition, this is not clear from the context but because the GP does not ask for a clarification, this pronoun usage is being treated as a non-issue. This might refer to the idea that there's room for improvement (later evidenced by the PT's ''not 100%'' utterance) which then links to the GP's use of 'today' and how the self-evaluation of 'today' relates it to other days.

This turn design neatly handles the PT's doctorability problem: if she was completely better today she might struggle to come back, therefore this turn presents claims of legitimacy for continued care.

Example 10: Example of HAY+ treated as a request for problem presentation but the consultation itself is not straightforward

GP: How are you doing?

PT: Yeaaahh::

GP: [laughter} Alright?

PT: [laughter]I've got two new glasses and I'm not quite sure what to do them.

GP: Oh I know that feeling. It's difficult to know which ones to have on your head.

PT: Yes, yes. I'm still getting used to the fact that I need them, don't let me go without that because I'll be so screwed.

GP: Ah yes, no I won't.

PT: Yes, I'm fine.[jobbie 0:00:52] yes, which I kept forgetting to phone in about.

I'm still old-fashioned and expect people to phone me back.

GP: Sorry, yes.

PT: No it's not you, I'm saying when they get the results in if that is what they used to do.

GP: Yes.

PT: About thirty years ago I think they did that still. (Laughs)

GP: So that was normal, it was 2.7.

The GP initiates the consultation with HAY+ doing. The PT is in the process of getting seated and responds with ''yeaaahh'' and by the end of that utterance the PT has turned to face the GP. the GP responds with laughter which the PT reciprocates. The use of laughter might accomplish several things, for example as a way to navigate a delicate situation or to ease tension, or to ease the tension that comes with defying normative expectations (Haakana, 2001).

The PT's 'yeaaahh' is a way of postponing responding to the HAY+. This is evidenced by following two turns. The GP next asks ''alright?''. This utterance might serve a function of giving a token of a positive recognition of the possible state of the PT's struggle. ''Alright is often used as a shorthand to communicate that the person is aware and tuned in that there might be something going on with their conversation partner. Moreover, the 'alright' can be both a token of encouragement and a way of moving the consultation along. In the next turn, the PT treats the GP's utterance as a token of encouragement of expressing their current struggle. This is evidenced by '' …I am not quite sure what to do with them'' that might serve the function of indicating a state of distress and a request for reassurance. This is evidenced by the way the GP responds in their turn, which offering reassurance by empathising with the shared experience.

The PT then seemingly answers the HAY by stating ''yes I'm fine''. This answer at first glance might give the impression that the PT treats the HAY+ as an extended greeting but when taking into account the following talk, we can see that this is not the case. This is evidenced by the surrounding talk regarding the test results, therefore making the 'yes I'm fine' semantically empty as the talk that follows is a self-repair and a not-straight forward way of going into the problem presentation. The self-repair of 'I'm fine' is shown by the way the PT treats their turn, after that utterance there is left no room for the GP to respond, and the PT attaches immediately a new token of topic orientation (''jobbie'') that the following few turns are focusing on. This is further evidenced by the way the GP treats the PT's turn, which is to respond to the issue of the problem presentation by addressing the test results. This means that the GP recognised the ''I'm fine'' as semantically empty because of how it was framed – the preceding and the following talk did not support the 'I'm fine' utterance.

This example shows a more complicated way of responding to HAY+ that is still being treated as a problem elicitation but this happens through self-repair.

7.6 Discussion

7.6.1 Summary of main findings

HAY Seems to be treated by the PTs in various ways and therefore can be an ambiguous way of initiating the consultation. Firstly, HAY may be treated only as a form of extended greeting by producing the normative response ‘’I'm good, HAY” (See Example 1). This normative expectation presents an obstacle for the PT to overcome. Claiming they are ‘fine’ poses the problem of incongruence - they may be heard as stating they are well and then in the problem presentation phase seemingly contradict this claim by presenting the reasons for the visit, i.e. they are -”not fine”. This might be especially difficult for PTs who have experienced epistemological injustice and stigmatisation, and therefore might be more sensitive to show themselves as credible witnesses whose testimonials can be trusted.

Another obstacle to consider is the other part of the normative response – the reciprocal HAY inquiry. The normative way of repeating the HAY back might pose an obstacle for the patient and the GP to overcome. As the GP might not answer in a socially expected normative way and the conversation sequence has been interrupted, therefore creating the possibility of experiencing social alienation.

Moreover, HAY in a medical setting, is a nonspecific way of evoking general self-evaluation, as there are several self-evaluation domains that the HAY could be targeting. Therefore, it might be the case that the PT might be doing well in the domain of interpersonal relationships or work or school or received some good news, but in the medical domain might be doing poorly. This means that the PT could struggle to come up with a general answer that would answer the question accurately and would still be socially appropriate for the medical setting.

However, this again poses the problem of incongruence which might be especially difficult for PTs who have experienced epistemological injustice and stigmatisation, and therefore might be more sensitive to show themselves as credible witnesses whose testimonials can be trusted.

7.6.2 Comparison of the use of HAY and HAY+

The using of HAY+ seems to mitigate the ambiguity of the HAY. This seems to be done by adding a specifier, that narrows down the ways of treating the HAY+. When the GPs are using HAY now/today/been etc, then this seems to indicate the initiating of the medical consultation and request for self-evaluation and problem presentation. Another thing that the HAY+ is accomplishing is that it refers to a prior relationship and indicates that the GP remembers and knows of the PT's symptoms and problems. This could be a part of non-specific and therapeutic treatment factors that have shown to be a positive influence on therapeutic alliance and treatment outcomes(Howe et al., 2019). This small token of recognition might be something that is important for PTs who have to go to the doctor often and re-explain their symptoms to new health care professionals, making the clinical consultations not only burdensome but emotionally and psychologically demanding.

There might be small ways of changing the linguistic tools that the clinicians use that incorporate being mindful about offering the PTs the patient-centred and continuous care that they need and deserve.

7.6.3 Discussion of subtle linguistic changes on patients' responses

Previous findings on closing sequences (Welch, 2010) provide a strong foundation for understanding the importance of linguistic subtlety in medical consultations. This study extends those insights to consultation openings, examining how minor phrasing variations in GP interactions influence patient responses, particularly for stigmatised conditions like PPS/FDs. By investigating the ambiguous nature of HAY, this study aims to contribute to a broader understanding of how subtle communication choices impact patient care, consultation effectiveness, and the perpetuation of epistemic injustice in healthcare settings.

For patients with PPS/FDs, these linguistic subtleties can be even more consequential. Patients who experience stigmatisation may already feel that their symptoms are not taken seriously and may be hyperaware of conversational cues that signal credibility or dismissal. If an ambiguous opening phrase (such as HAY) is used, patients may hesitate to introduce their concerns fully, anticipating dismissal based on prior negative experiences. Moreover, patients with PPS/FDs may be particularly attuned to GP intonation and phrasing, as they often struggle with: Establishing legitimacy as a patient in medical interactions. Deciding how much information to disclose based on perceived openness from the GP. Navigating epistemic injustice, where their experiences are dismissed due to a lack of biomedical markers for their condition.

Given Welch (2010)'s findings on closing sequences, the decision to investigate consultation openings in this study is both timely and crucial. If closing phrases can shape what and how patients disclose symptoms, then it is reasonable to hypothesise that opening phrases, particularly ambiguous ones such as HAY, could potentially significantly impact the trajectory of the entire consultation.

Therefore, this study builds upon previous findings by extending the conversation analysis focus to the opening sequence and examining how small wording changes influence patient participation. This is done by exploring the impact of ambiguity in GP phrasing on patients with stigmatised conditions and taking into consideration how epistemic injustice may be reinforced through subtle conversational dynamics.

7.6.4 Discussion of the ambiguity that the PT might overcome when answering HAY

The proposed possible juxtaposition of the possibilities of answering HAY from pt's perspective - options are 4 -fold and they carry different connotations and implications. (1) PT ignores HAY - risk breaking the normative expectation, which can carry a risk as the PT is already at a delicate position. (2) PT answers as a form of extended greeting "fine HAY" – therefore risking epistemic injustice and there might be a risk of not seeming a credible PT when stating seemingly contradictory things ''fine, but there is a doctorable problem' and they were being incongruent with their previous statement. (3) PT answers in a way that acknowledges the HAY but still leaves them room for their complaint, foreshadows not being fine example "could be worse, not too bad etc" - risk this takes cognitive and emotional load for the PT and puts then in a position where they need to be balancing societal interactional expectations with their lived experiences. (4) PT addresses directly the HAY by saying they are not well - risks breaking normative expectations or not conforming to societal expectations for interactions therefore the risk of being socially othered.

7.6.5 Discussion of the use of HAY/+ in other patient groups and

This study is best described as hypothesis-generating rather than hypothesis-testing, as the findings suggest potential issues with ambiguity in GP consultation openings, but do not yet establish causal relationships or generalisability beyond PPS/FD consultations. The initial finding is that HAY is ambiguous and requires patients to navigate its meaning and this is not necessarily unique to PPS/FD consultations. To determine whether PPS/FD patients experience greater difficulty navigating this ambiguity a comparative study is needed with non-PPS/FD consultations. Without this comparison, it remains unclear whether the additional challenges experienced by PPS/FD patients arise from the HAY structure itself or from pre-existing patient concerns about credibility and epistemic injustice. Given that HAY is a common GP opening phrase, a comparative analysis with non-PPS/FD patient groups would be necessary to determine if non-PPS/FD patients experience similar ambiguity?

Another important topic to consider is whether the impact of HAY is more negative for PPS/FD patients due to their history of epistemic injustice? Also, does GP tone, intonation, or non-verbal cues influence patient responses differently across patient groups? Without these comparisons, it remains unclear whether the ambiguity of HAY is an inherent issue across all medical consultations or whether it disproportionately affects PPS/FD patients.

The results also suggest that HAY+ (e.g., "How are you doing now?") is clearer and more effective in eliciting responses, but this may not be entirely due to its linguistic structure. The study's findings might suggest that the GPs tend to use HAY+ when they already have a prior relationship with the patient, which could make responses easier simply because the patient feels more comfortable. This creates a potential confounder, as patients may engage more freely in consultations where they already trust their GP, rather than due to the specific phrase used. Future research should control for the GP-patient relationship by analysing responses to HAY and HAY+ in both new and established patient-GP interactions.

The analysis of patient responses to HAY in this study shows that most patients find ways to navigate the ambiguity. Patients often use strategies such as hedging ("not too bad"), humour, or delayed responses to manage uncertainty. This does not negate the issue of ambiguity, but suggests that patients develop coping strategies, meaning that

HAY's impact may depend on the specific vulnerabilities of PPS/FD patients rather than the phrase itself.

7.6.6 Strengths and limitations

This study has a few limitations. Firstly, the recordings were collected in the GP practices that were interested in participating in the one in a million database set. Therefore, both the GPs and the PTs were aware of being recorded and this might have influenced their behaviour during the consultations.

Another limitation is the small number of cases, prohibiting the building of collections as is the norm in CA work and instead necessitating the comparison of each case in which a HAY/HAY+ occurred. However, this could also be viewed as a strength because it allows in depth consideration of the patients' behaviours.

The strength is that there is both the video and the transcript data, which gives a lot of nuances to analysing the interactions.

7.6.7 Implications for practice and policy

The findings from this study highlight several important implications for both clinical practice and health policy. For clinical practice, the preliminary findings suggest that GPs should be mindful of the potential ambiguity inherent in common opening phrases such as HAY. Given that such ambiguity can exacerbate patients' anticipatory anxiety, especially among those with PPS/FDs who may have previously experienced epistemic injustice, practitioners are encouraged to adopt clearer, more explicit forms of greeting—such as using time-specific variants (e.g., "How are you doing today?")—that more directly invite problem presentation. This adjustment in communication may help ensure that patients feel both validated and understood from the outset, potentially enhancing therapeutic relationships and improving consultation experience. From a policy perspective, these findings underscore the need to integrate communication skills training into medical education curricula and continuing professional development programmes, with a particular focus on reducing stigmatisation and mitigating epistemic injustice. Policy-makers might also consider structural reforms, such as allowing longer consultation times or redesigning care pathways, to enable more thorough and patient-centred interactions. By embedding these changes into both clinical guidelines and educational frameworks, health systems can better address the nuanced challenges faced by stigmatised patient groups and promote more equitable, effective primary care.

7.6.8 Future research directions

This study provides valuable insights into how subtle linguistic choices impact patient responses, particularly in the context of stigmatised conditions such as PPS/FDs. However, without direct comparisons to other patient groups, it remains unclear whether these challenges are unique to PPS/FD patients. Future research should control for prior GP-patient relationships, explore potential confounders, and examine whether ambiguity in consultation openings disproportionately affects certain patient groups. Moreover, research could benefit systematically examining how the structure and the linguistic and non-linguistic components of the consultation affect the experience of stigmatisation and patient health care trajectory.

7.7 Conclusion

This study has laid the groundwork for researching the use of HAY in consultations for PPS/FDs and the possible obstacles that this might carry. As those PTs are likely to face stigmatisation and epistemic injustice, it might be important to consider how to initiate the medical consultation with PTs who might have had experiences of not being treated as a legitimate patient and needing to present themselves as credible. Therefore, it is important to choose a wording of the initiation of the consultation that is less ambiguous and oriented more towards the explicit request for medical self-evaluation.

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8 Stigmatisation in clinical consultations for persistent physical symptoms/functional disorders: A conceptual framework for reducing stigma and promoting alliance in consultations

Authors

Hõbe Treufeldt a

Peter Lucassen b

Christopher Burton a

a Division of Population Health, University of Sheffield, Samuel Fox House, Northern General Hospital, Sheffield, S5 7AU, UK

b Department of Primary and Community Care, Research Institute for Medical Innovation, Radboud University Medical Center, Nijmegen, Netherlands.

Corresponding Author: Hõbe Treufeldt. h.treufeldt@sheffield.ac.uk

8.1 Preface

The final study in this thesis focused on bringing together all of the information that was gathered on the topic to synthesise an actionable framework. The aim of this framework is to not only identify and counteract the stigma and stereotypes when it does happen, but to help clinicians pre-emptively understand the components of the consultations that work to build the alliance and therefore act to reduce stigma.

8.2 Abstract

Introduction

Stigma is a social attribute that links a person to an undesirable characteristic and leads to actions that increase the social distance from that person. This includes different or discriminatory treatment. Stigma is common in healthcare, particularly in people with persistent physical symptoms (PPS) and functional disorders (FD). The aim of this study is to create a new actionable framework for understanding and dealing with stigma in clinical consultations about PPS/FD.

Methods

This framework development used three stage approach create a new conceptual stigma framework in clinical encounters for PPS/FDs for reducing stigma in consultations for PPS/FDs. The stages included selection of an initial framework from existing frameworks; conducting a review of already existing interventions and stigma reduction frameworks and medical consultation models. And synthesising those findings to form a new conceptual framework.

Results

The framework consists of: 3 stereotypes regarding PPS/FDs and the stigma reduction interventions that would target the reduction of those stereotypes; and 6 target actions that promote alliance and reduce stigma in clinical consultations: humanising, legitimising, collaborative planning. collaborative reassurance, building therapeutic alliance, and exploring psycho-social contributors. Each of those actions consist of further sub-actions that are practical and actionable.

Conclusions

This new conceptual framework for reducing stigma and promoting alliance in clinical consultations for PPS/FDs has a potential to be a practical tool for clinicians.

Keywords

Stigma, medical consultation, persistent physical symptoms, functional disorders, best fit framework synthesis

Practitioner Points

- In consultations for PPS, stigmatisation can occur in various ways in the communication process.
- There are no practical frameworks of stigma reduction interventions in clinical consultations for PPS/FDs
- This new conceptual framework has a potential to be used as a practical guide for the clinicians in their consultations on how to reduce stigma.

8.3 Introduction

Persistent physical symptoms (PPS) is an umbrella term for symptoms lasting at least three months; this includes symptoms which are disproportionate to underlying organ-system disease (Aamland et al., 2014; Löwe et al., 2022; Löwe et al., 2024). These symptoms can exist on their own (for example abdominal pain) or as part of a syndrome, which are referred to as functional disorders (FDs). PPS/ FDs represent a spectrum of severity, ranging from mild symptoms to severe and chronic disorders (Rask et al., 2021). PPS currently cannot be described by any single consistent cause (Burton et al., 2020a) but they can be understood as arising from a complex interaction of biomedical, psychological and social factors (Henningsen et al., 2018). PPS are common; approximately 1 in 6 patients with persistent symptoms had at least 1 symptom diagnosis persistent more than a year (Chaabouni et al., 2023; Kroenke, 2003; Löwe et al., 2022). In 2010, a Europe wide review on disability burdens found that the 12-month prevalence rate is estimated to be around 5% (i.e., 20 million individuals in Europe) (Wittchen et al., 2011).

Stigmatisation is a process that increases social distance between individuals (Kurzban & Leary, 2001). This is a social process that starts with an identification of a difference that is then connected to a culturally present negative stereotype. This is a process of increasing social distance which then leads to the labelled persons' experiencing differential treatment and discrimination that lead to unequal outcomes Stigmatisation related to a medical conditions 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 identified with a particular health problem" (Weiss et al., 2006b). Certain medical conditions have been found to carry negative social connotations and therefore can be more stigmatising. There is evidence that PPS/FDs can be experienced as more stigmatising, than medical conditions, which have an established medical diagnosis or cause (Eger Aydogmus, 2020; Fox et al., 2018; Kirmayer et al., 2004). A survey conducted by the functional neurological disorder advocacy organisation (FND Hope) found that 85% of patients reported feeling disbelieved and disrespected when visiting a medical professional and stigma was believed to be a salient negative influence in clinical interactions (Macduffie et al., 2020). Moreover, it has been found that patients who have experienced higher levels of stigma, are less likely to adhere to treatment or show improvements in symptoms, depression, or anxiety after treatment (Feingold & Drossman, 2021). Those processes has an affect on stigmatised people's every day functioning and well-being and might affect their (Hatzenbuehler & Link, 2014; Link & Phelan, 2001).

The findings from a recent scoping review of stigma in medical consultations for PPS/FDs suggest that stigmatisation is present across the spectrum of PPS/FDs in a variety of medical specialities, in different medical settings and across countries and cultures(Treufeldt & Burton, 2024). This is significant because those widespread societal-level conditions, cultural norms, and institutional practices that negatively affect the treatment of patients who are affected by PPS/FD. Together these can be considered as form of structural stigmatisation (Hatzenbuehler & Link, 2014; McLoughlin et al., 2024). We recently developed a framework to categorise stigma occurring during medical consultations for PPS/FDs (Treufeldt et al., 2024).

Interventions have been developed to reduce stigma in many areas of society and medicine. Stigma reduction interventions can be broadly defined as interventions with the aim to reduce negative attitudes and beliefs associated with a condition(McLoughlin et al., 2024). Although PPS/FDs are common and patients face stigma on multiple levels (McLoughlin et al., 2024; Treufeldt & Burton, 2024), the strategies for reducing stigma associated with those conditions are scarce. Currently stigma reduction methods have been researched in functional neurological disorder (FND) (McLoughlin et al., 2024) but there no identified stigma reduction intervention strategies for PPS/FDs. Moreover, there are no resources or actionable frameworks that are designed for clinicians to use in clinical consultations. Therefore, there is a need to synthesise the already developed stigma reduction interventions with the knowledge of stigma in PPS/FDs.

This paper aims to develop a new conceptual framework of ways to reduce or prevent stigma in consultations for PPS/FDs along with actionable behaviours.

8.4 Methods

8.4.1 Overview

The current study is part of the innovative training network ETUDE (Encompassing Training in fUnctional Disorders across Europe) (Rosmalen et al., 2021).

We use the term conceptual framework to describe the state of known knowledge in this field, to identify gaps and to synthesise the knowledge to better understand and describe the problem (Varpio et al., 2020).

This study used a five-step approach to building this new conceptual framework:

Step 1 - To identify existing frameworks and stigma reduction interventions in clinical consultations.

Step 2 - To map the content of stigma reduction frameworks to an existing framework of stigma in clinical encounters for PPS/FDs.

Step 3 – To identify additional frameworks of clinical encounters to identify data to which can be added to the mapping in step 3.

Step 4 – Synthesis of mapped findings to create a new conceptual framework of interventions to reduce stigma in consultations for PPS/FDs.

8.4.2 Step 1: To identify existing frameworks and stigma reduction interventions in in PPS/FDs and other conditions

We searched for stigma reduction interventions or frameworks in PPS/FDs, and in other health-related fields. We used a structured search of Medline and PsycINFO via Ovid (1980-present) and supplemented it with a keyword search in Google Scholar. The search strategy consisted of terms of the following concepts: systematic review; stigma reduction; interventions; clinical or health consultations.

We included studies that looked at common stigma reduction interventions, the effectiveness of certain stigma reduction interventions and, the stigma reduction interventions involving different domains. We focused on stigma reduction interventions in health consultations for various settings, including mental health and conditions that have a more well-established biological pathology but carry stigma. This decision was made due to the findings that stigma in PPS/FDs encompasses several features from mental health and physical health stigmas (Treufeldt & Burton, 2024). We included studies that looked at stigma reduction interventions relating to weight stigma, health stigma, visible skin disease stigma and substance use disorder stigma. The final decision to include studies was made through the consensus of the team.

8.4.3 Step 2: Mapping content to the stigma in consultations framework

The next step involved the mapping of stigma reduction interventions content to our framework of stigma in consultations for PPS/FDs (Treufeldt et al., 2024). We extracted the already identified stigma reduction intervention reviews and looked at the stigma reduction aims and the interventional strategies that they reported. We then grouped the interventions according to what kind of stigma domain those interventions were targeting and mapped that to the stigma in PPS/FDs framework.

8.4.4 Step 3: Identifying additional frameworks to fill in gaps following step-3

Following step 3, when we finished the mapping of the stigma reduction interventions to the stigma in PPS/FDs consultations' framework, it became clear that there were gaps, that the stigma reduction interventions were not able to address. Therefore, we carried out a search for clinical consultation models that would be able to fill those gaps. To do this we identified key papers that were focusing on different aspects, factors, values, actions, and general findings that would promote good clinical consultation experiences. This was done by team consensus, led by one of the team (PL) who has extensive experience in teaching and research on medical consultations.

8.4.5 Step 4: Synthesis of mapped findings to create a new conceptual framework of interventions to reduce stigma in consultations for PPS/FDs

The final step was to synthesise the relevant information to create the new conceptual framework with the existing framework of stigma generation (Treufeldt et al., 2024). As the existing framework has categories of stigmatising actions, we aimed to find stigma-reducing actions that prevented or countered the stigmatising ones. The synthesis involved extracting the relevant data from the identified studies to from conceptual stigma reducing actions.

8.5 Results

8.5.1 Step 1: Identifying existing frameworks and stigma reduction interventions in in PPS/FDs and other conditions

The search found three relevant papers. First, the framework for catogorisation of stigmatising actions and stereotypes in PPS/FDs (Treufeldt et al., 2024). Second, the systematic review of stigma in functional neurological disorder (FND)(McLoughlin et al., 2024). And third, the development of the Persistent Somatic Symptom Stigma scale for Healthcare Professionals (PSSS-HCP) (McGhie-Fraser et al., 2024). The overview of the studies is in **Table 8.1**. As the stigma framework in PPS/FDs is the only framework that categorises the actions and stereotypes that the patients and the clinicians have experienced in the consultations, we chose to use that as the initial framework. The other two studies looking at stigma in PPS/FDs were complementary to the findings of the stigma framework in PPS and therefore were added to data for step 2.

Our search identified no existing stigma reduction interventions in clinical consultations for PPS/FDs. We looked for existing stigma frameworks in PPS/FDs that could be adapted and for reviews of general stigma reduction interventions in the field of PPS/FDs. This can be found in **Table 8.1 Frameworks of stigma in persistent physical symptomsError! Reference source not found.**.

Table 8.1 Frameworks of stigma in persistent physical symptoms

Study	**Field**	**Method**	**Findings**
Stigmatisation in clinical consultations for persistent physical symptoms/functional disorders: A best fit framework synthesis Treufeldt et al. (2024)	Stigma in PPS/FDs	A best fit framework synthesis: new framework	The framework comprises prejudice, stereotypes and actions to increase social distance. Stereotype refers to the focus of stigma: this may be the condition, the patient, or their behaviour. Actions that increase social distance include: othering; denial; non-explanation; minimising, norm-breaking; and psychologising.
Stigma in functional neurological disorder (FND) – A systematic review (McLoughlin et al., 2024)	Functional neurological disorder	Systematic review of 127 studies	Stigma as a systemic process, with intrapersonal, interpersonal and structural aspects. Identified anti-stigma intervention strategies: Education interventions presenting factual information about the condition with the goal of correcting misinformation or contradicting negative attitudes and beliefs. Interventions that aim at changing characteristics of the individual such as knowledge, attitudes, behaviour, self-concept, self-esteem, coping skills, and empowerment are defined as “intrapersonal stigma interventions”

			Communication strategies: leaflets, communication protocols
Measuring persistent somatic symptom related stigmatisation: Development of the Persistent Somatic Symptom Stigma scale for Healthcare Professionals (PSSS-HCP)(McGhie-Fraser et al., 2024)	Persistent Somatic Symptom Stigma scale for Healthcare Professionals	Development of a stigma measure	The provisional version of the PSSS-HCP contains 19 items across three domains: Stereotypes, Prejudice, Discrimination

We included 19 reviews of stigma reduction interventions in the fields of mental health, substance use, weight-related conditions, and visible skin disease. The overview of the studies is found in Table 8.2. The most common stigma intervention strategies that were identified in these studies were: Contact; public, institutional, and structural awareness; education, skills training; condition specific awareness; self-stigma, social stigma. Moreover, reviews concluded that the effectiveness of the interventional studies were mixed, and the longitudinal effects are not well understood.

The stigma reduction frameworks in other relevant fields identified interventions such as education, contact, and skills training which seem relevant to changing the stereotypes regarding the condition, the person and the behaviour. Otherwise, the stigma reduction interventions are relatively broad and general and therefore are better designed for population-level interventions rather than within medical consultations. As a result, we found little practical guidance on how to reduce stigma on an individual level within the clinician-patient interaction. that the clinicians could refer to when dealing with patients with PPS/FDs.

Table 8.2 Overview of stigma reduction interventions from other fields

Study	Field	Method	Findings
Stangl 2019 (Stangl et al., 2019)	Health-related stigma	Framework	Describes broad framework for stigma with manifestations, practices, drivers, and facilitators. Little about interventions to reduce stigma
Mehta 2015(Mehta et al., 2015)	Mental health-related stigma	Systematic review	Modest evidence for the effectiveness of anti-stigma interventions beyond 4 weeks follow-up in terms knowledge and attitudes. No evidence to favour one specific intervention type.

Thornicroft 2022 (Thornicroft et al., 2022)	Health-related stigma	Umbrella review of 216 systematic reviews	Interventions based on the principle of social contact (whether in person, virtual, or indirect) that have been appropriately adapted to different contexts and cultures are the most effective ways to reduce stigmatisation.
Setchell et al. (2017)	Weight stigma in physiotherapy	Methodological approaches of action research	Interventions require context-specific understandings such as fostering professional reflexivity and improving understandings of stigma.
Chen et al. (2024)	Health students' stigma toward schizophrenia	A scoping review of 29 studies	Studies used various approaches, including face-to-face or online education, direct contact with individuals with schizophrenia, or a combination thereof, to diminish stigma among health professional students.
Heijnders and Van Der Meij (2006)	Stigma-reduction strategies and interventions in the field of HIV/AIDS, mental illness, leprosy, TB and epilepsy	A literature review	Multilevel interventions needed. Propose a patient-centred approach, which starts with interventions targeting the intrapersonal level, to empower affected persons to assist in the development and implementation of stigma-reduction programmes.
Klein et al. (2022)	Health practitioners' attitudes and practice in treating people with borderline personality disorder	Integrative review – 9 studies	Training health practitioners through BPD-related educational interventions can enhance positive attitudes and change practice.
Lien et al. (2021)	Mental illness stigma in healthcare professionals and students	A systematic review and network meta- 18 studies from 9 countries.	Education combining social contact is the most effective anti-stigma intervention, which can be implemented in clinical practices to help reduce this stigma and improve healthcare services for patients with mental illness.
Livingston et al. (2012)	Stigma in substance use disorders	A systematic review of 13 studies	The interventions were comprised of educational factsheets leaflets and motivational interviewing. The majority of the structural stigma interventions were designed to improve attitudes of medical students towards people with substance use problems,
Henderson et al. (2013)	Mental Illness Stigma		Findings suggested that the presence of strong positive attitudes might be more relevant to help seeking and disclosure than the absence of negative attitudes.

Magnan et al. (2024)	Substance Use Disorders Among Health Care Professionals	A Systematic Review of 32 articles (17 observational studies and 15 intervention studies)	Most intervention studies found small but significant reductions in stigma after intervention in studies that included active learning pedagogies that involved interactions with persons with SUDs.
McCullock and Scrivano (2023)	Mental illness stigma	A systematic meta-review of meta-analyses systematic meta-review of 19 meta-analyses, drawing from the Health Stigma and Discrimination Framework, to address these gaps.	Included metanalyses were of relatively poor quality and that interventions primarily addressed either public or self-stigma, while overlooking other stigmas. There was little evidence to suggest that interventions were effective longitudinally.
Nurul Nadiah bte Abd Malik CHIA (2012)	Mental illness stigma	A systematic review of 22 studies	Both mental health-related theoretical education and clinical placement in mental health settings are effective in changing the attitudes of health care students towards mental illness
Topp et al. (2019)	Stigma related to visible chronic skin diseases	A systematic review of 19 studies	Evaluated interventions were mainly multi-faceted incorporating more than one type of intervention. The present review revealed a lack of high-quality studies
Tostes et al. (2020)	Substance use stigma	A Systematic Review of 28 studies	No evidence confirms the effectiveness of the proposed interventions. It is essential to invest in approaches other than those traditionally adopted.
Toth et al. (2023)	Mental health related stigma in the workplace	A systematic review of 22 intervention studies	We found a significant reduction in stigmatising attitudes in almost all studies
Wong et al. (2024)	Mental illness stigma	A systematic review and meta-analysis of 25 studies	Statistically significant medium and small effect sizes for attitude improvement showing the association between educational interventions and improved attitudes among healthcare professionals and students

8.5.2 Step 2: Mapping the content of stigma reduction intervention to an existing framework

The stigma reduction intervention studies shared certain core interventional strategies that are relevant for this synthesis. In the consultation setting, the common elements of stigma reduction interventions included the elements of (1) education, (2) contact, (3) skills training: (4) public, institutional and structural awareness; (5) specific awareness.

Those target interventional strategies that aimed to reduce stigma were mapped into the stigma in PPS/FDs initial framework, as those strategies target the negative stigmatising stereotypes. In the stigma in PPS/FDs framework, this would help to understand the three negative stereotypes that underlie the stigmatisation process: Individual, Condition, Behaviour. Therefore, those stigma reduction intervention strategies could be used to address and reduce the underlying stereotypes and/or prejudices in the consultations for PPS/FDs.

The overview of the intervention strategies is in Table 8.2.

8.5.3 Step 3: Identifying additional frameworks of clinical encounters to identify data to which can be added to the mapping in Step 3

The stigma framework in PPS/FDs has both the three underlying activated negative stereotypes (Individual, condition, and behaviour) and the six actions (othering, denial, non-explanation, minimising, norm breaking, psychologising) that are used to enact stigmatisation. As the stigma reduction interventions identified in the previous step were mapped onto the framework, we found that the interventions were applicable to reduce the activated negative stereotypes. Whereas the stigma reduction intervention strategies did not describe or involve addressing the stigma-reducing actions. Therefore, the decision was made to look for consultation models that address specific actions that promote good consultations and advocate for what patients would need from their consultations.

The search included 9 papers about good consultation practices, including one framework of PPS/FDs consultations – The REAL model (Fryer et al., 2023) (included in Table 8.3). This model was developed and tested to deliver explanations regarding PPS in clinical settings and focused on cultivating a positive working alliance between the clinician and the patient by focusing on communication. The other papers focused on different aspects and domains in medical consultations that would be beneficial to reduce the stigmatisation actions in PPS/FDs.

Table 8.3 Overview of good consultation practices

Study	**Field**	**Method**	**Findings**
Fryer 2023 (Fryer et al., 2023)	GP with extended role clinic for persistent physical symptoms and functional disorders	Process within RCT of an extended-role GP "Symptoms Clinic".	Recognition, Explanation, Action, Learning (REAL) is a teachable consultation model addressing specific clinical communication issues for people with persistent physical symptoms.
Mistiaen et al. (2016)	Communication between patients and health care practitioners and its effect on pain	Systematic review of 51 studies	Encouraging positive patient expectations, and increasing practitioner empathy (with or without additional procedures) have sometimes significant, but small, effects on pain..
Mazzi et al. (2016)	Improving medical consultation: multicentre European study	Sequential mixed method approach. 798 patients, representing United Kingdom, Italy, Belgium and the Netherlands,	Four doctor behaviours should always be part of doctor–patient communication: listening attentively; taking the patient seriously; treating the patient as a person; and granting enough time.
Howe et al. (2019)	Patient–Provider Interaction	Framework	By framing patient–provider interactions in terms of provider competence and warmth, we have capitalised on decades of research in social perception to begin to unpack how and why patient–provider interactions can boost placebo response.
Fuertes et al. (2017)	physician-patient working alliance	Overview and a meta-analysis of 7 empirical studies	Results of the meta-analysis found medium to large effect sizes between the working alliance and various behavioural care indices.
Evers et al. (2018)	Patient's expectancies · Clinical practice · Patient-clinician communication · Evidence-based ethical recommendations	A survey and interdisciplinary expert meeting by invitation was organised as part of the 1st Society for Interdisciplinary Placebo Studies (SIPS) conference in 2017. Twenty-nine internationally recognised	There was consensus that maximising placebo effects and minimising nocebo effects should lead to better treatment outcomes with fewer side effects

		placebo researchers participated.	
Bensing et al. (2011)	Medical consultation	258 Lay people in the United Kingdom, Italy, Belgium, and the Netherlands, distributed over 32 focus groups	Listening to patients, showing empathy and personal attention seem to have a universal value.
Barry (2001)	doctor–patient communication in general practice	Qualitive study of 62 case studies, comprising 62 patients visiting 20 doctors in the midlands and southeast England.	When doctor and patient both used the voice of medicine exclusively this worked for simple unitary problems. When both doctor and patient engaged with the lifeworld, more of the agenda was voiced and patients were recognised as unique human beings. Poorest outcomes occurred where patients used the voice of the lifeworld but were ignored or blocked.
Wampold (2015)	Psychotherapy	Contextual model	The evidence, primarily from meta analyses, is presented for particular common factors, including alliance, empathy, expectations, cultural adaptation, and therapist differences.

8.5.4 Step 4: Synthesis of mapped findings to create a new conceptual framework of interventions to reduce stigma in consultations for PPS/FDs

The final step was to synthesise all of the relevant information to create the new conceptual actions and sub-actions to promote alliance. This involved modifying the new conceptual framework by adding the social cohesion and therapeutic alliance actions and specifying on how to promote those actions by synthesising the sub-actions that the clinician can take. The final detailed conceptual framework is summarised in Table 8.4.

This conceptual framework aims to integrate the stigma reduction interventional strategies that target the stigmatising stereotypes by using the interventional strategies shown to be effective. The other part is to target the stigmatising actions; these are labelled as alliance promoting actions in the new conceptual framework. The alliance promoting actions were based on the general synthesising of findings from the consultations models, stigma framework in PPS/FDs (Treufeldt et al., 2024) and using the REAL model (Fryer et al., 2023) to form specific sub-actions.

Table 8.4 New conceptual framework for alliance and stigma reduction in PPS/FDs

<table>
<tr><th>Stigmatising stereotypes</th><th colspan="2">Target interventional strategies used to reduce stigma</th></tr>
<tr><td><i>Condition</i></td><td colspan="2">Contact, public and Institutional, structural awareness, education, skills training
(Barry, 2001; Bensing et al., 2011; Mazzi et al., 2016)</td></tr>
<tr><td><i>Individual</i></td><td colspan="2">Contact, public and Institutional, structural awareness, Education (Bensing et al., 2011; Mazzi et al., 2016)</td></tr>
<tr><td><i>Behaviour</i></td><td colspan="2">Education, contact, skills training (Alabas et al., 2012; Bensing et al., 2011; Elwyn et al., 2014; Fryer et al., 2023; Howe et al., 2019; Mazzi et al., 2016; Mistiaen et al., 2016)</td></tr>
<tr><td></td><td></td><td></td></tr>
<tr><td>Stigmatising actions</td><td>Stigma reducing/ social cohesion promoting action</td><td>Sub- actions</td></tr>
<tr><td><i>Othering</i></td><td><i>Humanising</i></td><td>Creating a non-fault situation where the patient is being treated the same way as with a medically well-established diagnosis/condition</td></tr>
<tr><td><i>Denial</i></td><td><i>Legitimising</i></td><td>Making the patient being believed regarding their condition
Approaching the examination and the patient’s responses in an open manner, exploring the complaints and making the patient being believed regarding the serious nature of their complaints</td></tr>
<tr><td><i>Non-explanation</i></td><td><i>Explaining/discussing/offering a way forward</i></td><td>Offering possible explanations or ways to carry forward, referrals, interpreting and understanding the symptoms, helping to make sense and prioritising finding a way to help the patient to understand their symptoms/condition in the terms that are accessible for them. This includes finding a way for the clinician to explain possible symptoms contributors even in the event that the pathology/aetiology is not known.</td></tr>
<tr><td><i>Minimising</i></td><td><i>Collaborative reassurance</i></td><td>Properly acknowledging and addressing patients’ concerns/symptoms and making the patient feel that they are heard increases reassurance.
Helping the patient understand what might be expected symptoms, what might be ‘’normal range” experiences,
Addressing patient’s concerns on how to manage and where to get help/what to do to help themselves</td></tr>
</table>

		Collaborative reassurance that takes into account patient's perspective and concerns helps to gain a more balanced understanding of the future projection and helps to manage anxiety
Norm breaking	***Building therapeutic alliance***	Using well established social skills, like listening, reflecting, making conclusions, responding to patients' complaints, using the language that the patient uses
Psychologising	***Exploring psycho-social contributors***	Helping the patient understand what might be the possible contributions in a non-accusatory way to their condition. This is a collaborative effort which patient needs to participate or lead from their own volition, clinician can offer the exploration of the topic but the depth of the issue should depend on the patient Relying on the cues from the patient, using the same language, reflecting on the psycho-social issues that the patient has brought up and giving new information and context on how those factors might be influencing the somatic aspects, therefore inviting the patient to co-create a new understanding from their experience together with the medical knowledge.

8.6 Discussion

8.6.1 Summary of main findings

We systematically developed a new actionable framework which can be used to reduce or prevent stigmatisation in medical consultations about PPS/FDs. It comprises an underlying prejudice about PPS/FDs, the negative stereotypes regarding the condition or the behaviour the or the person with PPS/FDs and lastly the actions used by the clinicians to stigmatise.

8.6.2 Relationship to other research

Existing stigma reduction frameworks typically focus on one health condition in isolation and often concentrate on the psychological pathways occurring among individuals. This tendency has encouraged a siloed approach to research on health-related stigmas, focusing on individuals, impeding both comparisons across stigmatised conditions and research on innovations to reduce health related stigma and improve health outcomes (Stangl et al., 2019).

Moreover, the importance of shifting perspective from stigma reduction to promoting good consultations, which in their essence should act as anti-stigmatising with added knowledge of specific stigmas that might be more present. The field of stigma reduction would benefit if it would aim to synthesise of what is known about good medical consultations with the knowledge of patients' lived experiences with their condition related prejudices, stereotypes, discrimination and stigmatisation.

Furthermore, there is evidence that stigmatisation and trauma in PPS/FDs might be related, as there might be a link between experiencing stigmatisation in consultations for fibromyalgia and experiencing trauma symptoms [Treufeldt, Burton in preparation]. This might indicate for the need for moving away from' anti-stigma' intervention approaches in clinical settings and to incorporate more of trauma aware approaches when dealing with patients with PPS/FDs.

In doing so, this paper proposes to move on from the label 'anti-stigma' to a more positive descriptive label, as to accurately represent the process that this 'anti-stigma' research aims to promote. As we know from research, negative descriptions of medical labels, i.e. to define something by what it is not, is not a helpful way of approaching a phenomenon (Edwards et al., 2014).

Therefore, when focusing on how to build an actionable framework in clinical consultations to reduce stigma and promote social alliance, it is important to focus on the general stigma reduction intervention strategies, as well as taking into account the condition related stigmas, and the specific actions that the patients need from good clinical consultations.

8.6.3 Discussion of the ambiguous language in the opening of the medical consultation in relation to the new conceptual framework

Previous study "How are you" ambiguity from the outset in consultations about persistent physical symptoms investigated the role of ambiguous language in medical consultations, particularly focusing on the use of "How are you?" (HAY) and its variations in consultations for PPS/FDs using conversation analysis (CA). The findings suggest that ambiguity in clinical communication can increase the burden on patients, particularly those who have experienced stigma. This study, on the other hand, develops a conceptual framework designed to reduce stigma and promote therapeutic alliance. This discussion critically examines the relationship between these two studies, evaluating their coherence, potential for integration, and implications for clinical practice.

The findings in CA analysis study of GP openings described in Chapter7 highlight that seemingly minor linguistic choices in the opening of the medical consultations could be difficult to navigate. The ambiguity of HAY forces patients to navigate a complex decision: whether to treat the phrase as a greeting or an invitation to discuss symptoms. This additional cognitive and emotional load may exacerbate epistemic injustice—where patients feel disbelieved or that their experiences are dismissed. This aligns with the "Legitimising" action of the Stigma-Reducing Alliance Framework, which emphasises the importance of affirming patient experiences to counteract stigma.

A key recommendation in from that CA study is that clinicians could potentially modify their approach by using HAY+, which includes a specifier such as "How are you doing now?" or "How have things been?" This minor modification provides clearer guidance for patients, reducing ambiguity and fostering an environment where patients feel their symptoms are taken seriously. This aligns with the "Explaining" component of the framework, which advocates for clinicians providing transparent and validating explanations of symptoms, even when a definitive biomedical cause is absent.

The new developed Stigma-Reducing Alliance Framework outlines specific clinician behaviours that mitigate stigma and enhance the clinician-patient relationship. The findings in the CA study (Chapter 7) directly support several of these actions. Firstly, applying the action Humanising. This would involve treating patients with PPS/FDs as credible individuals with legitimate health concerns. By reducing ambiguous phrasing, clinicians avoid inadvertently making patients feel delegitimised. Secondly, applying Collaborative Reassurance. In Chapter 7, patients showed tension between giving a normative response ("I'm fine") and presenting their symptoms honestly. A stigma-aware approach, as outlined in this study would encourage clinicians to signal openness to patients' concerns, fostering a safe environment for disclosure. Lastly, the action of Building Therapeutic Alliance. The CA study findings suggest that ambiguous phrasing may inadvertently distance patients from clinicians, contributing to a strained doctor-patient dynamic. In contrast, the framework developed and presented here, advocates for explicit efforts to build trust and social cohesion, which could include modifying initial phrasing to reflect active listening and concern.

One of the core insights from the CA study is that language is not neutral—it reflects and reinforces broader societal biases and structural stigma. The findings reinforce the need for clinicians to be mindful of how even routine conversational patterns may subtly uphold power imbalances that contribute to epistemic injustice. This new stigma reducing-alliance promoting framework aims to address these issues by encouraging clinicians to avoid non-explanation and minimisation, instead engaging in transparent discussions about symptoms and treatment options. Moreover, by providing guidance on how to reframe psychosocial discussions in ways that validate rather than dismiss patient concerns.

The insights from the CA study provide empirical support for the development of this conceptual framework. By integrating conversation analysis findings, the Stigma-Reducing Alliance Framework gains an additional micro-level, interactional dimension. Future iterations of the framework could explicitly incorporate guidance on linguistic strategies that clinicians can use to avoid stigma-reinforcing ambiguity. This could include for example: training clinicians to use linguistically precise and patient-centred phrasing; developing scripts or communication models that align with best practices in reducing epistemic injustice; and encouraging clinicians to recognise when patients hesitate or struggle with ambiguity, allowing them to adjust their phrasing dynamically.

8.6.4 Discussion of this new conceptual stigma reduction and alliance building framework and the relationship to trauma aware practice

Both trauma-informed practice and the new alliance promoting-stigma reducing framework share a common goal of improving patient care through enhanced understanding of patient experiences. However, they differ in their primary focus and scope. Trauma-informed care is designed to recognise, avoid re-traumatisation, and promote healing for individuals with past trauma. Its principles include safety, trustworthiness, choice, collaboration, and empowerment (Services, 2014). In contrast, this new alliance promoting stigma reduction framework developed for consultations regarding PPS/FDs specifically addresses the ways in which language and interactional practices in clinical settings can contribute to stigma and epistemic injustice. While trauma-informed care emphasises creating a safe and supportive environment that is sensitive to the impact of trauma, the alliance promoting framework focuses on modifying clinicians' communication strategies through actions such as humanising, legitimising, and collaboratively reassurance with an aim to directly counteract stigmatising stereotypes and behaviours.

One key point of convergence between the two approaches is the emphasis on the therapeutic alliance. Research indicates that a strong, trust based relationship could potentially mitigate the adverse effects of both trauma and stigma (Comiskey, 2024). Moreover, trauma-informed practices stress the importance of validating patient experiences and fostering empowerment, which aligns with the anti-stigma framework's call for clinicians to legitimise patients' symptoms and experiences.

A further contrast lies in the focus of interventions. Trauma-informed care typically involves a comprehensive, multi-level approach that extends beyond the individual encounter to include staff training, policy reform, and changes in the physical setting (Services, 2014). In comparison, this alliance promoting framework is primarily aimed at guiding clinicians during the consultation itself. By providing actionable sub-actions (e.g., avoiding ambiguous language that may lead to epistemic injustice), the framework fills a gap in the literature that often treats stigma reduction and trauma awareness as separate issues. In doing so, it adds specificity by addressing how subtle linguistic choices—such as the difference between "How are you?" and "How are you doing today?"—could potentially influence the patient's perception of communication (Treufeldt, Burton, Walker in press, Chapter 7) (Welch, 2010).

Furthermore, trauma-informed care does not provide guidance on how to counteract the stigma associated with PPS/FDs. Our framework contributes to this discussion by articulating targeted stigma reduction strategies that can be integrated into trauma-informed approaches. For instance, by explicitly recommending practices that humanise patients and validate their experiences, the framework encourages clinicians to not only prevent re-traumatisation but also to actively dismantle the stigmatising discourses that often complicate the care of PPS/FD patients.

While both trauma-informed practice and the alliance promoting framework aim to create more supportive and respectful clinical interactions, the latter adds value by offering practical, interaction focused strategies for mitigating stigma. It complements trauma-informed approaches by highlighting specific communication tactics that can help counteract epistemic injustice and reduce the additional burden of stigma on patients with PPS/FDs.

8.6.5 Strengths and limitations

The strength of this research is in incorporating different fields and synthesising diverse set of findings. In doing so the underlying principles that this framework addresses should be generalisable to diverse settings and situations.

The main limitation of this research is that this is a conceptual framework and therefore there is a need for further validation and testing. That would mean that in the future with new findings and feedback there could be added or changed some categorisations or findings. This framework should be treated as a first step toward building more productive, inclusive and cohesive way of communicating in consultations where the patients are likely to have had either first- or second-hand experience of stigmatisation o social alienation.

Another limitation might be that this conceptual framework development was not a straightforward best fit framework adaptation (Carroll et al., 2013). However, this was necessary because there was no framework to adapt from, therefore the strategy of choosing a stigma experiences in PPS/FDs and synthesising those findings with other relevant findings to create a conceptual framework. This could also act as a strength, as those findings seem to have certain core elements that are similar across different healthcare fields and are evidenced by different systematic reviews and research approaches. Therefore, the new conceptual framework needs to be subjected for further validation, but currently seems to respond to clinical need and carry potential to be helpful for consultations.

8.6.6 Implications for practice, policy and research

PPS/FDs are common in consultations, and unfortunately patients with these conditions experience stigma in different levels, including structural, interpersonal, and medical stigmatisation and discrimination. Clinicians need to know and understand that in order to provide care for these patients. There are ways we can understand and categorise the stigmatising stereotypes and actions that these patients experience. Moreover, this conceptual framework offers practical guidance of how to approach those patients, how to communicate, and how to make sure that by acting in a way that does not activate the already experienced stigma, the likelihood of a good consultation experience that promotes a productive therapeutic alliance.

8.7 Conclusion

We have developed new conceptional framework to promote alliance and reduce stigma in clinical healthcare consultations for PPS/FDs. In contrast with previous, more broad conceptual approaches, this new framework can be used to understand individual consultations and experiences and provides actionable suggestions for improving consultations.

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9 DISCUSSION

9.1 Review of the research questions

This thesis aimed to address three research questions:

Research question 1: What is currently known about stigma in healthcare consultations about persistent physical symptoms? This research question was answered in study 1: scoping review. This found that while stigma in PPS/FDs has often not been explicitly defined, there is evidence that it is ubiquitous, and appears to be a structural problem in consultations across disciplines, countries, and healthcare systems.

Research question 2: How is stigma conveyed and perceived in consultations about persistent physical symptoms? This research question was dealt with in studies 2, 3 and 4 using complementary methods and approaches. In study 2, the framework development for PPS/FDs identified, described, and categorised common forms of stigmatising stereotypes and actions that patients might face in consultations. Study 3 used focus groups to understand the effects of experiencing stigma on a personal level and found that stigmatising experiences could result in avoidance and anticipatory anxiety and have similar effects to (re)traumatisation. Study 4 used conversation analysis to take a microanalytic approach to understand if the common way GPs initiate the consultations might be difficult and found that the use of ‘how are you’ is ambiguous, particularly where there is anticipatory anxiety about the consultation. This study proposed that by modifying the language only slightly, communication could become clearer.

Research question 3: How can consultations for persistent physical symptoms be modified to reduce or avoid stigma? This was addressed in study five, which developed an actionable framework that build on the previous findings in order to develop guidance for clinicians on how to promote alliance and reduce stigma in consultations for PPS/FDS.

9.2 Summary of main findings

The studies in this thesis form a coherent approach to understanding stigma in PPS/FDs. The thesis set out to understand and describe the scope of the problem of stigma in medical settings for PPS/FDs. The overarching theme of the five studies is the pervasive and complex nature of stigmatisation faced by patients with PPS/FDs in clinical consultations.

The studies highlight how stigma in healthcare settings is not merely an interpersonal phenomenon but ingrained in the structural, cultural, and communicative norms of the medical profession.

The Study 1, a scoping review, was a first study of its kind and the findings suggested that stigma in PPS/FDs is widespread and can be understood as structural stigma. This also highlighted the lack of cohesion in this field, namely that stigma was loosely defined, and the research lacked clarity. Therefore, it is important to bring clarity for the stigma concept, and with that we can understand this phenomenon better and to be able to provide useful insights and propose improvements. Another main finding was the discovery of the structural and ubiquitous nature of stigma in PPS/FDs. This was reflected in identified studies which included: variety of medical settings; countries; world regions; both patients and different health care professionals; and the discriminatory attitudes patients faced from different settings form general public to the consequences that the sick leave and disability policies had on the patients. This means that those conditions are often subject to implicit biases and related stereotypes that arise from the broader societal prejudice that "organic" disorders can be seen as more legitimate than ''functional" disorders. This bias leads to negative stereotypes, where patients with functional disorders are perceived as less credible or less deserving of care. The actions resulting from these biases exacerbate the social distance between clinician and patient, resulting in poor therapeutic alliances and unfavourable healthcare trajectory.

The findings of Study 1 were then used as the basis of the best fit framework synthesis that was carried out in Study 2, which aimed to categorise and describe in depth patients' experiences of stigma in medical consultations for PPS/FDs. This resulted in the first stigma framework to be proposed for medical consultations for PPS/FDs. The framework sets out to describe the stigmatisation process as experienced by patients. Those stages are: present underlying prejudices that are emotion-inducing, pre-cognitive and implicit in our society; negative stereotypes; and stigmatising actions that increase social distance and result in discrimination. The underlying prejudices are regarding to what is a legitimate illness and who gets to have access to the sick role, in this case the legitimacy of the PPS/FDs is contested. These prejudices in turn influence the three main stereotypes that carry stigma in PPS/FDs: the condition, the individual, the behaviour. Lastly, the framework proposes six general categories of stigmatising actions: othering, denial, non-explanation, minimising, norm breaking, and psychologising.

Both study one and two found that stigma in PPS/FDs can be understood as structural and omnipresent across cultures, which carries over to the medical profession where patients with PPS/FDs can experience of being treated as not a legitimate patient that results them feeling not heard, isolated from the medical establishment and alone with their persistent health concerns. This can contribute to the perpetuating of negative stereotypes and can result in discriminatory healthcare practices which have a long-lasting effect on both individual health care trajectory but also effect the erosion of social cohesion. The findings point to perpetuating epistemic injustice, where patients are systematically disbelieved, or their accounts of their symptoms are devalued. The first two studies together suggest that stigmatisation is not just an individual experience but a reflection of broader institutional structures that perpetuate these harmful actions.

Following the two more over-arching, macro-level studies, the third study aimed to take an in-depth look at the experiences of patients who have been stigmatised. This study used a focus group method, where patients with fibromyalgia were able to share their stigmatising experiences. The findings showed that fibromyalgia patients vividly recall repeated experiences of stigma. Those negative experiences of stigmatisation had a profound impact on the participants, and the effect was similar to the effect of (re)traumatisation (Grasser & Jovanovic, 2022). This included having intrusive thoughts and memories, negative feelings and thoughts about themselves, heightened isolation, and fear for seeking new medical help which sometimes led to avoidance of healthcare. The participants voiced that the experienced stigma had left them on high alert in order to avoid this kind of experience again and resulted in anxiety before healthcare visits. This highlighted the iatrogenic harm that might be experienced by this vulnerable patient group and the idea that stigmatisation could involve or lead to re-traumatisation. Those findings address the importance of trauma-informed care and the need for changes in the way the clinicians communicate about PPS/FDs. Study 3 adds to the knowledge of the very real and harmful consequences of experiencing stigma by showing the findings that repeated experiences of stigmatisation in healthcare could be linked to (re)traumatisation for patients with PPS/FDs. This (re)traumatisation could manifest as avoidance of healthcare, anticipatory anxiety about future encounters, and worsening of both the quality of life and mental health. The findings suggest a relationship between stigmatisation and the mental health of patients with PPS/FDs, underlining the importance of trauma-informed care.

The fourth study was designed to take a detailed look at possible communication troubles in GP consultations. This study took the finding from the Study 3, that patients experience anticipatory anxiety and sometimes can tell if a consultation goes awry from the beginning. This inspired to examine if there might be anything that the clinician does in the initiation of the consultation that might contribute to the experienced difficulty for the patient. The study micro-analysed video recordings of GP consultations about PPS/FDs using conversation analysis. The findings showed that commonly used consultation initiation 'how are you' is in its essence ambiguous and can be treated very differently by patients, and might contribute more obstacles to overcome for patients, who must navigate the tension between normative responses and presenting their medical issues. The study found a slight modification of 'how are you' could mitigate the trouble and help the patients to understand what kind of response is expected. This finding is important because the previous studies have highlighted nature of structural stigma in PPS/FDs and given the insight of patients might be anticipating stigma because of their existing repeated negative consultation experience. Therefore, it might be useful for clinicians to focus on promoting the use of slight modification of language to help the patients to feel more at ease. The fourth study highlights how subtle linguistic choices in consultations could contribute the experience of reinforcing or challenging the legitimacy of patient experiences. This together with the other findings in this thesis suggest that in the context of structural stigma, and repeated negative experiences, the minor linguistic choices might play a far larger role for the individual consultation experiences than previously thought.

The final study of this thesis aimed to synthesise all the previous findings of the four studies into a comprehensive framework to reduce stigmatisation that could be used in medical consultations. This framework aims to reduce stigma in consultations by integrating known stigmatised features of PPS/FDs, educational interventions, and sigma reduction interventions, and synthesising this knowledge into a novel actionable framework that aims to give clinicians practical guidance on how to promote therapeutic and social alliance and reduce stigma. It identifies practical actions clinicians can take to counteract stigmatisation, such as avoiding language that dismisses symptoms, using trauma-informed approaches, and actively working to create therapeutic alliances with patients. The framework moves beyond simply reducing stigma, emphasising the importance of actively destigmatising patients with PPS/FDs by creating a healthcare environment that is socially inclusive and patient centred.

9.3 Relationship to other relevant research

The findings of these five studies presented in this thesis both complement and add to the existing knowledge. The findings of this thesis complement the current research trajectory, that stigma is a significant challenge in various conditions including chronic pain, fibromyalgia, and functional neurological disorders. For instance, Nettleton et al. (2005) noted that patients with "medically unexplained symptoms" often feel that their experiences are trivialised, resulting in frustration and dissatisfaction with healthcare providers. Similarly, Briones-Vozmediano et al. (2018) found that fibromyalgia patients frequently encounter the psychologisation of their symptoms, which aligns with the framework presented in this thesis on stigma as a key issue when seeking treatment.

Fricker (2007) and the concept of epistemic injustice is also highly relevant to these findings, especially in Studies 2 and 3. According to Fricker, individuals are often discredited due to societal biases, which mirrors the experiences of patients with PPS/FDs, who are frequently seen as unreliable narrators of their own health. Scholars like Blease et al. (2017) have argued that this lack of credibility contributes to inequities in healthcare, particularly for conditions without clear biological markers. Interestingly this notion of epistemic injustice is reflected on both micro-and macro levels, as previously mentioned the studies 2 and 3 both try to address those issues on different levels. There needs to be both qualitative in-depth understanding of the issues that the patients experience and the consequences that the structural stigma results for individuals and their lives, for example how the study 2 aimed to understand the effects of stigma for patients. But as well how the structures uphold and perpetuate stigma and how this could be challenged and changed.

Study 3 extends the current knowledge about what is known of trauma in PPS/FDs by linking repeated stigmatisation to (re)traumatisation, a connection supported by trauma-informed care research. It has been suggested that psychological trauma, especially childhood trauma, is a risk factor for the onset of fibromyalgia (Gardoki-Souto et al., 2022). Moreover, a recent systematic review (Kaleycheva et al., 2021) confirmed a significant association between stressor exposure and adult fibromyalgia. Similarly it has been proposed that individuals with trauma histories, especially those managing chronic conditions, are particularly susceptible to retraumatisation in healthcare environments where their symptoms are dismissed (Fallot & Harris, 2009). This is corroborated by Dallam (2010), who documented healthcare avoidance as a common response to such experiences.

Additionally, the conversation analysis in Study 4 sheds light on how everyday phrases, such as “How are you” can complicate patient-clinician interactions. Previous research has found that the way clinicians phrase questions can profoundly influence patient trust and disclosure (Heritage & Robinson, 2011). Study 4 contributes to this by highlighting what might make it more difficult for patients with PPS/FDs to navigate these conversations, often reinforcing the epistemic dissonance that undermines their credibility.

Study 5’s exploration of stigma reduction strategies highlights the scarcity of interventions specific to PPS/FDs, though broader research in mental health and HIV care suggests that education, contact, and skills training can effectively reduce stigma (Corrigan et al., 2012). However, as noted in the study, these interventions generally target population-level stigma and require adaptation for use in clinical settings. The structural dimensions of stigma, identified in Studies 1 and 2 and expanded upon in Study 5, resonate with Link and Phelan’s (2001) work on institutional stigma, which argues that healthcare systems often perpetuate unequal treatment of marginalised groups. This thesis extends that discussion to include the unique challenges of patients with PPS/FDs, who frequently encounter stigma due to the current absence of objective diagnostic markers.

This highlights the need to bring together findings from different disciplines for example, Fricker’s (2007) epistemic injustice in healthcare in order to improve trust between patients and clinicians which could deepen our understanding of how biomedical ambiguity leads to stigmatisation. Moreover, how integrating trauma-informed care principles with healthcare practices, as suggested by Fallot and Harris (2009), could, along other developed strategies also help to mitigate the retraumatisation experienced by vulnerable patient populations in PPS/FDs. Study 4’s findings on patient credibility could also link with shared decision-making models, such as those explored by Charles et al. (1997), to empower patients in clinical consultations. Finally, adapting successful stigma reduction strategies from mental health and HIV care (Corrigan et al., 2012) when adapted to the specific forms of stigma in the PPS/FDs context, could offer a more comprehensive approach to reducing stigma both interpersonally and structurally.

9.4 Strengths and limitations of this PhD thesis

9.4.1 Strengths

One of the primary strengths of this PhD thesis is its use of different methodological tools to try to build a comprehensive understanding of the complex topic. This thesis consists of five studies that take an in-depth look at a phenomenon using a range of methods, including scoping review, thematic synthesis, best fit framework synthesis, qualitative focus group study, conversation analysis, and a general actionable framework synthesis. The reasoning for using mixed methods and research approaches is that these kinds of sociological phenomena are complex in nature and the research needs to include a triangulation of methods to ensure the wide scope of the topic has been adequately represented and that the results are valid and reliable (McKim, 2017).

Another strength is the inclusion of a diverse sets of patients' experiences. Study 1 and 2 covered a wide range of PPS/ FD therefore establishing that the problem of stigma is transdiagnostic. In study 3, the participants from eight European countries had a uniting FD diagnosis of FM, but the settings for their experiences were very different, therefore their shared experiences of stigma are cross national. Those findings indicate that stigma in PPS/FDs is a wider problem, that affects patients across different cultures, medical settings and healthcare contexts. This pan-European perspective on stigma in FDs is important to consider and to research further. Study 4 had multiple different symptoms in the same GP setting, meaning that PPS and the communication is important also in a single practice. Study 5 is transdiagnostic and is designed to provide guidance for promoting cohesive communication and reducing stigma in different conditions in PPS/FDs and in different settings.

Furthermore, this thesis makes a significant contribution to the theory of stigma by addressing the epistemic injustice faced by patients with PPS/FDs and highlighting the novel findings of long-term psychological impact of repeated stigmatisation that can have a long-lasting effect on the mental health and health care trajectory. The exploration of links between stigmatisation and (re)traumatisation in Study 3 introduces a novel area of research in the cross sections of mental health, medical sociology, stigma and PPS/FDs. This proposes the need to re-think trauma-informed care in healthcare settings. This is a vital step toward understanding the iatrogenic harm that might be experienced in healthcare encounters and opens the door for future interventions aimed at reducing both trauma and stigma.

Another key strength is the development of an actionable framework for social alliance and stigma reduction in Study 5. This framework synthesises knowledge from different fields, such as stigma reduction interventions in different medical fields, key findings in the field of good medical consultations and the research done on stigma in PPS/FDs. This aims to provide healthcare practitioners with concrete tools to reduce stigma and promote therapeutic alliance. This framework not only builds on existing research but proposes moving away from traditional "anti-stigma" approaches. This includes advocating for a positive, strength-based approach that emphasises social cohesion, collaborative care, while being aware of the prejudices, stereotypes and stigmas associated with PPS/FDs and shifting the focus on the patients' lived experiences.

9.4.2 Limitations

Despite its strengths, this thesis also has some limitations. First, although the studies provide a comprehensive view of stigmatisation within clinical encounters, Study 3's focus on patients from European countries restricts the global generalisability of the findings. While the cross-national design strengthens the research in a European context, future studies would benefit from including more geographically diverse populations, particularly from non-Western or low-resource healthcare settings, to ensure the framework's applicability across a broader range of cultural and healthcare environments. There is some evidence that this issue of stigmatisation in PPS/FDs might be similar across different continents and in different cultural and economic settings. As the study 1, the scoping review, found studies that dealt with the problem of stigma in PPS/FDs in Japan, Mexico, South Africa, Australia, and New Zealand. This also brings up the limitation of this study that the intersectionality of stigma needs to be understood better. It would benefit from the research to aim to include racially, ethnically, culturally diverse populations of peoples and their lived experiences and further the knowledge of intersectionality and the compounding risk of experiencing stigmatisation in vulnerable and marginalised populations.

Another limitation lies in the secondary nature of some of the data used in the studies 1 and 5. For instance, the scoping review and thematic synthesis in study 1, relied on existing literature, which may have introduced selection bias toward more polarised accounts of stigma. This usage of previously published studies means that the stigma framework is influenced of the quality and scope of those original studies. Additionally, much of the qualitative data were recalled accounts rather than direct observations, which may introduce recall bias and limit the precision with which stigmatisation in real-time medical encounters is understood. Those limitations were addressed in the process of creating the framework. As well acknowledging that those descriptions in the first and the second study are recalls of the events, the framework and the grounding methodological underpinnings of this thesis and these research studies, does not view peoples' experiences as existing in a vacuum, rather than understanding them in a complex social and personal experiences. Therefore, these experiences of people experiencing stigma and adverse effects, are valid in themselves. Moreover, this brings up a topic for nuanced research as in one medical context those patients experience stigma but in other medical contexts not. This thesis has hopefully demonstrated that the issue of stigma in PPS/FDs is relatively common and widespread, people are exposed to it and are reporting it. But in the future studies hopefully there can be more ways of designing the research to triangulate and understand the issue in a more nuanced way.

In Study 4, the conversation analysis is based on a relatively small sample size of video-recorded consultations, which, while providing detailed insights into the nuances of clinical communication, limits the ability to generalise those findings. Moreover, the awareness of being recorded may have altered both clinician and patient behaviour, potentially influencing the natural dynamics of the consultation. Future research would benefit from larger datasets and a more representative sample of clinical interactions to solidify the conclusions drawn from these analyses. This study aimed to do an exploratory analysis of using the 'how are you' in consultations about PPS/FDs, as it was the first study to do so. Therefore, laying the groundwork for the future research to design a more comprehensive study.

Another limitation is that while the thesis offers a comprehensive framework for reducing stigma, it does not provide extensive empirical validation of the proposed interventions. Study 5 introduces an actionable framework for reducing stigma and fostering social cohesion, but further testing and validation of this framework in clinical settings is necessary to assess its real-world effectiveness. While the conceptual framework is robust, the absence of empirical testing means that its practical implementation and long-term outcomes remain speculative.

Finally, the thesis is largely focused on individual-level interventions within clinical encounters, such as improving clinician-patient communication and reducing stigma through better interpersonal relationships. However, systemic and structural factors, such as broader healthcare policies, resource allocation, and institutional biases, were not the primary focus of the research. Addressing these macro-level factors is crucial for achieving sustainable change in reducing stigmatisation in healthcare and improving the treatment of patients with PPS/FDs. Future research should explore how the proposed framework could be integrated into institutional policies and medical education to drive systemic change.

9.5 Future Research Directions Based on the findings of this PhD

9.5.1 Stigmatisation, trauma, and (re)traumatisation in healthcare consultations

One of the key findings from Study 3 is the potential link between patients with PPS/FDs and their experiences of stigmatisation in clinical consultations and the symptoms of (re)traumatisation that this stigmatisation has brought. Moving forward, research should delve deeper into how iatrogenic harm—damage caused by medical interactions or interventions—and epistemic injustice contribute to trauma symptoms in marginalised patients. Since many individuals with PPS/FDs experience invalidation of their symptoms in clinical settings, repeated stigmatisation may not only exacerbate existing trauma or other mental health difficulties, but also create new traumatic experiences. Future studies could examine how this (re)traumatisation impacts patients both psychologically and behaviourally, potentially leading to healthcare avoidance, heightened anxiety, or growing distrust in the healthcare system. Furthermore, it is crucial to explore how patients with intersecting vulnerabilities—such as those related to race, gender, sexuality, ethnicity, or socio-economic status—are particularly at risk for iatrogenic harm and (re)traumatisation. This direction of research could focus on highlighting the need for more inclusive and trauma-informed care in clinical teaching and practice regarding PPS/FDs.

9.5.2 Body-mind dualism in medical education and practice

The body-mind dualism prevalent in medicine is likely to have contributed significantly to the stigmatisation of conditions like PPS/FDs. This might be partially due to over reliance of scientific advances of bio-medical tests and imaging methodology which detect robust structural changes but the detection of functional dysfunctions is still developing

(Roenneberg et al., 2019). This means that bothersome physical symptoms that are not verified by examinations or other means of validation are more prone to be dismissed as not very serious. This can be traced back to dualistic thinking that separates the mind and body, leading to the devaluation of conditions that lack a clear physical or organic cause (Löwe et al., 2022; Löwe et al., 2024). Future research should aim to challenge this outdated paradigm by investigating how medical education can be reformed to adopt a more integrated, holistic understanding of the body-mind relationship. There is increasing evidence that designing non-dualistic personalised explanations are an effective approach (Saunders et al., 2024).

Emerging research in fields like neuroscience (Palmer, 2019), functional disorders (Kozlowska et al., 2023), and embodied cognition (Fischer, 2024) are already showing that the human body and mind are deeply interconnected. Future research could build on these findings to design curricula for medical students that emphasise this complexity. It would benefit the more complex needs of chronic conditions and the needs that aging population has, as this requires from medicine to provide more personalised care. There are already advances being made in countries such as the Netherlands and Denmark where the medical curriculum includes PPS/FDs. Synthesising the experiences of other countries in tackling those issues, would give the opportunity to investigate the impact of educational reforms that incorporate a more complex biopsychosocial model of health, which views physical, psychological, and social factors as interconnected. This would involve reshaping not only the teaching of PPS/FDs but would also benefit for students learn to understand all medical conditions in a more integrated way. Long-term studies could track how changes in medical education impact the ways future clinicians treat patients with PPS/FDs and whether it reduces stigmatisation and improves their health trajectory.

A recent review (Nagel et al., 2024) highlighted that there was a widespread lack of teaching about PPS. They found that: educators and learners viewing the topic as awkward, learners feeling that there was no science behind the symptoms, and the topic being overlooked in the taught curriculum. The gap between the taught curriculum and learners' experiences in practice was addressed through informal sources and this risked stigmatising attitude towards sufferers of PPS. Future research should focus on closing down the epistemic incongruence when teaching PPS/FDs, focusing on finding ways to provide medical students training that would prepare them for clinical reality. This in turn could help to reduce stigma amongst clinicians regarding PPS/FDs.

Further research could also explore institutional barriers to implementing this paradigm shift within healthcare systems. Investigating how systemic hierarchies of medical knowledge—which prioritise biomedical explanations over more holistic ones—can be restructured. Would this lead to broader changes in medical practice and help to improve the treatment that patients with PPS/FDs experience?

9.5.3 The ambiguity of common clinical phrases

Building on the findings from Study 4, future research should delve deeper into how seemingly neutral conversational phrases, that is commonly used to initiate the clinical consultation "How are you" can contribute to the negative patients' experiences in medical settings, particularly for patients with conditions like PPS/FDs. The results suggest that the ambiguity in this phrase might leave the patients uncertain of what kind of a response if expected of them. This research could use conversation analysis to examine how both patients and clinicians navigate these micro-level interactions.

Future studies could analyse a larger set of doctor-patient interactions to identify patterns of ambiguity and how these affect patients' abilities to communicate their symptoms effectively. Expanding the scope beyond simple greeting phrases, research could examine other areas of clinical talk that might unintentionally reinforce power dynamics or patient silencing, such as closing statements, diagnostic language, or the way clinicians respond to patient narratives. This could lead to the development of communication strategies that reduce ambiguity in already difficult medical consultation.

9.5.4 Shifting the paradigm from anti-stigma to promoting social cohesion and therapeutic alliance

In Study 5, it was proposed to move away from the negative framing of "anti-stigma" in interventions that aim to promote stigma reduction. Instead, the case was made that it would be useful for stigma research to shift the research direction to reflect its aims and goals, which are promoting social cohesion and therapeutic alliance. The research could explore the underlying values that emphasise building positive, inclusive relationships between clinicians and patients, rather than focusing solely on reducing stigma. As stigmatisation is different across conditions, and reflects culture and times, the knowledge of why and what carries stigma for specific conditions is crucial to include. But the future research should explore how this paradigm shift could be practically implemented in clinical settings.

9.6 Conclusion

Stigma in consultations for PPS/FDs is ubiquitous and appears to be structural in nature. It exacerbates negative patient experiences, contributing to a cycle of (re)trauma and poor health outcomes. This research has produced frameworks for both recognising and reducing or avoiding stigmatisation in these consultations. It offers a number of ways forward to employ clearer communication strategies and trauma-informed care, in order to improve patients' experience.

Reflections

The journey through my PhD has been transformative, not only as an academic endeavour but also as a period of significant personal and professional growth.

With a foundation in experimental psychology and later experience as a clinical psychologist treating complex mental health conditions, I entered this PhD with a unique perspective. My lived experience with chronic pain, alongside my work treating PPS/FDs in the university hospital, had already made it clear that many aspects of current clinical practice are not effective for both patients and clinicians. This PhD has allowed me to explore these issues from a fresh perspective, shifting my focus from an individual-level concerns to a more nuanced understanding of how sociological factors and individual (dys)functions intertwine. This new perspective will profoundly shape my future practice as a clinical psychologist, influencing the way I treat patients, collaborate with healthcare professionals, teach, and conduct research.

Throughout this journey, I have also gained a deep appreciation for qualitative research. I have learned to analyse disparate fields, synthesising knowledge to create conceptual and actionable frameworks. This process has sharpened my ability to identify commonalities and emerging themes in research data and to conceptualise these insights into broader, more abstract ideas. I have also developed the skill to select relevant methodologies to address complex research questions—skills I previously lacked, such as conversation analysis, which I now recognise as a valuable tool. My appreciation for qualitative methodologies has deepened, as they provide critical insights into understanding complex, multifaceted problems.

Managing the PhD project has been both challenging and rewarding. From designing studies, writing research papers, and presenting at conferences to collaborating with international colleagues, handling project finances, and navigating ethics applications, this experience has greatly enhanced my research management skills.

I consider myself incredibly fortunate to have been part of the ETUDE program. Working alongside such talented and hardworking individuals from diverse backgrounds has broadened my perspective and enriched my understanding of the key research and clinical issues that require attention. While my supervisors provided invaluable guidance, I learned the most from my fellow ESRs. Their varied perspectives and experiences have significantly contributed to my growth as a researcher.

This PhD has already reshaped how I approach both research and clinical practice, and I am eager to continue building on these foundations as I move forward in my career.

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