

**Understanding The Unexplained: Healthcare Professionals’
Attitudes Towards and Understanding of Medically
Unexplained Symptoms**

Thesis submitted in part fulfillment of the degree of
Doctorate in Clinical Psychology
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Declaration

I confirm that this thesis is my own original work. It has been written for and is being submitted in part-fulfilment of the degree of Doctorate in Clinical Psychology (DClinPsy). No part of this work has been submitted for any other academic award or been submitted elsewhere. It has been checked for errors and for completion prior to submission.

Understanding The Unexplained: Healthcare Professionals' Attitudes Towards and Understanding of Medically Unexplained Symptoms

Sanaa Kadir

Thesis Abstract

Systematic Literature Review

The literature review explored why healthcare professionals have negative attitudes towards patients with Medically Unexplained Symptoms (MUS) and how these attitudes developed. Six databases were searched and twelve papers were found. A meta-ethnography approach was used to synthesise the papers and draw overarching understandings. All of the papers researched medical doctors in Europe. The synthesis revealed that a *lack of training* contributed to negative attitudes. The *attribution of symptoms* impacted attitudes. The *doctor-patient relationship* was found to be a key mediating factor for attitudes. Professionals also had to manage their own *emotional reactions to MUS presentations*. The review suggests that negative attitudes may reflect the difficulty for professionals in working with the MUS presentation. Further education and support is required.

Empirical Research Project

Research suggests that culture can impact the presentation of symptoms and engagement with psychological services. However, how culture impacts this specifically within the context of Medically Unexplained Symptoms (MUS) is not known. Twenty psychologists took part in semi-structured interviews to explore this. The transcripts were analysed using Thematic Analysis. *Cultural identity and sense-making* was an overarching theme which noted the impact of cultural narratives, faith and spirituality, and intersectionality on the explanations of MUS. *Systemic barriers to access* were found to be related to family narratives, stigma and institutional discrimination. The link between *mental health and MUS* was emphasised, with the link between mind and body and the cycle of poor mental health being contributing factors. Earlier psychological intervention and co-construction of meaning were noted as key in *improving the patient journey*. It was clear that culture needed to be considered within MUS to improve patient outcomes.

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I would like to dedicate this to my Dad and Grandma. I miss you both so much. The love and support you gave me helps me through each day. I wish you could have been here to see me achieve this. Without you, I would not be where I am today. Thank you.

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*** Denotes mandatory appendices**

Addenda

Anonymised transcripts of each interview submitted in a separate document¹

¹ Participants have been assigned participant numbers to ensure confidentiality, and identifiable information has been changed or removed.

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Chapter One: Systematic Literature Review

**Why They Are '*Difficult*': A meta-synthesis of doctors'
attitudes towards patients with MUS**

Abstract

Background/Aims: Medically Unexplained Symptoms (MUS) are a frequent presentation within healthcare services, yet there are few guidelines for professionals on how to manage it. Healthcare professionals often view patients presenting with MUS negatively. Previous research has begun to explore these attitudes, but how and why they have developed is unclear. Thus, this review aimed to explore healthcare professionals' attitudes towards patients with MUS, examine differences in attitudes and how they developed.

Method: The PICO search strategy was utilised to define the relevant terms, which were applied to six databases. Initially, this produced 1247 papers but only twelve remained after the application of the exclusion criteria. Quality appraisal and data extraction occurred simultaneously. A meta-ethnography approach was used to synthesise the studies and create overarching understandings from the synthesis.

Results: All studies researched medical doctors in Europe. Four overarching domains were noted. *Lack of education* referred to the absence of formal teaching on medical courses about MUS. *Attributions of symptoms*, either to 'attention-seeking' or manifestation of psychological distress, appeared to influence attitudes. *The doctor-patient relationship* was highlighted as a key factor in managing MUS, however, time and service constraints prevented this. Lastly, *emotional reactions to MUS presentations* considered the common feelings stirred in professionals and this included powerlessness and anxiety. Although, a small minority of professionals felt it was a '*positive challenge*'.

Conclusions: Negative attitudes towards MUS patients were influenced by how doctors attributed symptoms and their emotional reactions. This suggests negative attitudes may reflect the difficulty in working with the MUS presentation. Further training and support is required.

1. Introduction

1.1. What Are Medically Unexplained Symptoms?

Medically Unexplained Symptoms (MUS) is an umbrella term for physical symptoms that cannot be fully explained. The NHS describes MUS as 'persistent physical complaints that don't appear to be symptoms of a medical condition' (NHS, 2018). Generally, MUS encompasses isolated symptoms, symptoms not fitting the 'normal' presentation of physical health problems and established unexplained difficulties, such as chronic fatigue syndrome (CFS). MUS is just one of a number of terms which categorises these symptoms. Others terms include but are not limited to; functional disorder, functional somatic syndromes, bodily distress disorder, somatic symptom disorder, psychosomatic disorder and somatoform disorder. Which term is most appropriate is currently debated and as of yet, researchers and clinicians have been unable to reach a consensus (Burton et al., 2020; Creed et al., 2010). The term MUS is still widely used among healthcare professionals, because some feel that this term does not imply a psychological cause (Guthrie, 2008; Sharpe, 2002). MUS is the preferred term on the NHS website and therefore has been adopted for the purpose of this review (NHS, 2018).

The NHS (2018) definition of MUS states that 'medically unexplained symptoms are common, accounting for up to 45 *per cent* of all GP appointments and half of all new visits to hospital clinics'. Research evidences that the patient² journey is long and difficult, with multiple appointments with numerous professionals before concluding the symptoms are unexplained (Edwards et al., 2010). The pathway generally begins

² The term 'patient' is debated in the literature. As most of the MUS literature comes from physical health settings where 'MUS patients' is most commonly used, this term was adopted in this review for consistency.

by presenting to General Practitioners (GPs) in primary care before being referred on for further investigations, and bouncing between the two.

1.2. Clinical Context

MUS costs healthcare services a disproportionately large amount when compared to explainable medical conditions, due to the number of appointments and investigations (Barsky et al., 2005). Research exploring MUS patient experience consistently cites the patient journey as long and frustrating, exacerbated by not feeling heard or taken seriously by professionals (Chew-Graham et al., 2017). Patients feel that their symptoms are trivialised or explained away because the tests cannot provide conclusive evidence that something is wrong (Edwards et al., 2010). This can lead to anger, anxiety, depression or a combination of these for patients, and result in disengagement from or increased presentations to healthcare services (Stone, 2014).

At times, the number of appointments is judged by healthcare professionals as 'care-seeking behaviour', with negative connotations arising about patient intentions (Desai & Chaturvedi, 2016). This alludes to the negative perceptions healthcare professionals may hold about patients with MUS. But these perceptions appear to be influenced by individual differences. Vijayaprasad et al. (2009) found that professionals with positive attitudes and increased knowledge about MUS spent more time with patients, which led to better outcomes. Hanssen and Rosmalen (2019) asked 112 professionals "what is the first word that comes in your mind when you think about patients with MUS?" 39.8 *per cent* used negative descriptors and the most frequent descriptor was 'difficult'. The authors considered how a negative attitude might impact the ability to provide the best care for patients. Ali et al. (2008) found that 57 *per cent* of GPs believed that patients presenting with MUS had 'personality problems' and held negative perceptions about them. Although this

research identified the negative attitudes, they did not explore why healthcare professionals held these attitudes or how these attitudes developed.

The studies all recommended further education and training for healthcare professionals about MUS to improve the patient experience but did not explain what was required or how this would help. Some research suggests that training to create a safe, therapeutic environment can improve MUS patients feeling heard and consequently improve the patient journey (Hartman et al., 2018). However, how achievable this may be when professionals hold negative attitudes towards these patients is questionable. Epstein et al. (2006) felt that further exploring the interaction between professionals and poor clinical outcomes was required to understand the role of mutual distrust between patient and professional.

Healthcare professionals routinely working with MUS can experience burnout and exhaustion (Edwards et al., 2010; Stone, 2014). Perhaps this correlates with MUS patients being '*difficult*' (Ali et al., 2008). However, it is unclear what makes MUS patients '*difficult*', how this contributes to burnout and why some professionals hold these attitudes and others do not. Previous research has not yet explored this, despite the suggestion that MUS presentations can lead to burnout. The majority of research has focused on GPs, perhaps due to high presentations of MUS within primary care. Although the research calls for further training, it is unclear how significantly this could change attitudes without understanding their origins.

1.3. Frameworks of Understanding MUS

Healthcare systems in the UK and other European countries are dominated by biomedical explanations of difficulties. Thus, MUS is also understood through this framework. GPs are therefore the first line of service for patients and, understandably, they generally approach this from a biomedical perspective.

However, some argue that this perspective struggles to adequately explain MUS, leading to an epistemological incongruence with potentially negative outcomes for both patient and professional (Johansen & Risor, 2017). For example, the Royal College of Psychiatrists (2015) suggest that antidepressants should be the first line of treatment for MUS followed by talking treatments, yet this does not fit the biomedical approach that would generally prioritise the treatment of physical symptoms. It suggests the biomedical framework does not provide an adequate understanding of MUS. This in turn can limit the range of interventions that healthcare professionals privileging this approach can use. In addition, some patients oppose psychiatric medication or referrals to mental health services as they see this as blaming them and that their symptoms are not being taken seriously (Kanaan, 2018). This therefore relies on professionals to sensitively consider other models with patients in order to remove barriers to patients accessing the appropriate care (IAPT, 2014).

The conceptualisation of MUS has changed across time. Initially, MUS was understood as an organic physical disorder where the underlying cause had not yet been discovered. However, with time there has been recognition that some symptoms could not be explained. In the 1900s, the concept of somatisation was widely adopted to explain MUS, suggesting that the symptoms were a manifestation of mental health difficulties (Guthrie, 2008; Hotopf et al., 1998; Sharpe & Carson, 2001). However, in the 2000s research found that there was little evidence that somatisation could exclusively explain MUS, despite psychological distress contributing to the development and maintenance of the symptoms (Guthrie, 2008). This also aligned with organisational changes within the healthcare system in the UK where many patients previously managed under secondary care services were now being held in primary care (Guthrie, 2008). As a result of these changes in understanding, the focus changed from treatment of the symptoms to symptom

management. This emphasised the doctor-patient relationship and the ability for professionals to sensitively explain, normalise, empower and empathise with patients (Guthrie, 2008; Priory Group, 2020). However, it is unclear how widespread the adoption and implementation of this focus on the doctor-patient relationship has been, with some professionals still privileging the biomedical framework or the theory of somatisation. More recently, reattribution training, which considers psychosocial explanations of MUS, has been provided to some GPs in the UK with the aim to reframe symptoms and improve attitudes (Morriss et al., 2006). This has developed a more supportive and facilitative doctor-patient relationship (Gask et al., 2011). However, uptake and engagement with this has been variable (van Ravesteijn et al., 2008).

The professional-patient relationship therefore appears to be impacted by the professional's conceptualisation of the difficulties. Cognitive appraisal models such as the Self-Regulation Model (SRM), also known as the common sense model of self-regulation (Leventhal et al., 1984), have provided another framework for healthcare professionals to understand symptoms and patient behaviour (Benyamini & Karademas, 2019). The SRM can also be used to understand the behaviour of patients with unexplained conditions. SRM suggests that a patient's cognitive representation of their illness, personal perceptions and goals guide their coping behaviours (Fiske & Taylor, 1991; Leventhal et al., 1984). This model suggests that individuals actively monitor and adapt their behaviour over time to progress towards their goal, which may be to manage their illness and reduce the negative emotions associated with it (Cameron & Moss-Morris, 2010; Fiske & Taylor, 1991). SRM goes further than other cognitive models by suggesting that alongside the cognitive processing, there is a simultaneous and inter-related emotional processing (Cameron & Jago, 2008; Figure 1).

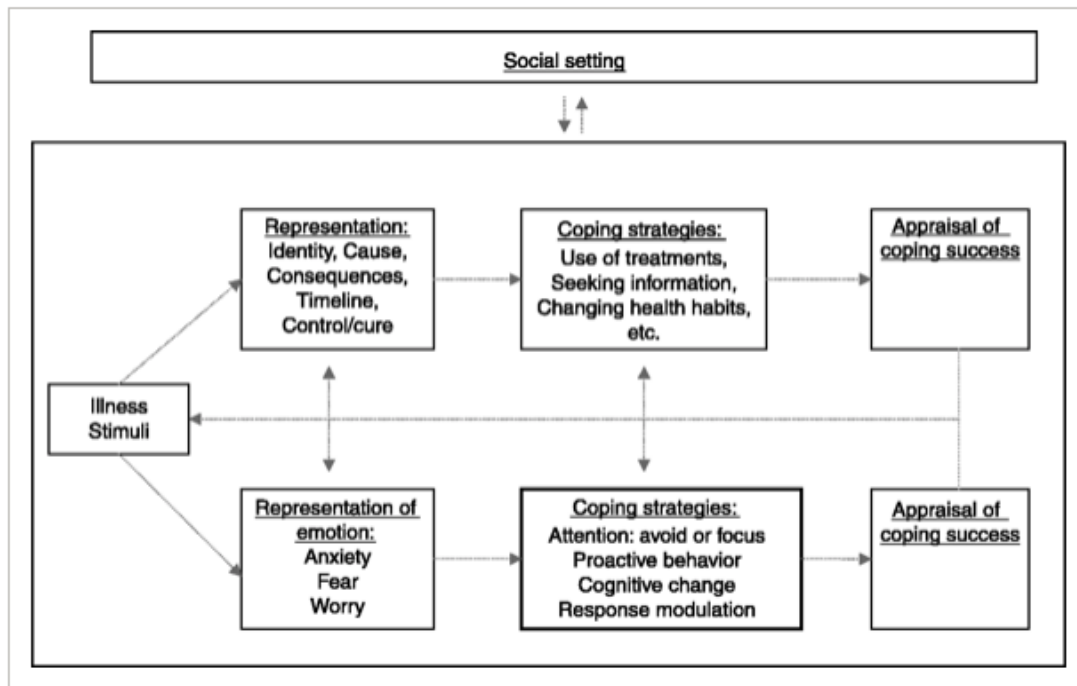


Figure 1. Visual representation of the Self-Regulation Model

Applying this model to patients with MUS, the goal may be to find the cause of their symptoms, with a high level of urgency due to the impact the symptoms have on quality of life and the level of distress they cause. Their behaviour may then be to meet with healthcare professionals to simultaneously seek the answers to their symptoms and relief from their symptoms. Yet, healthcare professionals may perceive these intentions and behaviours negatively. This may be furthered by the implicit bias of grouping patients with MUS and judging them by existing normative standards (Hernandez et al., 2012). These negative attitudes can be further exacerbated by a dissonance for both patient and professional, with neither feeling their needs have been met through repeated healthcare appointments (Hernandez et al., 2012). This link has not been explicitly explored previously, particularly in relation to MUS. The aim of this review is to better understand how and why healthcare professionals hold negative attitudes towards patients with MUS, and understand if perceived patient intention impacts these prevailing attitudes.

1.4. Previous Reviews

Reviews on MUS and healthcare professionals generally focus on medical doctors and treatment options or explanatory models (Gask et al., 2011; Heijmans et al., 2011; van Ravenzwaaij et al., 2010). Few have explored the link between a healthcare professional's approach and the outcome for their patients.

The review by Edwards et al. (2010) explored the treatment options for doctors treating patients with MUS. Within this, they concluded that patient-centred approaches that were attentive to individual biopsychosocial needs were required. They felt that careful assessment would identify appropriate treatments. The way in which the biopsychosocial needs were to be attended to was not detailed.

Johansen and Risor (2017) undertook a meta-synthesis to explore the 'problem' with MUS for GPs. They found an epistemological incongruence between the dominant biomedical model of understanding difficulties and the patient's perspective. They found both GPs and patients experienced negativity as a result of the application of this model. Yet, when GPs focused on the doctor-patient relationship, both perceived outcomes that were more positive.

Salmon (2007) explored how communication problems characterised doctors' consultations about MUS. He found a conflict between the patient's authority on their symptoms and the professional's authority on physical health. He suggested that consultation outcomes therefore relied on power-play. This showed the variability in support patients might receive, dependent on their healthcare professional's view of them and their difficulties.

These reviews suggest that professionals play a large part in the patient experience and outcome for MUS. They allude to negative attitudes and the difficulties experienced by patients and professionals, yet, why professionals hold these attitudes and how they developed requires further exploration.

1.5. Rationale for Current Review

Research has begun to explore doctors' attitudes towards patients with MUS, and generally found negative attitudes. However to date, a synthesis of the literature to better understand these attitudes has not been conducted nor to explore other healthcare professionals' attitudes. Without this, identifying potential differences between attitudes and how they developed is not possible. This review therefore aims to draw together the literature in a meta-ethnography to better understand the prevailing attitudes of professionals towards patients with MUS.

Thus, this review aimed to explore healthcare professionals' attitudes towards adult patients presenting with MUS. It hoped to examine differences in attitudes and how they developed.

2. Method

2.1. Epistemological Position

A critical realist position was taken (McEvoy & Richards, 2006; please see Appendix A for further detail).

2.2. Methodological Framework

A meta-ethnography framework was considered the best fit for this review (Noblit & Hare, 1998). A meta-ethnography not only compares and contrasts studies, but also synthesises them to develop an overarching understanding of the concept (Cahill et al., 2018; France et al., 2016). This can provide new conceptual understandings of the topic (Allen, 2017). Atkins et al. (2008) updated the recommendations of a meta-ethnography and these were utilised in this review (Table 1). Atkins et al. (2008) suggested that despite being a useful methodology, the initial process of a meta-ethnography (Noblit & Hare, 1998) remained ill defined. Through undertaking a meta-ethnography approach themselves, they reflected on the difficulties of the process and lack of clarity. They therefore added further clarity to the process of each step to ensure a more thorough synthesis and more clarity for the reader to understand the process that was undertaken. Therefore, this revised process was adopted for this review.

Table 1. Atkins et al. (2008)'s process for completing a meta-ethnography

Seven Step Meta-Ethnography Process		
1	Getting started	What is the research question?
2	Deciding what is relevant	Focus of the review, inclusion criteria, quality appraisal tool
3	Reading the studies	Using quality appraisal and data extraction to become familiar with the studies
4	How are the studies related?	Themes from the study are compared and contrasted against other studies
5	Translating the studies	Organising the studies in similarities and contrasting features

6	Synthesising translations	Bringing the themes into overarching understandings
7	Expressing the synthesis	Clinical applications and recommendations from the synthesis

Schutz (1971) distinguished between participants' understandings (first-order interpretations) and authors' interpretations of these (second-order interpretations) to support the development of overarching understandings. This was adopted in this review. The meta-ethnography approach was considered from the outset and guided the conduction of the review, allowing an inductive and interpretive approach.

2.3. Search Strategy

The PICO search strategy (Schardt et al., 2007) was used to focus the question and define the search terms. Patient was defined as adults with MUS, Intervention was contact with healthcare professionals, Comparison was differences in professionals' attitudes towards those with MUS and Outcome was understanding how and why these attitudes developed.

Six databases were initially searched between the 7th August 2020 and 22nd August 2020, and again on the 7th January 2021: PsycINFO; Scopus; Medline; Web of Science; CINAHL³; and AMED⁴. These databases allowed access to literature from a breadth of professional backgrounds. The search terms "medically unexplained symptoms or MUS" AND "healthcare professionals or healthcare workers or healthcare providers or physician or nurse or doctor" AND "attitudes or perceptions or opinions or thoughts or feelings or beliefs" were entered into each database. A variety of different search terms were initially inputted into the databases in order to elicit more results and explore the most appropriate search terms. Search terms such as "allied health professionals" and "Psychologists" were among some of the other

³ Cumulative Index of Nursing and Allied Health Literature

⁴ Allied and Complementary Medicine Database

search variations attempted to broaden the results found, however, these returned no results. This could have been due to differences in indexing across the databases (please see Appendix B). Thus, the search terms used within this review were the terms that returned the most papers relevant to the review aims.

2.4. Article Selection

The search produced 1247 papers across the databases. Initial inclusion criteria included only using papers published from 2000 until present. This reflected the shift in the understanding of MUS as more complex than somatisation in the early 2000s, and how treatment approaches reflected this understanding and treatment of MUS in the early 2000s (Guthrie, 2008; Sharpe & Carson, 2001). It was felt that the change in conceptualisation and increased management within primary care services might elicit differing attitudes to when previous conceptualisations were being adopted. It also supported the exploration of whether these changes in conceptualisation were being seen in practice. Only papers written in English or with an English translation were included, leaving 1152 papers. The titles and abstracts of each of these were examined against the review question. The full texts of the remaining articles were then examined against the inclusion criteria (Appendix C), leaving 71 papers. Duplicates were removed from within and across databases, leaving 12 studies. The process is depicted in the PRISMA flow diagram (Figure 1; Moher et al., 2010).

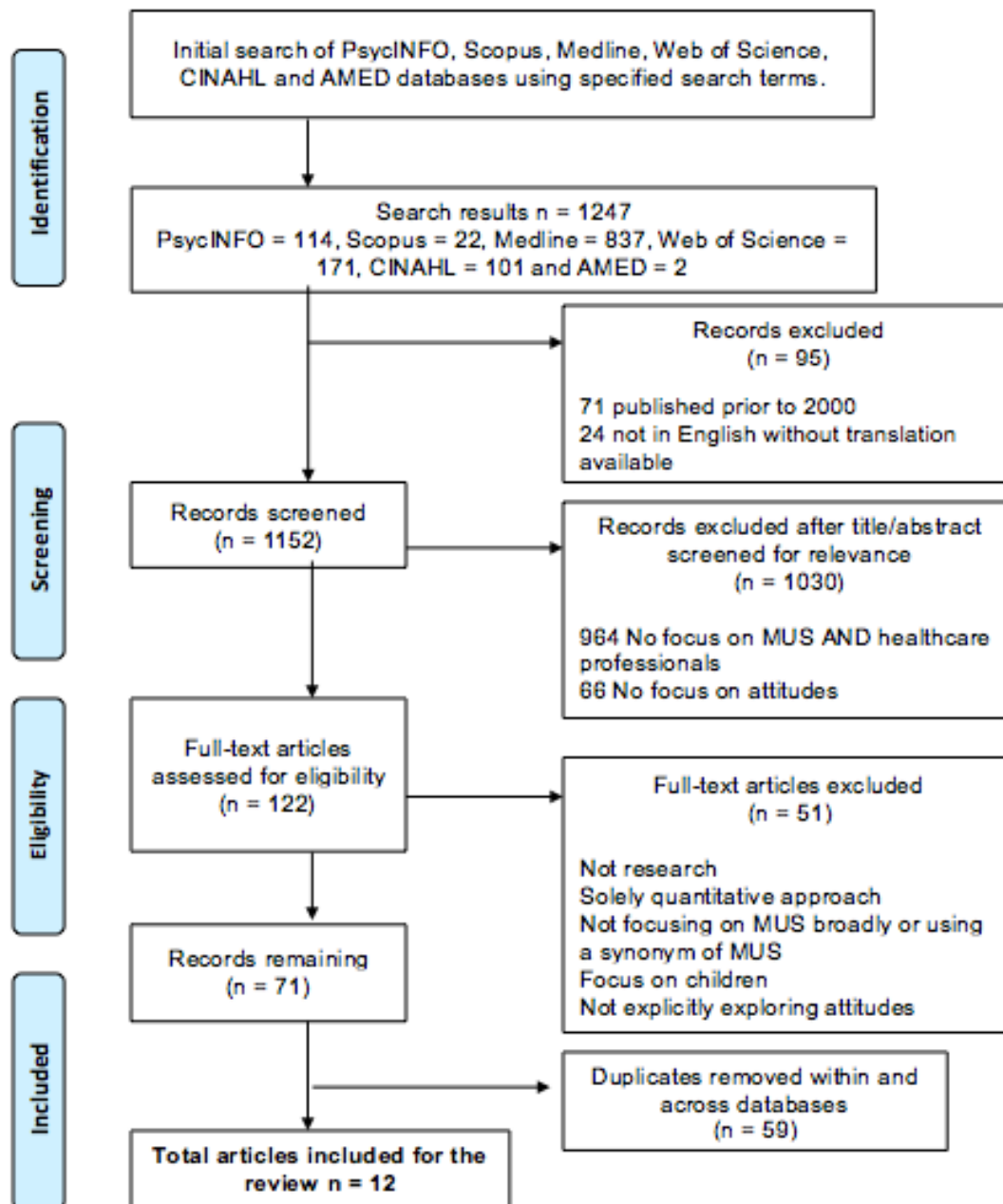


Figure 2. PRISMA Flowchart

2.4.1. Inclusion and Exclusion Criteria

MUS was defined as ‘persistent physical complaints that don’t appear to be symptoms of a medical condition’ (NHS, 2018) within this review. Studies that explored healthcare professionals’ attitudes towards adult patients with MUS were being sought. The exclusion criteria applied included papers that were not research; studies adopting synonyms of MUS; studies that did not focus on MUS broadly;

studies researching children; and studies adopting a quantitative approach (please see Appendix C for further detail).

2.5. Quality Appraisal

Peer-reviewed articles were used in this literature review. A decision was made to exclude grey literature from the review as, at times, grey literature can be lower in quality. It was felt therefore that including grey literature could have impacted the overall synthesis of the review and the quality of the conclusions drawn. However, grey literature was used to inform the introduction and discussion within the review. Walsh and Downe (2005) state it is crucial to judge the quality of studies, particularly because this varies considerably between qualitative studies. Sandelowski et al. (1997) argue that quality analysis is a subjective critique. Thus in this review, quality appraisal was used to compare and appropriately delineate the weight of the studies rather than to exclude (Walsh & Downe, 2005).

No quality appraisal tool was identified from previous MUS reviews. The ten-point CASP Qualitative research checklist (Critical Appraisal Skills Programme, 2018; Appendix D) was deemed most appropriate for this review. This focuses on validity, appropriateness of the methodology adopted and clinical applicability. The tool can also incorporate varied qualitative methodologies. A 'traffic-light system' was implemented which correlated with the study's CASP quality score. Good quality was represented by green, fair by amber and poor by red. Nine studies were deemed good quality and three fair (please see Appendix E).

2.6. Data Extraction

The Centre for Reviews and Dissemination (2008) suggests that data extraction forms must vary between reviews to be tailored to the research question, particularly within qualitative research. They state that data extraction supports quality

assessments and allows immersion into the data. Thus, quality appraisal and data extraction were completed simultaneously in this review.

Some recommend that standard extraction tools should be adapted to capture salient elements of each study and identify similarities, differences and overarching concepts within the data (Munro et al., 2007; Noyes & Lewin, 2011; Sandelowski et al., 1997). Thus, the data extraction form developed by Munro et al. (2007) was adapted for this review (please see Appendix F). This tool was chosen as it aligned with the meta-ethnography approach and adopted the distinction between first- and second-order constructs (Schutz, 1971). Therefore, participants' quotes were extracted separately to the authors' interpretations of these, with comparisons made within and across studies. This method of analysis informed the creation of overarching constructs (third-order interpretations) of the results (please see Appendix G).

3. Results

3.1. Overview of Studies

This review synthesised the literature to examine healthcare professionals' attitudes towards patients presenting with MUS, explore differences in attitudes and how these may have developed. Twelve studies were included (Table 2).

Table 2. Overview of studies included in this review

Author(s)	Year	Country	Aim	Participants				Method	Quality Appraisal
				Service	Sample Size	Title	Speciality		
Czachowski et al.	2011	Poland	Establish what challenges Polish GPs encounter while dealing with patients with MUS	Primary Care	14	GP	General Practice	Focus Groups	Green
Dowrick et al.	2008	England	Explore practitioners' views on patients with MUS, and the value and barriers to implementing reattribution in practice	Primary Care	24	GP	General Practice	Interviews	Amber
Ivetić et al.	2013	Slovenia	Determine the views of Slovenian family medical physicians on MUS and explore potential treatment options	Primary Care	15	Family Physicians (GPs)	General Practice	Focus Groups	Green
Maatz et al.	2016	England	Explore secondary care specialists' experiences with and attitudes towards patients with MUS	Secondary Care	17	Consultants / 1 Senior Registrar	Gastroenterology, Pain, Respiratory, Surgery, Cardiology, Geriatrics, Rheumatology	Interviews	Green
Mik-Meyer & Obling	2012	Denmark	Gain a deeper insight into how GPs classify and recognise patients with MUS	Primary Care	21	GP	General Practice	Interviews	Green
Ringsberg & Krantz	2006	Sweden	Explore GPs' perceptions of patients with MUS	Primary Care	27	GP	General Practice	Focus Groups	Green
Salmon et al.	2007	England	Identify how GPs' attitudes to patients with MUS might inhibit their participation with training to improve management	Primary Care	33	GP	General Practice	Interviews	Amber
Shattock et al.	2013	England	Examine medical trainees' beliefs and influences about MUS	NA	43	Medical Trainees	NA	Interviews	Green
Warner et al.	2017	England	Explore the ways in which doctors working in secondary care approach and manage patients with MUS	Secondary Care	20	Consultants / 9 Speciality Trainees	Neurology, Cardiology, Gastroenterology, Rheumatology	Interviews	Green
Wileman et al.	2002	England	Explore GPs' attitudes to the management of patients with MUS in primary care	Primary Care	15	GP	General Practice	Interviews	Amber
Woivalin et al.	2004	Sweden	Explore GPs' perceptions and ways of managing patients with MUS	Primary Care	27	GP	General Practice	Focus Groups	Green
Yon et al.	2015	England	Explore junior doctors' knowledge about and experiences of managing MUS patients	NA	22	Junior Doctors	NA	Interviews	Green

3.1.1. Study Characteristics

All studies adopted either semi-structured interviews or focus groups. All studies researched medical doctors (BMA, 2020) in European countries. Unfortunately, no studies exploring nurses or other healthcare professionals' attitudes were found, which prevented comparison across professionals but allowed some comparison between medical doctors.

Of the 12 studies, two (Shattock et al., 2013; Yon et al., 2015) researched medical trainees and junior doctors, respectively, two studies (Maatz et al., 2016; Warner et al., 2017) explored secondary-care consultants and speciality trainees, and the eight remaining studies researched GPs (Czachowski et al., 2012; Dowrick et al., 2008; Ivetić et al., 2013; Mik-Meyer & Obling, 2012; Ringsberg & Krantz, 2006; Salmon et al., 2007; Wileman et al., 2002; Woivalin et al., 2004).

3.2. General Themes

Negative attitudes towards patients with MUS were seen across all of the studies. This was seen across countries and type of doctor (trainees, GPs, consultants). Common negative descriptors of patients with MUS across the studies included '*difficult*', '*attention-seeking*', and '*frustrating*'. To explore this further, first-order themes (participant quotes) were compared and contrasted with second-order themes (authors' interpretations) across the studies. These were then synthesised into four overarching understandings: lack of education, attribution of symptoms, the doctor-patient relationship and emotional reactions to MUS presentations (Figure 2).

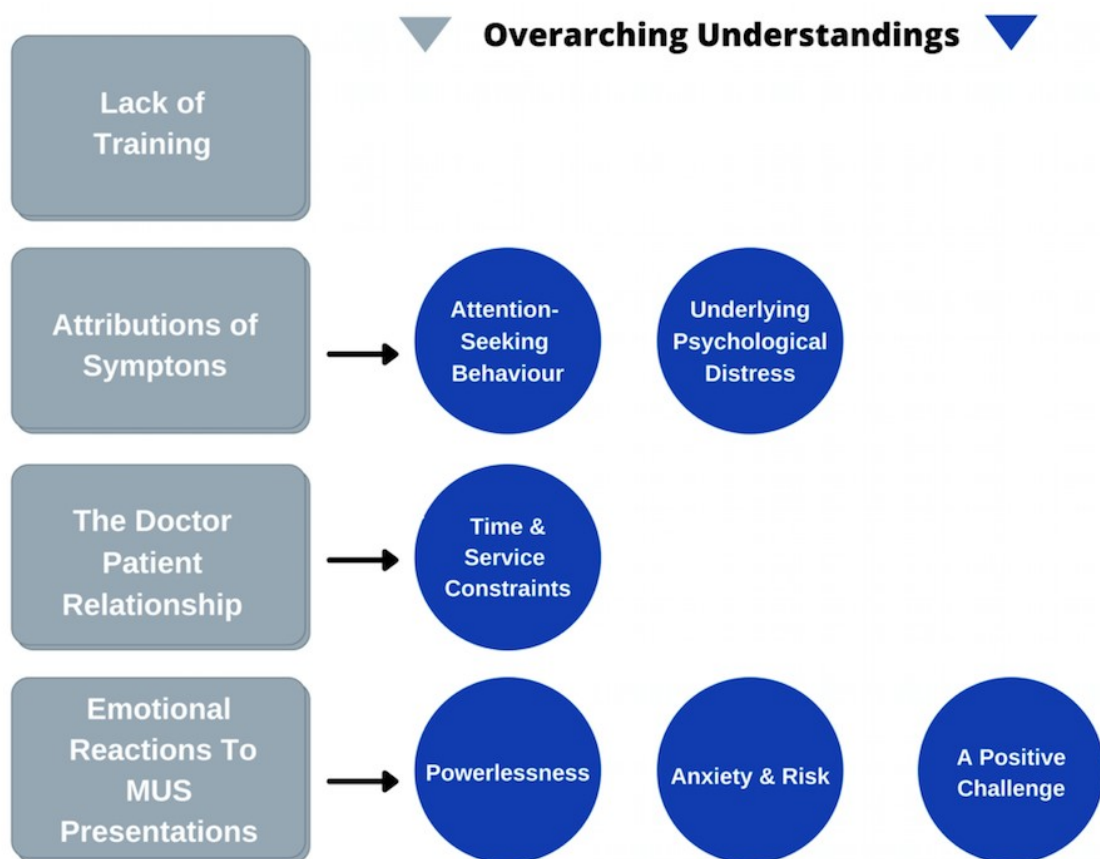


Figure 3. Overarching understandings and subthemes identified in this review

3.3. Overarching Understandings

Domain 1: Lack of Education

Participants in all of the studies, across the countries, commented that they had not received formal education during their medical training about the causes or management of MUS:

‘I don’t think doctors are particularly well trained to deal with that sort of thing’
(Shattock et al., 2013)

Shattock et al. (2013) researched medical trainees and Yon et al. (2015) researched junior doctors’ attitudes towards patients with MUS. Both found that negative attitudes towards the patient group had already developed. They both found that in the absence of formal training, trainees and junior doctors relied upon their seniors to

learn about MUS whilst on placement. Through this, they were exposed to and influenced by the negative attitudes their seniors held. One participant shared:

‘The minute she walked out, the doctor was like ‘She’s making it up!’
(Shattock et al., 2013)

Both studies found that some participants held sympathetic views towards the patient group and felt that formal training on the course would be beneficial:

‘Given that MUS is very common, and actually takes up a heck a lot of resources, I think it’s a good idea [to provide training]’ (Yon et al., 2015)

The lack of training about MUS could represent the unconscious lack of importance this condition may be given by medical trainers, inadvertently influencing or reinforcing negative attitudes.

Czachowski et al. (2011) explored how GPs in Poland managed patients with MUS. They felt that the absence of formal training was a vital factor in doctors developing their individual strategies to manage MUS, creating inconsistency between doctors. However, some of their participants felt that training about MUS would not be helpful due to the wide range of complexities and presentations:

‘We will be acting at our own discretion, in a non-standard way, because in the majority of cases, I think, it will be very difficult to work out such standards’

Yet, when Dowrick et al. (2008) explored the views of GPs who had been offered reattribution training as a method of managing patients with MUS, they found that the

majority of doctors who had participated found the training beneficial as it helped them to reframe the symptoms and adopt a different approach:

‘Because of the training I’ve thought lets just stop and look, what are we actually achieving’

This suggested that despite the varying presentations, training was still beneficial even at a later stage of career trajectory. The authors of all but one of the studies (Mik-Meyer & Obling, 2012) recommended that further education and training about MUS should be provided for doctors, either during training or once qualified.

Domain 2: Attributions of Symptoms

Across the studies, there appeared to be two ways in which the doctors attributed the symptoms of MUS. These could be broadly categorised into attention-seeking behaviour or the manifestation of psychological distress. Differences in these attributions were seen across individual doctors. Some suggested that patients could be grouped into these categories based upon personality characteristics (Mik-Meyer & Obling, 2012), whilst others felt that all patients differed with no personality or demographic characteristics connecting them (Ivetić et al., 2013). Importantly, the explanation the doctor privileged appeared to impact their attitude and, for some, their approach with the patient.

2.1 Attention-Seeking Behaviour

Some participants felt patients were either making up or over-exaggerating their symptoms to achieve hidden agendas.

‘The patient might have gains from their, from their symptoms’ (Dowrick et al., 2008).

The explanations for why the patients were 'attention-seeking' varied across individual participants yet appeared to generally elicit negative attitudes towards patients. For some participants, this understanding was representative of *all* MUS patients:

'The patient who is an attention seeker' (Czachowski et al., 2012)

Whilst, for others, it was certain patients with MUS who may be using doctors to fulfill their agenda. The negative attitudes of patients being '*attention-seeking*' or '*exaggerating*' led some doctors to dismiss patients.

'I've got another young girl who's going off her feet slowly but surely, and there's no reason... And she thinks it's great' (Wileman et al., 2002)

Ringsberg and Krantz (2006) identified stressful situations for GPs when working with MUS patients and their management strategies for these situations. They found that frequently attending patients were seen as less credible and the GP struggled to respond compassionately and mobilise interest in them, which may have perpetuated negative attitudes towards them:

"They simply present a flora of symptoms and they surprise you. You can't see any structure and you think, Oh, God, I have 15 minutes to get out of this"

They also found some GPs showed their negative attitude towards patients as a deliberate strategy to '*extinguish*' behaviour, for example attending without an appointment.

Wileman et al. (2002) explored how GPs managed consultations with patients with MUS. They also found that negative attitudes impacted patient care:

'You can get yourself into the position where you will never spot an illness in this patient if it was staring you in the face and they were dead on the floor, because you will feel it's just their bloody somatising'

They also found that this prevented some GPs from referring onto specialists in fear of reinforcing symptoms:

'What it does give them is a huge audience'

2.2 Underlying Psychological Distress

Another attribution was that the symptoms were physical manifestations of the psychological difficulties patients were experiencing.

'Sometimes it's a way of presenting unhappiness with everything in their life'
(Salmon et al., 2007)

Woivalin et al. (2004) explored how GPs managed patients with MUS. They found GPs used different approaches, switching between them when necessary. Within this, they found that the biomedical approach was limited in sufficiently explaining MUS; therefore, an alternative psychological understanding of distress was needed. When this psychological understanding was privileged, doctors appeared more likely to be sympathetic, believe the patient and want to help.

'Whether [the symptoms] are really actually there, or whether it's a manifestation of some kind of psychiatric disorder or something else, I do think that generally people do suffer from them' (Yon et al., 2015)

Some participants felt that not attributing the symptoms to psychological distress could have a negative impact:

'Medicine's failed them really, and I suppose it would leave them feeling quite lost' (Shattock et al., 2013)

Yet, differences in how psychological distress was conceptualised varied across studies and individual participants, which impacted attitudes towards and treatment of MUS patients. For example, Mik-Meyer and Obling (2012) explored how GPs classified patients with MUS in Denmark. They found that GPs identified a *'fundamental human weakness on both a social and personal level'* in patients with MUS, but this classification allowed them to see the patients as *'legitimate patients'* and treat them. Other participants felt they were not *'best-placed'* to work with these clients, but some felt they could try:

'Equal partners with a common problem, which we will or will not solve. But at least we try to solve it together' (Ivetić et al., 2013)

However, attributing MUS to psychological distress brought its own difficulties. Wileman et al. (2002) explored how GPs managed MUS consultations and found that some patients rejected psychological explanations, as it did not fit with their understanding of their symptoms:

'They just seem to be stuck with the belief that they have something wrong'

Woivalin et al. (2004) also reported this and found GPs were more likely to explore organic causes if the patient adopted a biomedical understanding. This led to a dilemma for doctors who believed the psychological understanding best explained the symptoms but this was rejected by the patient.

Domain 3: The Doctor-Patient Relationship

Regardless of the attitude held or the attribution of the symptoms, all of the studies found that the doctor-patient relationship was key in managing patients with MUS:

‘I think the key is to have a trusting relationship with the patient, that they’re confident, they’re happy that you have their best interests at heart’ (Warner et al., 2017)

Ivetić et al. (2013) created categories for factors influencing MUS consultations with GPs and highlighted the importance of the doctor-patient relationship in managing consultations. They suggested that by equipping professionals with the competencies and tools to have open conversations whilst also coping with the potential emotional demands of working with the patient group was important to improve the doctor-patient relationship. Other studies also found focusing on the doctor-patient relationship could help doctors to better understand and support MUS patients.

‘These patients take time... To treat them properly you need to give them more time than anybody else. You need to develop a relationship with them’ (Warner et al., 2017)

Warner et al. (2017) explored secondary-care consultants and speciality trainees' experiences of MUS and found individual doctors managed the relationship differently. Doctors developed individual techniques to manage and contain these patients, such as acknowledging experiences whilst managing their expectations:

'I'm sure you have that symptom but we can't explain it. What we do know is it's not something worrying or dangerous or life threatening...and it's something that I think we can manage conservatively.'

The approach adopted, however, appeared to be influenced by the attitude towards the patient. For example, participants who saw patients as having agendas were more likely to assert their authority in the relationship:

'But sometimes with patients on these lines...you take more control earlier on in the consultation than otherwise' (Wileman et al., 2002)

3.1 Time and Service Constraints

Despite the acknowledgement of the importance of the doctor-patient relationship in managing this patient group, participants often felt restricted in developing this.

'A difficult group of patients, not easy to deal with [and] unfortunately lack of time and lack of support services' (Maatz et al., 2016)

Ringsberg and Krantz (2006) found that building a good doctor-patient relationship with MUS patients required time, skill and expanding the biomedical approach to consider psychosocial factors. But many participants felt restricted by time, demand and service constraints in developing their relationship and further understanding their patient. Czachowski et al. (2011) explored the challenges Polish GPs

encountered working with patients with MUS. They found that lack of continuity of care and changes to service provision had impacted the doctor-patient relationship and disrupted the patient journey:

'Patients are assigned theoretically to one doctor, but each time they end up with a different person...and here is a failure' (Czachowski et al., 2011)

Domain 4: Emotional Reactions To MUS Presentations

The studies all revealed the emotional impact working with this patient group had on doctors and this could be seen as a contributing factor for the negative attitudes held. Maatz et al. (2016) linguistically analysed the word '*difficult*' in relation to patients with MUS amongst secondary-care consultants. They found that at a surface level, '*difficult*' referred to patient characteristics. But on exploration, this was a projection of the difficult emotions experienced by professionals when working with MUS. This was influenced by the difficulty in managing the presentation.

Across the studies, '*powerlessness*' and '*anxiety*' appeared to be the most frequent emotional reactions to MUS patients, leading to professionals feeling '*emotionally drained*'. Conversely, a minority of participants felt '*positively challenged*'. The emotional reaction that was evoked impacted the way in which the patient was viewed and treated. Individual patients did not appear to influence the emotional reaction experienced. Thus, consistent emotional reactions were seen to all patients with MUS, rather than differing emotional reactions between individual patients. Ivetić et al. (2013) proposed the key to coping with these emotional demands was focusing on the doctor-patient relationship.

4.1 Powerlessness

For some participants, uncertainty about the cause of MUS and a lack of understanding of the patient in front of them led to feelings of powerlessness and incompetence. Ringsberg and Krantz (2006) identified this as '*getting stuck*', which led to uncertainty and helplessness in treating the patient:

'It's just a feeling of uneasiness. It's hard to say why. Because they [patients] are not really a threat to us. But we're not used to not knowing the answer, not knowing what to say.'

Some participants reacted to the feeling of powerlessness by suggesting that they were not '*best-placed*' to work with these patients beyond excluding a physical cause (Warner et al., 2016). Others referred onto other specialist services in hope of answers and to give themselves '*breathing space*' (Ringsberg & Krantz, 2006). Woivalin et al. (2004) found that GPs felt lost if they attributed the symptoms to psychological distress but the patient already had a mental health diagnosis. This caused a lack of understanding about what was going on or how to help. Service pressures and a lack of guidance around the management of MUS added to powerlessness:

'Time pressure is such that you're looking at certain quick fixes, you may not be consciously looking outside the box' (Dowrick et al., 2008)

Salmon et al. (2007) researched GPs who had been offered reattribution training. They suggested that doctors who devalued their psychological skills felt powerlessness due to feelings of incompetence. They concluded that negative attitudes towards patients with MUS might be a coping strategy against the emotional challenge of working with the patient group:

'I do not consider myself to be burdened at all...it remains their problem, I don't take it on board'

Adopting a defensive stance could lead to the avoidance or dismissal of these patients. How the doctor attributed the symptoms did not appear to impact the feeling of powerlessness. However, this attribution did impact how some participants responded to the patient, such as avoidance versus wanting to help.

4.2 Anxiety and Risk

Ringsberg and Krantz (2006) identified the fear of missing a serious diagnosis as a stressful situation for GPs working with MUS:

'So you are afraid that there may be something after all'

The anxiety associated with this meant that doctors ordered more investigations and referrals to specialists. This concern of missing something organic was seen across eight of the studies and was often fuelled by a fear of disciplinary action or litigation:

'You're never criticised for over-diagnosing and inappropriately over-treating patients but you can lose your job for missing a diagnosis, so the whole thing tips completely the wrong way, and not in the patients' favour' (Dowrick et al., 2008)

Woivalin et al. (2004) found participants felt that the biomedical model could not sufficiently explain the symptoms, but would often come back to explore organic causes due to fear of litigation:

'You have to analyse that part first in order to satisfy the disciplinary board'

GPs across the studies felt that referring onto specialist services not only mitigated this risk but also provided them with '*breathing space*'. Ringsberg and Krantz (2006) suggested that this anxiety reduced the more experienced the doctor was, due to the development of an '*instinctive feeling*'. This could suggest that the anxiety associated with working with patients with MUS contributes to the negative attitudes towards them. As Maatz et al. (2016) suggested, these patients might be seen as '*difficult*' due to the additional pressure and stress associated with working with them.

The concern about litigation was seen more frequently in the studies assessing GPs' attitudes than in secondary-care consultants or trainees. Czachowski et al. (2012) suggested that GPs' ten-minute appointment slots contributed to this pressure.

4.3 A Positive Challenge

Maatz et al. (2016) and Warner et al. (2016) found approximately six participants between their studies who enjoyed working with MUS patients. These participants were more experienced secondary-care consultants, who suggested the work was '*rewarding*' and '*a positive challenge*'. Perhaps this related to their level of training and expertise, or '*staying with patients*' on their journey, given that time and service pressures were still experienced.

4. Discussion

4.1. Summary of Findings

A meta-ethnography approach was utilised to synthesise studies exploring healthcare professionals' attitudes towards patients with MUS. Overarching understandings of the results are discussed. The results discussed here are an interpretation of the synthesis. Therefore, the results go further than simply describing the themes identified in the process of synthesis, but are an author's interpretation of the synthesis to seek to understand them in more depth within their context. For example, many of the papers suggested that further training was required for doctors. However, through the synthesis it could be seen that the lack of training contributed to feelings of incompetence, which in turn contributed to the development of negative attitudes towards patients with MUS.

Only studies exploring attitudes of medical doctors in Europe met the inclusion criteria for the review. This review found that generally doctors held negative attitudes towards patients with MUS. This was seen across all countries and types of doctors. However, some doctors across the studies held more sympathetic or positive views. The attribution of the cause of the symptoms (attention-seeking or manifestation of psychological distress), level of experience, engagement in reattribution training and individual differences appeared to be contributing factors for these differences in attitudes. The attitudes appeared to have developed through exposure to senior doctors' attitudes during training, time and service pressures and the emotional reactions experienced when working with patients with MUS. Patients with MUS were often treated as a homogeneous group and individual patient differences contributed less to doctors' attitudes. For many doctors, their attitude impacted their engagement with and treatment of these patients. The importance of

the doctor-patient relationship in managing MUS patients appeared to be a significant factor.

4.2. Findings in Context

These findings are in line with previous literature, which also shows that doctors hold negative attitudes towards patients with MUS (Hanssen & Rosmalen, 2009). Often the patient group is referred to as '*difficult*' (Ali et al., 2008), but it was unclear why. This review suggests that, generally, the difficulty is working with the patient group, not something inherent about the patients themselves. The synthesis suggested that multiple factors might contribute to the perceived increased difficulty of working with this patient group. These may include uncertainty about cause of symptoms due to lack of training, feelings of incompetence and powerlessness, increased sense of jeopardy with regards to litigation, time and service pressures, the dominance of the biomedical model to identify organic causes and patients themselves seeking a biomedical explanation (Maatz et al., 2016). Hence, the negative attitudes towards patients with MUS could be a psychological defence against the emotional reactions they stir, as suggested by Salmon et al. (2007).

The self-regulation model (Leventhal et al., 1984) suggests that behaviour is driven by goals and personal behaviour. Within this review, it could be seen that doctors in the papers also made sense of patient behaviour in terms of patient goals and behaviours. Many doctors in this review appraised patient intention negatively, for example suggesting that repeated appointments were a result of 'care-seeking behaviour' and that patients had something to gain from this. Although this has been theorised, this review found an explicit link between patient intention and healthcare professionals' attitudes. This review found that a negative perception of patient intention contributed to a negative attitude towards the patient. This suggests that

doctors may use cognitive models such as SRM to explain patient behaviour, however may privilege only elements of these rather than the whole model.

Although some doctors focused on individual patient intention and the impact on behaviour, some doctors simultaneously grouped and homogenised patients with MUS. Although this could result in cognitive dissonance for the doctor, this grouping of patients appeared to support clinical decision-making for unexplained symptoms (Hernandez et al., 2012). Particularly for MUS, where the normative diagnostic model cannot be applied, this grouping may support doctors in treating patients (Burgess et al., 2008). However, this grouping can concurrently serve to remove blame from the doctors for not being able to effectively 'treat' the patient, perhaps allowing them as professionals to tolerate the uncertainty. This suggests that the focus on patient intention contributes to the development of negative attitudes towards patients with MUS, and may be a psychological defence against the difficulty in working with the patient group.

This review found that there is a lack of training in the medical curriculum and once qualified about the causes of MUS and management options, and that was a significant contributing factor to the negative attitudes towards patients with MUS. The lack of training and education also appeared to contribute to the emotional toll of working with the MUS presentation and the burnout these professionals experienced (Stone, 2014). Perhaps this is fuelled further by uncertainty and feelings of incompetence, and feeling that the patients have something to gain (SRM; Benyamini & Karademas, 2019). Dealing with patients' emotions whilst concurrently managing their own appears to be a contributing factor to professionals experiencing burnout. Individual differences between doctors in attitudes, attributions and treatment approaches were identified in this review. One could suggest that a lack of formal training contributes to the inconsistent approach to MUS (Woivalin et al.,

2004). The lack of training may also explain why doctors were adopting older understandings of MUS, for example MUS solely being understood as somatisation (Guthrie, 2008), or relying on the biomedical framework to treat the symptoms despite the framework being unable to provide this (Johansen & Risor, 2017). This also supports the finding that treatment of MUS is often contingent on the doctor's appraisal of the difficulties (Salmon, 2007).

Often patients with MUS feel unheard or dismissed (Chew-Graham et al., 2017). Findings from this review suggest that if the doctor felt the patient was attention-seeking, they may be less sympathetic, less likely to attend to their concerns and more often treat them as a homogeneous group and perhaps were more likely to behave in ways that left patients feeling dismissed or unheard. Therefore, the ways in which healthcare professionals appraise patients' symptoms has a clear impact on outcome. Patients reported feeling frustrated with the number of appointments (Edwards et al., 2010), whilst Ivetić et al. (2013) found that some doctors regularly booked in MUS patients to stop them attending unannounced or to give doctors '*breathing space*', perhaps suggesting this is a coping technique used by doctors. This supported the finding by Salmon (2007) about the incongruence in understanding between patient and professional. For doctors with a negative view of the patient, no wonder a mutual distrust can develop (Epstein et al., 2006).

Previous research has shown strong doctor-patient relationships promote better outcomes for patients (Hartman et al., 2018). This review also found this and suggests that this is because the strong relationship enables doctors to develop an understanding of the patient's difficulties, reducing negative attitudes and allowing consideration of the appropriate treatment options (Ivetić et al., 2013). These findings support the review by Johansen and Risor (2017), which concluded that the doctor-patient relationship was more important for treatment outcomes than the cause of

symptoms. Without this relationship and a treatment plan, doctors are more likely to feel powerless and experience anxiety. However, disintegration, fragmentation and service constraints prevent the development of relationships, interrupt continuity of care and perpetuate 'quick-fixes' (Davies, 2007).

4.3. Implications for Practice

This review reveals the impact doctors' attitudes have on the care received by patients with MUS and highlights a lack of understanding about the causes and management of MUS. It suggests that implicit bias and the framework privileged by doctors may influence the development of their attitudes. It emphasises the need for further training in undergraduate medical curriculums, to ensure trainees and qualified doctors are equipped to work with MUS and the uncertainty it brings (Shattock et al., 2013; Yon et al., 2015). Previous research and the papers within this review indicate that further training is required. Perhaps this should be within medical training to equip doctors at the start of their journey to manage presentations of MUS. However, this is seldom found. Joyce et al. (2018) found that negative attitudes and the erroneous assumption that MUS was covered elsewhere contributed to the lack of formal training about MUS on medical courses. Yon et al. (2017) found only 11 *per cent* of UK courses provided formal teaching about MUS, despite most feeling it was important to include. They argued that MUS teaching in medical training should include case studies and role-play supplementing learning about causes and suitable treatment options. Despite these findings and the call for further training, MUS continues to be largely excluded from medical curriculums.

For qualified doctors, opportunities to access reattribution training appears to be an appropriate tool (Salmon et al., 2007; Dowrick et al., 2008). This can support doctors to consider psychosocial approaches whilst reducing pressure to identify an organic cause. Gask et al. (2011) felt that reattribution training improved attitudes towards

MUS which consequently improving the doctor-patient relationship. This review suggests that the doctor-patient relationship is vital for improving outcomes for patients with MUS. Despite being a positive step, Gask et al. (2011) feel that reattribution training is not the whole solution. Thus, further research to understand how best to educate and support qualified doctors is needed.

Furthermore, a clearer patient pathway that identifies appropriate treatment options is needed (olde Hartman et al., 2013). In this review, many doctors attributed MUS to a manifestation of psychological distress. Therefore, earlier referrals to psychological services may be helpful (Edwards et al., 2010; Ringsberg & Krantz, 2006). This could improve the patient journey whilst reducing pressure on doctors, particularly GPs (Kisely & Campbell, 2007). Alternatively, having a multidisciplinary team approach that includes mental health specialists may share the burden of responsibility (Saint-Pierre et al., 2018) and improve access to appropriate services. The BPS (2020) recommends the integration of psychologists into primary care, and preliminary research has found positive outcomes for patients and professionals when this is implemented (Cooper et al., 2017; Durcan, 2020).

Whilst there are clear patient benefits, these approaches may require a significant paradigm shift through integrated working and changed referral pathways (Mitchell et al., 2008). Currently the biomedical model, which dominates European medicine, does not provide an adequate understanding of MUS and an integrated understanding is required (Woivalin et al., 2004). Therefore, doctors may have to move away from the biomedical approach and accept alternative ways of understanding to improve patient outcomes. Yet, this may lead to an epistemological incongruence as the dominant biomedical approach can medicalise psychosocial problems (Edwards et al., 2010; Johansen & Risor, 2017; Woivalin et al., 2004). A

strong doctor-patient relationship may help negotiate this with patients who also prefer to adopt a biomedical approach.

This review found that feeling powerless and fear of litigation increased when doctors worked with patients with MUS. These pressures increased the emotional toll of working with this group, particularly for less experienced doctors (Ringsberg & Krantz, 2006). A reflective practice space upon qualification, particularly for newly qualified doctors, to consider and reflect upon these feelings could be helpful. This space could subsequently improve the doctor-patient relationship and outcomes for both patient and professional (Ivetić et al., 2013; Johansen & Risor, 2017).

4.4. Review Limitations

The review process allowed the synthesis of the results of several papers to create an over-arching understanding of the topic. This felt appropriate for this review as the aim was to better understand how and why attitudes had developed rather than simply synthesising previous studies. These over-arching understandings were developed through independently extracting participants' quotes and authors' interpretations. However, the review process is a subjective process and relies on the author's engagement with the review. Therefore, the conclusions drawn are within the context of the author's subjective synthesis of the papers.

In addition, the review only included a small number of qualitative studies. Thus, conclusions are tentative and generalisability is limited. The number of studies found may have been limited by the inconsistent indexing of qualitative studies, with titles and abstracts varying in precision (Atkins et al., 2008; Cooke et al., 2012). Thus, relevant studies may have been missed. Furthermore, all of the studies were from European countries, therefore limiting the results to a European healthcare context.

The review only found studies looking at experiences of doctors, the majority GPs. This may reflect that most MUS patients are managed in primary care. Many participants stated they referred onto mental health services, yet no empirical research on these professionals' perspectives was found. Perhaps this suggests that the patients were unable to access these services, or that this has simply not been researched. In this review, this meant that cross-professional comparisons could not be drawn. Perhaps including well-known conditions such as CFS under the MUS umbrella could have captured a wider range of healthcare professional' views. Alternatively, using the different terms that also refer to MUS (such as somatoform disorder or functional disorder) may have returned more papers. Due to the small number of studies that met the inclusion criteria, comparisons between types of doctors were limited. Further research exploring differences within and across professional groups is needed to tailor education and training.

A quality appraisal tool was utilised to appropriately weight studies within the review, yet it could only be completed on information in the study. Word limits in journal articles could mean that the quality appraisal did not reflect the quality of the research but whether information was included (Sandelowski & Barroso, 2002).

4.5. Conclusion

This review found that doctors generally held negative attitudes towards patients with MUS. This was partly influenced by their attribution of the symptoms, attention-seeking versus psychological distress, and the emotional reactions they experienced. This review therefore suggests that the negative attitudes towards patients with MUS may reflect doctors' difficulty in managing MUS, rather than something inherent about the patients. It concludes that more training, education and support for doctors is required, both in undergraduate medical curriculums and within ongoing professional development.

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Chapter Two: Empirical Research Report

‘My Back Is Crumbling’: How Culture Influences the Experience of Medically Unexplained Symptoms

Abstract

Background/Aims: Patients with Medically Unexplained Symptoms (MUS) are generally sent to psychological services when an organic cause cannot be found. Research suggests that culture can influence the presentation of symptoms and patients' engagement with services. However, the way in which culture may impact MUS specifically and the unique barriers for those from culturally diverse backgrounds with MUS within psychological services has not been explored. Thus, the study aimed to investigate how culture influences the presentation and explanations of MUS. Furthermore, to consider the impact of culture on psychological treatment and explore specific barriers to access for MUS.

Method: Volunteer psychologists were interviewed. The transcribed audio files were analysed in accordance with Thematic Analysis (Braun & Clarke, 2006).

Results: Four themes were identified. *Cultural identity and sense making* considered how cultural narratives, faith and spirituality, and intersectionality impacted how patients made sense of their symptoms. *Systemic barriers to access* considered how family narratives, stigma and institutional discrimination could prevent patients from culturally diverse backgrounds with MUS from accessing services. *Mental health and MUS* emphasised participants' understandings that physical and mental health could not be separated; suggesting mental health could be a cause of symptoms, the result of symptoms, could perpetuate poor mental health or a combination of these. Lastly, *improving the patient journey* was considered through earlier psychological intervention and co-construction of meaning.

Conclusions: There was a clear impact of culture on meaning making for patients with MUS. Culture impacted this in a number of ways and therefore should be incorporated into treatment approaches. This research highlighted the need for culturally sensitive and person-centred treatment options for patients with MUS to improve patient outcomes.

1. Introduction

1.1. Medically Unexplained Symptoms

Many patients⁵ sit at the interface between physical health and mental health (Minhas & Nizami, 2006). These patients can be diagnostically clustered by umbrella terms such as Medically Unexplained Symptoms (MUS). One definition for MUS is 'physical symptoms that prompt the sufferer to seek healthcare but remain unexplained after an appropriate medical evaluation' (Richardson & Engel, 2004, p.18). Categorising patients with MUS under physical health or psychiatric diagnoses is unsatisfactory as they fit under neither (Sumathipala et al., 2008). The term MUS is therefore purely descriptive and refers only to the lack of objective pathology (Risør, 2009). Currently, no medical or psychological theories can fully account for MUS, leaving both physical and mental health professionals uncertain about its aetiology (Kirmayer, 1999). Hence, the aim is not to 'cure' symptoms, but manage them.

MUS commonly include pain, fatigue, musculoskeletal, and gastrointestinal problems (Kirmayer et al., 2004; Sharpe, 2002). Some established difficulties such as chronic fatigue syndrome (CFS) also fall under MUS. MUS presentations are seen across the population (Kirmayer et al., 2004). Other labels for MUS include functional, psychosomatic or somatoform disorders (Sharpe, 2002); however these can hold negative connotations, such as the patient being attention-seeking (Desai & Chaturvedi, 2016). MUS can significantly impact quality of life, mental health and socio-occupational functioning (Sharma & Manjula, 2013). For children, the consequences can become complex by impacting education (Vijayakumar et al.,

⁵ 'Patient' is a debated term in the literature. Most MUS literature comes from physical health settings where 'MUS patients' is most commonly used, thus this term was adopted for consistency.

2012). Despite this, many patients with MUS feel that their symptoms are not taken seriously and that their experiences are invalidated (JCPMH, 2017).

1.2. Clinical Management of MUS

UK healthcare is dominated by Eurocentric models, which privilege biomedical explanations (Wood & Patel, 2017). Therefore, when patients with MUS initially present to healthcare services they first undergo investigations to ascertain a biological cause of the symptoms as the professionals use the biomedical framework to guide their approach. For other physical health disorders this can provide a clear pathway to support the patient, however, for patients with MUS this approach can reinforce worries about physical causes and contribute to chronic disablement (Knott, 2014). The biomedical approach is limited in its explanation of MUS, and in turn limits the understandings of MUS and how it can be managed (Simon et al., 1996). At times, when an organic physical cause cannot be identified, patients are sent to psychological services to focus on symptom management (Creed et al., 2011; Kirmayer et al., 2004). This can be presented as a 'last resort', can leave patients feeling rejected and cause some to disengage from services (Fink et al., 2011; Greer & Halgin, 2006).

Within psychological services, MUS can be conceptualised by professionals as somatisation, the manifestation of psychological distress by the presentation of physical symptoms (Greer & Halgin, 2006). Generally, patients with MUS believe they are physically ill because they are experiencing and exhibiting physical symptoms (Paterson et al., 2011), and some reject the notion that their symptoms are a somatisation (Greer & Halgin, 2006). Suggesting symptoms are an expression of distress can be stigmatising, invalidating and elicit less sympathetic responses from healthcare professionals, employers and family systems (Weiner et al., 1988). Burbaum et al. (2010) found that patients perceived even subtle suggestions of

somatisation as threatening and 'othering'. Furthermore, recent research has found that understanding MUS as the result of somatisation is reductionist and cannot fully explain the physical symptoms that are being presented (Guthrie, 2008).

Although the concept of somatisation alone cannot explain MUS, the role of psychological distress in maintaining the physical symptoms can nonetheless be seen (Guthrie, 2008). Research has therefore found that psychological interventions, such as cognitive-behavioural therapy (CBT) and psychodynamic approaches, can provide effective MUS management strategies (Abbass et al., 2009; Kroenke, 2007; van Ravesteijn et al., 2014). Therefore, perhaps there is a need to change the way psychological services are introduced into the patient journey (Lidén et al., 2015). Integrating physical and psychological healthcare services for patients with MUS would improve quality of life and access to services, and reduce cost to healthcare services and reduce stigma (Royal College of Psychiatrists et al., 2015). NICE guidelines suggest that patients with MUS should be able to self-refer to psychological therapies via IAPT (Improving Access to Psychological Therapies) and have meaningful choice in their treatment (NICE, 2018). Despite the need, these recommendations are seldom in place.

Thus, the conceptualisation of MUS by healthcare professionals is key in determining the treatment pathway they recommend. Biomedical conceptualisation leads to increased investigations for an organic cause, whilst somatisation conceptualisation leads to interventions related to psychological distress (Sham et al., 1996). Professional knowledge and previous experience may guide the conceptualisation a healthcare professional privileges, even when this is not the most evidence-based approach (Godin et al., 2008; Grol & Wensing, 2004; Hernandez et al., 2012). Professional understanding cannot only impact patient choice but also patient outcomes. McAndrews et al. (2019) completed a meta-analysis and found that

attributing MUS to a psychological cause was related to negative health outcomes and negative emotional coping. Yet Kennedy et al. (2017) found that healthcare professionals often used education to support patients, particularly in understanding psychological causes. This privileged healthcare professional understanding over patient understanding, despite there being no current consensus on the cause of MUS.

Cognitive theories on decision-making highlight the role of cognitive bias. Cognitive reasoning processes in clinical diagnosis can lead to decision-making biases (Korteling et al., 2018). Numerous biases influence decision-making and the delivery of healthcare services and interventions, including cognitive, affective, stereotyping and attributional biases (Featherston et al., 2020). These biases are often implicit, yet can influence professionals to see a patient as part of a homogenous group which can in turn influence their approach and treatment of that patient. This is often seen with patients with MUS (Burgess et al., 2008). It can also lead to confirmation bias where only supporting evidence is acknowledged and conflicting evidence is ignored (Mendel et al., 2011). This may include professionals privileging particular understandings of a concept (Stone & Cooper, 2001). Research from the medical field has shown the impact of these implicit biases on patient care. It has been shown that a patient's race, for example, can impact their treatment (Burgess et al., 2008; Green et al., 2007). Featherston et al. (2020) undertook a scoping review exploring the impact of cognitive biases on decision-making in allied healthcare professionals. They found that biases seriously impacted the quality, accuracy and consistency of decision-making. These biases therefore influence healthcare professional behaviour.

1.3. The Impact of Culture

It has long been recognised that the presentation of symptoms and somatic complaints can be influenced by one's ethnicity, culture and their associated values (Hausteiner-Wiehle et al., 2011; Kirmayer & Young, 1998; Lee 2004). Cultural expressions of distress can normalise similar experiences between people (Migliore, 1997). In the UK, research has found that after accounting for levels of distress or illness, those from a South Asian background were still more likely to present with additional bodily symptoms (Gater et al., 2009), whilst White Europeans were more likely to present with CFS (Hausteiner-Wiehle et al., 2011). Not only does this suggest that presentations may differ, but also that certain cultures may adopt different understandings of their symptoms.

Risør (2009) believed that illness explanations are how individuals perceive their symptoms and make sense of their suffering. Risør believes that multiple explanations can be held at once and that the appraisal of the symptoms can impact the route through which support is sought. This theory is able to explore the way in which cultural beliefs interplay with illness explanations. Within this theory, cultural beliefs can also influence the explanations patients may hold for their MUS. The explanation that is privileged most by the patient may influence their route for support. For example, if MUS is seen as a result of physical health problems, a biomedical explanation may be sought (Sham et al., 1996). Alternatively, if a spiritual discourse is held about the symptoms, healthcare systems may not be accessed. Sumathipala et al. (2008) found that common narratives for MUS in Sri Lanka included: 'a poison has got into my body'; 'because I breastfed my child while another child was watching'; and 'because of chewing betel'. However, they felt that these explanations may be unfamiliar to and disregarded by Western professionals. Again, this may relate to cognitive bias where these cultural explanations do not fit into professionals' usual approach to understanding difficulties and therefore may be rejected, whether explicitly or implicitly. Within the theory of illness explanations, if

the explanation provided by a professional is at odds with a patient's own explanations, this could result in conflict for the patient, which could lead to disengagement from services (Salmon et al., 2004). For example, Röhricht and Elanjithara (2014) found that those from culturally diverse backgrounds⁶ who sought body-based solutions for their MUS found talking therapies less acceptable. This was because the therapy opposed their narrative and joint narratives were not explored. Other Health Psychology models support the illness explanation model and suggest that illness explanations can predict health outcomes (Benyamini & Karademas, 2019). However, this theory may over-emphasise the importance of the explanations. For example, some patients may have malleable illness explanations, hence, they seek out healthcare professionals or others for guidance.

This can be understood within the context of social identity theory (Tajfel & Turner, 1979). This suggests that the groups we identify as belonging to, including cultural and family groups, provide us with an identity and narratives (Tajfel & Turner, 1979). Social categorisation can create 'them' and 'us' distinctions, through which implicit biases and prejudiced views develop (McLeod, 2019). Within MUS, professionals rejecting patients' cultural explanations of their symptoms can deepen the 'them' and 'us' distinction (Sumathipala et al., 2008). Implicit bias amongst healthcare professionals is the same as that of the wider public and can impact clinician-patient interaction (FitzGerald & Hurst, 2017). This theory can help one understand the impact of professionals and patients' holding opposing views on their therapeutic relationship. Particularly within MUS, where an evidence-based explanation cannot be found, these implicit biases may become more prominent. Although the model may be seen as reductionist or simplistic, it can continue to provide a helpful framework to understand how biases may be seen in services. For example,

⁶ Numerous debated terms refer to people from different cultural backgrounds. Within this study, the term 'culturally diverse backgrounds' was adopted due to its inclusive nature.

psychology is influenced by Eurocentric⁷ models that assume that Western norms and practices are more valid than those of non-dominant cultures (Wood & Patel, 2017). Privileging the Western discourse that MUS is an expression of distress does not consider its cultural appropriateness and can silence other cultural discourses.]

1.3.1. Cultural Mistrust of Services

This contributes to the wider sense of mistrust of healthcare services amongst those from culturally diverse backgrounds. Whaley (2001) argues that cultural mistrust is an important psychological construct that professionals must attend to. Western mental health systems can serve as a barrier to access by only providing mainstream services based on Eurocentric models (Amri & Bemak, 2012; Williams et al., 2006). Research suggests that additional barriers can include disregarding faith and spirituality, not addressing the patient's understanding of their illness, not considering expectations of healthcare and overlooking the stigma associated with receiving psychological support (Aggarwal et al., 2016; Amri & Bemak, 2012). Aggarwal et al. (2016) also found that barriers could increase mistrust of services and suggested that professionals could improve treatment participation and outcomes for those from culturally diverse backgrounds in mental health services by incorporating the patient's view of their difficulties, targeting stigma and using tailored language. Sidhu and Begum (2017) found that culturally adapting evidence-based IAPT treatments made them more accessible by addressing gaps in provision and barriers to access. They felt that therapists needed to be sensitive to patients' ethnic, cultural and spiritual beliefs. Vahdaninia et al. (2020) concluded that integrating culturally sensitive mental health services was feasible, improved engagement and improved outcomes.

⁷ Eurocentric refers to the focus on European contexts and narratives to the exclusion of wider worldviews.

Cultural sensitivity becomes increasingly important when symptoms are unexplained. For MUS, when cultural understandings of symptoms are elicited and used in clinical practice, 'Western' therapies could become more applicable (Kleinman & Benson, 2006). Some suggests that therapists could adopt medical pluralism, acknowledging multiple explanatory models, rather than simply privileging the Western biomedical narrative (Green et al., 2006; Yeung & Kam, 2008). However, not all patients may hold multiple explanations. Therapists could also consider wider systemic contexts and influences, such as family narratives (Weisblatt et al., 2011). Burton (2003) suggests that professionals empowering patients to include their own explanations is central to the successful management of MUS.

1.4. Rationale for Current Study

The need for race equality in healthcare has been long recognised (Lau, 2008). Outcomes for patients with MUS are poor if they do not have access to appropriate treatment, and this is amplified for those from culturally diverse backgrounds (JCPMH, 2017; Williams et al., 2006). Research suggests culture can impact presentations and explanations of MUS. Yet, how it impacts these has not been explicitly explored. Currently, there is little understanding of the impact this has on psychological treatment, nor guidance to support therapists. The lack of this research may lead to poorer outcomes for patients (Chaturvedi, 2013). Better understanding these factors is important to improve outcomes for those from culturally diverse backgrounds with MUS. This research hopes to advance this understanding and identify potential barriers in an attempt to inform the development of equitable and culturally competent services (Alexakis et al., 2015).

Thus, the study aimed to investigate how culture influences the presentation and explanations of MUS. Furthermore, to consider the impact of culture on psychological treatments and to explore specific barriers to access for MUS.

2. Methodology

2.1. Participants

A poster circulated in relevant social media groups was used to recruit participants through volunteer and snowball sampling (Appendix H). The inclusion criterion was mental health professionals who had experience of working with MUS. Participants were not screened for level of experience with cultural diversity as this could potentially limit the exploration of barriers to access. No other exclusion criteria were applied due to the exploratory nature of the study. The sample size was determined by methodological approach, earlier research and an inductive thematic data saturation approach (Saunders et al., 2018).

2.2. Measures

A semi-structured interview schedule (Appendix I) was created to meet the research aims. This method was deemed most appropriate as it guided questions pertaining to the research aims, but allowed expansion of these. The interview schedule focused on participants' experience of working with MUS, any differences in presentation and explanation they had noticed related to culture, their professional understanding of MUS and their treatment approach. The interview schedule was piloted with the first three participants; who were asked about their experience of the interview and for any suggestions for improvement. Consequently, the interview questions were reworded for clarity.

2.3. Procedure

Participants were recruited using a poster circulated in relevant social media groups. Volunteers who participated also circulated this to encourage snowball sampling. Interested participants were asked to email to register their interest. Participants

were sent the participant information sheet (PIS) and consent form (Appendices J and K). Their experience of working with MUS and their level of experience working with culturally diverse populations were checked, although the latter was not used as an exclusion criterion. If the participant met the inclusion criteria, an interview was arranged and they were asked to send the consent form back prior to the interview. At the time of the interview, the research aim and ethical issues were discussed and verbal consent was gained. The interview schedule was used and the interview was recorded on a secure dictation machine. The audio recording was then transcribed. Transcriptions were analysed in accordance with Thematic Analysis (Braun & Clarke, 2006). This can comprehensively create themes across a dataset and allow the analysis of relationships (Alhojailan, 2012). Thematic Analysis allows interpretation of meaning by going deeper into content analysis (Crowe et al., 2015). It is not tied to a theoretical position and is epistemologically flexible, which was appropriate for this study (please see Appendix L and M for further detail).

A field researcher involved in the clinical application of the project coded a subset of the transcriptions independently. This was to ensure that the codes were data-driven and accurately reflected the dataset. They shared their codes and similarities and differences between the codes were discussed. Overall, the coding was very similar. The differences were discussed and the codes, which felt most representative of the data set were chosen. Codes were sorted into broader themes and subthemes. A University research supervisor compared the list of codes with the themes and subthemes that had been developed. Again, this was to ensure they accurately captured the dataset. The 'story' of the theme and sub-theme was discussed and the most appropriate phrase for telling the story of the cluster of codes were discussed and refined (full details outlined in Appendix N).

2.4. Ethical issues

Participants were provided with the PIS and consent form prior to arranging the interview to ensure they had time to read through the relevant issues pertaining to the study. Consent forms were returned prior to the interview. Ethical issues were explicitly discussed before the interview. This included confidentiality and its limits, the audio recording, transcription and the ability to withdraw from the study. Verbal consent was gained at this point.

If participants opted for a telephone interview, their contact details were stored securely but separately from their consent form and audio recording. Their phone number was deleted immediately after the interview. If participants opted for a video call, only their email address was used. Participants who wanted the results of the study provided consent for their email address to be kept to provide this feedback. The consent forms, audio recordings and transcriptions were stored securely on the University of Leicester drive. The majority of audio recordings were transcribed by an independent, university-approved transcription service. Following the transcriptions, audio files were deleted.

2.5. Position of the Researcher

The epistemological position taken in this study was a critical realist position (Koch, 1999; please see Appendix A for further detail). Prior exposure to the topic area came from consultation of the literature. It was assumed that individual experiences of participants working with MUS and culturally diverse backgrounds could influence the results. This assumption fit with the critical realist position where value is given to participants' experiences. It was hoped the study could be a valuable addition to understanding this topic area. Quality is considered in Appendices O and P.

3. Results

3.1. Participants

Twenty participants participated in the study; at which point data saturation was achieved. All participants were applied psychologists in the UK, and all except one were Clinical Psychologists or Trainee Clinical Psychologists.

Table 1. Participant Characteristics

Participant Characteristics		
Position	Trainee Clinical Psychologists	3
	Clinical Psychologists	17
	Forensic Psychologist	1
Gender	Female	17
	Male	3
Regions of the UK covered*	London	1
	North East	1
	North West	1
	Yorkshire	3
	East Midlands	3
	West Midlands	2
	South East	1
	East of England	2
	South West	1
	Ireland	1

* The regions covered is not an extensive list as not all participants made reference to their regions and some participants made reference to multiple regions they had worked in.

3.2. General Overview

Participants had worked with patients with MUS in a number of services and with both child and adult patients. Participants varied in how frequently they had seen presentations of MUS, some seeing the presentation multiple times a month and others seeing it a few times in their careers. They also differed in the variety of presentations they had seen. This appeared to be partly determined by the services they had worked in, for example participants in neurological services often saw patients with unexplained seizures. Pain was the most common symptom seen and included localised, generalised and chronic pain (Figure 1).

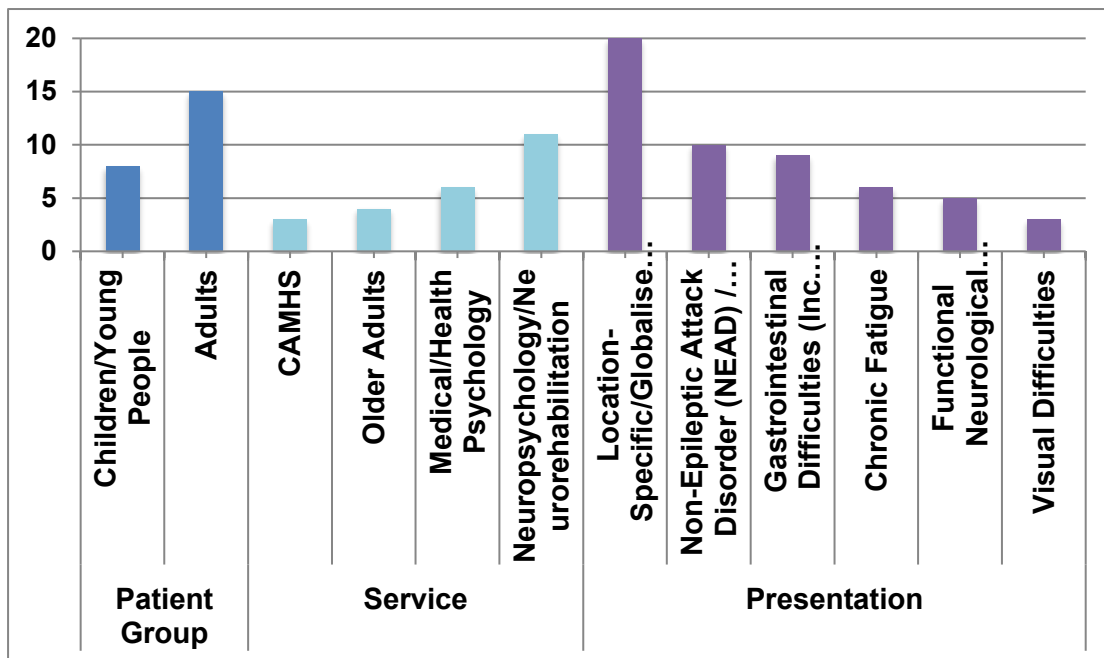


Figure 1. Graph depicting patient groups, common services and most common presentations seen⁸

3.3. Themes

Four themes and subthemes were identified during the Thematic Analysis (Figure 2).

01	Cultural Identity & Sense-Making	1.1 Cultural Narratives 1.2 The Interaction of Faith & Spirituality 1.3 Intersectionality
02	Systemic Barriers To Access	2.1 Family Narratives 2.2 Stigma 2.3 Institutional Discrimination
03	Mental Health & MUS	3.1 The Link Between Mind & Body 3.2 The Cycle of Poor Mental Health
04	Improving The Patient Journey	4.1 Earlier Psychological Intervention 4.2 Co-Construction of Meaning

Figure 2. Themes and subthemes found through the Thematic Analysis

⁸ Frequencies do not represent number of participants

Theme 1: Cultural Identity and Sense Making

Participants' experience of whether culture impacted the presentation of symptoms varied. Some participants felt that these factors were not linked, others that particular cultures more commonly presented with certain symptoms, whilst some felt they could not comment on the link. However, most participants felt that culture played a significant role in how patients made sense of their unexplained symptoms.

'Generally, people's explanatory models and people's cultural beliefs and how they make sense of the world has a huge impact on how they make sense of everything that happens in their life, medically unexplained symptoms would be kind of a part of that' [Participant 9]

It was found that culture impacted sense making through cultural narratives, faith and spirituality, and intersectionality.

1.1 Cultural Narratives

Many participants felt that patients drew on cultural narratives to make sense of their experiences.

'I think where someone's from changes how they make sense of their difficulties anyway' [Participant 3]

They emphasised the role of cultural narratives in not only understanding MUS but also mediating the experience of it. For example, an individual may be more likely to seek a biomedical explanation for their difficulties due to the cultural narrative that physical symptoms are a result of physical problems. Whereas, another may not seek support as in their culture the physical symptoms were not be appraised to be

distressing. Participants felt that cultural narratives and language therefore could impact how the symptoms were appraised.

'I think just in terms of cultural understandings around physical and mental health, and [the importance of] language and communication' [Participant 4]

Alongside this, participants identified specific idioms of distress within cultures. Participants felt that cultures had different approaches to expressions of distress. They suggested that language was closely associated to how these cultural idioms were expressed and used to make sense of experiences.

'I think lots of cultures have really kind of beautiful vocabularies for explaining what they're seeing in their body, but they might not medicalise it' [Participant 7]

This highlighted that patients may use language to describe their experiences, which could provide rich understandings for professionals in how the patient was making sense of their symptoms. Attending to these cultural idioms and expressions of distress therefore felt important.

'Patients describing things like, 'oh my back is crumbling'. Or 'one of the screws has come loose and that's why I'm having the pain there, it's jabbing me'
[Participant 16]

1.2 The Interaction of Faith And Spirituality

Alongside culture, participants drew attention to the importance of faith and spirituality in the experience of MUS. Participants noted that this could also be used to give meaning to the symptoms as well as a coping strategy.

'Religious views on different bodily sensations and symptoms and what that might mean to someone given different kind of religious and cultural beliefs'

[Participant 4]

Within this, differences were seen in how faith and spirituality was used to explain the symptoms. Differences among individual patients were noted in whether these explanations were positive or negative:

'In some way it was a punishment of some sort' [Participant 12]

'It's seen as a gift, it's seen as a spiritual and kind of a spiritual explanation for it' [Participant 9]

A patient appraising their symptoms related to their faith might then impact their experience of the symptoms. Again, this was different for individual patients. For example, some participants noticed that patients who saw the symptoms as a punishment were more likely to accept the symptoms, whereas others were more distressed by the symptoms.

Alongside providing an understanding, participants noted that faith and spirituality could also be a protective factor for some patients and serve as a treatment option:

'People who have found help, even if it's temporarily, through prayer'

[Participant 10]

This emphasised the importance of considering faith and spirituality when working with the MUS presentations, to consider if and how it may give meaning and context to patients.

1.3 Intersectionality

Participants felt that the experience and explanation of MUS was very individual. Some participants felt that for particular patients, other identities interplayed with culture and faith/spirituality, whereas for other patients these other identities and contexts were more important.

‘More gender stuff and mainly women presenting with quite generalised kind of fatigue and pain’ [Participant 18]

Participants noted that, as with cultural identities, other identities could inform patients’ approaches to health services. For example, men feeling less inclined to access mental health services due to narratives about ‘*stoicism*’. In addition, one participant considered the role of age and cohort effects:

‘Older adults, there are very different cohort beliefs and a very passive approach to healthcare, so wanting medical professionals to be the experts’
[Participant 7]

This suggested that cultural identity could intersect with other identities the patient held and emphasised the importance of understanding how intersectionality made the patient’s experience unique. It suggested the need for a holistic approach.

‘I think about people’s gender, their age, their religion, their ethnicity, their education – how this all impacts the people that we are how it impacts the way that things are understood and perceived’ [Participant 14]

Theme 2: Systemic Barriers to Access

Participants identified that patients with MUS, particularly those from culturally diverse backgrounds, experienced systemic barriers to accessing services. These included barriers including family narratives, stigma and institutional discrimination.

2.1 Family Narratives

Participants felt that family narratives were also important in determining how patients with MUS made sense of their experiences. This was generally alongside and reinforcing of cultural narratives. Some participants focused on how families may have modelled physical symptoms, suggesting that the expression of symptoms was something that had been learnt:

'Mum's like it, dad's like it, even the four year old little brother...is like it'

[Participant 12]

Others considered the way in which family narratives could add pressure, impact treatment options and become barriers to accessing psychological services.

'Needing again a medical diagnosis because the family were looking towards them as some kind of concrete explanation for their presentation' [Participant

13]

Participants noted that family narratives could serve to maintain and reinforce the symptoms. Generally, participants did not feel this was intended to be negative, however, could still significantly impact how the patient managed their symptoms.

'Family narratives are so critical in how we understand things. I think [especially] when you've been brought up in a family that is maybe of a fix it, solution focused family' [Participant 19]

'The partner was overly helpful and supportive to the extent of deskilling'

[Participant 6]

Participants felt these family narratives could prevent patients from seeking support or being able to engage with therapy. Participants who had worked with children or young people with MUS felt that family narratives were a particularly strong influencing factor, whether positive or negative. Thus, many participants spoke about the importance of including families in therapy if possible, especially if the patient was a child.

2.2 Stigma

Many participants who spoke about the impact of culture on explanations also discussed how cultural narratives could serve as a barrier to the patient seeking support, particularly psychological support. This was notably related to stigma and shame.

'A fear of that being kind of found out by other people in the community, that's been a big theme with people that I've worked with and that's a huge barrier'

[Participant 10]

Stigma appeared to be more profound when patients from culturally diverse backgrounds were accessing psychological services compared to physical health services. Participants felt that this related to the way in which psychological distress may be conceptualised in cultures and the connotations this may hold.

'It's mental health which therefore means that you're crazy' [Participant 14]

'In some cultures perhaps having a physical difficulty or a physical complaint is more culturally, sociably acceptable' [Participant 2]

This could prevent some patients from accessing services, or perhaps refusing to see a psychologist. For others, the barrier became in what was culturally acceptable to consider within the therapeutic space.

'You don't really talk about things like in his culture' [Participant 12]

2.3 Institutional Discrimination

Lastly, participants spoke about the implicit and explicit institutional discrimination that people from culturally diverse backgrounds with MUS may face when attempting to access services. Participants felt these could relate to a number of factors.

Firstly, some participants spoke about the dominance of the biomedical model and how it could prevent those that did not ascribe to that narrative from accessing services. Participants felt there was sometimes little space for patients to challenge the biomedical narrative or feel empowered to present their own narratives.

'We don't take the time to find out what someone's framework is before telling them ours' [Participant 7]

Some participants considered their own role in perhaps maintaining these barriers.

'I think we live in a Western culture and a big theme to me was trying to find an explanation or an answer' [Participant 19]

Secondly, participants considered the role professionals may play in preventing those from culturally diverse backgrounds from accessing services.

'Minority groups weren't represented, even in the referrals to the service on the whole level' [Participant 17]

It was noted that there were fewer referrals for those from culturally diverse backgrounds to psychology services, although participants were unclear about why this was. One suggestion was that other professionals were less likely to consider the psychological underpinnings or impact on mental health if someone was from a culturally diverse background. Another may relate to patients refusing services due to stigma.

Lastly, participants considered the way in which services had been set up and how this could inherently prevent access to some groups.

'Services that are set up predominantly with white people in mind or by white people and maybe not even aware of the bias' [Participant 11]

Within this, one participant noted that sometimes this discrimination could be explicit. For example, not providing the funding needed for interpreters when working with patients from different cultures:

'It's just another way in which the organisations and institutions are saying, you need to help yourself and we're not going to give you a helping hand'
[Participant 20]

The majority of participants who worked in culturally diverse areas of the UK felt that their caseload did not represent the demographics of the geographical area.

'I'm thinking of my caseload for the last year, it does not represent that cultural diversity that I see when I leave the hospital' [Participant 14]

Theme 3: Mental Health and MUS

All participants spoke about the role mental health played in the experience of MUS. Mental health was spoken about in terms of causing the symptoms, being a result of the symptoms, made worse by the symptoms or a combination of these. Most felt physical health and mental health were connected. Some participants felt they could work with the impact the symptoms had on patients' mental health, without suggesting it was a cause and therefore not challenging the patients' cultural understanding.

3.1 The Link Between Mind and Body

Most participants felt that physical and mental health could not be divided into separate entities.

'Mind and body together as a unit of health rather than being organ specific'
[Participant 15]

Yet, MUS patients who were told there was nothing physically wrong with them so it must be psychological often experienced this division. Therefore, participants emphasised the need to consider the interrelatedness between these with patients.

'Help someone understand the connection between mind and body'

[Participant 3]

Some participants felt that for patients who believed that their symptoms were a result of an organic cause, this could be a helpful way to engage them in psychological therapy without challenging their narratives.

'More about retraining their brain for the functions they are impaired at the moment' [Participant 8]

Many participants proposed that the link between physical health and mental health could reveal the precipitating factor for the symptoms. Participants suggested that for many patients with MUS, the symptoms were a result of trauma, particularly from early childhood, and difficult life experiences.

'Complex and long-standing traumas from early childhood and often I think one of our assessment tools was the ACES' [Participant 16]

'Early childhood adversity, trauma' [Participant 6]

Some participants included attachment difficulties in this. Others spoke of '*small traumas*', which related to difficult life experiences that served to precipitate or perpetuate the symptoms.

‘Small ‘t’ traumas. So, for some people it is the kind of the ACEs, but for other people it’s just a series of very invalidating relationships or families that refuse to acknowledge emotions’ [Participant 7]

These participants suggested that patients may not consider themselves as having experienced trauma, perhaps because these experiences were common and not be labelled in such a way. Yet, experiences such as a high-pressured job could impact MUS, whether this was causing or maintaining symptoms. However, one participant felt that simplifying MUS to trauma was reductionist and ignored other factors.

‘We can’t go with that assumption that, oh, they have to have some mental health history and that’s why they’re having this difficulty’ [Participant 8]

3.2 The Cycle of Poor Mental Health

Participants spoke about patients being stuck in a vicious cycle whereby the symptoms they experienced caused or contributed to poor mental health, which in turn worsened their symptoms.

‘Whole vicious cycle of like anticipation, anxiety and then like too much attention onto their physical symptoms and then that like you know catastrophising and exacerbation’ [Participant 8]

Participants felt that regardless of the underlying cause of the symptoms, poor mental health often accompanied the experience of MUS. This was due to the impact MUS had on socio-occupational functioning and overall quality of life.

‘Withdrawing from seeing friends, school, other activities which aren’t like to do with the pain or the symptoms’ [Participant 5]

Therefore, psychologists may be well placed to support patients with MUS with the ongoing poor mental health they may be experiencing, irrespective of how the patient makes sense of their symptoms.

'Managing stress and managing the additional factors that might be contributing to long recovery' [Participant 13]

Theme 4: Improving the Patient Journey

Lastly, all participants spoke about the MUS patient journey being overwhelmingly negative. This included not being believed by professionals, numerous appointments and poor care from services. Participants suggested ways in which to improve the patient journey and how best to work therapeutically with patients with MUS.

4.1 Earlier Psychological Intervention

Participants described the MUS patient journey as '*long*', '*complex*' and with '*many appointments and medical investigations*'. This led to confusion and hopelessness for many patients. Yet, these negative emotions were superseded by not being believed by professionals.

'People often have to tell their story repeatedly and what their symptoms are repeatedly and are often met from medical professionals with not disbelief but scepticism' [Participant 17]

'It's hard when they're calling them a liar, you're not helping them on their healing journey' [Participant 1]

Participants spoke of the paradox of the dominant biomedical model closing other cultural narratives, and yet when patients accepted this narrative, they were told that it could no longer explain their symptoms. Participants felt this approach was detrimental to patient engagement with psychological services and invalidating for patients. Participants suggested that when patients were referred to psychology, they could experience this as the blame being internalised.

'I don't think it's very helpful that quite often doctors refer people to psychology or psychology support when they reach the end of the line with treatments' [Participant 2]

Some felt an important way to improve the patient journey was to provide earlier access to psychological interventions. Many felt that psychology was presented at the '*end of the road*' with connotations that there was nothing else that could be done, leaving the patients with little hope.

'There's a need to rule out medical but if we can get psychology going early, it can certainly help the outcomes' [Participant 15]

One participant worked in a service where psychology was embedded into primary care and spoke of how this could significantly improve the patient journey, as psychological support and investigations for an organic cause were concurrently provided. This gave importance to seeking answers through both avenues. Involving psychology earlier in the patient journey could not only improve access to services but also improve the patient journey and coping strategies.

4.2 Co-Construction of Meaning

Given the importance of culture on how a patient makes sense of their experiences and the additional barriers faced by those from culturally diverse backgrounds, participants felt co-constructing meaning with the patients was important.

'My formulation would be very different for medically unexplained because we're trying to work together to sort of you know co-construct meaning'

[Participant 13]

Many felt that validation was the first step to building the therapeutic relationship by overcoming the defensive barriers of not being believed.

'It's a real experience and you are really experiencing this pain and really showing the person that I believed that their pain was real' [Participant 5]

Once a therapeutic relationship was established, they felt they could elicit the patient's individual experience of the symptoms and the meanings they attached to these.

'Working with what's culturally meaningful to that person because it's not our place to say that that's right or wrong' [Participant 9]

'Trying to get some kind of common ground, some acceptable way of talking about [the symptoms]' [Participant 18]

Participants felt this could allow the use of 'Western' therapeutic approaches whilst incorporating the patient's understanding. These therapies often included accepting the symptoms and developing compassion for oneself. Other participants felt that the treatment they adopted needed to be meaningful for the individual and be tailored to the patient's needs.

'More sort of complimentary approaches could be really beneficial for people and could match their cultural approach much better than some of our more westernised models' [Participant 7]

'What was their goal would really depend on what treatment is most appropriate or useful' [Participant 11]

The need for services and clinicians to provide culturally sensitive and appropriate interventions was highlighted. This drew attention to the benefit of psychologists working with this patient group, being able to use an eclectic approach for individualised treatments.

4. Discussion

4.1. Summary of Findings

This study sought to investigate if and how culture influenced the presentation, explanation and treatment of MUS in psychological services, and to explore cultural barriers to access to services. Data was collected through semi-structured interviews with psychologists. Overall, it was found that culture had a significant impact on the experience of MUS. Although there were differences of opinion about the impact of culture on presentation, participants revealed the clear impact of culture on understandings of MUS and the need to adopt treatments to reflect this. Within culture, the role of language, cultural idioms, faith and spirituality, family narratives and stigma were recognised as important factors that influenced the patient experience. Participants acknowledged that institutional discrimination could prevent access to services and that change was needed. Participants felt that physical health could not be treated as separate to mental health. They suggested that mental health could be the cause of MUS (somatisation), a negative outcome because of MUS, a perpetuating factor for the symptoms or a combination of these. Additionally, participants recognised the role psychology had in supporting patients with MUS, suggesting that earlier involvement in the patient journey could mitigate some of the negative patient experiences. Participants felt validation and co-constructing meaning with patients were vital to building the therapeutic relationship, after which psychological treatments became more appropriate. Lastly, a salient finding was that the individual experience of MUS varied significantly between patients. For example, two patients could appraise the symptoms as a punishment but engage with this in different ways. It emphasised that patients with MUS should not be treated as a homogeneous group, and for improved patient outcomes, an individualised approach was required.

4.2. In Context of the Literature

This study's findings were inconclusive about the impact of culture on presentation. Perhaps this relates to the services in which patients were seen or that some participants had limited exposure to patients from culturally diverse backgrounds with MUS. The findings are in contrast with previous research findings that suggest that culture can influence presentation (Hausteiner-Wiehle et al., 2011). This study's findings did, however, support the literature suggesting that culture could influence patients' explanations of their MUS symptoms (Sham et al., 1996; Sumathipala et al., 2008). Thus, social identity was seen as an important theory to understand sense making within MUS and to consider within treatment in psychological services (Tajfel & Turner, 1979). This study went further than previous studies by identifying how culture impacted explanations: through cultural idioms; language; family narratives; and faith and spirituality. The findings particularly emphasised the need for psychologists to consider faith and spirituality alongside eliciting cultural idioms of distress. This study supported research suggesting that cultural influences could impact engagement with treatment (Sham et al., 1996), and highlighted the need for psychologists to provide culturally sensitive approaches to reduce barriers to access.

As found in previous research, some participants used somatisation to understand MUS symptoms (Greer & Halgin, 2006). Within this study, prior trauma was considered a significant precipitating factor. Yet, McAndrews et al. (2019) found that this attribution could lead to negative outcomes for the patient. This supports previous research that highlights professional biases in conceptualisation can impact patient care (Godin et al., 2008; McAndrews et al., 2019). A professional focusing on the patient's illness explanation could overcome this bias to some extent (Colquhoun et al., 2017). Participants in this study felt that they could support with symptom management and the impact MUS had on the patient's mental health, regardless of their illness explanation. However, research has shown that for effective change of

healthcare professional behaviour, particularly behaviour related to bias, reflection is key (Kember et al., 1996; Mann et al., 2009; Teal et al., 2010). Reflective practice spaces can provide some of this reflection and are commonly used with Clinical Psychology practice. However, Sukhera et al. (2020) emphasised that the reflective space needed to be explicit in looking at biases and implementing educational strategies. Participants felt that in order to improve the patient journey and provide culturally appropriate treatment options, validation and co-construction of meaning were emphasised. This required professionals being aware of their own biases and ways of meaning-making and prioritising a joint meaning-making process with the patient. As Colquhoun et al. (2017) found, engaging patients and identifying personal barriers can be an effective way to change professional behaviour, alongside reflective spaces.

These study findings also supported previous literature relating to wider mistrust of mental health services by those of culturally diverse backgrounds (Amri & Bemak, 2012; Whaley, 2001). A further dimension identified in these findings was that for MUS patients from culturally diverse backgrounds, this could be a result of: stigma; family narratives; language barriers; and institutional discrimination. Participants felt that co-constructing meaning with patients could overcome some of these barriers by adopting the patient's illness explanation and adopting medical pluralism (Green et al., 2006; Risør, 2009). This study also revealed the significant role of family narratives and the need to include families in sessions, particularly if the patient was a child. Participants also recognised their own biases, which could inadvertently reinforce the 'them' and 'us' distinction if they adopted an explanation or treatment approach that was not culturally sensitive (FitzGerald & Hurst, 2017; Tajfel & Turner, 1979). Or by adopting a narrative that led to poorer outcomes for the patient (McAndrews et al., 2019). Some participants reflected that they tried to understand MUS through a biopsychosocial lens, yet this model is based on the biomedical

model and therefore remains inherently problematic (Butler et al., 2004). The need to move away from dominant Western narratives and consider the patient's family and cultural narrative were seen as necessary to engage the patient. This could reduce the 'them' and 'us' distinction by not threatening the patient's cultural identity (McLeod, 2019). This supported previous research, which emphasised that adopting cultural narratives made talking therapies more acceptable for those from culturally diverse backgrounds (Aggarwal et al., 2016; Röhrich & Elanjithara, 2014; Salmon et al., 2004). This study also revealed that recommendations from research exploring cultural mistrust of healthcare systems were not yet being implemented into practice within psychology, highlighting that recommendations are not always in practice due to professionals' predispositions leading to potentially suboptimal care (Godin et al., 2008).

For all patients with MUS, regardless of cultural background, the study findings supported the notion that the dominant biomedical narrative could reinforce concerns about physical causes (Knott, 2014). The findings corroborated the argument that the division of physical and psychological services was detrimental (Royal College of Psychiatrists et al., 2015), particularly as some participants considered MUS a result of somatisation and therefore suggested they could not be separated. This highlights that the adoption of the biomedical framework in supporting patients with MUS can be unhelpful and that practice should move away from this. However, how achievable this is in a healthcare system dominated by the biomedical framework is questionable. Participants suggested that earlier psychological support was important to allow validation and collaborative meaning making between psychologist and patient. For patients with MUS, this is particularly pertinent and should be the accepted convention (Lidén et al., 2015).

4.3. Dissemination and Implementation

This study's findings suggest that patients with MUS are a heterogeneous group, with numerous complex and multifaceted factors, including culture, influencing the patient's explanation and experience of their condition. However, patients with MUS may be grouped as a homogenous group by healthcare professionals to support clinical practice. To improve treatment outcomes for patients with MUS and make psychological interventions more accessible to those from culturally diverse backgrounds, individualised treatment approaches are required (Dwamena et al., 2009). This should include eliciting how the individual explains their symptoms, considering the role of culture and wider systemic influences, acknowledging intersectionality, exploring the impact of the symptoms upon mental health and adapting the treatment to reflect these. Within this, psychologists must acknowledge their own explanatory biases which impact their preferred treatment options and accept cultural explanations of symptoms (Cuevas et al., 2017). This relies on psychology as a profession recognising its biases in adopting dominant Western explanations and the limitations this imposes (Wood & Patel, 2017). With these considerations in place, the patient experience can become more culturally sensitive and it may be possible to improve the efficacy and appropriateness of Western therapies (Abbass et al., 2009; Kroenke, 2007; van Ravesteijn et al., 2014). There is ample research about the need to modify interventions to improve their cultural applicability, however, it did not seem this was being implemented when psychologists were working with patients with MUS. Therefore, teaching on how culture impacts MUS, adopting culturally-informed approaches where meaning is co-constructed and having effective supervision is required to achieve this (Patallo, 2019; Tajfel & Turner, 1979).

Many participants felt that earlier psychological intervention could improve the patient journey, experiences and outcomes. Earlier referrals to psychologists within health/medical psychology services or to IAPT may be one feasible option (NICE,

2018). Greco (2012) noted that the classification of MUS contributed to conflict between professional knowledge and patient experience. Thus, absorbing MUS into wider physical care services may be cost-effective and allow more targeted teaching about the cultural impact of MUS. Referring a patient because they are experiencing distress, regardless of the cause or lack of cause of the symptoms, may also overcome patients feeling blamed and cultural barriers of stigma (Weiner et al., 1988). This could provide validation, improve the patient journey and reduce the 'them' and 'us' distinction (McLeod, 2019). These services could then be developed to offer culturally informed and appropriate treatment options (Sidhu & Begum, 2017; Wood & Patel, 2017). This would allow the move away from somatisation to focus on individual experiences and explanations of MUS. However, this would require the restructuring of services and perhaps a change in attitudes towards patients with MUS.

Alternatively, integrating psychological services into primary care could significantly improve the MUS patient journey and address barriers to access for those from culturally diverse backgrounds (Royal College of Psychiatrists et al., 2015). Currently, there is little integration and it may take a significant reorganisation of services and reform of the dominant biomedical model (Gunn & Blount, 2009). However, piloted integrated services have demonstrated improved outcomes for patients with MUS, particularly for those from culturally diverse backgrounds (Gerskowitch et al., 2015). Further research into this field could support the improvement of the pathway for patients with MUS.

4.4. Study Limitations and Further Research

This study had a small number of participants with varying levels of experience with and exposure to patients from culturally diverse backgrounds presenting with MUS. Therefore, the results are tentative and limited to that context. All cultures were

grouped together, yet they are markedly heterogeneous with ethnic, cultural, linguistic and religious differences (Prajapati & Liebling, 2021). Due to the exploratory nature of this study and the lack of previous research on this topic, a decision was made to take this broad approach. However, further research exploring specific cultural barriers for patients with MUS and their nuanced experiences is vital to the development of culturally competent services and treatments. This study found inconclusive evidence for the impact of culture on presentation with MUS, perhaps due to the sample. Research to better understand this is required, perhaps by purposively sampling those with relevant experience. This study could not explore individual factors within intersectionality thus it would be useful to explore this further. Participants in this study felt that those from culturally diverse backgrounds were less likely to be referred to psychological services but why this was the case was unclear. Further research to explore this specifically within MUS may support services to remove barriers and encourage equitable access. Lastly, the understanding of the interaction between culture and MUS was sought from professionals, rather than the patients themselves. Gaining the patient perspective is crucial in developing this understanding.

4.5. Conclusion

This study found that culture played a significant role in how MUS were understood by patients. For improved patient outcomes and engagement with psychological services, treatments need to incorporate cultural explanations. A number of factors interacted with culture, emphasising the need for individualised approaches. Co-constructing meaning and earlier referrals to psychology were seen as vital to improving outcomes for patients with MUS, particularly for those from culturally diverse backgrounds.

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Appendices

* Denotes a mandatory appendix

Appendix A*

Epistemological Position Taken in This Thesis

Qualitative research is often based on philosophical assumptions about reality and knowledge. Willig (2013) posits that to locate oneself epistemologically three things should be considered. Firstly, what kind of knowledge does the methodology aim to produce? Considering objectivity, subjectivity and context within this. Secondly, what kind of assumptions does it make about the reality? Lastly, what is the role of the researcher? These questions were used to guide the epistemological position and consider the way this would impact the research.

Through these questions, a decision was made to take the position that there is some 'real world' but it sits behind subjective and experiential knowledge (Madill et al., 2000). This is the critical realist perspective, which sits between realism and relativism. A critical realist perspective suggests that our perceptions of reality are influenced by socio-cultural meanings, previous experiences and knowledge. Thus, direct access to reality is not possible (McEvoy & Richards, 2006).

Therefore, research from this epistemological position seeks to explore the participants' interpretations of their reality, rather than the '*universal truth*' (Clarke et al., 2015). This position recognises that as individuals our perception are constrained and influenced by own experiences, perspectives, purposes, cultures and language (Camic et al., 2003). Adopting this epistemological position within research uses people's individual realities as a foundation for knowledge and therefore it is argued that this can influence meaningful change (Braun & Clarke, 2013). Also within this context, the researcher inevitably plays a role in the analysis and interpretation of the data as they are also seeing it through their own lens (Noble & Smith, 2015).

The critical realist position was considered in both the literature review and the empirical research. Within the context of the literature review, this approach was felt to be most appropriate because it was seeking to explore healthcare professionals' attitudes. When seeking attitudes about a subject, to seek objective truth is not appropriate, as value should be given to the individual's experience. Furthermore, it is helpful to view the experiences and attitudes of healthcare professionals as 'real' to consider how best to support them and consider the link to patient care.

With regards to the empirical piece, again experiences were being researched. Additionally, the healthcare professionals were speaking about the experiences of the clients they had worked with. Gaining this third-person perspective would not allow for the 'truth' to be sought and rather importance was given to how this was understood by participants. Understanding the participants' experience of the interaction between culture and Medically Unexplained Symptoms (MUS) as 'real' could also contribute to knowledge about this experience for patients.

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Appendix B

Literature Review: Process of Defining Search Terms

A variety of search terms were attempted across the different databases in order to elicit the most appropriate results. Due to the use of databases that differed in formatting, search strategy and precision, it felt important to assess this to ensure relevant studies were found. The tables below illustrate examples of some of the combinations of the wording that were used and the number of searches they returned across the databases.

Table 1. The final wording used to search the databases in this literature review

	PsycINFO	Scopus	Medline	Web of Science	CINAHL	AMED	<u>Total</u>
Wording	“Medically unexplained symptoms or MUS” AND “Healthcare professionals or healthcare workers or healthcare providers or physician or nurse or doctor” AND “Attitudes or perceptions or opinions or thoughts or feelings or beliefs”						
Articles Found	114	22	837	171	101	2	1247
	After applying inclusion/ exclusion criteria:						12

Table 2. An example of different wording used to search the databases

	PsycINFO	Scopus	Medline	Web of Science	CINAHL	AMED	<u>Total</u>
Wording	“Medically unexplained symptoms or MUS” AND “Allied health professionals or health care professional” AND “Attitudes or beliefs or perceptions”						
Articles Found	6	5	30	25	4	2	72
	After applying inclusion/ exclusion criteria:						0

Table 3. A further example of different wording used to search the databases

	PsycINFO	Scopus	Medline	Web of Science	CINAHL	AMED	<u>Total</u>
Wording	“MUS or medically unexplained symptoms” AND “Allied health professionals or AHPs or psychologists” AND “Attitudes or beliefs or perceptions or views”						
Articles Found	11	9	18	9	7	0	54
After applying inclusion/ exclusion criteria:							0

Other variations of wording, including using truncations for words, were also attempted. Not all are presented here. The wording used within this literature review (Table 1) was the most appropriate as it elicited the most relevant results and the highest number of studies meeting the inclusion/exclusion criteria.

It is noted that using different wording options for the different databases may have optimised the results found. However, for ease of replicability, this was not done.

Appendix C

Literature Review: Full Inclusion Criteria, and Application to Papers

Table 1. Inclusion and exclusion criteria applied

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> Shows healthcare professionals' attitudes towards adult patients with medically unexplained symptoms (even if the exploration of attitudes is not the explicit aim, to ensure relevant articles are not missed) Was published from 2000 onwards (to reflect the shift in the understanding of MUS) Is in English or with an English translation available 	<ul style="list-style-type: none"> Is not a piece of research Uses a quantitative approach (excluded as it is felt this cannot provide the depth required for this review) Does not specifically explore MUS or uses synonyms of MUS (as this may change the focus and elicit different attitudes) Focuses on a specific condition within MUS, rather than on MUS broadly (again as this may elicit different attitudes) Focuses on children (as they may be seen by different professionals) Does not explore attitudes to at least some extent Ascertains attitudes by using video recordings of consultations (as this relates to the researchers' interpretations rather than directly exploring healthcare professional's attitude)

Table 2. Search terms used, inclusion/exclusion filters applied and number of papers

	PsycINFO	Scopus	Medline	Web of Science	CINAHL	AMED	Total
Wording	"Medically unexplained symptoms or MUS" AND "healthcare professionals or healthcare workers or healthcare providers or physician or nurse or doctor" AND "attitudes or perceptions or opinions or thoughts or feelings or beliefs"						
Initial search	114 articles produced	22 articles produced	837 articles produced	171 articles produced	101 articles produced	2 articles produced	1247
Filter: published in the last 20 years	113 articles	22 articles	778 articles	164 articles	97 articles	2 article	1176
Filter: English language	109 articles	21 articles	772 articles	151 articles	97 articles	2 article	1152
Filtered relevant titles (to include MUS AND healthcare professionals)	36 articles	8 articles	67 articles	40 articles	36 articles	1 article	188
Abstracts filtered (explored attitudes)	21 articles	5 articles	45 articles	28 articles	22 articles	1 article	122
Inclusion/exclusion criteria applied	14 articles	5 articles	24 articles	16 articles	12 articles	No articles	71
Removal of duplicates within and across search engines:	12 articles remaining						59 articles removed

Appendix D

Literature Review: Blank CASP Qualitative Research Checklist



CASP Checklist: 10 questions to help you make sense of a **Systematic Review**

How to use this appraisal tool: Three broad issues need to be considered when appraising a systematic review study:

- ▶ Are the results of the study valid? (Section A)
- ▶ What are the results? (Section B)
- ▶ Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA ‘Users’ guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Systematic Review) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

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Paper for appraisal and reference:

Section A: Are the results of the review valid?

1. Did the review address a clearly focused question?

Yes ☐
Can't Tell ☐
No ☐

HINT: An issue can be 'focused' in terms of

- the population studied
- the intervention given
- the outcome considered

Comments:

2. Did the authors look for the right type of papers?

Yes ☐
Can't Tell ☐
No ☐

HINT: 'The best sort of studies' would

- address the review's question
- have an appropriate study design (usually RCTs for papers evaluating interventions)

Comments:

Is it worth continuing?

3. Do you think all the important, relevant studies were included?

Yes ☐
Can't Tell ☐
No ☐

HINT: Look for

- which bibliographic databases were used
- follow up from reference lists
- personal contact with experts
- unpublished as well as published studies
- non-English language studies

Comments:

4. Did the review's authors do enough to assess quality of the included studies?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: The authors need to consider the rigour of the studies they have identified. Lack of rigour may affect the studies' results ("All that glisters is not gold" Merchant of Venice – Act II Scene 7)

Comments:	
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5. If the results of the review have been combined, was it reasonable to do so?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider whether

- results were similar from study to study
- results of all the included studies are clearly displayed
- results of different studies are similar
- reasons for any variations in results are discussed

Comments:	
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Section B: What are the results?

6. What are the overall results of the review?

HINT: Consider

- If you are clear about the review's 'bottom line' results
- what these are (numerically if appropriate)
- how were the results expressed (NNT, odds ratio etc.)

Comments:	
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7. How precise are the results?

HINT: Look at the confidence intervals, if given

Comments:

Section C: Will the results help locally?

8. Can the results be applied to the local population?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider whether

- the patients covered by the review could be sufficiently different to your population to cause concern
- your local setting is likely to differ much from that of the review

Comments:

9. Were all important outcomes considered?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider whether

- there is other information you would like to have seen

Comments:

10. Are the benefits worth the harms and costs?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

HINT: Consider

- even if this is not addressed by the review, what do you think?

Comments:

Appendix E

Literature Review: Quality Appraisal Checklist

Author	Clear aims?	Qualitative approach appropriate?	Appropriate research design?	Appropriate recruitment strategy?	Appropriate data collection?	Researcher-participant relationship considered	Ethical issues considered?	Appropriate data analysis?	Appropriate statement of findings?	Clinical applicability?	Overall Rating
Czachowski et al. (2011)	Yes	Yes	Can't Tell	Yes	Yes	No	Can't Tell	Yes	Yes	Yes	Green
Dowrick et al. (2008)	Yes	Yes	Can't Tell	Yes	Can't Tell	No	Can't Tell	Yes	No	Yes	Amber
Ivetić et al. (2013)	Yes	Yes	Yes	Can't Tell	Yes	No	Can't Tell	Yes	Yes	Yes	Green
Maatz et al. (2016)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	No	Yes	Green
Mik-Meyer & Obling (2012)	Yes	Yes	Yes	Yes	Yes	Can't Tell	Yes	Can't Tell	Can't Tell	Yes	Green
Ringberg & Kantz (2006)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't Tell	Can't Tell	Yes	Green
Salmon et al. (2007)	Yes	Yes	Can't Tell	Yes	Yes	No	No	Yes	No	Can't Tell	Amber
Shattock et al. (2012)	Yes	Yes	Yes	Yes	Yes	No	Can't Tell	Yes	Yes	Yes	Green
Warner et al. (2017)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Green
Wileman et al. (2002)	Yes	Yes	Yes	Can't Tell	Yes	No	No	Can't Tell	Yes	Yes	Amber
Woivalin et al. (2004)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Green
Yon et al. (2015)	Yes	Yes	Yes	Yes	Yes	No	Can't Tell	Yes	Yes	Yes	Green
Key for each category:	No	Did not meet criteria		Can't Tell	Insufficient evidence to make a judgement		Yes	Fully met the criteria			
Key for overall rating:	Red	Poor Quality: only 1-3 categories are ves		Amber	Fair quality: 4-6 categories are ves		Green	Good quality: 7-10 categories are ves			

Appendix F

Literature Review: Data Extraction Tool

Table 1. Standard Data Extraction Form (Munro et al., 2007) and the adapted version of this used in this review

Standard data extraction form (Munro et al. 2007)	Adapted Data Extraction Form Used In Review
Country	Aims of Study
Aims of study	
Ethics – how ethical issues were addressed	Study Setting and Country
Study setting	
Theoretical background of study	Sampling Approach
Sampling approach	Participant Characteristics
Participant characteristics	Data collection methods and analysis approach
Data collection methods	
Data analysis approach	Key themes identified in the study (1 st order interpretations)
Key themes identified in the study (1 st order interpretations)	Data extracts related to the key themes
Data extracts related to the key themes	Author explanations of the key themes (2 nd order interpretations)
Author explanations of the key themes (2 nd order interpretations)	Recommendations made by authors
Recommendations made by authors	Assessment of study quality
Assessment of study quality	

Reference

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Appendix G

Literature Review: Development of Overarching Constructs

Table 1. Example of the development of overarching constructs from first and second order constructs using two papers

	First-Order Constructs (<u>Participant Quotes</u>)	Second-Order Constructs (<u>Researcher Interpretations</u>)	Third-Order Constructs (<u>Overarching Understandings</u>)
Shattock et al. (2012)	It's psychological Has to be medical / cause not yet found Less serious than other conditions Some make it up Importance of doctor-patient relationship Feelings of hopelessness/powerlessness We are their only hope	Attitudes towards patients with MUS were learnt through seniors Formal teaching was not received by medical trainees about MUS, nor how to break 'no news' to patients Training needs to be evidence-based and clinically relevant	The role of teaching about MUS is important to medical trainees to equip them to manage this presentation. Attitudes about MUS can be learnt; perhaps the impact of this is perpetuated by not receiving teaching?
Yon et al. (2015)	Feelings of powerlessness No formal training * What would help? / It's not my job It's psychological Has to be medical / cause not yet found * They are malingering * Better to over-investigate to avoid litigation Less serious than other conditions * Service pressures * They are demanding * Patients cause uncertainty Attitudes learnt through seniors * Investigations as an avoidance strategy	* There are significant gaps in training about MUS: particularly understanding of causes and management strategies Negative attitudes are learnt * Frustration and lack of competency can lead to over-investigation or avoidance * More training is required	There is an emotional impact on professionals working with MUS. MUS are not always considered serious/real.

* Symbolises that this construct was not found in the first paper. This allows for the recognition of similarities and differences across the papers

Appendix H

Empirical Research: Research Poster

The poster has a purple-to-pink gradient background with a white vertical line on the left. The University of Leicester logo is in the top right corner. The title 'RESEARCH PARTICIPANTS WANTED' is in large white serif font. The text is centered and uses a mix of bold and regular weights in white serif font.

 UNIVERSITY OF
LEICESTER

RESEARCH PARTICIPANTS WANTED

**Have you worked with clients who
have had symptoms that cannot be
fully explained by a medical diagnosis?
If so, we would love to hear from you!**

**We are researching the impact of
culture on the experience of Medically
Unexplained Symptoms (MUS), as part
of a Doctorate in Clinical Psychology.**

**Taking part would involve a short
interview (15-30 minutes).**

**To find out more or to take part
PLEASE EMAIL:
sk772@leicester.ac.uk**

Appendix I

Empirical Research: Interview Schedule



Interview Schedule

Welcome and Introduction

Ethical Issues and consent to be discussed

Assign participant number

Making Sense of MUS

1. How often have you seen clients with Medically Unexplained Symptoms and what do they typically present with?
2. Do you feel presentations differ across cultures (race/ethnicity)? And in what way?
3. How do clients with an MUS presentation generally try to make sense of it?
What do you feel influences how they make sense of it? Carers/family/peers/media
Are there any differences across culture about how people try and make sense of MUS?
4. What factors do you believe may predispose or maintain the symptoms?

Coping with MUS

5. Is working with clients with MUS easier or harder than working with other clients? And in what ways?
What contexts/circumstances make it easier or harder?
Are there ways in which cultural differences impact this? (For example barriers)
6. Are the clients you have seen with MUS are representative of the demographic makeup of geographical location?
7. What treatment approaches have you used with this client group?
Does this differ across cultures?
How do clients receive these treatments?

Anything not covered? Is there anything we haven't covered you would like to mention?

Closing and thanks - check that the participant is still happy for you to use all the information provided and offer the possibility to erase sections of the recording.

Appendix J*

Empirical Research: Participant Information Sheet



Participant Information Sheet (PIS)

Research Project title

Understanding The Unexplained: How The Experience of MUS Is Culturally-Mediated

Invitation paragraph

Our research team would like to invite you to participate in a research study. The research is being led by a Trainee Clinical Psychologist at the University of Leicester as part of a Doctorate qualification in Clinical Psychology. To help you decide if you would like to participate, we would like you to understand why the research is being done and what it would involve for you.

What is the purpose of the research project?

We are researching how people who have medically unexplained symptoms explained (MUS) and are from culturally diverse backgrounds make sense of their symptoms, what influences this and how they cope with it. We are interviewing healthcare professionals who may have worked with this client group to understand their experiences of this. The project will run for approximately six months and will be based on short interviews.

Why have I been invited to participate?

It would be helpful to understand your experiences of working with this client group, how you believe they make sense of their symptoms and any cultural differences you have noticed. We hope to do this via interviews.

Do I have to take part?

No. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully. This will include a privacy notice that will explain how your data will be collected and used. You are free to decide whether or not to take part in this study. If you choose not to take part, this will not impact you in any way. Please feel free to ask any questions or for more information. If you do decide to take part, you are still free to withdraw at any time and without giving a reason, by contacting the researcher.

What will happen to me if I take part?

If you do decide to participate, you can email the research team at sk772@leicester.ac.uk to express your interest. Your name and contact details will be noted and will be held securely. We will then organise a time and date for the interview that works around your commitments. This will be virtual and so either a telephone conversation or via a video platform. The interview is expected to last approximately 15-30minutes and will be recorded on an encrypted Dictaphone. After the interview, that will be the end of your involvement. The audio recording will be transcribed and then analysed to compare and contrast with other participants.

What are the possible disadvantages and risks of taking part?

We do not anticipate that you will not be harmed in any way by participating in the study. You have the right to end the interview at any point or not answer a question.

**What are the possible benefits of taking part?**

There are no direct benefits. Although, it may be interesting to take part in research and give your opinion. The results of the study may be used to create an information sheet for services.

What data will you collect about me?

Your name and contact details will be collected for the purpose of making contact and organising the interview. This will be held securely on the University of Leicester research drive. The audio recording from the interview will also be stored in the same way. These will be stored here for 5 years in line with Section 5 of the Research Code of Practice and then destroyed.

Will what I say in this research project be kept confidential?

When you participate in research, you have a right to confidentiality, which means that what you say will not be shared with other people without being anonymised. Only the research team may see/hear what you have said before it is anonymised. However, if you share something that makes the researcher concerned about yours or someone else's safety, they may have to tell the relevant people about this. They will always try to speak to you before doing this. You will be given a participant number prior to the interview and this will be used with your transcription. Your name will not be associated with the audio file to ensure anonymity.

How will you look after the data you collect about me?

Your normal rights under the Data Protection Act and the General Data Protection Regulation apply. However, we need to manage your records in specific ways for the research project to be reliable. This means that we won't always be able to let you see or change the data we hold about you. At all times this research study will comply with the General Data Protection Regulations (GDPR, 2018) approved by the EU parliament on 14 April 2016 and passing into UK law with effect from 25 May 2018. We need to ensure that you understand what will happen to data we collect about you as well as your legal rights. This document is accompanied with a separate Privacy Notice providing further details. All of your data will be held securely on the University of Leicester research drive. Due to the need to undertake the research project virtually, there will not be any paper files with any identifiable data of yours on it. Your audio file will be linked to a participant number to ensure anonymity.

If you would like to withdraw from the study, please email sk772@leicester.ac.uk. They will then make a note that you would like to withdraw from the study. Please note that data collected up until that point may still be used. Please be aware that once the audio file has been transcribed and the participant number assigned, you will no longer be able to withdraw your data as we will not be able to identify which is yours. There will be no negative consequences as a result of withdrawing from the study.

If you require more GDPR data protection information then you can access this via the University's Information Assurance Services:

Information Assurance Services

University of Leicester

University Road

Leicester

LE1 7RH

T: +44 (0)116 229 7945

E: ias@le.ac.uk

W: <https://www2.le.ac.uk/offices/ias>

What will happen to the results of the research project?

Once all of the participants' files have been transcribed, the researcher will explore what you and others have said and look for themes. This will be written up for a Doctoral Thesis for the Doctorate in Clinical Psychology and may be published in a journal. Direct quotes from what you have said may be used within this, however, your name will not be included. If you would like the copy of the findings of the research project, you can email sk772@leicester.ac.uk and the results will be sent to you.

What should I do if I want to take part?

If you do decide to participate, you can email the research team at sk772@leicester.ac.uk to express your interest. Your name and contact details will be noted and will be held securely. We will then organise a time and date for the interview that works around your commitments. Prior to the interview, we will go through this information sheet before asking you to provide Informed Consent. The consent form will include different issues related to the project. This will confirm you understand how your data will be processed, protected and reviewed for research purposes.

Who is organising and funding the research project?

The research is being undertaken as part as doctoral research for a Doctorate in Clinical Psychology. Hence, the research team is made up of a student and member of staff. There is no funding for the project.

What if something goes wrong?

In the very unlikely event of you being harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for legal action but you may have to pay for it.

Who has reviewed the research project?

The research project has been approved by the University of Leicester Research Ethics Committee.

Contact for Further Information

If you have any further questions or would like to participate in the study, please email the research team at sk772@leicester.ac.uk and they will get back to you as soon as possible.

If you have any concerns or queries about the way in which the research project has been conducted, contact the Chair of the University Research Ethics Committee on ethics@le.ac.uk.

Thank you for taking the time to read this information

Sanaa Kadir

sk772@leicester.ac.uk | Trainee Clinical Psychologist | University of Leicester | Chief Investigator

Appendix K*

Empirical Research: Template Consent Forms

Participant Consent Form

BACKGROUND INFORMATION

Title: Understanding The Unexplained: How The Experience of MUS Is Culturally-Mediated

Researchers: Our names are Sanaa Kadir and [REDACTED] from the University of Leicester School of Psychology.

Purpose of data collection: Doctoral research.

Details of Participation: We are recruiting psychologists who have had experience of working with people presenting with Medically Unexplained Symptoms from culturally diverse backgrounds. Participation will involve a 15-30 minute semi-structured interview about your experiences.

CONSENT STATEMENT

1. I understand that my participation is voluntary and that I may withdraw from the research at any time, up until the audio recording has been transcribed, without giving any reason. In order to withdraw, please email sk772@leicester.ac.uk.
2. I am aware of what my participation will involve.
3. My data are to be held confidentially and only Sanaa Kadir and [REDACTED] will have access to them.
4. My data will be kept electronically on the University of Leicester Research Drive for a period of at least five years after the appearance of any associated publications. The transcriptions will be kept for the same length of time, after which they will be deleted.
5. I give my permission for quotes from what I say to be used verbatim in published reports and any publications. I understand that anything that is included in the results will be anonymised, and all personal detail removed, so I will not be identifiable.
6. The overall findings may be submitted for publication in a scientific journal, or presented at scientific conferences.
7. This study will take approximately six months to complete.
8. I will be able to obtain general information about the results of this research by emailing sk772@leicester.ac.uk.
9. I agree to the interviews being recorded on an encrypted Dictaphone. I understand that the researcher or an independent transcribing company may be used to listen to the interviews and transcribe these. When it is written up, it will be anonymised so I cannot be identified.

I am giving my consent for data to be used for the outlined purposes of the present study

All questions that I have about the research have been satisfactorily answered.

I agree to participate.

Participant's signature: _____

Participant's name (please print): _____

Date: _____

If you would like to receive a summary of the results when the study is complete, please email sk772@leicester.ac.uk.

If you have further questions about this study, you may contact Sanaa Kadir on sk772@leicester.ac.uk.

This study was reviewed by the University of Leicester Psychology Research Ethics Committee (PREC). You may contact the Chair of PREC [REDACTED] at [REDACTED] if you have any questions or concerns regarding the ethics of this project.

Please note that this form will be kept separately from your data

Appendix L

Empirical Research: Methodological Considerations

Within this research, Thematic Analysis (Braun & Clarke, 2006) was used as the analytic method. The research question and epistemological position directed this decision. Given the exploratory nature of the research question and the use of interviews, a number of qualitative methods were considered. Some were excluded due to a lack of fit with the research question, for example grounded theory was excluded as the research aim was not related to theory development and IPA was excluded as the research was not idiographic in nature.

Larkin (2015) suggested the use of epistemology to guide research methods. A critical realist position was taken within this research, where it is considered that reality is influenced by subjective experiences and interpretations of the world. Therefore, an analytic method that could allow the critical realist position was necessary. Thematic Analysis is an epistemologically flexible and methodologically flexible approach (Clarke et al., 2015), and therefore felt like an appropriate fit for this research.

Furthermore, Thematic Analysis provides a rich and detailed account of data and can generate data-driven insights (King, 2004; Nowell et al., 2017). This was felt to be important as it focused on the meaning the participants were making. Thematic Analysis is also structured and therefore is able to provide clear data analysis and interpretation, which is important for considering quality within the epistemological position (King, 2004). A criticism about Thematic Analysis is that its flexibility can lead to a lack of coherence and inconsistency; however, this can be overcome by explicitly applying the epistemological position (Holloway & Todres, 2003).

The flexibility of Thematic Analysis also reduces the preconceived assumptions it brings to the analysis of data. Within Thematic Analysis, one can position themselves in different ways to ensure analysis remains epistemologically congruent (Nowell et al., 2017). Therefore, an open coding process was used to ensure codes were data-driven rather than using pre-set codes. Also, an inductive approach was used whereby analysis went beyond simply describing patterns of meaning in the data, but exploring their deeper meanings and importance.

Given the relevance to the research question, epistemological congruence with the position taken and flexibility within the use of the method, Thematic Analysis was felt to be the most appropriate analytic method for this exploratory research question.

References

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Appendix M*

Empirical Research: Process of Thematic Analysis

Steps in Thematic Analysis	Application In This Research
Step 1: Become familiar with the data	A number of methods were used to become familiar with the data. Conducting the interviews was the first stage of familiarity. The interviews were then listened back to. Some of the audio files were transcribed which allowed further familiarity with the data. All of the transcripts were read and initial thoughts were noted down.
Step 2: Generate initial codes	<p>Because the interviews were addressing a specific research question, a predominantly theoretical framework within Thematic Analysis was adopted whereby all data that was interesting and relevant was coded. Open coding was used as the codes were developed through the coding process rather than utilising pre-set codes.</p> <p>The coding was completed on PDF versions of transcripts. The coding was then transported to qualitative data analytic software Nvivo, which collates the codes and can produce graphs to consider the frequency of the codes across the transcripts to support theme generation. For each transcript, interesting or relevant data was highlighted and a code put against this. As this process was applied through the transcripts, recurrent codes were noticed and these were considered and modified before moving to the next transcript. All codes were listed in a separate document and the frequency that the code appeared within and across transcripts was noted.</p> <p>A second analyst independently coded a randomised sub-section of the transcripts. These were then assessed against the initial codes that had been created and high level of agreement between the two analysts in the coding of data was found.</p>
Step 3: Search for themes	Analysis of the listed codes and Nvivo graphs revealed patterns between the codes, as some clearly fit together. At this point, preliminary themes were created. They were descriptive in nature and explained what that broader theme said about the dataset.
Step 4: Review themes	<p>These preliminary themes were then reviewed and modified. Data relating to each code was assessed against the preliminary theme to ensure the theme captured the data. At this point, subthemes for the preliminary themes were created.</p> <p>The different themes were then compared against each other. At this point a number of points were considered; was there significant overlap; could each theme stand on its own; were there themes that were missed; and what did each theme mean?</p> <p>A third analyst independently reviewed the codes and themes to ensure an appropriate 'fit' and that the themes were adequately describing the codes.</p>
Step 5: Define themes	In this stage, the themes were refined through considering how they could be defined. The relationships between subtheme and theme were also considered and the subthemes were refined. The data used to illustrate the subthemes and themes was also reviewed. A thematic map was created.
Step 6: Write up	The result section of the empirical piece was then written, attending to each theme and subtheme. Within this, further consideration of what the data was saying and the context behind it was provided.

Appendix N*

Empirical Research: Theme Development

In the analysis of the data, codes were put against interesting pieces of data in a line-by-line coding method. These codes from the transcripts were then noted, in alphabetical order on a separate page. A tally was put against the code if it was mentioned multiple times within a transcript or was noted in other transcripts (Figure 1).

Initial List of Codes	
Additional contextual factors	
Additional/positive outcomes of symptoms	I
Attachment	
Cannot reduce to only mental health difficulties	
Complex presentation	
Complexity with professionals	I
Cultural acceptance of mental health	
Cultural barriers	
Cultural expectations	
Cultural expectations of healthcare	
Cultural expressions of distress	
Cultural idioms of distress	
Cultural norms	
Cultural understandings of distress	
Cultural/understanding impacts presentation	
Difficult life experiences	
Diversity in patient journey	I
Division of physical and mental health /professionals	
Engagement depends on sense-making	I
Equal access to services	I
Externalisation vs internalisation	
Faith narratives	I
Family narratives	
Fear of something being missed	
Frequently seen	
Harder working with MUS	I
Impact of culture on presentation	
Impact of culture on understanding / sense-making	
Impact of culture	
Impact of culture on treatment	
Impact of faith community	
Impact of families	
Impact of labelling	
Impact of patient journey on outcome	
Impact of professionals	
Importance of a diagnosis	
Importance of culturally-informed/sensitive treatments	
Importance of formulation	
Importance of systemic approach in formulation and treatment	I
Importance of therapeutic relationship	
Importance of understanding cultural context	
Importance of understanding the symptoms	
Importance of validation	
Individual differences	
Institutional influences on patient journey	
Involvement of family in therapy	
Lack of patient pathway (lack of resources)	
Lack of support from others	
Language and communication	
Link to mental health	
Little cultural variation in presentation	
Medical model /diagnostic narrative	
Mind-body connection	
More frequent in certain cultures	I
Multiple understandings/explanations at once	I
Need an individualised approach	
Need for earlier psychological intervention	
Need for MDT approach	
Need to acknowledge professional-client differences	
Need to co-construct meaning/shared understanding	
Need to improve quality of life	I
Negative attitudes of others	
Negative experience of the patient journey	
Negative systemic influences (media/online)	I
Not challenging their perspective	I
Not frequently seen	
Patient looking for answers	
Professionals not considering the influence of culture	
Professionals not understanding	
Psychological impact of symptoms	
Religion/spirituality as a means to make sense	
Religion/spirituality as a coping strategy/treatment	
See it as physical health	
Similarities between people with MUS presentations	I
Societal expectations	I
Stigma	
Systemic Influences	I
Trauma	
Uncertainty	
Unclear referrals	I

Figure 1. A list of all codes in alphabetical order from coding the transcripts

During this process, codes that could be clustered together into themes or subthemes were noticed. Once all transcripts were coded, the relationship between the codes was explored. This enabled the creation of initial themes and subthemes (Figure 2).

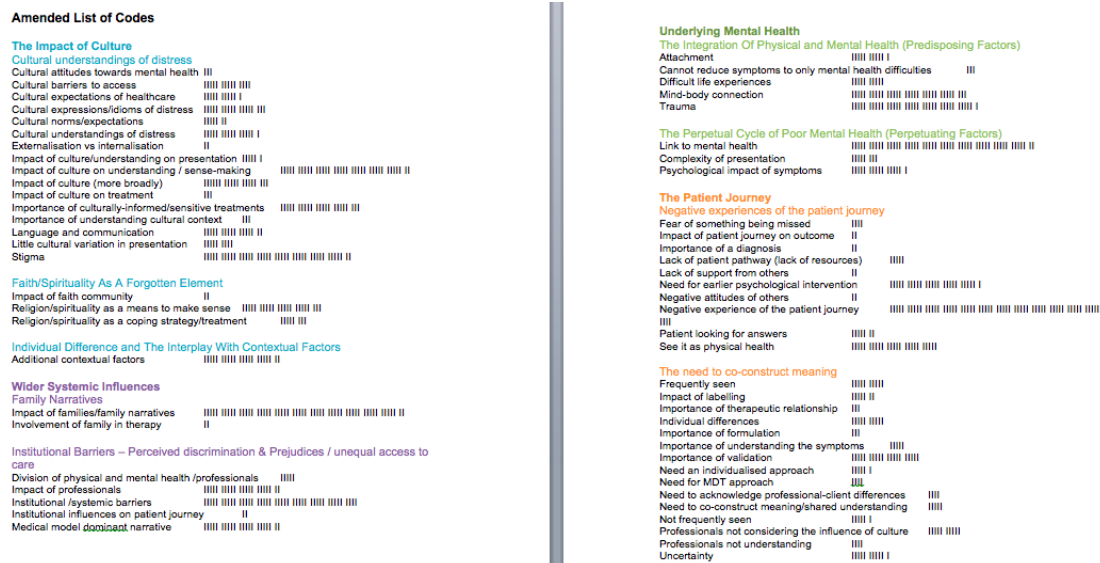


Figure 2. Initial groupings of codes into themes and subthemes

Once the initial groupings had begun, the transcripts were then assessed against the initial grouping process to ensure that the themes and subthemes were data-driven and representative of the dataset. At this point, the highlighted codes in the transcriptions were colour-coded for clarity and relevant quotes across all participants were noted beneath the themes and subthemes (Figure 3). Through this process, the themes and subthemes were re-arranged.

Appendix O*

Empirical Research: Quality Assurance Methods

Quality

Initially, in the research development phase, the criteria developed by Dixon-Wood et al. (2004) were used to consider the quality of the research. This considered clarity of the research question, appropriateness of fit between methodology and research question, clearly describing and considering the appropriateness of the sampling, data collection and analysis, and whether the research would make a useful contribution. These elements were considered when considering the research idea, writing the research protocol and were assessed by a number of academic and clinical professionals.

However, whilst undertaking the research and considering its quality, a different approach was taken. Sale (2008) stressed the importance of utilising epistemologically congruent quality appraisal tools, as many criteria recognised methodological differences between quantitative and qualitative research but not ontological differences. Barbour (2001) argued that methodology-weighted criteria might not do justice to qualitative approaches with differing philosophical paradigms. Cohen and Crabtree (2008) suggested that rich content, clear descriptions of the methodological process, researcher self-reflection and demonstrating how results were attained were important factors. This approach was also appropriate within the context of the critical realist position.

Consequently, the quality of the research data itself was assessed using the 15-point checklist of criteria for good Thematic Analysis (Braun & Clarke, 2006; checklist in Appendix P). This considered quality at multiple levels of the data analysis, enabled

the production of rich content, promoted researcher self-reflection and could be used to demonstrate how the results were attained. It also explicitly considered the epistemological position within the analysis and throughout the research. The written report section of the checklist was also consulted when writing the results section of the empirical study. A reflective diary was also kept to attend to reflexivity and enable self-reflection.

Reliability

When considering reliability within qualitative research, the literature speaks about the importance of 'trustworthiness' of the findings and 'dependability' of the method of analysis (Braun & Clarke, 2013; McLeod, 2001; Noble & Smith, 2015). Noble & Smith (2015) approach that adopted. They suggested that clear and transparent decision trails and considering researcher bias was important to allow another researcher to find comparable findings. Within critical realism, there is an expectation that the researcher's engagement with the research will impact it. Therefore, the aim was not to reduce bias per se, but to assess that the codes and interpretations were coherent and data driven.

Numerous researchers recommend the use of an independent individual to look at data segments or the coding (Barbour, 2001; Barry, 1999; Noble & Smith, 2015). It encourages the consideration of different codes and themes that may have been missed to try to ensure that the dataset is represented as a whole (Barbour, 2001). This can provide thoroughness by exploring the data and accounting for how the analysis took place (Barbour, 2001).

Therefore, a subset of the transcriptions was sent to an independent second analyst who had not been involved with the interviews or seen any coding of the data. This ensured that the analysis included more than one perspective to ensure it made

sense to others, that the data interpretations were consistent and transparent and that the analysis was coherent (Yardley, 2015). Five transcripts were sent to the second analyst; this was considered an appropriate number as it represented a quarter of the sample and met the time constraints the second analyst had. A random number generator was utilised to pick which transcripts were analysed. The codes generated by the second analyst were very similar the codes that were initially generated, suggesting the codes were representative of the dataset. They also showed that the coding was coherent and consistent.

A quantitative assessment of reliability (such as Cohen's Kappa) was not utilised to assess inter-rater reliability. This was in the context of the debate that surrounds being able to ascertain reliability in qualitative research. Also, seeking a quantitative assessment of reliability could suggest a realist perspective and would be epistemologically incongruent (Yardley, 2015).

Noble & Smith (2015) also felt that 'trustworthiness' could be evidenced by use of verbatim descriptions to support findings, which was adopted in this study. Lastly, they stressed the importance of demonstrating the thought process for data analysis, which was considered through the structured approach in Thematic Analysis (Appendix N).

Validity

There is debate surrounding how best to evidence validity in qualitative research. Yardley (2015) suggested four criteria by which to assess the validity: sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance. She felt that most validity assessments for qualitative research covered these criteria and this approach could be epistemologically flexible.

Within this research, sensitivity to context was attended to by considering the services and populations the participants worked with and how this may influence their perspective. For example, it appeared that most participants in neurological services saw MUS more frequently and therefore had more experience with patients with MUS. The socio-cultural and linguistic context was attended to by considering the fact that the dominant biomedical narrative in the UK may have influenced all of the participants in the study. By adopting an open coding approach for the Thematic Analysis ensured sensitivity to the data as codes were derived from the transcripts, rather than utilising pre-conceived codes.

Commitment and rigour is referred to as an in-depth engagement with the topic and consideration of the research methods (Yardley, 2015). Reviewing the relevant literature and speaking to clinical services about their experiences of MUS prior to data collection considered this. An academic supervisor and field supervisor also reviewed the appropriateness and relevance of the research methods. This was particularly important given the numerous changes to the project due to COVID-19 restrictions and a lack of participants. An ethics committee and research sponsorship team reviewed the final research project through which they assessed the validity of the research methods.

Transparency and coherence was attended to by using a third analyst to review the list of codes against the themes and subthemes that had been generated. This allowed the exploration of whether the themes and subthemes accurately represented the themes generated from coding the dataset. It allowed some assessment of the validity of the results. They also reviewed the overall results and discussion section to also ensure that these were representative of the findings and were answering the research question.

Lastly, impact and importance were considered from the inception of the research idea to the final write up. The way in which the results of the research could add knowledge to services and clinicians was considered. The services initially approached to take part in the study were asked about the utility of this research. The participants in the research affirmed the importance of the research and its clinical applications.

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Appendix P*

Empirical Research: Quality Appraisal Checklist

The Braun and Clarke (2006*) 15-point checklist for good Thematic Analysis is shown. This quality appraisal checklist was chosen due to its appropriateness in assessing the analytic method adopted in this research and due to its flexibility in meeting the epistemological position taken in the research.

Process	No.	Criteria	Considered
Transcription	1	The data has been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'	Yes
	2	Each data item has been given equal attention in the coding process	Yes
Coding	3	Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive	Yes
	4	All relevant extracts for each theme have been collated	Yes
	5	Themes have been checked against each other and back to the original dataset	Yes
	6	Themes are internally coherent, consistent and distinctive	Yes
Analysis	7	Data have been analysed – interpreted, made sense of – rather than just paraphrased or described	Yes
	8	Analysis and data match each other – the extracts illustrate the analytic claims	Yes
	9	Analysis tells a convincing and well organised story about the data and topic	Yes
	10	A good balance between analytic narrative and illustrative extracts is provided	Yes
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing phase or giving it a once-over-lightly	Yes
Written Report	12	The assumptions about, and specific approach to, thematic analysis are clearly explicated	Yes
	13	There is a good fit between what are you claim to do, and what you show you have done – i.e. describes methods and reported analysis are consistent	Yes
	14	The language and concepts used in the report are consistent with the epistemological position of the analysis	Yes
	15	The researcher is positioned as <i>active</i> in the research process; themes do not just 'emerge'	Yes

*Checklist taken from Braun, V., & Clarke, V. (2013). *Successful Qualitative Research: A Practical Guide for Beginners*. London: SAGE Publications Ltd.

Appendix Q*

Empirical Research: Chronology of the Research Process

Stage of Research	Timescale
Consultation with field and university research supervisors	January 2019
Development of the research proposal	January – May 2019
Interview panel	June 2019
Amendment to research proposal and development of research material	June – November 2019
Peer review panel of research proposal	November 2019
Received approval from service-user reference group (SURG)	November 2019
Refinement of research proposal and research material	November – December 2019
Received research cost approval	December 2019
Received research sponsorship from the University of Leicester	January 2020
Application to REC and HRA via NHS Ethics	January 2020
Received favourable opinions from REC and HRA approval	April 2020
Submitted substantial amendment (to amend interviews to being conducted online and remove the UHL recruitment site due to COVID-19)	June 2020
Received R&D approval from recruitment sites	July 2020
Submitted substantial amendment (amended to include clinicians in interviews)	December 2020
Application with the University Ethics Procedure to encourage recruitment through social media	January 2021
Ethical approval from University Ethics Procedure	January 2021
Recruitment of participants via social media and snowball sampling as per University Ethics Procedure	January – February 2021
Data collection*	February 2021
Transcription and data analysis	March 2021
Write up of thesis manuscript	February – April 2021
Thesis submission to the University of Leicester	May 2021

* Participants were only recruited from the University Ethics pathway; no participants were identified or volunteered via the NHS Ethics pathway. The appendices therefore relate to the University of Leicester pathway.

Appendix R*

Empirical Research: Ethical Approval From the University of Leicester

Ethics Process



School of Psychology Research Ethics Committee

26/01/2021

Ethics Reference: [REDACTED]

TO:

Name of Researcher Applicant: [REDACTED]

Department: Psychology

Research Project Title: Understanding The Unexplained: How The Experience of MUS Is Culturally-Mediated

Dear [REDACTED],

RE: Ethics review of Research Study application

The School of Psychology Research Ethics Committee has reviewed and discussed the above application.

1. Ethical opinion

The Committee grants ethical approval to the above research project on the basis described in the application form and supporting documentation, subject to the conditions specified below.

2. Summary of ethics review discussion

The Committee noted the following issues:

The proposed amendment does not pose any additional ethics issues.

3. General conditions of the ethical approval

The ethics approval is subject to the following general conditions being met prior to the start of the project:

As the Principal Investigator, you are expected to deliver the research project in accordance with the University's policies and procedures, which includes the University's Research Code of Conduct and the University's Research Ethics Policy.

If relevant, management permission or approval (gate keeper role) must be obtained from host organisation prior to the start of the study at the site concerned.

4. Reporting requirements after ethical approval

You are expected to notify the Committee about:

- Significant amendments to the project
- Serious breaches of the protocol
- Annual progress reports
- Notifying the end of the study

5. Use of application information

Details from your ethics application will be stored on the University Ethics Online System. With your permission, the Committee may wish to use parts of the application in an anonymised format for training or sharing best practice. Please let me know if you do not want the application details to be used in this manner.

Best wishes for the success of this research project.

Yours sincerely,

A black rectangular box used to redact the signature of the Chair.

Chair

Appendix S*

Empirical Research: Sample Annotated Transcript

	<p>Interviewer That's okay.</p> <p>Respondent I'm not really sure. I think, I mean in languages or dialects the vocab or the concept of...of...mental health difficulties or certain, yes, certain psychological concepts – so you might have to think about how to make therapies or certain approaches accessible and culturally sensitive. If language was a particular barrier, I might be inclined to look at kind of EMDR or art based drawing approaches. Or something that isn't as reliant on language and understanding of language.</p>	<p>Impact of culture on understanding</p> <p>Language and communication</p> <p>Culturally-sensitive / individualised treatment approaches</p>
Need for culturally-sensitive treatments		
	<p>Interviewer Yes.</p> <p>Respondent I guess I would also want to think systemically with my supervisor and think about the social graces of are my expectations or kind of my ideas about this person different because of the differences between us culturally? Culturally, economically, educationally – lots of different things. So, I'd want to kind of consider all of those things, yes.</p> <p>Interviewer Yes, that's great. So, that was all the questions I had – is there anything else that we've not covered that you'd like to mention?</p> <p>Respondent Just I...one of my absolute bug bears is when people refer to services at the end of the line, kind of when everything else has been tried. Because I...I have the approach that every physical medical problem has a psychological component, even if it is medically explained. There are psychological aspects to living with that condition. So, actually, if psychology can be integrated from the start, it kind of overcomes some of these cultural, some of these myths of it's all in my head. Or they've given up on me. Yes, but I do think there also needs to be education and some myth busting around some of this stuff. And thinking really practically about how we can reach harder to reach communities that are perhaps less likely to access psychological services, medical services and linking with community centres, community leaders and things and thinking on a local community level</p>	<p>Additional contextual factors</p> <p>Link to mental health</p> <p>Institutional/systemic barriers to access</p>
Need to acknowledge practitioner-client differences		
Need for earlier psychological intervention		
Need for earlier psychological intervention		

Figure 1. Snapshot of an annotated transcript from one participant. Shows Step 4 in the Thematic Analysis as the codes are beginning to be grouped together, denoted by the use of colour.

Appendix T*

Empirical Research: Attendance To Reflexivity

Reflexivity can be defined as an awareness that the researcher contributes to the construction of meaning in the research process (Nightingale & Cromby, 1999). Reflexivity highlights that the researcher is a self-interpreting being and is important to make explicit for readers (McLeod, 2011). Dodgson (2019) commented that reflexivity was a dual process; increasing credibility of the findings whilst deepening the researcher's understanding of the work. Within Thematic Analysis, it is recommended that researchers keep self-critical accounts of the research process (Tobin & Begley, 2004). This is not only for personal reflections but also to record logistical and methodological decisions (Nowell et al., 2017).

Below are extracts from the research reflective dairy. The '*brain dump*' method, developed by Marhkam (2017), was used in these. This can be more formally thought of as elicitation of self-directed introspection (Marhkam, 2017). At numerous points during the research process, the research writes their thoughts relating to reflexivity under timed conditions (three minutes) and is not allowed to stop or re-read these until the end. The researcher can then go back and use reflexivity to consider underlying assumptions, decisions and interpretations that they may have. Below are two extracts from the research diary that attend to reflexivity:

Reflections prior to research

In developing the research protocol, I was aware of my own prior experiences being a motivating factor in better understanding this topic. Identifying as an individual from a different cultural background to the predominant one in this country, I am eager to better understand how culture can influence people's experiences. I am very

motivated to support services to become more culturally sensitive and attend to cultural needs. I was aware through the process that it was important to ensure I stayed with the research question, and therefore noted and parked my own biases when conducting the research. It was important that the research remained meaningful, relevant and applicable to services.

Reflections during an interview

During one particular interview, I noticed how different it felt conducting research over the telephone compared to in person. I felt that a lot was missed. At one point, when a participant spoke about their personal experiences of MUS, it reinforced how distant and disembodied it felt over the phone. It also made the need to investigate this topic more pertinent as it highlighted the real impact MUS can have on people's lives. I was not expecting an emotional response given that I was interviewing professionals and this was something I needed to attend to. At times, my role as a trainee Clinical Psychologist tempted me to make notes during the interview or hold onto themes or subthemes that felt important. However, it was important for me stay firm in the role of being a researcher and put aside being a trainee.

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- Nowell, L.S., Norris, J. M., White, D.E., & Moules, N.J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal Of Qualitative Methods*, 16(1), 1-13.
- Tobin, G.A., & Begley, C.M. (2004). Methodological rigour within a qualitative framework. *Journal of Advanced Nursing*, 48, 388–396.

Appendix U*

Guidelines for Authors for the Journal Targeted for the Literature Review

BMC Medical Education guidance for authors

<https://bmcmmededuc.biomedcentral.com/submission-guidelines/preparing-your-manuscript/review>

<https://bmcmmededuc.biomedcentral.com/submission-guidelines/preparing-your-manuscript>

Appendix V*

Guidelines for Authors for the Journal Targeted for the Empirical Study

British Journal of Health Psychology guidance for authors

<https://bpspsychub.onlinelibrary.wiley.com/hub/journal/20448287/homepage/forauthors.html>

Appendix W

Personal Reflections

Completing both the literature review and the empirical piece allowed a more developed understanding of not only the topic at hand, but also wider issues within the healthcare framework.

Reading some of the comments participants made in the papers used in the literature review were quite emotive and demonstrated how important interactions with healthcare professionals could be for patients. It emphasised the impact that negative experiences with healthcare professionals could have on the patient journey, for example disengaging from services. On the other hand, it also served as a reminder of the stress and pressures that healthcare professionals experience and how easily this can lead to burnout. I felt able to simultaneously empathise with the pressures of being a healthcare worker in the NHS and the impact of a negative experience when I have been in the role of a patient.

Conducting the empirical piece solidified the rationale for being interested in this research. Some participants thanked me for doing this research and many were very keen for the results to be shared with them. Participants felt understanding Medically Unexplained Symptoms more broadly was also extremely important, particularly as this presentation was frequently seen within some services.

Participants also acknowledged the need to develop culturally sensitive services, recognising this was often overlooked. I recognised the need for this on a personal level too. As a person of a different cultural background, I found myself being able to relate to experiences of services not being equipped to consider and support cultural

differences and feeling there was no space for this discussion. It felt confirming that many participants felt that culture and the role it plays in meaning making was something they needed to give more time and attention to. I felt positive that through my role as a trainee Clinical Psychologist, and hopefully in the future as a qualified Clinical Psychologist, I could contribute to research about topics that are important to me, and hopefully contribute to knowledge and change in the area.

Appendix X*

Checklist Assuring Confidentiality/Anonymity of Participants

	Checked In Abstracts	Checked In Main Text	Checked In Appendices
Pseudonym or false initials used	√	√	√
Reference to pseudonym/false initials as a footnote	√	√	√
Removed any reference to names of Trusts/hospitals/clinics/services (including letterhead if including letters in appendices)	√	√	√
Removed any reference to names/specific dates of birth/specific date of clinical appointments/addresses/ location of client(s), participant(s), relatives, caregivers, and supervisor(s).	√	√	√
Removed/alterd references to client(s) jobs/professions/ nationality where this may potentially identify them.	√	√	√
Removed any information that may identify the trainee (consult with course staff if this will detract from the points the trainee is making)	√	√	√
No Tippex or other method has been used to obliterate the original text – unless the paper is subsequently photocopied and the trainee has ensured that the obliterated text cannot be read	√	√	√
The "find and replace" function in word processing has been used to check the assignment for use of client(s) names/other confidential information	√	√	√