How do Health Professionals experience working with people living with or affected by Medically Unexplained Symptoms (MUS) in South Wales Secondary Care Services? An exploration using reflexive thematic analysis

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Dedication:

This thesis is dedicated to the ten remarkable participants whose experiences contributed to and enriched this research inquiry. Your humility, honesty, and wisdom have nurtured my curiosity and ignited a desire for continuous understanding.

I also dedicate my thesis to the countless individuals who live and are affected by Medically Unexplained Symptoms (MUS). I see you...

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1. Abstract:

Background: Medically Unexplained Symptoms (MUS) present persistent challenges for people living with or affected by MUS, marked by uncertainty and stigmatisation. Equally, healthcare professionals face complex diagnostic and treatment dilemmas when working with these often un-diagnosable and untreatable conditions. Despite these challenges, research in this area has to date been limited in Wales, particularly within the Swansea Bay University Health Board (SBUHB) region. This lack of research and resources complicates efforts to understand how best to support healthcare professionals in their care for people living with or affected by MUS.

Aims: To explore the experiences of healthcare professionals in secondary care services at SBUHB, South Wales, when working with people living with or affected by MUS. The aim is to understand how these experiences affect them personally as individuals and in their professional roles, with the goal of enhancing support for both healthcare professionals and patients.

Methods: Ten participants were recruited from secondary care services in SBUHB. Semi-structured interviews focused on their experiences of working with people living with or affected by MUS and were analysed using a critical realist orientated Reflexive Thematic Analysis (RTA). **Results:** The analysis produced three overarching themes, offering a complex and multifaceted nature of MUS: (1) 'Lost in the Fog of Uncertainty' (2) 'Health Professionals Subjective Journeys' and (3) 'Beyond the Fog: Envisioning Future Care for MUS'.

Conclusions: This is the first known inquiry that asks health professionals in Wales about their experiences of working with people living with or affected by MUS, addressing critical gaps in the existing literature. It highlights the role of uncertainty, shared emotional burdens, vulnerability to Potential Morally Injurious Events (PMIE), and the fragility of the therapeutic relationship. Additionally, this inquiry illuminates the complex interplay between healthcare professionals' personal and professional identities, emphasising how these intersecting identities can shape perceptions of patients, influence patient responses, and ultimately affect the care provided in healthcare practice for people living with or affected by MUS.

Implications for Counselling Psychology: This inquiry advocates for a patient-centred paradigm shift, urging the recognition of addressing systemic challenges, advocating for reflexive practices, and a nuanced linguistic approach in MUS care. Counselling Psychology can lead these conversations and foster interest in the field of MUS in Wales, ensuring that the voices of healthcare professionals and people living with or affected by MUS are not only heard but also actively integrated into care practices. Moreover, findings highlight the importance of fostering reflexivity when working with people living with or affected by MUS. By championing self-awareness and reflective practices, Counselling Psychology can help equip healthcare professionals in navigating their ontological positions, deepening their understanding of their role in the therapeutic relationship, and shaping the trajectory of care.

2. Introduction

"They may not feel validated if you are internally thinking I do not believe what you are saying. I do not believe this is a true disorder. You may not be saying it, but they may pick up on your body language the way you are talking, the way you are framing the questions, and they could think well, he did not believe this... It does come across in your encounters, albeit not necessarily through the word spoken, but through body language phrases, values, judgments. They can all be interpreted by the patient."

(David, Nurse)

2.1. Chapter Overview:

This first chapter will serve as the backdrop to the following research inquiry, which centres on the experiences of health professionals working with people living with or affected by Medically Unexplained Symptoms (MUS), in South Wales secondary care services. This is important, as it will help define the extent of the issue, to help situate the research inquiry clearly. Particular emphasis will be placed on service provision within Swansea Bay University Health Board (SBUHB), South Wales, to illuminate a noticeable gap in research and interest in this region. This disparity will set the stage for the importance and relevance of my research, while forming the basis for a more comprehensive exploration in the subsequent narrative literature review (*See Section 3*); where the focus will extend beyond the scope of South Wales.

2.2. Understanding the scope of the 'problem' of MUS:

Medically Unexplained Symptoms (MUS) is an umbrella term to describe a heterogeneous group of conditions of persistent physical complaints that do not appear to be symptoms of a medical condition (NHS, 2021). The literature offers various definitions and categorisations of these experiences (Kinsella & Moya, 2022). MUS covers a wide spectrum of physical complaints that vary in nature, site, severity and chronicity; it can present as mild discomfort for some and for others with more severe symptoms that can cause disability and impairment to daily functioning (Jadhakhan et al, 2022). In the UK National Healthcare Service, amongst the conditions that fall into this category include Fibromyalgia, Irritable Bowel Syndrome (IBS), Functional Neurological Disorder (FND) and Non-Epileptic Seizures to name just a few. Moreover, there is an on-going debate around the status of an additional illness, namely Myalgic Encephalomyelitis/Chronic Fatigue

Syndrome (ME/CFS) (NHS, 2021). See more details in *Section 3.3: Exploring Suitable Terminology*.

MUS is highly prevalent across various UK healthcare settings, constituting approximately 45% of general practice cases (Haller, Cramer & Lauche, 2015) and 20%-25% of frequent attenders in medical clinics (Jadhakhan et al, 2022). This high prevalence rate often results in repeated visits to different secondary care settings, including A&E, outpatient clinics, general wards, rehabilitation, stroke services, and mental health services. Previous UK literature indicates that people living with or affected by MUS can represent up to one in five primary care presentations (De Waal et al., 2004), with an even higher prevalence rate suspected in certain secondary care clinics (Nimnuan, Hotopf & Wessely, 2001). The financial strain on the NHS is substantial, affecting both physical and mental health services and accounting for up to 10% of the total NHS expenditure (Bermingham et al., 2010). It is important to note that the prevalence and cost data for the UK are outdated, with a notable absence of published information specific to Wales, particularly in the South Wales region. This information gap becomes more significant, given the heightened prevalence of this patient group due to the COVID-19 pandemic (Hunt, 2022). The aftermath of COVID-19 has resulted in a surge of non-organic cases associated with long COVID and COVID-19 vaccinations across healthcare services. Additionally, sub-groups within the long COVID bracket are currently lacking diagnostic biomarkers, and there are indications that influential proponents are framing these subgroups as a form of MUS (see Hunt, 2022). Therefore, the findings from this research inquiry may also be relevant for the long-term approach to the care and treatment for sub-groups of long COVID. This is because despite there being a clear genesis to long COVID, i.e. the COVID-19 virus, the response is still to position people living with or affected by long COVID as having 'unexplained' illness.

The high prevalence rates of MUS across the UK suggests that healthcare professionals in the NHS are routinely engaging in clinical interactions with people living with or affected by MUS - interactions that often involve experiences that are difficult to diagnose or treat, creating persistent challenges marked by uncertainty, which may affect both professional and patient (Meyer, Giardina, Khawaja & Singh, 2021). Although, there are a few studies that have acknowledged the doctor-patient relationship (Stone, 2014)

and doctors' attitudes towards people living with or affected by MUS (Kadir, 2022). Gaining a better understanding into experiences of healthcare professionals in their interactions with people living with or affected by MUS, is important for developing effective support systems. This is particularly pertinent given the absence of comprehensive research in Wales exploring the nuanced experiences of healthcare professionals working with this patient group.

2.3. Addressing the MUS Research Gap in South Wales:

This research inquiry takes on added significance, as it is centred in Wales. Research and interest in MUS in Wales is notably limited. The academic literature on this subject is scarce, with only two notable papers as exceptions. One paper surveyed newly qualified doctors in Wales and England regarding the teaching of MUS (See Yon et al., 2017). A second study conducted by the Health Research Agency at Cardiff University aimed to estimate the co-morbid prevalence of Post-Traumatic Stress Disorder and Medically Unexplained Physical Symptoms (MUPS) in primary care settings (See Downes, 2022). An additional study, titled "Why do children have chronic abdominal pain, and what happens to them when they grow up? Population based cohort study," included some data from Wales (See Hotopf et al., 1998). In terms of grey literature, the Welsh government published a document in 2019 titled 'Living with Persistent Pain in Wales.' Additionally, while not specific to Wales, the Royal College of Psychiatrists published a document in 2012 titled 'Liaison psychiatry and the management of long-term conditions and medically unexplained symptoms'. It is evident that MUS, is an under-represented area in research across Wales. It is hoped that this research inquiry will make a meaningful contribution to the limited literature and address the lack of attention given to people living with or affected by MUS in Wales. Understanding the experiences of healthcare professionals in Wales will be essential towards thinking of ways to enhance healthcare practices for both professionals and people living with or affected by MUS.

2.4. Disparities for Service Provision MUS in SBUHB:

The disparities in service provision for MUS within SBUHB highlight significant challenges in delivering effective care for people living with or affected by these conditions. The absence of clear and explicit pathways for managing MUS exacerbates these challenges,

leading to fragmented services and limited support for patients. While ideally, references would substantiate these observations, the absence of existing literature on this specific issue underscores the under-researched nature of service provision for MUS within SBUHB. Therefore, this section draws from initial consultations and discussions with healthcare professionals to provide insights into the current landscape of service provision for people living with or affected by MUS in SBUHB. It will also add very general references to substantiate the importance of having pathways.

Discussions highlighted that while most mental health and general health services within SBUHB offer fragmented care implicitly, there is a noticeable absence of comprehensive support tailored to the diverse and multifaceted needs of individuals living with or affected by MUS. For instance, within neurology services, the absence of an established pathway for Functional Neurological Disorders (FND) is apparent (O'Keefe et al., 2021; Jones, 2020). While there exists a limited pathway for patients diagnosed with Non-Epileptic Attack Disorder (NEAD), access to this pathway remains contingent on receiving this specific diagnosis by chance (Dickson et al., 2017a, 2017b). Presently, advocacy efforts are underway in SBUHB to establish a dedicated service for those living with or affected by FND. However, it is crucial to acknowledge that this initiative primarily caters to a subset of patients with neurological attributes among those living with or affected by MUS. Consequently, the broader spectrum of individuals with MUS will continue to be underserved (Wortman et al., 2018) or, as per discussions with healthcare professionals, may be referred to primary mental health services for psychological therapies (Geraghty & Scott, 2020)

2.5. Building a strategic case for MUS Research in Wales:

In alignment with strategic initiatives in Wales, this research inquiry addresses key directions set by the Welsh government, emphasising the necessity for care to meet the needs of individuals accessing services and to support them in managing their conditions while thriving in their communities (HEIW, 2020; Welsh Government, 2018). Focused on healthcare professionals within SBUHB, the study aims to understand the personal and professional implications of working with people living with or affected by MUS, with the goal of enhancing care provision in the SBUHB region. This effort aligns with the 'Wellbeing of Future Generations (Wales) Act (2015),' (Welsh Government, 2015) which

emphasises a shift towards preventative and wellness-focused care (Davies, 2017; Welsh Government, 2015). Furthermore, it supports the 'Healthier Wales: long-term plan for health and social care' outlined in the Parliamentary Review of Health and Social Care in Wales (2018) (Welsh Government, 2018), which aims to maximise physical and mental well-being and promote behaviours conducive to future health. Understanding the impact of MUS on healthcare professionals can inform strategies to enhance care delivery, ultimately benefiting a significant portion of the population affected by these conditions.

2.6. Situating the study: South Wales Coast and Valleys:

This section provides an exploration into the South Wales context, particularly the Swansea Bay region. This section is important, because patient-professional interactions – just like individual therapy – can potentially at best be limited, and at worse harmful, if we do not consider the wider challenges and context to individual experiences (see Bostock, 2017).

Wales, despite its relatively small size, has a population of around 3.13 million people reported in 2022 (Tranter, 2023). Notably, its coastal areas, including Cardiff and Swansea Bay, are densely populated, with approximately 372,000 and 241,000 residents, respectively (Clark, 2024). Until recently, coastal communities have been overlooked in public health literature, possibly due to a tendency to associate socioeconomic deprivation with inner cities (Asthana & Gibson, 2021). However, research suggests that coastal communities in fact face significant health challenges, including low life expectancy, poor access to health services and high rates of major diseases, alongside issues such as unemployment, low incomes, and poor educational attainment (Jones et al, 2019). Professor Sir Chris Whitty, in the Chief Medical Officer's Annual Report (2021) discussed these issues, describing coastal communities as having "Some of the worst health outcomes in England, with low life expectancy and high rates of many major diseases".

This neglect of coastal areas mirrors the broader socioeconomic struggles experienced across Wales, where nearly a quarter of the population lives in poverty, surpassing the UK average (Welsh Government, 2020c). Health needs in Wales are

estimated to exceed those of England and Scotland (Tranter, 2023). The decline of traditional industries like steel and coal in the 1960s has left a lasting impact on regions like South Wales, characterised by persistent social deprivation. Despite the decline, local communities in the Valleys endure, coping with economic challenges that translate into limited access to and quality of public services, exacerbating health disparities, emotional well-being issues, and social dynamics among residents (Byrne, Elliot & Williams, 2016).

These socioeconomic factors significantly influence beliefs and attitudes, shaping health behaviours in communities (Terry & Hogg, 1999; Kruglanski & Stroebe, 2005, Smith & Hogg, 2008), despite this impact, research on health beliefs and behaviours in Wales, particularly regarding MUS, remains absent. Nevertheless, as a reflexive study, I can draw from personal experiences as a 32-year-old Welsh woman raised in the Welsh valleys to offer anecdotal insights into potential issues, despite this lack of empirical evidence.

In my community, I felt that cultural norms prioritised work over education and health, with mental health and physical vulnerability stigmatised, and discussions about family matters rare. There was a strong emphasis on securing employment, viewed as both a priority and a privilege. Moreover, there appeared to be an emphasis on self-reliance and resilience, fostering a sense of stoicism. McGinty's (2023) findings on South Wales Valley cultures highlighted a tendency to normalise mental distress, economic hardship, and poor mental health literacy within the valleys, often evoking feelings of personal responsibility and shame. This supports my anecdotal evidence, suggesting that similar dynamics may extend to physical health within Welsh communities.

In light of this, individuals in these communities may prioritise enduring hardships without seeking external assistance until necessary. These cultural norms can also extend to expectations placed on patients or family members, complicating matters, especially for those experiencing often 'invisible' conditions like MUS. The invisibility of such illnesses, coupled with cultural expectations, may exacerbate feelings of invalidation and isolation, particularly in interactions with healthcare professionals, family members, or employers, as they too hold their own health beliefs and identities. This highlights that there are perhaps unique challenges faced by Welsh people navigating their healthcare experiences of MUS, within the broader context of cultural norms and societal expectation.

3. Narrative Literature Review:

3.1. Chapter Overview:

In this section, I will expand on the previous chapter by exploring deeper into a broader knowledge base of the experiences of healthcare professionals working with people living with or affected by MUS. To facilitate this exploration, a narrative literature review employed a storytelling approach, aligning with the principles advocated by Rother (2007) to explore the diverse perspectives surrounding this topic. Due to the significant gap in research focused on this area within Welsh healthcare services (detailed previously in section 2.1), the vast majority of the literature reviewed here extends beyond the Welsh context. This approach will allow for a more comprehensive overview of research related to MUS. In addition to healthcare professionals' experiences, this review will also encompass the perspectives and experiences of people living with or affected by MUS. However, the primary emphasis will remain rooted in understanding how healthcare professionals experience this patient group, and the consequent personal and professional implications. The review concludes by identifying further gaps in the existing knowledge of MUS and healthcare professionals' experiences, which will lay a deeper foundation for a detailed rationale underpinning this research inquiry.

3.2. Key words:

I conducted an extensive literature search between the periods of January 2021 to January 2023. Due to the varied terminology used to describe experiences of physical symptoms lacking organic causation (*see section 3.3 Exploring Suitable Terminology*), this search included all possible terms used to refer to individuals living with or affected by physical symptoms with no identified organic cause. It incorporated a combination of these terminologies, with terms such as therapeutic relationship, challenges, assessment, treatment, conceptualised, uncertainty, complexity, intervention, experiences, risk management, and expertise, along with specific terms like Counselling Psychology, Psychology and Wales. Databases that were explored included, PsycINFO, PubMed, CINAHL, ERIC, Scopus, Web of Science, ProQuest Psychology Journals, Social Sciences Citation Index (SSCI), PsycARTICLES, and Google Scholar.

3.3. Exploring Suitable Terminology:

Throughout the literature, the absence of a universally agreed-upon definition or classification for people living with or affected by MUS underpins the uncertainty that surrounds the diagnosis, treatment and prognosis of this condition (Han, Klein & Arora, 2011; O'Leary, 2018). This uncertainty manifests in the wide array of terms used to refer to people living with or affected by physical symptoms with no visible organic cause, such as 'uncertain illness' (Dumit, 2006), 'illness that cannot be diagnosed' (Jutel, 2010), 'illness without disease' (Aarseth, Natvig, Engebretsen & Lie, 2016) and 'symptoms that cannot be classified' (Kornelsen, Atkins, Brownell & Woollard, 2016). Less flattering phrases such as 'frequent attenders' (Lloyd-Rees, 2023), 'frequent flyers' (Clark & Brudney, 2021), 'heart sink patients' (Calne & Jackson 2023), 'thick folder patients' (Greco, 2012), and, particularly in the field of mental health 'malingering' (Boeberg, Jeppensen, Arnfred & Nordgaard, 2023) are prevalent in the medical literature.

The challenge of articulating physical symptoms without an identifiable organic cause is further complicated by diagnostic labels, including Functional Neurological Disorder (FND), Functional Somatic Symptoms, Medically Unexplained Physical Symptoms (MUPS), Psychosomatic Symptoms, Hypochondriasis and Conversion Disorder (Brown, 2006; The Joint Commissioning Panel for Mental Health, 2017). Moreover, the term 'MUS' is often employed to describe poorly understood illnesses, such as Fibromyalgia, irritable bowel syndrome or Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). Rasmussen (2020) characterised the MUS category as a 'junk drawer' in medical science, a repository of things we need to keep but have no designated place to put them.

The diversity and overlap in the use of these terms highlight one of the many challenges in this contentious field of study (Burton, Fink, Henningsen, Lowe & Rief, 2020); for instance, the ME/CFS Association highlights the difficulties in defining ME/CFS, due to the absence of clear diagnostic criteria. Health professionals often rely on their judgements when diagnosing ME/CFS, potentially leading to flawed and overly broad research studies that may include people who are experiencing fatigue for reasons other than ME/CFS, such as depression.

This variability in definition may result from differences in theoretical perspectives and positioning or may stem from the fact that there is no clear medical explanation. The ME/CFS association highlights the struggles with defining ME/CFS, determining who does

or does not have it, and consequently, what constitutes change. This issue serves as an exemplar to demonstrate the wider debate for other kinds of MUS.

In summary, the extensive use of terms and phrases to describe physical symptoms with no visible organic cause in the literature highlights the complexity and challenges associated with this condition. This complexity has the potential to lead to confusion among healthcare professionals, researchers, and patients themselves when encountering different terminology in various contexts.

Given the absence of consensus across the literature regarding the most appropriate term, I will use the term 'Medically Unexplained Symptoms' as the term aligns with the terminology used within the NHS (NHS, 2021). I will use MUS as an umbrella term to describe a heterogeneous group of conditions of 'persistent physical complaints that do not appear to be symptoms of a medical condition' (NHS, 2021). It felt important to make sure that throughout my thesis I am precise with my use of language; therefore, I will refer to my participants as people who are living with or affected by MUS. Although, I appreciate that this may be a more cumbersome form of language, not only is it more precise, but I also think it helps hold onto the person rather than a disease entity.

3.4. The Spectrum of Understanding: Exploring Explanatory Models:

This clear lack of consensus in terminology extends to how people living with or affected by MUS are understood in the literature (Marks & Hunter, 2015; Creed, Barsky & Leiknes, 2011). This diversity of perspectives on MUS appears to present significant challenges for health professionals in comprehending the nature of these symptoms, both from their standpoint and when communicating with patients (see Crimlisk et al., 2010). In the absence of a clear diagnostic criteria and guidelines, health professionals must often rely on their subjective clinical judgement to comprehend, explain and determine the direction of patient care.

The diverse explanatory models proposed across the literature (van Ravenzwaii, 2010) further amplify this complexity. Over time, various attempts have been made to develop a more comprehensive understanding of conditions characterised by MUS (Mewes, 2022; Lipowski, 1988). These explanatory models encompass a spectrum of perspectives, including physical, psychological, social and existential explanations, with

none holding a dominant position (Risor, 2009). While this research inquiry will not attempt to understand the causation of MUS, it is essential to outline key underlying concepts to illustrate the complexity that health professionals encounter in their practice with people living with or affected by MUS:

3.4.1. Western Medical Model and Distress:

The biomedical model, which is deeply ingrained in Western healthcare systems and extensively employed by the NHS, views *'ill health'* as a *'disorder'* attributed to physiological factors that necessitate treatment, typically involving medication or surgical interventions (Crossley, 1998). However, MUS challenges this explanation, as people living with or affected by MUS do not always fit neatly within current guideline-based treatment approaches. A predicament that can often leave patients with feelings of shame, stigmatisation, hopelessness (Rausch, 2021), and perceptions that their symptoms are dismissed as being *"all in the head"* (p.463) (Lilrank, 2003)

Within this biological explanation, one prominent model, which is also a psychological construct, is the 'Attention Model' (Brown, 2006). This model posits that the brain may allocate excessive attention to certain bodily sensations or functions, resulting in intensified attention to these sensations as physical symptoms. There are many other biological explanations scattered throughout the literature, each attempting to make sense of the complex nature of MUS. These include concepts such as central sensitisation (See Bourke, Langford & White, 2015), Dysregulation of the Autonomic Nervous System (ANS) (See Vreijiling, Troudart & Brosschot, 2021), and Immune system Dysregulation (See Husain & Chadler, 2021).

The lack of a definitive biological definition and causation in the literature frequently results in a dichotomous perception of MUS. When a purely physical cause remains intangible, alternative viewpoints from fields like Psychiatry or Psychology come into consideration (see Sanders, Winter & Payne, 2020). It is crucial to clarify that there exists a nuanced relationship between these levels; psychological or psychiatric processes are often not seen as emerging from illness, as is the case with identifiable organic causes like cancer. Instead, they are perceived either as causal, giving rise to the illness, or as contributing to its maintenance, where they are not originally causing it but are involved in preventing resolution or exacerbating the condition.

3.4.2. Psychiatric Explanation:

There is a wealth of literature that draws strong connections between MUS and individuals' past or present experiences with conditions such as depression, anxiety, panic disorders, and trauma (See Saunders et al., 2020; Smith, 2020). In particular, Smith (2020) validates the explanatory model, suggesting the prompt consideration of severe MUS as a red flag for underlying depression and anxiety. This conceptualisation characterises the relationship between anxiety, depression, and MUS as either causal, with anxiety and depression giving rise to MUS, or contributory to its maintenance. In the latter scenario, these mental health diagnoses may not be the original cause, but they play a role in impeding resolution or exacerbating the condition. He argues that an excessive focus on a biological framework, which tends to fall short in explaining MUS, can divert attention from the core issues of depression and anxiety. This was echoed by Saunders et al., (2020) who called for better alignment of mental health care for MUS after his study found that a significant number of children with 'psychosomatic symptoms' and related disorders did not receive mental health care despite having a clear mental health diagnosis.

Central to these psychiatric models is the concept of 'psychosomatic symptoms', implying that physical symptoms can be influenced by the mind and may arise from emotional stress, internal conflict, or negative thought patterns. Nevertheless, again there were multiple perspectives regarding somatisation across the literature. One common perspective attributes psychosomatic disorders to the physical response of the organs to excessive stress, burnout, or trauma that has gone too far (Sykes, 2020). In this context, the body reacts to intense experiences by secreting stress hormones, believed to subsequently contribute to illness and disease (Van de Kolk, 1994). When physical symptoms are seen as products of the mind and linked to emotional stress, internal conflict, or negative thought patterns, healthcare professionals may adopt a position where anxiety or depression can impact not only a person's mental state but also lead to physical symptoms (Sanders et al., 2020; Smith, 2020). Healthcare professionals, who align with the perspective of the Royal College of Psychiatrists (2015), would then consider anti-depressants the key treatment option for people living with and or affected by MUS.

Another common perspective on psychosomatic symptoms is the 'psychodynamic' account. Here, MUS is understood as an outward manifestation of inner psychic conflicts.

According to this view, certain conflicts are repressed because expressing them directly could lead to negative reactions (Luca, 2011). Consequently, these conflicts find alternative ways to manifest, with MUS serving as a means of communicating distress (Nowak & Fink, 2009). For instance, a case study presented by Summer & Barber (2015) in *Practicing Psychodynamic Therapy: A Casebook,* formulated that non-epileptic seizures could be a way for individuals to express their inner distress that they struggle to convey verbally. In this case, the seizures allowed the patient to receive attention and support from her family, even though she could not openly discuss or seek help for the abuse she endured from her father.

Health professionals who favour these perspectives may choose to refer patients living with or affected by MUS to psychiatric services. The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) could lead to a diagnosis of 'psychosomatic symptom disorder.' This diagnosis is characterised by psychological distress manifesting through physical symptoms on the body. It is typically a label given when health professionals believe that the physical symptoms cause distress and/or disability that seems disproportionate to any medical explanation (DSM-5, 2013). However, these explanations carry the potential risk of overemphasising mental distress, which may inadvertently invalidate patients' lived experiences and their physical symptoms as real. These reverse the causal nature of the relationship between physical illness and psychological functioning, compared to other medically explained illnesses. In doing so, they locate the origin or responsibility for the problem within the individual, or at least their immediate social relationships. That is, if these are Medically Unexplainable, then the implication is that they are by default psychologically explainable.

3.4.3. Psychological Approaches: The role of a psychologist working with MUS Psychologists in both health and mental health services are increasingly involved in secondary care for people living with or affected by MUS. However, due to the varying interpretations and a lack of consensus on MUS definitions, there is a lack of clarity regarding the most effective physiological and psychological support, and how psychologists can aid both healthcare professionals and those living with or affected by MUS.

Psychologists can assume various roles in addressing MUS. If MUS, is primarily understood as psychogenic, which refers to the origin or cause of a condition or symptom as being psychological in nature. It suggests that the condition is primarily related to emotional or mental health factors rather than a physical or organic cause. In this context, psychologists may be called upon to provide assessment and treatment, and their role might resemble that of treating depression, assuming the existence of underlying psychological factors or uncovering insights related to early childhood experiences and unconscious forces (See Luyten et al., 2013). Therefore, interventions may resemble a protocol from the Cognitive Behavioural Model (CBT) (Gautam et al, 2020) for depression. However, caution should be taken as this approach may have the potential to pathologise an individual's emotional distress as solely intrapsychic, rather than a form of self-regulation in a system of uncertainty (Adams et al., 2019).

On the other hand, if MUS is understood as an as-yet unidentified physical illness, the psychologist's role is rather different. It may resemble a medical crisis care model, such as cancer care, where medical crisis care takes centre stage and becomes the primary focus of intervention (See Pollin, 1996). In this approach, a non-pathological perspective recognises that even people with good mental well-being can experience significant psychosocial challenges when confronting a lasting medical condition, particularly an undiagnosed illness, which is often characterised by a sense of 'waiting to see what will come to pass', giving rise to a pervasive element of uncertainty that heightens cognitive and psychological distress (Pollin, 1966). This pursuit of a diagnosis can be filled with uncertainty, tension, and complexity (Meyer et al., 2021) and as stipulated by Sanders et al. (2018) "the most uncomfortable place to be" (p. xvi), for both patients and healthcare professionals alike. Here, strong emotions like depression, fear, anxiety and anger are viewed as normal responses to serious illness and uncertainty.

The additional uncertainty linked to the unexplainable nature of MUS poses further challenges for healthcare professionals and people living with or affected by MUS, as both attempt to comprehend and articulate experiences that have unclear aetiologies and treatment pathways. As modern medicine with all its advancements, continue to fall short in providing answers, people living with or affected by MUS find themselves repeatedly encountering a narrative gap (Sanders, 2018). Therefore, it is understandable

that the mental health status of people living with or affected by MUS may be significantly worse than those with physical symptoms attributed to an organic cause (Burton et al., 2011, 2012).

The Leventhal Self-Regulatory Model of Illness (Leventhal et al., 2001), rooted in health psychology, provides healthcare professionals with another framework for comprehending patient symptoms and behaviours (Benyamini & Karademas, 2019). This model acknowledges that people may require support in adjusting to life-altering illnesses. It may also be helpful for understanding the choices of patients living with or affected by MUS. It suggests that patients possess cognitive representations of their illness, personal perceptions, and goals, which inform their coping behaviours (Fiske & Taylor, 1991; Leventhal et al., 1984). This psychological approach suggests that patients have health identities, and will actively monitor and adapt their behaviour over time to progress toward their goals, whether it involves managing their illness or alleviating associated negative emotions (Cameron & Moss-Morris, 2010). For instance, if a patient's goal is to identify the cause of MUS, due to the impact on their quality of life and distress levels, they may regularly seek answers from healthcare professionals to alleviate their symptoms. Nevertheless, just like The Leventhal Self-Regulatory Model of Illness (Leventhal et al., 2001), which proposes patients hold distinct illness beliefs, and goals, that inform their coping behaviours (Benyamini & Karademas, 2019). It is important to acknowledge that healthcare professionals will also maintain their own set of health identities and beliefs, which will also influence their interactions with people living with or affected by MUS and play a pivotal role in determining subsequent treatment approaches.

3.5. The Practitioners Stance:

These diverse models demonstrate the potential for varied approaches to the diagnosing, understanding and care for people living with or affected by MUS. Given the absence of clear diagnostic criteria and the multitude of explanatory models, healthcare professionals must often rely on their clinical judgement to define and categorise this patient group. This judgement is largely subjective, influenced by the experiences, attitudes, and perspectives of the healthcare professionals. Additionally, patients living with or affected by MUS may not neatly fit within current guideline-driven healthcare

models, and healthcare professionals may struggle to see beyond the boundaries of their own specialty and subjective viewpoints. This also perhaps is why variability is reflected in the many different terms used to describe this patient group.

3.6. Guidelines and Legislations Surrounding MUS:

The availability of guidelines and legislation to support healthcare professionals working with people living with or affected by MUS are notably limited and often subject to debate. In the United Kingdom (UK) the National Institute for Health and Care Excellence (NICE) provides guidelines for health professionals, primarily based on analysis of treatment efficacy. Currently, NICE have offered no specific guidelines for psychological treatments specifically designed for people living with or affected by MUS, with the exception of certain syndromes like ME/CFS and Irritable Bowel Syndrome (IBS).

This lack of guidance is concerning, given that many healthcare professionals advocate for psychological therapies as the primary treatment for this patient group (Kaur et al., 2022). It is worth mentioning that recent draft NICE guidelines for ME/CFS have withdrawn support for treatments such as Cognitive Behavioural Therapy (CBT) or Graded Exposure Therapy (GET) due to concerns about the low quality of evidence and the potential risk of exacerbating underlying pathophysiological abnormalities with physical stressors (Geraghty et al., 2019; Scott, Crawford, Geraghty & Marks, 2022). Marks (2023) explored treatment harms in patients living with or affected by ME/CFS, and found significant research suggesting harm towards many of these patients from CBT and GET. These findings raised ethical concerns, which called for a more collaborative effort between scientists, therapists and patients to make more helpful scientific progress in this difficult field. Further details on psychological intervention for MUS can be found in Section 3.4.3 & Section 3.7.

The Joint Commissioning Panel for Mental Health (JCP-MH, 2017) also recommends the establishment of services that provide access to appropriate care, tailored to the severity and complexity of patients' difficulties. It advocates for a multidisciplinary approach that integrates both physical and mental health perspectives into patient care. However, despite this call for a multidisciplinary team (MDT) approach to bridge the gap between physical and mental health, limited service provision can hinder implementation, and some health professionals may struggle to view people living

with or affected by MUS, or have the resources, to see beyond the scope of their speciality (Brownell, Atkins, Whiteley, Woollard & Kornelesen, 2016; Wu et al., 2020).

3.7. Exploring Existing Contributions and Services beyond Wales:

In the quest to address the research gap in South Wales regarding MUS, as detailed extensively in the previous section 2.1, it felt important to recognise that other regions in the UK have made developments and progress in this field. This section will explore the various psychological interventions suggested throughout the literature as an 'attempt' to 'treat' people living with or affected by MUS (Balbanovic & Hayton, 2020). To provide a comprehensive perspective, this review incorporates the contributions of other fields, such as Health Psychology, Clinical Psychology, and related fields. Exploring the existing contributions and the progress in MUS and related fields beyond Wales, allows for a more comprehensive understanding and may serve to strengthen a case for considering new models in Wales. This exploration may highlight opportunities for Counselling Psychology to strategically position itself in this evolving landscape, and thereby contribute to an advancement of research, policy, and practice in this field.

Psychological therapies have been suggested as effective treatment for people living with or affected by MUS (Stone et al., 2020). These studies include interventions such as psycho-education, Eye Movement Desensitization Reprocessing (EMDR) (Cope, Mountford, Smith & Agrawal, 2018), Psychodynamic Therapy (Luyten, Van Houdenhove, Lemma, Target & Fonagy, 2013) Emotion Focus Therapy (Town, Lomax, Abbass & Hardy, 2019), Body Psychotherapy (Calsius, De Bie, Hertogen & Meesen, 2016) and the use of second and third wave Cognitive Behavioural Therapies (CBT) (McDevitt-Petrovik & Kirby, 2020), i.e. Acceptance and Commitment Therapy (Hayes, Strosahl & Wilson, 2009), Dialectical Behaviour Therapy (Linehan, 2020) and Compassion Focused Therapy (Gilbert, 2009). Despite this variation, treatment approaches for people living with or affected by MUS are relatively underdeveloped (Balabanovic & Hayton, 2020), with the majority of the literature focusing on CBT based interventions (Jones & Williams, 2019; Kleinstauber, Witthoft & Hiller, 2010).

Notably, within the domain of Health Psychology, Rona Moss-Morris and her team at Kings College, London, have made significant contributions. Their research primarily aligns with CBT and explores how psychological factors influence the experience and

management of various health conditions. Recent studies, such as 'Efficacy of therapist-delivered transdiagnostic CBT for patients with persistent physical symptoms in secondary care: a randomised controlled trial' (See Chalder et al., 2023) and 'A cognitive—behavioural therapy programme for managing depression and anxiety in long-term physical health conditions: mixed-methods real-world evaluation of the COMPASS program' (cf Seaton et al., 2023), demonstrate their ongoing work. By favouring a CBT approach, derived from Beck's model, they base 'treatment' on a cognitive formulation that identifies maladaptive beliefs, behavioural strategies, and maintaining factors as characteristics of specific disorders (Alfor & Beck, 1994; Beck 2020). These interventions favour a psychogenic perspective, which refers to the origin or cause of a condition or symptom as being psychological in nature. It suggests that the condition is primarily related to emotional or mental health factors rather than a physical or organic cause.

In England and Wales, routine healthcare practice has predominantly relied on cognitive and behavioural modification as the primary intervention for a range of psychological difficulties, with CBT being deeply entrenched within the NHS (See Layard, Clark, Knapp & Mayraz, 2007; Leaviss et al., 2020). Government initiatives, such as 'Improving Access to Psychological Therapies' (IAPT) in England and 'Matrics Cymru' in Wales (2017), have portrayed CBT as the most effective treatment for psychological distress. The IAPT program, which commenced in 2007-2008, was allocated £173 million for its first three years, reflecting its significance in NHS initiatives. More recently, the scope of IAPT, has expanded to include the routine care of people living with or affected by MUS in England, extending its reach beyond patients with mental health difficulties (Clark, 2018). Wales has its equivalent program to IAPT known as Matrics Cymru (2017). Matrics Cymru draws heavily from the Scottish Matrix (NES 2015) and incorporates parts from the IAPT program in England, along with standards established by the Royal College of Psychiatrists and the British Psychological Society (BPS) for service delivery. In Wales, Psychological therapies are typically provided within Local Primary Mental Health Support Services (LPMHSS), and they offer a range of evidence-based, time-limited interventions tailored to individual clinical needs for treating common mental health struggles and psychological distress. However, there remains no routine care for people living with or affected by MUS within these initiatives in Wales.

Nevertheless, there are many critics, who raise concerns about the effectiveness of CBT as routine care for people living with or affected by MUS. Moreover, these criticisms even extend to the use of CBT as a routine care method for addressing mental health difficulties. For example, see Ahsan (2022) 'I'm a psychologist- and I believe we've been told devastating lies about mental health' and Risq, (2013) 'IAPT and thought crime: Language, bureaucracy and the evidence-based regime', who underscore the controversial nature of CBT's efficacy and how it can lead to patients' internalisation of their mental health struggles (see Milton, 2017).

These debates have sparked controversy with some researchers cautioning against the widespread use of CBT and emphasising the need for healthcare professionals to be mindful of potential limitations. They also draw attention to the misleading nature of poor-quality evidence regarding the effectiveness of CBT in routine practice for people living with or affected by MUS (Geraghty et al, 2019; Scott et al, 2022). For example, within NICE guidelines, CBT study results have typically been considered valid. Although, this is not true for the 2021 guidance, which downplayed the relevance of The PACE trial (Pacing, graded Activity, and Cognitive-behavioural therapy: a randomised Evaluation). The trial faced substantial criticism from patient advocacy groups and some researchers. Critics raised concerns about the trial's methodology, the definition of recovery used, and the way in which the results were reported. Some patients argued that the trial downplayed the organic nature of their illness and that exercise-based treatments like Graded Exposure Therapy could be harmful (ME/CFS Association, 2022) and may include people who are experiencing something very different to ME/CFS, like anxiety and depression. Recent developments echo these concerns, criticising CBT led interventions, and questioning whether the support offered aligns with the nuanced needs of many people living with or affected by MUS (See Scott et al. 2022).

I recognise the diverse perspectives and practices in the care of people living with or affected by MUS across the literature. I have attempted to remain impartial and refrain from advocating the adoption of any specific model in Wales. A fundamental part of this chapter was to examine current practices and the ongoing discussions concerning the routine care of people living with or affected by MUS. This illustrates the diversity of healthcare professionals' approaches towards this contested issue. Understanding these

experiences among healthcare professionals in Wales will be an essential step towards identifying ways to improve healthcare practices for both healthcare professionals and patients.

3.8. Living with or affected by MUS: The burden of invisibility:

Living with or being affected by MUS can be an extremely challenging experience, as people often struggle to be heard and taken seriously within a healthcare system that predominantly adheres to the medical model (Hutchinson & Dhairyawan, 2017; Sowinska & Czachowski, 2018). Since there are no available diagnostic biomarkers, these patients may face difficulties in gaining recognition as people with 'real illnesses', not only within the healthcare system but also among their social circles (Masana, 2011; Van Wersch, 2010). The term 'real illnesses' here implies conditions that are widely accepted and validated often backed by identifiable and measurable biological markers.

Those with lived experiences of MUS often describe a profound sense of isolation and undeserved blame for their undiagnosed symptoms, describing feeling bad when they have done nothing wrong (Nettleton, 2006). This may be the result of having their symptoms defined as being psychogenic, where symptoms or conditions are believed to have a psychological origin rather than a clear, identifiable physical cause. This communicates the message that symptoms are often thought to arise from mental or emotional factors, such as stress, trauma, or psychological distress, rather than from a specific physiological dysfunction or disease. Although, not intentionally this may be why people living with or affected by MUS feel invalidated, especially when this is presumably not the intention of clinicians.

In their quest to validate their invisible experiences, people living with or affected by MUS often grapple with feelings of blame, shame and hopelessness (Lillrank, 2003; Rausch, 2021; Church, 2017). Unlike illnesses with visible biological markers, the term 'invisible experiences' refers to the absence of easily observable physical symptoms, which makes it challenging for people living with or affected by MUS to convey the tangible impact of their conditions. This invisibility can contribute to the difficulties they face in gaining understanding and recognition for the validity of their health struggles. Some reach a point where they are so disheartened and rejected by their interactions with healthcare professionals and services, that they withdraw from seeking care

altogether. For many, this avoidance is likely to be driven at least in part by their inability to endure a process that invalidates their suffering (McGowan et al., 2010; Stone, 2014). This invalidation extends beyond medical settings, with reports of scepticism from family members who doubt the reality of an undiagnosed illness (Thompson et al., 2018; Thompson & Parsloe, 2019). Such scepticism can leave those living with or affected by MUS feeling invalidated and fearing that their symptoms were merely "in their head" (p.463) (Lillrank, 2003). Given the significant challenges faced by this patient group in their interactions with healthcare services, understanding the experiences of healthcare professionals is important. It can provide valuable insights into the meaning of why patients may feel invalidated, especially when this is presumably not the intention of clinicians.

3.9. Challenges faced by Health professionals in managing MUS:

Healthcare professionals working with people living with or affected by MUS may have their own personal and professional challenges. These challenges not only impact the relationships between professionals and patients but also take a toll on the professionals themselves. Numerous studies in the literature highlight a strained relationship between health professionals and patients in this area, characterised by high levels of tension, conflict and ruptures (Lian & Nettleton, 2015). Health professionals may often grapple with the emotional responses triggered by patients living with or affected by MUS (Stone, 2014) or perceive these patients as challenging, frustrating and difficult to manage (Ring et al., 2004; Steinmertz & Tabenkin, 2001). This complex dynamic might explain why health professionals sometimes respond in seemingly contradictory ways offering reassurance while also making referrals 'just to be on the safe side' (Salmon et al., 2004).

Furthermore, the uncertainty and the quest for diagnostic clarity may not be exclusive to patients living with or affected by MUS but may also be deeply felt by health professionals. A review of the literature found that many healthcare professionals report feelings of being underprepared, frustrated, and exhausted when confronted with patients experiencing physiological symptoms and distress that persist despite normal test results (Daniels et al., 2020; Yon et al., 2015). The elusive nature of MUS can leave health professionals feeling inadequate, causing them to either over-investigate or avoid patient contact due to a lack of knowledge, direction and the inherent challenges posed

by MUS (Yon, Nettleton, Walters et al., 2015). This creates a recurring cycle that continues to challenge both the healthcare professional and person living with or affected by MUS. Given the scarcity of guidelines for health professionals on managing the complexity of MUS and the wide range of explanatory models available in the literature (Van Ravenzwaaij, 2010), it's not surprising that health professionals often find themselves pushed to the limits, relying on their subjective experiences, attitudes, and perspectives to understand MUS in their clinical practice and to guide treatment decisions.

3.9.1. The impact of working with unexplained or untreatable conditions:

Working with patients living with or affected by unexplained or untreatable conditions could potentially have a profound emotional impact on healthcare professionals.

Healthcare professionals often express a desire to provide the best care possible to their patients (Marynissen & Spurrier, 2018). However, in the case of people living with or affected by MUS, where clarity and solutions are often lacking, healthcare professional may find themselves repeatedly compelled to act in ways that challenge their professional ethics and values. Whether this is through further investigations, precautionary prescribing or instant discharge of patients. This constant inability to alleviate patients' suffering and offer the answers both patients and healthcare professionals seek, could potentially lead to what has been referred to as 'moral injury' among healthcare professionals (See Cartolovni et al., 2021). Moral injury occurs when individuals engage in, fail to prevent, or witness actions that contradict their deeply held values or beliefs, often in situations they perceive as avoidable or when they feel powerless to effect change (Griffin et al., 2019).

Surprisingly, there is a gap in the literature regarding the specific experiences of moral injury in healthcare professionals working with people living with or affected by MUS. This gap is particularly noticeable, if we consider the traditional role of healthcare professionals as sources of answers and solutions, a role that is further challenged by the nature of MUS. Healthcare professionals have to grapple with not knowing the solution, let alone the underlying problem. Nevertheless, instances of moral injury have been explored in other contexts, such as healthcare professional's responses to the COVID-19 pandemic. During this crisis, healthcare professionals faced difficult decisions, which often meant prioritising the most severely ill patients. This meant that people they would

normally treat in one way, could not be treated in such ways, or at all in some incidents. These decisions may have conflicted with their personal and professional values (See Litam & Balkin, 2021). Research in the field of Emergency Medicine went further and drew parallels between moral injury and Post-Traumatic Stress Disorder (PTSD), with some experts considering moral injury a subset of PTSD (Giwa et al, 2021).

Given these complexities and the challenges associated with working with people living with or affected by MUS, it is quite plausible that healthcare professionals would often find themselves pushed to their limits or compelled to work in ways that may not align with their personal beliefs and values, potentially affecting their sense of moral integrity. Further research and understanding is needed in this area to address the emotional well-being of healthcare professionals to consider improved support systems that enable them to deliver effective care to people living with or affected by MUS.

3.10. Why Counselling Psychology Should Care about MUS:

This literature review highlights some of the most dominant theoretical positioning of MUS, that can be seen as important observations for Psychology and locating the role of Counselling Psychology. Where the psychological origins of somatisation seem to be positioning a person living with or affected by MUS within an analytical framework. The intersection of uncertainty in the therapeutic alliance, and the emotional implications of working with people living with or affected by MUS, appears to take more of a position in line with Counselling Psychology values, within a relational and humanistic framework.

While the existing literature on MUS predominantly seeks to address challenges related to identifying causation, treatment, and mental health issues (Rief & Broadbent, 2007; Konnopka et al., 2012). Counselling Psychology, with its emphasis on understanding individuals' subjective and intersubjective experiences, placing paramount importance on the therapeutic relationship as the foundation for achieving positive change (BPS, 2016), can offer a distinctive perspective. Counselling Psychology recognises that genuine understanding can only be gained from the individuals themselves. This adds to the study rational, for why this research inquiry will stay close to the experiences of health professionals working with people living with or affected by MUS, to gain further understanding into the personal and professional implications of these encounters.

A dominant thread running throughout this review, is the presence of a high degree of uncertainty, which is experienced by both people living with or affected by MUS and healthcare professionals. The existing literature suggests that healthcare professionals with a low tolerance towards uncertainty, will tend to respond to unclear clinical situations in two primary ways. First, they will grapple with undesirable emotions themselves, such as stress, anxiety and discomfort (lannello et al., 2017; Milne, Lomax, & Freeston, 2019). Second, driven by fear of judgement or a perceived devaluation of their expertise, they may opt not to disclose their uncertainty to others (Alam et al., 2017; Gerrity, DeVellis, & Earp, 1990; Strout et al., 2018). This complexity is further compounded when working with people living with of affected by MUS, as healthcare professionals will find themselves working with conditions that are often un-diagnosable and untreatable.

Quinlan, Schilder & Deane (2021) highlighted that psychologists, especially Counselling Psychologists, are in a unique position to adeptly navigate this uncertainty and ambiguity, aligning with the core principles of their profession. Their study found that a higher tolerance for uncertainty is associated with increased pluralistic practice, emphasising the potential for a pluralistic approach in enhancing shared decision-making and client outcomes. Counselling Psychologists, with their training in working pluralistically—simultaneously drawing from multiple modalities—alongside a substantial emphasis on theoretical and relational foundations in their practice (DCOP, 2009), possess a distinctive skill set tailored for this purpose. McAndrew et al. (2019) concluded that the unique skillset of Counselling Psychologists- including cultural understanding, attunement to therapeutic processes, and a focus on prioritising patients' perspectives and quality of life- could effectively address critical gaps in research on MUS and contribute distinctively to healthcare service delivery. However, further exploration is needed.

Counselling Psychology can offer another important element – that of being reflexive. This involves supporting healthcare professionals to understand a) their own position in terms of an emotional response, b) their role as part of a wider system, c) working collaboratively with colleagues within that broader system to facilitate a reflexive approach. As a Trainee Counselling Psychologist, I am well placed to support healthcare

professionals reflect on their experiences of working with the uncertainty of MUS, to gain further understanding of personal and professional implications. This distinctive perspective not only aims to find innovative approaches, but also to substantially aid support offered to healthcare professionals. Ultimately, this research hopes to contribute to advancing more effective care for people living with or affected by MUS, enriching the existing literature with a unique perspective rooted in Counselling Psychology.

3.11. Study Rationale:

The preceding chapters examined current practices and ongoing discussions concerning the routine care of people living with or affected by MUS, already building up a detailed rationale for this research inquiry. Section 1, clearly outlined a notable gap in Welsh literature, and detailed how this inquiry aims to contribute to a limited body of knowledge and interest; aligning with Welsh strategic measures, particularly, 'Well-being of Future Generations (Wales) Act (2015)' and the 'Healthier Wales: long term plan for health and social'. The preceding paragraph also robustly justified the exploration of health professionals' experiences of people living with or affected by MUS through a Counselling Psychology lens. Emphasising the potential for unique insights, contributions, and advancements in effective care.

The prevalence rates and NHS expenditure for MUS, detailed in Chapter 1, illustrates that healthcare professionals in the NHS are routinely engaging in daily clinical interactions with people living with or affected by MUS. These encounters with conditions that are often unexplainable or untreatable create persistent challenges marked by uncertainty, which may affect both healthcare professionals and the patient (Meyer, Giardina, Khawaja & Singh, 2021). On the one hand, people living with or affected by MUS frequently feel unheard and stigmatised, perceiving their symptoms as dismissed by healthcare professionals, particularly when 'negative test results means that nothing is wrong' is cited as the most common explanation given by doctors' (Edward et al.,2010). On the other hand, healthcare professionals report feeling 'frustrated', finding people living with or affected by MUS 'difficult' or 'challenging' (Ring, Dowrick, Humphris & Salmon, 2004; Steinmetz & Tabenkin, 2001; Kadir, 2002).

There are a few studies that have acknowledged the doctor-patient relationship (Stone, 2014) and doctors' attitudes towards people living with or affected by MUS (Kadir, 2022), however further understanding is needed. Particularly given the near absence of research in Wales, with no studies exploring healthcare professionals' experiences of working with people living with or affected by MUS. Moreover, current UK studies mainly focus on primary care settings (Yon et al., 2015; Stortenbecker et al., 2018; Rosendal et al., 2019), yet people affected by MUS present across diverse medical and psychiatric services. This necessitates a broader examination of healthcare professionals' experiences. Therefore, this inquiry aims to address this gap, by exploring shared experiences and potential differences in how people living with or affected by MUS are experienced across both general and mental health secondary care services. Recognising the likelihood of distinct experiences between secondary and primary care clinicians. If healthcare professionals generally find it increasingly challenging to navigate this landscape, it is reasonable to assume that people living with or affected by MUS will consequently face even greater difficulties.

In the context of Counselling Psychology literature, how we experience our clients in the therapeutic relationship, through the interchange of thoughts and feelings, both conscious and unconscious has been found to significantly influence both the therapeutic relationship and our personal and 'professional' responses towards it (see Buirski, Haglund & Markley (2020), *Making sense together: The intersubjective approach to psychotherapy*). The way in which healthcare professionals experience and understand patients living with or affected by MUS may profoundly influence their personal and professional implications.

To gain a nuanced understanding of healthcare professionals' experiences of working with people living with or affected by MUS in SBUHB, South Wales, it is essential to engage directly with them. In shaping decisions on how to best support healthcare professionals and patients in this context, it is important to be informed by local insights rather than relying solely on practices and experiences from other locations – beyond Wales (See section 2.6. Situating the Study: South Wales Coast and Valleys). This research inquiry hopes to inspire a systemic shift toward improved care and support for this patient group, in Wales. It is hoped that a qualitative design, will allow an opportunity to

see whether health professionals in SBUHB, Wales, resonate with the issues highlighted in the existing literature and to understand their experiences within these challenges. The objective is for this research to contribute to the limited literature on people living with or affected by MUS in Wales, using the voices of healthcare professionals to offer better support and care for this patient group, which, in turn, can highlight opportunities for Counselling Psychology to strategically position itself in this evolving landscape in Wales.

4. Aims and Objectives:

This research inquiry aims to conduct a qualitative exploration of health professionals' experiences of working with people living with or affected by MUS across Swansea Bay University Health Board (SBUHB), South Wales. Specifically, this study seeks to shed light on the under-explored aspect of how this clinical encounter impacts on health professionals both personally and professionally. The ultimate aim is to develop a deeper understanding of how health professionals experience MUS within their respective specialities, the potential significance of these experiences, and the challenges that emerge in their clinical practice. By achieving this understanding, this inquiry aims to illuminate how these dynamics may affect the professional-patient relationship and influence the direction and future of patient care within the healthcare system:

To fulfil these <u>aims</u>, I developed the following research questions and extension questions:

- 1. How do health professionals in secondary care services within SBUHB, South Wales, experience working with people living with or affected by MUS?
 - i. How does the experience of working with people living with or affected by MUS affect healthcare professionals both personally as individuals, and in their professional roles?
- 2. Based on insights gained through this research inquiry, how can the field of Counselling Psychology contribute to support for both healthcare professionals and patients living with or affected by MUS, in SBUHB, South Wales?

5. Methodology:

5.1. Chapter Overview:

This chapter includes what I did, how I did it and why I chose this approach. It examines how I integrated Reflexive Thematic Analysis (RTA) (Braun & Clarke, 2019) principles and why the research was designed and conducted in chosen ways. It will start by providing insight into the subjectivity of the researcher, outlining my research position and philosophical orientations. This will demonstrate my unique perspective I brought to the study that influenced the process. To ensure transparency and clarity in presenting the research process, I will adopt a first-person narrative style. This will allow my role as a researcher and influence on findings to be visible. The chapter will detail the decision to employ a qualitative research design and the reasons behind selecting RTA. It concludes by detailing the process of participant recruitment and information, ethical considerations and a detailed account of how I proceeded through data collection and analysis, to offer a clear understanding of the research journey.

5.2. Positioning:

My personal experiences, values, philosophical stance, and evolving identity as a Counselling Psychologist have inevitably intertwined and shaped my research inquiry. Qualitative research is inherently subjective (Clarke & Braun, 2021), and it would be naïve to assume that my subjectivity hasn't influenced various stages of the research process, from study design and data collection to analysis and reporting, whether intentionally or inadvertently. While this subjectivity is what introduces variability in research, it is also what makes it valuable.

5.2.1. A bit about the researcher:

As the researcher behind this inquiry, it is important to acknowledge my distinct identity among researchers. In all interpretive research there is an assumption that knowledge is situated in relations between people (See Bukamal, 2022). The person doing the researcher role takes a central role in the interpretation of findings (Cohen, 2014). Therefore, as the researcher, all my beliefs, attitudes forged by my background and lifehistory, will be an integral part of the research process. This tends to be the rational for why in qualitative research, no two narratives are identical, as each researcher —

participant- will draw from their unique perspective, identity, and experiences to construct knowledge and make choices of methodology – or future direction of care. Therefore, it felt very important to provide a preliminary glimpse into the person conducting and writing this research – me.

I am a white British female, who is in her early thirties. I am currently a Trainee Counselling Psychologist, on the cusp of qualification, with this research thesis marking the final piece of my journey. My lifelong aspiration has been to become a Psychologist, potentially driven primarily by a desire to comprehend and navigate my own childhood environment. I have worked in many settings with people living with high emotional distress since the age of 19, but my interest in emotional distress dates even further back. Mental Health and caregiving has consistently occupied the core of my life from a young age. Therefore, I recognise that my perspective and preconceptions may be rooted in a mental health framework, particularly passionate about social justice and breaking down barriers.

This research looks into the experiences and challenges of working with a condition that is often un-diagnosable or un-treatable, and reflects some of my personal Journey of living with MUS, particularly dysmenorrhea. During my Counselling Psychology doctorate training, I was required to do psychotherapy and explored potential relational traumas as contributions to my pain. Although, this was extremely beneficial in developing my sense of self and self-awareness, it did very little for the pain I experienced every month.

After declining contraceptive medication, anti-depressants and a course of Cognitive Behavioural Therapy (CBT) from my local General Practice. I explored acupuncture and supplements. This allowed me to uncover heat in my body and a dairy intolerance, allowing me to make changes that offered partial relief. This revelation does not fit into a medical or psychogenic model. While I am not entirely pain free, the difference is significant, enabling me to lead a life without the constant burden of embarrassment, fatigue, or debilitating migraines. This highlights the importance of holistic perspectives, recognising that relief may often extend beyond conventional medical or psychogenic understanding and approaches. Healthcare professionals might need to navigate

uncertainty alongside the individual, understanding that diverse paths to healing may or may not exist, and what works for one may not work for another.

5.2.2. The 'Insider' and 'Outsider':

Before the analysis, I dedicated time to exploring and reflecting on my position as a researcher. This step was important because, as highlighted by Braun and Clarke (2013), the topics we find ourselves interested in are said to mirror who we are, therefore any knowledge produced will reflect this. It wasn't until this stage that I truly grasped the extent to which our core ways of being manifest and seep into every aspect of our lives, including choices - whether consciously or not.

A researcher is considered an 'insider' when they share particular attributes with the participants of the study (Braun & Clarke, 2013). They are considered an 'outsider' when he or she does not belong to the group to which the participants belong (Braun & Clarke, 2013). Initially, I identified as an 'insider' within healthcare services but recognised myself as an 'outsider' to the experience of living with or affected by MUS. However, as my research journey unfolded over the three years of my doctorate training, I came to the profound realisation that my struggles with what I now understand as MUS had not only drawn me to this research but had significantly influenced the trajectory of my inquiry. For many years, I have struggled with persistent, debilitating 'Dysmenorrhoea' — painful menstrual cycles- that not only physically cripple me, but also leaves me feeling isolated from my life, once a month. In light of this, I transitioned from viewing myself as an 'outsider' to an 'insider', as I learned that this research interest closely aligned with my own pursuit for answers within the complex landscape of Western medicine.

Furthermore, my professional experience differed from that of all participants I recruited, particularly in terms of working with people living with or affected by MUS. While I collaborated with colleagues interested and challenged by this field, my direct professional experience remained limited. Breen (2007) would describe my position here as 'in the middle,' neither an 'insider' in experiences of working with, nor an 'outsider' regarding professional engagement.

5.2.3. Philosophical Assumptions:

This study was conducted from a critical realist ontological stance; critical realism challenges the objectivity of knowledge and interrogates social, political, and cultural factors implicated in its construction. It takes a position that assumes a real and knowable world that sits behind the subjective and socially located knowledge that a researcher can access (Madill, Jordan & Shirley, 2000; Pilgrim, 2013). Parallel to RTA principles, critical realism goes beyond what is currently observable and acknowledges that context and values are embedded in a scientific inquiry, whereby I, as the researcher am fully part of the object of enquiry (Pilgrim, 2019). I hold a contextualised perspective on epistemology whereby a single reality is not assumed, but rather knowledge emerges from certain contexts and might hold true for those contexts, but not necessarily others. In any case, a contextualised epistemology embraces the subjectivity of the researcher and thus reflects my position(s) (Madill, Jordan & Shirley, 2000). As I am saying that subjectivity, experiences and attitudes matter; it feels important to state that my theoretical stance is embedded in a relational framework; paying close attention to what is transpiring in the here-and-now of the therapeutic relationship to gain insight into the person's internal world. While simultaneously drawing on other modalities -mainly systemic and psychodynamic principles. I have always had a holistic view of the world and have actively sought to ensure that the therapeutic context does not occur in a political, social and cultural vacuum.

In qualitative research, subjectivity is always present. It can serve as a valuable tool when approached reflexively (Bumbuc, 2016), embracing and owning one's perspective (Elliot, Fischer & Rennie, 1999). I maintained self-awareness and reflection throughout my research, consistently examining my biases, preconceptions and my empathic connection with patient experiences (as an 'insider') compared to health professionals' experiences (as 'in the middle'). See Appendix A for an excerpt from my research diary where my preconceptions and 'in the middle' position influenced my perception of an interview.

5.3. Design:

5.3.1. Choosing a qualitative research design:

As a trainee in Counselling Psychology, I value and respect the scientist-practitioner model, which relies heavily on 'official' sources of theory and scientific evidence to build confidence among healthcare professionals in creating effective solutions in clinical practice (Woolfe, Dryden and Strawbridge, 2003; Bury & Strauss, 2006). However, scientists, which can include psychologists often align themselves with ontological reductionism, viewing the world as predictable, uniform and controllable through science. This perspective predominantly leans towards quantitative approaches firmly rooted in scientific origins, particularly in the context of data analysis through systematic reviews of Randomised Controlled Trials (RCTs).

While RCTs are suitable for certain types of research, they may not be the most appropriate methodology for exploratory studies. Humans are complex and influenced by numerous factors that interact with demographics, systemic elements and individual parts of the whole (Boulton et al, 2015; Hedges, 2005). Recognising these complexities, qualitative research is gaining acceptance and recognition for its ability to explore research questions that cannot be quantified. In particular, implicit and explicit attitudes, beliefs, preferences, and behaviours of both practitioners and service users (Shuval et al., 2011).

Furthermore, as a Counselling Psychologist, my professional identity places great importance on valuing the personal and subjective experiences of people, prioritising these over diagnostic labels, assessments, and treatment protocols. Given these considerations, I have chosen a qualitative research design for this study. The primary research question aims to explore the experiences of healthcare professionals working with people living with or affected by MUS in secondary care services, a depth of understanding that cannot be achieved through quantitative methods. Therefore, a qualitative approach was deemed more suitable for this study.

5.3.2. Choosing Reflexive Thematic Analysis:

The chosen research method for this research inquiry is Reflective Thematic Analysis (RTA). I chose RTA for its flexibility; it does not have a pre-prepared theory, as it

encourages 'theoretical flexibility', whilst allowing for the exploration of collecting meaning-making across the data (Braun & Clarke, 2006).

However, through further exploration of Thematic Analysis (TA) literature, I learnt that while RTA falls under a broad family of TA methods, where meaning is identified at a pattern level across the dataset, it is not as straightforward to parse. Fundamental differences exist across these approaches, each with rather different conceptual foundations and ways of approaching the analysis (Braun & Clarke, 2021). Therefore, I will situate the particularity of the type of TA this study adopted.

Braun & Clarke (2021) categorise TA methods into three broad types; coding reliability approaches (See Guest, MacQueen & Namey, 2012), Reflexive Approaches (e.g. Clarke & Braun, 2021) and Codebook approaches (See King & Brooks, 2018). Coding reliability approaches are often associated with 'small q' qualitative research (See Braun & Clarke, 2021; Kidder & Fine, 1987), which aligns with positivist values. These tend to value the science-practitioner model, prioritising objective, generalisable, reliable and replicable knowledge. However, given this study – *and my* – theoretical positioning, which moves away from a positivist scientific perspective, a RTA approach was favoured.

This approach falls under 'Big Q' qualitative research, where qualitative research is viewed as more than just tools and techniques but is 'fully qualitative', where the inescapable subjectivity of the researcher is not bracketed or considered a bias (Clarke & Braun, 2021). Instead, subjectivity is integrated into the research process as an essential source of meaning and knowledge, as partial, situated and contextual (Lainson, Braun & Clarke, 2019; Clarke & Braun, 2021). This stands in contrast to coding approaches which perceive researcher subjectivity as a potential threat to coding reliability and manage it through the use of multiple coders.

5.3.3. Considering alternative methodology:

To choose RTA as the analysis method for this research, I felt it was important to have some understanding of different approaches, their concepts, and key distinctions.

Therefore, I spent time exploring alternative methods, including reading Braun and Clarke's (2021) article titled 'Can I use TA? Should I use TA? Should I not use TA?

Comparing reflexive thematic analysis and other pattern-based and qualitative analytical approaches'.

Within my Counselling Psychology cohort, Interpretative Phenomenological Analysis (IPA) appeared as a favoured methodology (Smith & Fieldsend, 2021). IPA is grounded in the theoretical framework of phenomenology and centres on comprehending and interpreting how humans experience and make sense of the world (Larkin, Flowers & Smith, 2021). It uses research questions that are more focused on participants' personal experiences and meaning-making within a specific context, using a small homogeneous purposive sample of first-person accounts (Spiers & Riley, 2019).

I discovered that, much like RTA, IPA places significant emphasis on the researcher's subjectivity. Spiers and Riley (2019) conducted a study using both IPA and RTA, analysing the same dataset of interviews with 47 GPS experiencing distress. The key distinction was that TA yielded breadth, whereas IPA provided depth. Given that my research inquiry aims to capture the diversity and shared meaning across a relatively large sample size (n=10), and the research question extends beyond solely personal experiences and sense-making, to encompass how health professionals experience working with people living with or affected by MUS related to a wider socio-cultural context, the choice of RTA over IPA aligned better with this inquiries objective (Braun & Clarke, 2021).

5.3.4. Choosing semi-structured interviews:

This research inquiry used semi-structured interviews as the chosen method for data collection. This decision was because I wanted a degree of consistency across interviews while allowing for information to be elicited interactively as data collection unfolded (Braun & Clarke, 2013). I wanted the interviews to facilitate discussion, as opposed to direction (Adeoye-Olatunde & Olenik, 2021).

The choice between semi-structured interviews and focus groups was considered extensively as my method of data collection. Several factors led me to choose semi-structured interviews. McGrath, Palmgren and Liljedahl (2019), suggest that semi-structured interviews are ideal when the researcher's goal is to gain a deep understanding, as opposed to seeking a generalised understanding of the phenomenon.

This method also allows for in-depth exploration of the individual's experiences, whilst aligning well with the inquiries which aim to construct shared meaning across the data set. Furthermore, I anticipated that potential participants might find it challenging to set aside dedicated one-hour slots for interviews, necessitating flexibility in scheduling to accommodate their clinical work and logistical constraints. This level of flexibility is not always feasible with focus groups. Finally, the use of semi-structured interviews was consistent with a critical-realism stance of this inquiry - and my ontological positioning – emphasising the inter-subjectivity of the participant-researcher interaction.

5.3.5. Development of the semi-structured interview schedule:

The semi-structured interview schedule was developed by drawing from the existing literature and the specific areas of exploration for this study (See Appendix B- Initial Topics of interest for development of the Interview Schedule). The questions were thoughtfully designed to enhance the depth and context of interviews, by eliciting open and honest discussion. The semi-structured interview went through a phase of refinement. Feedback from research supervisors was actively sought and changes were made to ensure that the semi-structured interview aligned with the principles of RTA.

Following this, a pilot test of the interview schedule (See Appendix M – Final Interview Schedule) was conducted with two colleagues. These colleagues were also female Trainee Counselling Psychologists working in SBUHB, carrying out their own research thesis. Neither worked directly with people living with or affected by MUS, but had encountered cases throughout their practice. This step is considered an integral process of qualitative research (Mikuska, 2017; Majid, 2017), and it provided valuable insights and feedback. As a result of this pilot phase, an additional question and its extension questions were added to the schedule. These included: 'What are your personal feelings of working with MUS?', 'How does working with MUS make you feel?' and 'Does these feelings impact on your clinical work with someone with MUS?' I added these additions to capture a more explicit understanding of how healthcare professionals, in the context of working with people living with or affected by MUS, articulate and express their subjective experiences.

5.3.6. Virtual interviews: Responding to the challenges of COVID-19:

During the data collection phase of this research inquiry, the world had just responded to the COVID-19 pandemic. In anticipation of potential anxieties and further restrictions associated with the pandemic, I had already decided at an earlier stage to offer participants the choice between virtual interviews, conducted via video technology (Microsoft Teams), and traditional face-to-face interviews. This approach was adopted to ensure flexibility and to have a contingency plan -a plan B – that would enable a seamless transition to online methodology if the pandemic continued to pose challenges.

While face-to-face interviews are often considered the 'gold standard' for semi-structured interview data collection, virtual interviews are typically seen as a viable alternative when in-person interactions are not feasible (Oltmann, 2016). However, I did acknowledge that virtual interviews might compromise certain aspects such as the depth of presence, close observations, and the interpersonal nuances that are crucial in qualitative research – and my position as a Counselling Psychologist (Pierre, 2008; Roberts, Pavalakis & Richards, 2021). Nonetheless, it is not uncommon to offer participants a choice of interview methods. This flexibility and autonomy in choice can empower participants to have a voice in the research process (Seymour, 2001) and can help alleviate any apprehensions or anxiety they may have regarding the interview process or concerns related to COVID-19. <u>All</u> participants made individual choices to engage in their semi-structured interview virtually.

5.4. Participants:

5.4.1. Inclusion criteria:

Establishing the inclusion and exclusion criteria for this research inquiry proved to be a challenging task. Initially, I encountered difficulty in defining stringent inclusion criteria, an important step before starting participant recruitment. I understood that it was important to ensure that participants would offer relevant meaningful contributions that aligned with the research objectives. Equally, these participants had to exist and be accessible and available for recruitment. Therefore, all participants were required to meet the following criteria:

5.4.1.1. Identification as 'Gatekeepers' to services:

To justify this inclusion and exclusion criteria, of needing to identify as a 'gatekeeper' to services. It is important to provide a clear definition of who qualifies as a 'gatekeeper' within this inquiry. In the framework of the NHS or healthcare systems in general, the term 'gatekeeper' is used to refer to a primary care provider who serves as the initial point of contact for patients seeking medical care (See Sripa et al, 2019; Blinkenberg, 2019). The role of a gatekeeper often involves assessing and managing patients' healthcare needs, determining the appropriate level of care, and referring patients to specialists or other healthcare services when necessary (Sripa et al, 2019). In many healthcare systems, including the NHS, patients typically require a referral from a primary care physician (the gatekeeper) to access specialised care when deemed medically necessary and appropriate (Narayanasamy, 2014; Machin, 2023). This inquiry acknowledged that most this literature, focuses on healthcare professionals in primary care services, with limited attention to healthcare professionals in secondary care who also serve as gatekeepers. In this research inquiry all potential participants needed to identify as a 'gatekeeper' in secondary care services, to meet the inclusion criteria.

5.4.1.2. Speak the English Language:

All participants had to be able to comfortably communicate through the English Language. As English is my spoken language, this criteria was essential to ensure clear and effective communication during the semi-structured interviews, allowing for a comprehensive exploration and understanding of the research questions.

5.4.1.3. Clinical experience of working directly with MUS:

Participants were required to have prior clinical experiences of working directly with people living with or affected by MUS, in secondary care services across Swansea Bay University Health Board (SBUHB), South Wales. Participants' years of experience were not screened, however, years of experience were discussed during interviews and recorded. This inquiry did not impose restrictions based on participants' professions or disciplines since the primary goal was not to identify potential differences in attitudes or their development but rather to explore shared meanings of health professionals' experiences

of working with people living with or affected by MUS across the diversity of secondary care services.

5.4.1.4. Swansea Bay University Health Board (SBUHB):

Participants had to be employed by SBUHB. They were eligible to participate regardless of their specific location within secondary care services across SBUHB, South Wales.

5.4.2. Exclusion Criteria:

Temporary employees of SBUHB or those classified as 'in-training' were excluded from the inquiry. No other exclusion criteria were applied due to the exploratory nature of this inquiry. Participants who did not meet the inclusion criteria were informed of their ineligibility and provided with an explanation. For instance, one such scenario involved a SBUHB staff member who had personal experiences of living with MUS and completed paperwork for referrals of MUS patients but lacked direct clinical experience with this patient group.

5.4.3. Participant Recruitment:

A self-selecting opportunity sampling approach was utilised for participant recruitment, allowing individuals who wished to engage with the researcher and met the specified inclusion criteria (refer to section 5.3.1, Inclusion criteria) to participate. Given the ambiguous nature of MUS, if I had been too focused and used a purposive sampling method, I might have inadvertently excluded key individuals who could offer valuable insights into their experiences with people living with or affected by MUS. Initially, recruitment efforts involved reaching out to targeted Swansea Bay University Health Board (SBUHB) line management and special interest groups relevant to the research topic, requesting the dissemination of a recruitment email (see Appendix C - Email for recruitment via management and special interest groups). This email contained a condensed version of the Participant Information Sheet (PIS) (refer to Appendix D - Participant Information Sheet for Qualtrics), creatively presented as an engaging informative flyer (refer to Appendix E - Recruitment Flyer circulated via email). This approach aimed to attract a diverse and representative sample of participants, ensuring a comprehensive exploration of the research topic.

As recruitment progressed, I realised that despite the wide circulation of my flyer within SBUHB, the response rate remained relatively low. I received several emails from potential participants who were uncertain about whether their area of work fell under the category of MUS – a reflection of the inherent ambiguity surrounding this concept perhaps. For instance, some participants were unsure about the inclusion of chronic pain or fibromyalgia categories. I realised that the uncertainty that underscored the hidden nature of MUS was potentially making it challenging to reach potential participants. Consequently, a snowball sample approach was incorporated, where participants who had already taken part in the study were kindly asked to share the recruitment flyer and further details with colleagues whom they deemed relevant to the research inclusion criteria.

5.4.4. Participant information:

This inquiry conducted interviews with a total of **10 participants.** Demographic data and information data were collected during interviews and through the Participant Demographic Form (Appendix F- Demographic Information Form for Qualtrics). To maintain anonymity, pseudo-names were used. Initially, a summary of participants' demographics was presented in a table. However, due to limited interest and awareness of MUS in SBUHB, efforts were made to anonymise the table further, by generalising individual participant details, to prioritise anonymity. Yet, due to the number of demographic tags, or identifiers, linked to the person, I was concerned about compromising confidentiality.

Recognising this heightened risk, as the sample was specific from a small geographical area, in line with recommendations from Morse and Coulehan's (2015) paper 'maintaining confidentiality in Qualitative Publication'. I made the decision to aggregate participant demographics further to minimise this risk of violating confidentiality. Therefore, this inquiry will not publish table that lists participants' demographic information – age, gender, ethnicity, occupational role, specialty and so forth – line by line. Instead, following the guidelines put forward by Morse and Coulehan (2015), demographics characteristics will be reported as group data in ranges, presenting only pertinent information related to the research topic. This approach will be more sensitive to participants' information while still providing sufficient relevant details (See Morsee, 2008, "what's Your Favourite Colour").

The participants in this research fall into two primary healthcare specialties: Mental Health and General Health. In the Mental Health category, there were four participants, while the General Health category comprised six participants, including two Occupational Therapists, three Nurses, and five Consultant Doctors. The age distribution reveals three participants below the age of 40 and six participants in the 40-65 age range. In terms of gender, the study encompasses four males and six females, ensuring a diverse and representative sample of healthcare professionals.

5.5. Ethical Considerations:

This research inquiry was granted full ethical approval from the Faculty Research Ethics Committee (FREC) (see Appendix G – UWE Ethical Approval) at the University of West England (UWE) on the 16th of December, 2021 (REF: HAS.21.11.032). Additionally, it obtained ethical approval from the Health Research Authority (HRA), Health and Care Research Wales (HCRW) (See Appendix H - Health Research Authority (HRA) and Health and Care Research Wales (HCRW) approvals) on the 3rd November 2021 (REC REF: 21/HCRW/0035, IRAS Project ID, 296590). Following confirmation of the capacity and capability at SBUHB to facilitate this inquiry on the 4th of March 2022, this inquiry was authorised to proceed. This authorisation was granted by Professor Olena Doran, Sponsors Representative for UWE (See Appendix I - Approvals from SBUHB management).

Throughout the ethics process, the 'British Psychological Society' ethical guidelines were considered (BPS, 2014) in the details of gaining ethical consent, as outlined below.

5.6. Informed consent:

To obtain informed consent, all eligible participants were provided with a link to access the Participant Information Sheet (PIS) (Appendix D - Participant Information Sheet (PIS) for Qualtrics) and the corresponding consent form (Appendix J - Consent Form for Qualtrics) through an online survey using Qualtrics. The PIS contained clear comprehensive information about the study, including its purpose, procedures, potential risks and benefits, as well as participants rights. The design of the PIS ensured that participants had access to sufficient information to make an informed decision about

their participation in the study. Participants who chose to sign and provide consent were subsequently contacted by myself, as the researcher, to schedule interviews. Additionally, the PIS was reviewed and discussed at the outset of each interview, allowing participants ample time to review, seek clarification, and decide whether they wished to proceed with participation.

5.7. Procedures for managing serious adverse events:

While I did not anticipate that this inquiry would cause harm or distress as a result of participation, there was a possibility that participants might experience distress when discussing their professional judgements or lack of knowledge regarding complex topics. Therefore, I made plans for how distress would be managed. I felt competent and prepared to offer my therapeutic skills gained through my academic and practical experiences. I also informed all participants that they could take a break during the interview, reschedule the interview, or withdraw if they felt distressed. Additionally, before data collection, arrangements were agreed that I could also provide details of my research supervisor, an experienced psychotherapist and clinical psychologist of 30 years. Information about accessing Occupational Health services for SBUHB employees were also provided as an option. Despite these options being communicated before the interviews, no participants reported or displayed any distress during the study.

5.8. Data Handling and Record Keeping:

5.8.1. Maintaining Confidentiality:

Participants were informed that their data would be treated confidentially and managed in accordance with the Data Protection Act (1998), NHS Caldicott Guardian guidelines, The Research Governance Framework for Health and Social Care and Research Ethics Approval and the University of West England (UWE) data management policy. To ensure anonymity throughout the reporting of participant details and quoted excerpts in this inquiry, all identifiable data was anonymised by the researcher.

5.8.2. Protecting participant data:

In compliance with the University of West England (UWE) data management guidance, all data was securely stored within a restricted folder on UWE OneDrive, with protected

password access. Personal data was stored separately from research data, and was only accessible to me, as the researcher. There was no hard copy data for this inquiry, and all interview recordings were again exclusively accessible to me, as the researcher. Any data shared with my supervisors was done under pseudonyms and fully disguised to maintain participant anonymity. Upon completion of this inquiry at the VIVA Stage, all confidential data and recordings will be securely destroyed. Pseudo- transcripts will be kept by my first supervisor and destroyed after three years. After VIVA, a copy of this inquiry will be archived at the UWE library and published in an academic journal.

5.9. Data Collection Procedure:

The inquiry received approval for data collection in March 2022 (see Appendix I - Approvals from SBUHB management), and participant recruitment and interviews occurred between August and November 2022. Interested participants contacted the researcher via email in response to the recruitment flyer circulated by management (see Appendix E- Recruitment Flyer circulated via email). Following this process, all eligible participants received an email (See Appendix K - Email for potential participants containing links to Qualtrics Forms), containing links to a Qualtrics online survey, providing access to the PIS, PCF, and the Participant demographic form. After reading the PIS and signing the PCF, those participants wishing to participate in the study were contacted to arrange interviews at mutually convenient times.

All 10 participants opted for an online interview, Microsoft Team meetings were scheduled in advance of the interview. At the outset of each interview, participants received reminders about the inquiry's aims and objectives, confidentiality, and data management. While the interviews were expected to last approximately one hour, durations varied among participants, with the shortest interview lasting 44 minutes and the longest 1 hour and 34 minutes. In total, the combined interview time for all participants amounted to 11 hours and 35 minutes. All participants further consented to be contacted after the study's conclusions to share the research findings, as indicated in the PCF.

6. Data Analysis:

Following transcription, all written data was analysed using Reflexive Thematic Analysis (RTA) (Braun & Clarke, 2021). I employed Braun and Clarke's (2021) six phases, as outlined in *Thematic Analysis: A Practical Guide*, to navigate this data analysis process, detailed in Table 1. This journey, as Braun and Clarke describe is "typically messy and organic, complex and contested" (p. xxvi). A detailed reflexive description of the data analysis process is thoroughly outlined in Appendix L, where I demonstrate how I brought myself into the process, reflecting on how I followed these six phases of RTA. While I viewed "subjectivity as something valuable, rather than problematic... essential to the process of reflexive TA... the fuel that drives the engine" (p.12) (Braun & Clarke, 2021, p12).

Table 1: Braun and Clarke's (2021) six phases of RTA, used to navigate the data analysis process.

Phase	Description
1	The 'Data familiarisation' phase commenced with immediate note-taking after each participant
	interview. To attain familiarity, I immersed myself in the data by revisiting all 10 interviews,
	rectifying transcript errors and extensively reading and re-reading transcripts. Simultaneously, I
	critically engaged with the data, actively seeking patterns of meaning. For an illustration of my
	note-making during this phase, see Appendix N.
	The 'Data Coding' phase, built upon phase 1, constituting a detailed systematic exploration.
2	Employing a discursive, critical psychology approach, I manually coded line by line, using both
	semantic and latent codes to capture specific meanings relevant to my research questions.
	Adhering to an inductive approach, I prioritised the data's guidance over imposing preconceived
	notions of knowledge and theory. This extensive process involved repeatedly refining and
	redefining codes, showcased in the photographs found in Appendix O. The outcome was a set of
	60 robust codes, detailed in Appendix P.
	In the 'Initial Theme Generation' phase theme creation began. My focus shifted from
3	interpreting individual data within the dataset, to exploring shared meanings across the dataset.
	I printed and cut out all 60 codes, which allowed me to visually engage in construing
	relationships between them, documented visually in Appendix Q. Themes were refined, merged
	or collapsed based on shared meaning. The phase concluded when I could produce a draft
	thematic map, illustrated in Appendix R of themes and sub-themes.
	This phase involved 'Developing and Reviewing Themes' in the context of coded data items and
4	interview transcripts. Guided by Braun and Clarke's (2012, p.65) key questions - is this a theme?
	(It could be just a code)? Are there enough (meaningful) data to support this theme? Is the data
	too diverse and wide ranging (does the theme lack coherence)? - These questions allowed me to

	consolidate themes that were merely codes and integrate a final theme from set aside codes.
	See final thematic map in Appendix S.
	In the 'Refining, Defining, and Naming Themes Summary' phase, I drafted narratives for each
5	developed theme and sub-theme, aiming to articulate their relevance to the dataset and
	research questions (See Appendix T). These narratives were shared with my supervisory team,
	which led to further refining. I revisited the dataset once more, collecting and organising quotes
	that supported themes and sub-themes. This rigorous process, brought my narrative of the data
	set to a meaningful ending.
	This final phase 'writing up Reflexive Thematic Analysis' symbolised the completion and final
6	scrutiny of the data analysis. By this stage, I had determined the sequence in which the themes
	would be reported. I wanted them to flow logically and meaningfully, building on a congruent
	narrative of the data. I felt confident that my themes and sub-themes were robust, rich and
	detailed, representing the dataset and closely aligned with my research questions. A detailed
	presentation of my results is provided in the subsequent chapter.

7. Results:

7.1. Chapter Overview:

This chapter will present in detail the themes and subthemes that I have generated from the 10 semi-structured interviews conducted. To respond to the research questions of this inquiry (See section 4). The analysis produced three overarching themes, illuminating the experiences of health professionals in SBUHB when working with people living with or affected by MUS: (1) 'Lost in the Fog of Uncertainty' (2) 'Health Professionals Subjective Journeys' and (3) 'Beyond the Fog: Envisioning Future Care for MUS'. This chapter opens by introducing the reader to the context behind this research inquiry, before discussing themes alongside their subthemes in further detail. This chapter will use verbatim quotes from participant's interactions to illuminate themes, patterns and insights.

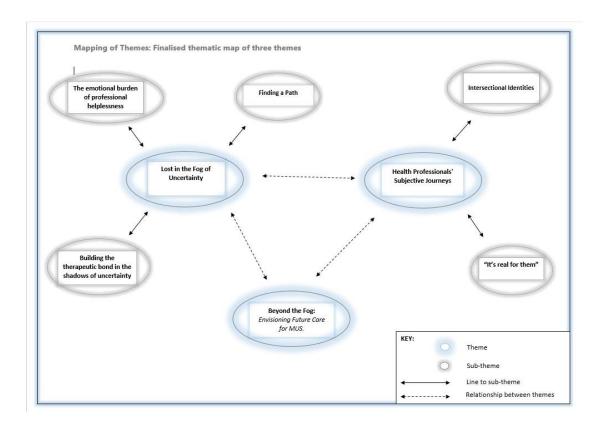
7.2. The Context:

Throughout the interviews, <u>all</u> participants openly shared their experiences of working with people living with or affected by MUS, within a broader context marked by noticeable absence of research interest and dedicated infrastructure to support this population in Wales. This overarching issue has been extensively discussed and acknowledged in the existing literature, as highlighted in section 1. Before presenting this research inquiry's themes, it is important to first situate my findings. While not introducing new information at this point, <u>every</u> participant discussed challenges arising from lack of guidelines, resources, time and dedicated research focus on MUS in Welsh healthcare services. By acknowledging these contextual realities encountered while navigating the complex landscape of addressing an illness that often feels untreatable or unexplainable. I can proceed to highlight the unique contributions of this research to the existing literature.

7.3. Visual Representation of Final Themes:

The use of a visual mapping technique proved to be extremely helpful throughout the analysis process. Firstly, it facilitated the organisation of provisional themes, allowing for an exploration of their interrelationships. Secondly, it helped me visually consider the overall story of my analysis (Braun & Clarke, 2021). **Figure 1** illustrates my final thematic map of three themes.

Figure 1: Final Thematic Map



7.4. Theme 1: Lost in the Fog of Uncertainty:

In Swansea Bay University Health Board, all participants spoke about the challenges of working with people living with or affected by MUS. Their combined narrative likened their experiences of working with MUS, to navigating through a dense obstructing fog of uncertainty. This metaphorical fog obscuring their well-trodden diagnostic pathways, clouding their usual judgements and decision-making processes. With no clear, familiar routes to follow, and repeated investigations continuing to reveal no organic origins, this often created an initial sense of disorientation. In this theme, I explore the personal and professional journeys of health professionals as they navigate this metaphorical fog, while attempting to provide support and care for conditions that defy traditional understanding and treatment.

This theme unfolds through three distinct sub-themes. The first, 'Finding a path' which highlights the experiences of health professionals' as they seek a path forward, to establish a solid foundation for effective patient care for conditions that are often unexplainable or untreatable. The second sub-theme, looks into the 'The Emotional Burden of professional helplessness', examining the emotional toll and its impact on

clinical practice as health professionals grapple with the personal and professional implications of being unable to 'fix' or diagnose effectively when their usual pathways are clouded. Finally, the third sub-theme 'Building the therapeutic bond in the shadows of uncertainty' discusses the formidable task of forging therapeutic bonds with people living with or affected by MUS, when the path ahead remains unclear.

7.4.1. Sub-theme 1: Finding a path:

All participants discussed ways of navigating the uncertainty of working with conditions that are often unexplainable and untreatable. They shared insights into their journey towards finding a clear, effective care approach for people living with or affected by MUS. For instance, Sophie, an Occupational Therapist, openly illustrates her quest for this right path. She expresses her openness to "any" suggestions and critiques to help her navigate through the murkiness of uncertainty, "I'm open to any suggestions, any criticism because I feel uncertain".

This uncertainty reaches beyond patient care, and encroached the very terminology health professionals' used to describe people living with or affected by MUS. Some professionals, adhered to specific terminology like "FND" (Functional Neurological Disorder) (Benjamin, Alex & David), while others grappled with the multitude of terms and diagnostic labels associated with MUS. This fluidity in terminology, highlights an inherent challenge – the struggle to define and categorise the diverse presentations of people living with or affected by MUS. Within this terminology haze, several participants hesitated to commit to a single term, opting to use various terminology. Their search for the right words and terminology is a reflection of the overarching theme of grappling with uncertainty. For some participants, MUS was simply referred to as "it" (Jean, Lisa, Sophie), while others sought clarity and confidence through numbers, by saying "we call it" (Lisa, Jean).

As professionals grappled with finding the right path when faced with uncertainty, they employed different discursive strategies to represent the complexity of their work. Notably, some professionals chose to walk along the path of uncertainty with their patients, embracing it as an integral part of their practice. For instance, Jean, an Occupational Therapist, emphasised the importance of openly admitting professional limitations when confronted with questions to which there are no clear answers. She

exemplifies this by frequently stating, "I don't know". Robert, a doctor, echoed this sentiment, highlighting the necessity of "making sure our patients are on board with this level of uncertainty" inherent to MUS. They emphasised the importance of raising patients' awareness regarding the uncertainty and unpredictability of the future of their symptoms and care, and that "there may never be a scanner or blood test that shows what is going on" (Robert):

They looking to you for answers and it be lovely to provide all those answers, but you don't want them to believe you are this expert and you have the answers, when you don't, it's not fair to make those false promises, is it?

(Jean, Occupational Therapist)

On the other hand, there were a group of participants that opted for a different strategy to confront this uncertainty, focusing on projecting an aura of expertise to instil patients with confidence in them as a health professional. Sheena, a doctor, in particular, demonstrated this approach by discussing the necessity for health professionals to carve a path forward that reflects and maintains assurance, even in the face of the uncertainty associated with often unexplainable and untreatable conditions. These insights share the delicate balance health professionals have to consider between offering transparency and hope in their interactions with people living with or affected by MUS, and how different professionals opt for different paths forward:

What we want to say is that actually we understand, we actually understand this condition. Although we may not know entirely, because still research is going on into the pathology of it ... but we still have experience in management ... also giving the patients the confidence that the clinicians are able to manage or help them manage ... because many of times you see that clinicians themselves are not able to, they don't have that understanding so may give that feeling that we don't know what we are doing here and you know ... I think one thing that patients would like to see is the confidence that the clinician knows what they're dealing with.

(Sheena, Doctor)

Within these narratives, uncertainty appeared to significantly shape how professionals' approached their practice when working with people living with or affected by MUS.

Take, for instance, Jean, an occupational therapist, who illustrates the impact of the

absence of research, direction and clinical guidelines towards her direction of care. She described her extensive, but fruitless research into finding ways forward, ultimately admitting, "I researched and researched everywhere... there wasn't much about it."

Confronted with this profound lack of certainty and concrete guidance, Jean's coping strategy involved leaning on her own professional training, ethical principles and personal values. Her approach often led to her "following basic OT principles". It is notable that several participants displayed similar tendencies (Lisa, Jean, Sophie) reverting to this "follow my nose" (Jean) strategy, following a path they know best, especially when confronted with obstructed and vanishing paths clouded by uncertainty. Although, grounded in an unwavering commitment to carving out patient care, such an approach can at times prove limiting, potentially constraining a more comprehensive view of a path beyond what is visible in front of them.

Furthermore, some participants, while navigating this uncertainty towards effective care for people living with or affected by MUS, were inclined to taking action, even when such actions didn't promise definite solutions. Sheena, a doctor, particularly, emphasised a need to move away from the notion that nothing can be done for this patient group, a sentiment echoed by Lisa, a nurse. They both emphasised that there are many ways to make a positive difference in the lives of people living with or affected by MUS, even when the path ahead remains obstructed and murky. Benjamin, a doctor, reinforced this idea by emphasising the ultimate goal should be to "restore function to normal" regardless of "whatever tool... I'll use whatever too":

We need to departure from the notion that nothing can be done for this patient, we all have something we can offer ...we need to do anything to help, we need to help as much as we can.

(Sheena, Doctor)

Whatever we do right, we got to have some positive impact, it's got to have some benefit ... if it works, it works. Brilliant. If it doesn't really. We've tried, you know.

(Lisa, Nurse)

However, there was a counter-narrative, where some participants stressed the importance of navigating this unknown terrain of uncertainty with caution. These participants highlighted that not all interventions are akin to well-trodden paths,

particularly when driven by approaches that are lacking strong evidence base. This illustrated the complex decision making process professionals navigate in the care of people living with or affected by MUS. David, a nurse, and Claire, a doctor, accentuated the potential harm associated with the notion of "doing anything to help" (Sheena), particularly those that involved pharmacological treatments and extensive investigations. David and Claire, particularly highlighted that embracing any available path forward is not without challenges and that taking a route merely for the sake of progress may not always be the best approach:

Pharmacology is a big hindrance for these people. I think we often end up turning to drugs and just make people worse rather than better. And you know, we often give some sort of neurological numbing pills, whether that's Amitriptyline, Gabapentin or Pregablin, and they have quite significant amount of side effects. I think they're using that almost as precautionary prescribing.

(David, Nurse)

There are no new or sinister findings clinically, then by commissioning more blood tests, more X-rays and re-referring the patient, actually we are causing patient harm. By taking yet more blood and investigating the person further. That's another needle stick. By doing more X-rays, that's more radiation ... and that's actually clinically negligent.

(Claire, Doctor)

The uncertainty of working with often unexplainable and untreatable conditions had an impact on health professionals decision-making regarding the process of referring patients living with or affected by MUS to other healthcare services. Sheena and Alex, both doctors, illustrated the multifaceted role of referrals, not only for obtaining additional investigations but also for providing reassurance to patients -and possibly themselves- within the foggy landscape of uncertainty. For Sheena, referring patients to other services was viewed as a strategic way of responding to uncertainty and offering patients a supportive pathway. Alex echoed this sentiment, using referrals as a means of seeking a second opinion for himself and validating his thoughts. But more importantly, referrals were also seen as a means of serving reassurance to patients, confirming that their conditions were not severe.

However, it is important to note that not all participants shared this view, and there was diversity in their approaches to patient care. For some participants, referrals were seen as a way "to refer on to somebody else, for somebody else to sort it out"

(Jenny), as a means to pass the burden of uncertainty onto others healthcare professionals. Benjamin, a doctor, also recognised the potential for health professionals to refer patients elsewhere once a diagnosis is made, indicating a desire to distance themselves from the ongoing management of such complex cases:

Offering them a bit more investigation, kind of. It's a way of kind of offering support, some sort of support, you know, and how do other clinicians provide support, is by ordering more investigation, medication, follow up, isn't it.

(Sheena, Doctor)

If there's something, a question I can't answer. Or some doubt this might be functional. I'll make a referral to the correct specialist to get their opinion on this...If they were worried that it was MS and I thought it wasn't MS, then I might ask, one of my colleagues who specialise in MS to see them to say I don't think it's MS.

(Alex, Doctor)

They've made the diagnosis and then wants them away in somebody else's clinic.

(Benjamin, Doctor)

On the other hand, some participants chose a different path to working with the uncertainties of caring for people living with or affected by MUS. Instead of passing the responsibility to other healthcare services, they committed to providing ongoing care within the healthcare system. For them, this approach was a way of protecting patients in a healthcare system marked with uncertainty when it came to MUS care. Alex, a doctor, particularly discussed this viewpoint, explaining how he might choose to continue providing long-term follow-up care for specific patients as a personal choice to shield them from the unpredictability of a healthcare system that could inadvertently fail to provide consistent care.

There are a few people who I have on, sort of long-term follow-up. Who I keep on the books because I think it contains their presentations to other people. Who I suspect if I were to discharge, they'd end up [Puts hands up in the air] Because of the nature of how medicine works.

(Alex, Doctor)

Amidst these narratives of the lack of scarce resources and limited service provision for people living with or affected by MUS, some participants shared insights into how they navigated this challenging landscape. Jean highlighted the importance of thinking creatively and to "think outside the box" when providing care for this patient group. Most participants recognised that this patient group "is not something that might fit into the traditional Western medical model" (Robert).

Among these strategies employed by participants, there was an interesting common thread. Firstly, all participants continually empathised with self-management and psycho-education as a primary intervention for people living with of affected MUS. Secondly, all health professionals continued to discuss their own self-learning and management experiences. This parallel process demonstrates an intrapsychic dynamic at play (See Adams, Estranda-Villalta, Sullivan & Markus, 2019), where the challenges of MUS are placed on the patient by the health professional and, reciprocally on the health professional by the surrounding healthcare system. This is demonstrated by participants desire to deepen their understanding, whether this was through "reading and reading" (David), "seeking out webinars", "following experts in the field" (Benjamin and Alex) or reading books such as "All in Your Head, by a neurologist" (Robert). Alongside this, all participants expressed their desire to deepen their patients understanding by advocating for "self-management" (Sophie, Benjamin, David) or "psycho-education" (all participants) as the primary intervention for people living with MUS. Sophie, an Occupational Therapist, illustrates this point, saying "treatment options are pretty limited...so basically it's just putting all the onus on people to sort of try and manage symptoms themselves".

This intrapsychic dynamic reflects a responsibility for addressing the uncertainty of MUS as jointly shouldered by the patient and healthcare professional, amidst the backdrop of lack of service provision and gaps in the support offered by SBUHB's healthcare system. The following excerpts from David illustrates one of many examples of this parallel process:

"It's only for the fact that I've spent time going over and over it and having to read about it and read about it, that I've got a bit more of an interest in it. I know a lot more about it now...there was an article in the Telegraph about seven or eight months ago talking about FND, because I think it was at the time when I was first seeing that patient and I sort of brought it up on the screen and I talked it through and it was a really interesting article."

"I think, it's that patient education, empowering them to know more about the diagnosis because I didn't know much about it. And I think patients probably know even less. So they're probably feeling worried, scared. But by empowering them, teaching them, learning about their illness, I think we're better able to process why they've got these symptoms. So I think at a low level, it's just going to be patient education."

(David, Nurse)

7.4.2. Sub-theme 2: The emotional burden of professional helplessness:

Embedded within the overarching theme of navigating the unseen uncertainty of working with conditions that are often unexplainable or untreatable, health professionals' narratives offered a window into the emotional burden they shoulder. In doing so, they illustrated how this emotional weight affects their professional decision-making, as they cope with the consequences of uncertainty obstructing their usual pathways. Addressing the core research questions.

Robert, a doctor, vividly depicts patients living with or affected by MUS as, "heart sink patients", exposing the emotional burden that healthcare professionals can shoulder when working with this patient group. This phase carries powerful negative connotations, encapsulating the emotional toll experienced by professionals when patients repeatedly present with debilitating physical symptoms lacking a clear biological explanation. Robert's reflection goes beyond terminology, as it reveals an inherent desire of health professionals to heal and enhance patient well-being. This inherent desire makes their experiences even more emotionally challenging when their efforts fall short. It casts a lingering shadow of inadequacy, particularly since health professionals' are often perceived as "experts" (Jean, Benjamin, Lisa) in understanding and addressing health issues. The expectations placed on them, as the ones who 'should' have all the answers, intensify a sense of feeling "bad" (Benjamin, Sophie). More so, as they not only are unable to provide solutions, but they often find themselves grappling with what the problem is to start. Jenny, a nurse, further illuminates the emotional toll of working with this patient group. She alludes to how the emotional strain can manifest in health professionals through their non-verbal cues and expressions, when encountering people living with or affected by MUS. The "look on their face" conveys this inner emotional

turmoil of helplessness. If Jenny can discern this emotional turbulence in her colleagues, it is conceivable that this may play a role in the patient-professional encounter:

We see them as heart sink patients, don't we? And they come through your door, you've seen them twenty times with the same issue. You haven't been able to fix it and therefore, yeah, your heart sinks when they walk through the door, 'it's frustrating, isn't it? Cause us as doctors we like making people better. And if we 'don't know how to make people better, we feel bad.

(Robert, Doctor)

It's very, very frustrating. And you know, people do the look on their face, says it all, and with the greatest will in the world, isn't it? You know, there are patients and you go ohh, you're not back again.

(Jenny, Nurse)

While some participants actively engaged in the diagnosis and treatment of people living with or affected by MUS, others expressed a profound sense of relief that they did not. They openly acknowledge that their roles do not necessitate dissecting or diagnosing the intricate nature of working with this particular patient group. Sophie, and OT, articulates this perspective, recognising the distinct role she plays in contrast to doctors who continuously cope with the diagnostic puzzle. Her relief emerges from not having to shoulder the emotional weight of challenging patient encounters and the daunting task of diagnosis. Lisa, a nurse, agreed humorously portraying her role as "the nice, cute bit", characterised by conversations rather than the diagnostic challenges faced by doctors. Together, these narratives of relief provide a glimpse of the emotional dynamics that unfold when working with this patient group. Sophie's narrative highlights the multifaceted nature of this emotional burden, which concerns the appropriateness of selected care and the internal struggle to justify ones role within a system that may, at times, neglect or misunderstand the suffering of people living with or affected by MUS:

I always feel like I'm relieved, and that I'm not having to like figure out or diagnose the symptoms. I guess it must be different if you're reading this as a doctor, isn't it? You're constantly probably trying to figure out what's going on. So I feel like, you know, that's a relief, I'm not having to. That's not my role.... I don't know if what we're doing is right. And I do worry that in the future, you know, 10 years down the line, it'll be like, Oh my God, I can't believe people used to just tell them

to, like, get on with it themselves. And I would feel bad because I'm part of that effectively.

(Sophie, Occupational Therapist)

That's not what my role is. I don't have to work in that scenario [lots of laughter], so it's a little bit easier for me. I'm doing the nice cute bit, but you know, just the talking.

(Lisa, Nurse)

Intertwined with this relief is a contrasting feeling of concern and anxiety. While some participants welcomed the relief of not having to grapple with intricate diagnoses, they were equally weighed down by apprehension. There was a shared fear of "missing something" (Lisa), as they walk the fine line between holistic patient care and the potential risk of overlooking underlying medical conditions. Sheena, a doctor, was one of three professionals' that discussed diagnostic overshadowing, shedding light on the challenging balance healthcare professionals must maintain. This concept highlights the risk that "functional symptoms" might mask serious medical issues, further intensifying the fear of overlooking critical details in their patient assessments. These fears were further compounded by an awareness of "horror stories" (Jenny) that could haunt health professionals' decision-making. Jenny articulates this concern, emphasising the need to tread carefully, ensuring that patients are not discouraged from seeking medical attention:

You have to be investigated because sometimes there HAVE been cases. You think that it's just part of the FND, but actually when you investigate the person has a fracture you know. There HAVE been cases. So the person ACTUALLY has a fracture and people have left it out because the person is known with a lot of functional symptoms. I am involved with a patient who's always been obsessed about her gut and she's been diagnosed with functional gut by the gastro consultant. But this year she was diagnosed with cancer in her bowel. This is why you have to work very carefully around this group of patients and any new symptom you know should be explored should be investigated.

(Sheena, Doctor)

I think we've got to be really careful because you know. We can't really put patients off from coming to see us because you know you do, then hear the horror stories of I was too afraid to go and then they end up really seriously ill isn't it.

The emotional responses towards people living with or affected by MUS appear to be intricately linked to the participant's professional role within the healthcare system, potentially influencing the trajectory of their practice. For doctors, exemplified by Robert and Sheena, they described grappling with a profound sense of professional helplessness when working with people living with or affected by MUS, at times contemplating pharmaceutical intervention, even in the face of uncertainty about their efficiency. This decision to prescribe medication can pose as significant emotional challenge, as it may conflict with their preference to address underlying causes to provide non-pharmacological treatments.

In contrast, when working with children who have lived experiences of MUS, as illustrated by Benjamin, a doctor, the emotional burden of helplessness is approached differently. There is a preference for, a maternal stance towards patient care, where healthcare professionals willingly assume all responsibilities and emotional burdens. Their goal is to shield young patients and their families from anxiety and uncertainty. This maternal approach reflects a strong emotional response to the suffering of their patients. These emotional responses are particularly compelling when considering the impact of working with often un-diagnosable or untreatable conditions, on healthcare professionals' practice and their own emotional well-being.

So you kind of feel very helpless. You feel very helpless as a doctor for all these kind of patients. And you wonder, you start ending up reaching for the prescription again, cause maybe some pills will make him get better, better. And they often don't.

(Robert, Doctor)

When we see so many patients with FND, we're not able to give a good explanation. ... Or having that feeling of inadequate, inadequate feeling of how you know, you know we won't be able to provide anything.

(Sheena, Doctor)

I think paediatrics is different from adult medicine. It's very matriarchal. All paediatricians, basically like mums. They just want to protect and look after these kids and these families, they don't want them to worry. They want to take on all the responsibility for themselves.

The majority of participant narratives, lacked emotional fulfilment and satisfaction in working with people living with or affected by MUS. This underlines the significant emotional burden that health professionals experience, towards the burden of not being able to 'fix' or diagnose. Robert, a doctor serves an illustrative example of this contrast. He points out that cases with well-defined diagnoses, typically provide an emotional response of a sense of accomplishment and professional's satisfaction, a sentiment rarely found when working with people living with or experiencing MUS. This disparity may explain the wide range of negative emotions expressed by healthcare professionals, who cope with the challenge of working with MUS. It is understandable, why this often leads to emotions such as "irritation" (Claire) and "frustration" (David, Lisa, Jean) in health professionals encounters with this patient group:

The symptoms are usually much broader, it relates to mental health or or it relates to concerns with housing or relates to domestic violence.... So for most of my colleagues. If I'm honest, if I'm really honest, I think they would. They'd find people quite irritating.

(Claire, Doctor)

They're not the kind of patients that you that, that that make you feel really kind of satisfied afterwards...sometimes you kind of make a difficult diagnosis and you feel great that you found that out, but that never tends to happen this with this kind of, it often kind of leaves you feeling sad you kind of feel like you know. And often I feel bad...I feel a bit lost in kind of offering further support with regards to that [MUS] which is completely different with someone who's got type 2 diabetes for example, who has got lots of options available to them you know.

(Robert, Doctor)

7.4.3. Sub-theme 3: Building the therapeutic bond in the shadows of uncertainty:

In the fogginess of the uncertainty of working with often unexplainable or untreatable conditions, health professionals discussed the formidable task of forging therapeutic relationships. This-sub theme outlines the intricate experiences of professionals as they navigate this misty landscape, endeavouring to build therapeutic bonds that offer essential support and care, even when the path ahead remains unclear. Within this complexity, the nature of the relationship between health professionals and their patient

can influence the direction of care. The bond, whether formed or strained, within the shadows of uncertainty shape how healthcare professionals construct this relationship and decision-making as they embark on their quest to provide meaningful care and support.

David, a nurse, among others, offered stories into the nuances of these relationships, sharing their encounters with particularly challenging cases of people living with or affected by MUS. David talked of the discomfort and unease experienced when faced with patients in distress or frustration. The therapeutic relationship hung in the balance, especially when patients expressed disagreement or dissatisfaction with the limited resources and explanations offered. Jean, an OT, echoed this sentiment, describing her relationship with a specific patient living with or affected by MUS as "draining". Her choice of language demonstrates how she could experience strong emotional reactions from the process of navigating the therapeutic bonds with people living with or affected by MUS. The exchange of experiences, thoughts and emotions, both conscious and subconscious, is a difficult dynamic for health professionals to navigate. What ties these accounts together is the profound impact the desire to maintain the therapeutic bond can have on healthcare professionals, leaving an imprint on both their professional decision-making and their personal well-being:

I do not like seeing patients get upset, get frustrated with you and have a negative experience of an interaction with you...anyone that I see and they get frustrated or don't agree with me, that can knock you a bit and knock your confidence.

(David, Nurse)

"She is very draining. I have snapped at her in the past, you put the phone down after 30 minutes of going around the loop and people in the office say God you've got the patience of job and you think ahhhhh, but I keep reminding myself that she is desperately unhappy... And to her, obviously it's all real and she is desperately worried. And I just have to keep putting myself in her shoes. And then, you know, you can get that compassion back"

(Jean, Occupational Therapist)

Most health professionals' showed the discomfort, frustration, and emotional strain experienced as they navigate establishing therapeutic relationships with people living with or affected by MUS. The challenge of working with unexplained or untreatable

conditions appeared to strain the therapeutic relationship, further impacting the well-being of both professional and patients. For most, the crux of this challenge often lied in the misalignment between patients' expectations and the reality of available care. In their accounts, many health professionals described the influence of patients' pre-conceived expectations, which were deeply rooted in the dominant Western medical model discourse. These perspectives were around the anticipation of clear diagnoses and straightforward solutions. Alex, a doctor, captures this discourse "patients expect you to say what's wrong, give you something and your problems fixed". However, MUS presents a unique challenge as it defies such straightforward categorisation. Patients may arrive with the hope of receiving definitive answers and treatment, as poignantly echoed by Sophie, only to be confronted with the reality of the uncertainty surrounding MUS. This stark dissonance between patient expectations, and the reality of the situation, creates fertile ground for patient frustration and dissatisfaction, further straining the delicate threads of the therapeutic relationship, as vividly demonstrated by Jenny:

Patients or services tend to think... that there's someone that's going to like, understand what's going on for them and their body and diagnose and provide treatment. And I think that's a part of it, realising that...I think a lot of people don't know or don't understand.

(Sophie, Occupational Therapist)

I think lots of people have the perception that, especially when you're seeing doctors that they should be able to give you the answers for everything. And I think sometimes they do get frustrated. [Puts on an angry voice] Well what do you mean? They medically unexplained! You have done an X-ray! Done my blood!! Why can't you explain it?

(Jenny, Nurse)

In these discussions, most participants acknowledged the delicate balance they faced when attempting to incorporate any psychological or psychiatric aspects into the therapeutic encounter. They recognised that their word choices and communication styles held a profound influence on patients living with or affected by MUS, and could potentially "muddy the waters" (Benjamin) of the therapeutic relationship. Alex, a doctor, particularly shared an example that highlighted the nuanced challenges faced through communicating their explanations. He emphasised how specific terminology could

inadvertently disrupt the therapeutic bond. He noted that certain terminology can get patients "hackles up". Jean, an OT, echoed these sentiments, emphasising the need for careful and considerate communication when working with people living with or affected by MUS. These accounts illustrate a recognition of the fragility of the therapeutic relationship with this patient group, where even a minor lapse in word choice, is up for interpretation. As this can hold significant meaning and explanation, which patients may not necessarily agree with, and potentially undermine the therapeutic bond:

I think if you use the word psychological or psychiatric, it immediately upsets them... I never used the term psychiatric because it tends to put people's hackles up.

(Alex, Doctor)

You have to be really careful though, wouldn't you? Not to insult her, you'd have to proceed very carefully... Would she be insulted if she would be told it's all in your mind? I mean, obviously you wouldn't put it like that, would you? Because that's the risk of people being told that.

(Jean, Doctor)

Most participants elaborated further on the fragility of the therapeutic relationship, discussing the strategies they employed when faced with the looming presence of ruptures in the therapeutic bond. Notably, these narratives showed how health professionals cope with the limitations of their ability to provide a solution in the therapeutic relationship. For instance, Jean, an OT, recounted a scenario where she would "back down" from discomfort to salvage the remnants of the relationship, often retreating from explanations or language rooted in psychological or psychiatric discourse. Similarly, Alex, a doctor, exercised caution in introducing his favourable perspective for explaining MUS, The Attention Model (See Rief & Broadbent, 2007), only doing so when he believed it would not shake the relationship bond and "set off their antibodies against me." These narratives emphasised the adaptions participants made to their communication strategies when they sensed the potential rupture in the therapeutic bond. Notably, these adaptions extended to their choice of language and the direction of care.

For instance, Jenny, a nurse, particularly spoke of how some colleagues result to "giving in...just bring them in, refer them to the team" for further investigations, to avoid

discomfort and maintain the therapeutic bond, even when the choice of care held no guarantee of a clear solutions. In contrast, other participants took a very different approach, opting to confront the emotions brewing in the therapeutic relationship and lean into the potential ruptures. Sheena and Benjamin, both doctors, who grounded their therapeutic relationship in honesty while navigating uncertainty and relational challenges, illustrated this approach. These narratives collectively showed, not only the diversity of strategies that health professionals utilise to manage potential ruptures in the therapeutic relationship, but how these strategies are deeply interconnected with how each health professional responds to the discomfort of being unable to provide solutions or diagnoses. Providing valuable insights into the experiences of health professionals in the dynamics of these critical relationships:

I think being really honest within that relationship is important. I'm lucky to have that relationship with many patients. So for example, when they don't turn up for appointments or when they switch off the video. I'm able to have that Conversation.... And, you know, we can talk. And that's more important. So, yeah. So having that good therapeutic relationship is vital, I think as well.

(Sheena, Doctor)

I will also try and build their empathy with me or their trust, and I will do that by explaining my thought process, so I can be as transparent as possible in terms of decision making.

(Benjamin, Doctor)

Throughout these interactions, a noticeable divergence in how participants talked about patients could be seen. Some participants used terms such as "cooperative" (Sheena), "accepting" (Jean, Sheena & Jenny), and "receptive" (Jean) to depict certain patients, while others labelled them as "challenging" (Jean) or "disagreeing" (David). These characterisations stemmed from health professionals' attempts to establish a foundation for broader perspectives within the therapeutic relationship. Jean, an OT's, comment, "she's not on board yet" captures this tension that healthcare professionals face as they attempt to integrate alternative hypotheses to medical solutions, like psychological or psychiatric factors, into the therapeutic dyad. This tension feels rooted in the spoken and unspoken beliefs of MUS origin. Sheena and Robert, both doctors, explored further into this concept of categorising patients within the therapeutic relationship and how the

clash of differing perspectives on the origins of MUS, can greatly influence how healthcare professionals experience and interact with their patients:

So she's not fully accepting...this one lady who is absolutely fixated on it being a medical physical cause and she's looking for the right medication. So she's not on board yet....but the others are great. I really enjoy working with them because they all appreciate that there's no magic answer.

(Jean, Occupational Therapist)

I mean there will be some patients in spite of all the help...they will keep on going. So you do have that subgroup, but on the other hand, you do have patients who when you provide a reasonably good explanation of what's happening, they seem to be able to take that on board and work on how other ways to improve.

(Sheena, Doctor)

"It depends if you're patients receptive to that, isn't it? There's a lot of patients that are not willing to accept that, that might be a cause of why they're having these kind of functional symptoms. If they're not accepting that, and I think they're not ready to be referred on to, for that. So they have got to have some sort of insight and be willing to be referred because they are not going to engage and there's no point is there."

(Robert, Doctor)

7.5. Theme 2: Health Professionals' Subjective Journeys:

This theme transitions deeper into exploring the inner world of healthcare professionals and how this impacts the healthcare journey of people living with or affected by MUS, especially amidst the uncertainty they face when working with often un-diagnosable and un-treatable conditions. To illustrate healthcare professionals' subjectivity, consider the metaphor of a camera lens of perception, which they view this patient group. This lens, like the filters in front of a camera, represent the amalgamation of their personal experiences, biases, and both implicit and explicit beliefs. These unique lenses shaping how healthcare professionals view and interpret a patient's condition, potentially either distorting or enhancing certain aspects of their situation. Jean, an OT, fittingly captures this as "following my nose", as subjectivity becomes a critical guiding light out of the fog. This ultimately resulting in diverse approaches and outcomes in healthcare.

This theme unfolds into two sub-themes. Firstly, sub-theme 1 'Intersectional Identities' which recognises that the personal and professional identities of healthcare

professionals intersect and interact with each other, contributing to the professional-patient interaction, as well as the trajectory of care. Secondly, Sub-theme 2, "It's real for them" highlights the diverse ways in which health professionals' beliefs, assumptions and value frameworks influence their approach to understanding, communicating with, and providing care for people living or affected by MUS.

7.5.1. Sub-theme 1: Intersectional Identities

The personal and professional identities of healthcare professionals intersect and interact with each other, shaping healthcare professionals experiences and perspectives. This subtheme goes beyond single-dimensional understandings of identity and acknowledges the complexity and psychological depth of human experiences. It recognises healthcare professionals' experiences of working with people living with or affected by MUS, are not solely defined by their profession, but also their personal and professional experiences and identities. These intersecting identities influencing how they perceive and interact with patients and how their patients perceive and respond to them. For example, a recurring narrative among many participants underscored the guiding role of 'experience' in shaping the trajectory of patient care. Claire, a Doctor, in particular, shared her view on the impact of 'inexperience' among junior clinicians' and how it influenced the direction of patient care, steering their practice in the opposite direction to her practice:

Juniors and inexperienced clinicians are much more likely not to be able to recognise it, medically unexplained symptoms and yet again further investigate...based on sets of observations and bedside investigations, which we would never not do. It's very much it's not an uninformed risk and the more senior you get the more you realise you can actually take those decisions without fear of mistake.

(Claire, Doctor)

In discussions about 'experience', six participants shared narratives detailing how their prior encounters with a patient living with or affected by MUS significantly shaped their professional understanding and approach. These personal stories seemed to serve as transformative moments, shaping their current practice and health beliefs. Claire and Jean, spoke of challenging cases that acted as turning points in their comprehension of MUS, while David, a nurse, emphasised drawing upon past experiences to inform his

practice; "I draw upon previous people I've worked with who've got it". This approach was common among participants, highlighting a learning process where professionals learn through their patients, utilising them as "a benchmark" (David, Benjamin, Claire) to comprehend MUS and provide explanations based on past encounters; "I've seen Mrs Thomas, she had similar symptoms to you. She's got FND. This is what we do" (David). Benjamin, a doctor, introduced another layer to this subjectivity by recounting a colleague's negative perception of MUS, shaped by a challenging case, which subsequently influenced her approach.

If you wanted a really negative opinion about the really horrible consequences of it, there's a doctor who's dealt with our most difficult case and I think still bears the scars of it, but she will be skewed in a very, very negative light towards this whole thing. She tries to avoid it like the plague now.

(Benjamin, Doctor)

Benjamin's extract is a powerful one. Reflecting on the choice of language, he illustrates vicarious learning vividly. His choice of language conveys the emotional impact and lasting impressions left by unique experiences of working with people living with or affected by MUS. Words like "horrible", "skewed" and "scars" evoke a sense of deep emotional and psychological resonance of these encounters. Such language can serve to highlight the lasting effect these experiences can have on healthcare professionals' perceptions and their subsequent practice, as illustrated by Benjamin's colleague's avoidance of such cases. It illustrates the unique experiences each healthcare professional can encounter, which, in turn, can inform each professional's viewpoint and future approach, as they remember their past experiences when interacting with patients living with or affected by MUS.

Several participants also highlighted the impact of mentors, colleagues and supervisors on their understanding and approaches to working with people living with or affected by MUS. David, a nurse, stands out as a compelling example of personal growth in his understanding and practice with this patient group. Initially, when faced with encounters with people living with or affected by MUS, David reported having "no knowledge", as he was "inexperienced" and had to heavily rely on observations and insights from colleagues. He spoke of internalising the health beliefs and perceptions of colleagues on the legitimacy of MUS, reporting that he initially "learnt that it was very

much fake, it's not real". This narrative underscores the complex interplay between personal and professional identities among healthcare professionals, as it highlights the impact of collective experiences on individual perspectives and practices. Jenny, a nurse, and Sheena, a doctor, further affirm this notion, highlighting the impact of their mentors and supervisors on their perspectives and practices regarding MUS. Claire, a doctor, adds another layer to this discussion, offering her personal insights as "somebody with chronic fatigue". Her experiences living with chronic fatigue influence her comprehension of MUS and how she conceptualises it:

I think they just go on their previous experience. You know, and sometimes their placements or their mentors can influence. The way that they practice but. I, you know, there's lots of material and a lot of reading material out there, but I mean. You could be reading 24 hours a day, sometimes couldn't you?

(Jenny, Nurse)

I think it helped I had my supervisor...who, although she's not a medical psychotherapist, you know, she's very psychologically minded.

(Sheena, Doctor)

Speaking personally, as somebody with chronic fatigue, I think there has to be, if investigations have proved that there's nothing that can be physically treated, then I think there has to be a psychological component which requires support, so it's about getting to that.

(Claire, Doctor)

Claire's perspective is interesting. She uses language that dichotomises her understanding of MUS, influenced by both her personal experiences and subsequent professional viewpoints. Her choice of language creates two distinct categories, either something is identifiable and can be physically treated OR it is seen as primarily psychogenic. This binary viewpoint may not readily accommodate alternative ways of comprehending people living with or affected by MUS. It does not leave room for other possibilities, such as rejecting the mind-body dualism approach (Sanders, 2017) or considering the existence of yet-to-be-understood mechanisms, which might not be immediately evident.

Claire, a doctor's narrative mirrors this common thread, illustrating how personal and professional experiences and characteristics, can significantly influence the patient-professional interaction and subsequently the direction of care for people living with or

affected by MUS. Jenny, a nurse, and Benjamin, a doctor also reflect on their personal journeys and health beliefs and how these identities intersect and interact with their occupational role. Jenny's first-hand encounter with "headaches" and "hypertension", where no quick and definitive medical solution existed, led her to question the limitations of conventional approaches and consider the broader dimensions of care required. Benjamin, on the other hand, learned empathy through his injury, through living with chronic pain and functional limitations. His personal journey prompted a shift from a focus on surgical solutions to a more holistic approach:

I ended up myself. I was suffering. I had the start of headaches in November.... And I ended up having sort of spontaneous integration, hypertension and it took me a couple of months to get better. And, you know, like speaking to the neurologist. It's like, Oh my God, how long are people like this for? I was told some people with this condition might be like this for months and months...But yeah, you don't realise. I think some conditions can be quite debilitating. I didn't realise until I had it. You know the treatment for it initially was caffeine, bed rest and analgesia. And there was no quick fix to some conditions. It's what I found out myself.

(Jenny, Nurse)

I managed to injure my knee being an idiot, skating and being a busy doctor didn't actually go and get anyone to sort it out... and just living with pain and feeling sort of pain every time you tried walking upstairs or bending your knee, you end up unconsciously limiting yourself from doing things... and in the end what I did not need was a surgeon poking around, what it actually needed because it had healed. It left me a working at a reduced functional rate and what I needed was physio to retrain, build up muscle mass around the knee for stability and then get walking again and I've got a lot more sympathy with these families since then. So yeah, functional disease for me is managed jointly between Physio and Psychology.

(Benjamin, Doctor)

These stories shed light on the nuanced ways in which healthcare professionals' personal experiences shape their perspectives on MUS and their approaches to patient care. Furthermore, embedded within the personal narratives of participants was the concept of 'confidence' as a central personal trait. This was seen to significantly influence health professionals' experience of people living with or affected by MUS. Jenny, a nurse, described confidence as an attribute that tends to be polarised, much like the focus of a camera lens - it's either something you have or you don't; "we don't seem to find a middle ground". This polarisation appeared to influence her colleagues' approaches to the direction of care for patients living with or affected by MUS. Some exhibiting characteristics that are "very, very cautious" and often inclined to "rescan, rescan". Others took a more dichotomous stance, asserting, "We have seen this lady, we are not doing anything else". Some participants, like Benjamin, a doctor, echoed the sentiment of confidence in practice, whilst they did not explicitly mention the influence of confidence in their practice, they primarily discussed high success rate with this patient group, possibly emphasising expertise and confidence in this area:

I have had one patient who was not fully recovered with these diseases and I probably had about 40 or 50 of them. I've got a very, very good cure rate for it. I am not trying to be arrogant. It's just that that's just how I managed them.

(Benjamin, Doctor)

Furthermore, Sophie, an OT, explored further, how her personal characteristics interfere with her identity as a healthcare professional, unintentionally interfering with their ability to navigate the complexities of working with people living with or affected by MUS. Sophie acknowledged experiencing feelings of uncertainty and worry in her work, attributing these emotions to her own personality type. She suggested that her personality traits might at times hinder her ability to effectively navigate this uncertain terrain. In essence, Sophie is recognising that her own personality and emotional responses can "get in the way" of her interactions and decision-making when working with this patient group. In a similar way, Jean, an OT refers to herself as a 'pushover' in the context of accepting any patient:

Yeah. So I guess my feelings of uncertainty. Sometimes worry...and I think it's all to do with, like myself and my personality type as well. So I guess I think that can get in, in the way maybe.

(Sophie, Occupational Therapist)

Not for me personally because I'm a pushover. I accept anybody, anybody. I mean, we take anyone with OT needs primarily OT needs.

(Jean, Occupational Therapist)

Many participants discussed essential qualities and characteristics they believed healthcare professionals should possess when working with patients living with or

affected by MUS. Jean, an OT, in her choice of language, suggested the importance of assertiveness and proactivity, through discouraging a "shrinking violet" approach to practice with this patient group. While, Sheena, a doctor, stressed the value of personal traits such as "resilience" to be able to navigate the challenges and uncertainty linked to interactions with people living with or affected by MUS. Additionally, Benjamin, a doctor, emphasised the need for health professionals to be well-prepared and equipped for their interaction with this patient group:

You have to have that willingness to work and you know to roll with resistance...And working, with the resistance from the patients and from yourself. So I think having that resilience is important.

(Sheena, Doctor)

This is the diagnosis, this is the plan you need to follow. Now do you think you've got the tool and skills, you've got the equipment and somebody else is taking on the risk for you, can you do this?

(Benjamin, Doctor)

Healthcare professionals' experiences of working with people living with or affected by MUS extended beyond their professional roles. Their interactions were shaped by the intersection of both personal and professional identities, affecting the dynamics of the patient- professional encounter, and subsequently the care provided.

7.5.2. Sub-theme 2: "It's real for them"

In discussions about health professionals' experiences of working with patients living with or affected by MUS, a common thread emphasised the importance of healthcare professionals fostering a genuine belief in patients' experiences. Sheena, a doctor, in particular, placed great emphasis on this idea, asserting that fostering a genuine belief in the legitimacy of MUS, is an important step towards providing more empathic care, regardless of diagnostic clarity. Sheena further illustrates how the choice of language categorisation, such as the term 'functional', which often implies a lack of clear physical causes for symptoms, can inadvertently cast doubts in the minds of healthcare professionals regarding the existence of MUS. This doubt arises as health professionals' grapple with labels of "functional" meaning there is "nothing wrong with

them" (Sheena) biologically. As explored earlier (see sub-theme 1), this can create a binary understanding of MUS. If symptoms are deemed 'functional' they might be construed as psychological or dismissed as being 'all in the patient's head' or 'not real' in the traditional sense of being physically observable or diagnosable. Furthermore, Alex's perceptions amplify this concept by highlighting the importance of acknowledging the authenticity of patients' experiences, even in the absence of diagnostic clarity. The core of this narrative recognises that patients seek medical care because they are facing tangible challenges; and even when the exact nature of these challenges remains unknown, providing care and support should remain paramount:

I think the key parts of that relationship is actually believing in the patient's symptoms. I think if you believe in the patient's symptoms, you'll actually be able to empathise in the true sense of what this person is experiencing, the effect it has on them, their family, their children...I I think because the nature of the diagnosis, the term functional, the professionals themselves think well, there's nothing wrong with them. What else can we offer, isn't it? Whereas if you start believing in their symptoms, start believing that they are actually in pain, they're not able to move their limbs and they need that support. We are able to provide that support better. I think believing, believing their symptoms is important.

(Sheena, Doctor)

I think that's the biggest issue is that people think it's not a real problem [Shakes his head] And actually, by virtue of the fact that they're in this acute setting with legs, that don't work... whatever their presentation, they do have a real problem... because they're in the hospital with legs that don't work and you know. Just because. "Well, I don't know what it is. I don't know.

(Alex, Doctor)

Fundamentally, Sheena and Alex advocate the need for a shift in perspective from doubting the authenticity of MUS to wholeheartedly believing and embracing patients' experiences when working with people living with or affected by MUS. David provides additional understandings into the subtle ways that scepticism can surface, manifesting through body language, word choices and nonverbal cues. This highlights the unspoken communication of healthcare professionals' subjective beliefs and biases, which patients can detect, even when not explicitly articulated. Not addressing such subjective biases, may leave patients feeling invalidated, if health professionals are harbouring doubts about the legitimacy of their condition - whether this is blindly or not:

They may not feel validated if you're internally thinking I don't believe what you saying. I don't believe this is true disorder. You may not be. You may not be saying it, but they may pick up on your body language the way you're talking, the way you're framing the questions, and they could think well, he didn't believe this... It does come across in your encounters, albeit not necessarily through the word spoken, but through again body language phrases, values, judgments. They can. They can all be interpreted by the patient.

(David, Nurse)

The narratives that were shared by participants as they discussed beliefs surrounding the authenticity of MUS offered intriguing observations. The majority of participants expressed the importance of believing and validating patients' experiences of living with or affected by MUS. As highlighted in David's, a nurse, account above, the subtle intricacies of non-verbal cues and language choice can inadvertently reveal a person's true thoughts and beliefs about MUS. In the midst of these discussions, participants' choice of phrasing stood out – particularly the recurring use of the phrase "real for them". This phrase, whilst intended to affirm the legitimacy of patient's experiences of living with MUS, inadvertently introduced an element of health professionals' subjective perspectives and potential doubt. Although the participant's intentions were undoubtedly to validate the patient's experiences, the phrasing unintentionally created further ambiguity. Instead of providing clarity, the phrase "real for them" introduces further uncertainty regarding the objective reality of these experiences. This insight was prominently demonstrated by David, Jean and Claire:

My professional understanding of it is, it is a condition, and it's a symptom. It's a syndrome they experience, <u>it's real for them.</u> I probably wouldn't ever discount it. I'm quite supportive of them with it. So I think that helps. Whereas I think in some people, if the professional doesn't understand it.

(David, Nurse)

They may have some kind of seizures..., these seizures are <u>often very real for</u> <u>them</u>...they're definitely having some kind of event...even with some of the people that keep self-presenting with abdo pains and chest pains that you spent a lot of time and effort and it is well physically we can't find anything wrong with you. But you know, <u>to them</u>, their symptoms are real.

(Jenny, Nurse)

I think it. I think it's one of trying to not dismiss them. And to say that their symptoms are real for them.

(Claire, Doctor)

Amid this ongoing narrative, a notable perspective materialised from certain participants, whilst their intention was to provide reassurance and comfort to patients living with or affected by MUS, this inadvertently demonstrated a belief that MUS patients were fortunate that they did not have an organic cause for their experiences. David, a nurse, underscored this notion, whilst other participants strived to reassure patients by "ruling out causes" (Jean, David, Clare, Jenny and Lisa):

It's not to discount them and just say every time she has a headache or neck, it's going to be because of the anxiety, which it may or may not be, but you need to be ruling out that she could be having a stroke, you know. So I think it's to, you know validate that those experiences are real for her. They're not. They're not made up. She did have these experiences. But luckily there's no underlying organic cause that we can see.

(David, Nurse)

This is good news. This is not a bad news scenario. I'm not telling you it's all made up. So it's not all made up. It's a very real disease.

(Benjamin, Doctor)

In essence, David's and Claire's narratives highlight a pivotal aspect of discourse surrounding MUS- the intricate balance between implicit and explicit communication and the profound impact this could have on patient care for people living with MUS. These insights demonstrate the challenge of validating and reassuring patients' experiences whilst steering clear of language that inadvertently downplays patients' struggles.

Sheena, a doctor further amplifies this understanding in the narrative below, highlighting how her own beliefs and value system manifest in her approach to patient support. Her beliefs surrounding the authenticity of MUS are intertwined in her offerings to extend equitable access to social care resources — embodying the belief in the authenticity of MUS; and subsequently, minimising any doubt about the legitimacy of the experience of MUS:

They are getting care.... They're getting care packages, that's happening. I can see that happening with many of my patients that care packages are happening, or sometimes we have even provided that support to the social services or to

recommend that they get the care package. So I was actually surprised. Well, actually that means people are taking on board how these people are struggling and are providing that care package which is good.

(Sheena, Doctor)

This exploration into participants' language choices as reflections of their beliefs takes us further into the subjective preferences for terminology of health professionals' when working with people living with or affected by MUS. These preferences for most were closely intertwined with their underlying beliefs and comprehension of MUS. Sheena, a doctor, offers a lovely example of displaying the messages behind terminology choice; for Sheena, the term "functional" carries a diverse range of interpretations, depending on whom you ask. While it might imply efficient functioning for some, it can, for many patients, insinuate that their symptoms aren't taken seriously. Sheena found solace in the phrase "persistent physical pain", as she believes this terminology removes this layer of explanation and instead conveys to the patient that we believe their symptoms have been enduring. However, some healthcare professionals, particularly Jean, an OT, and Alex, a doctor, bring another viewpoint to the table, as they prefer using "FND symptoms." For them they felt it is a term with fewer negative connotations. While Claire, a doctor, demonstrates how her choice of terminology reflected how she experienced people living with or affected by MUS, leaning towards "frequent service users" when describing patients who visit the healthcare system frequently. Her choice is based on the frequency of attendance and serves to capture how she experiences the essence of these patients' interactions with the healthcare system:

You know functional can mean differently for different people. It can mean, as in really functioning, isn't it... functioning as in the system, the bodies working as it should. But also for many patients, it can mean that we're not taking their symptoms seriously and it's, you know, 'functional'. So that terminology, I think minimizes their experience when you use the term functional. Whereas when you use the term persistent physical pain, it takes away that side of the explanation you know, the kind of stigma where it is functional... it gives an understanding for the patient that they are kind of they've remained persistent for them... I think it's a way of communicating between the clinicians that this has gone on for a long time.

(Sheena, Doctor)

So frequent service users... And that is based on frequency of attendance. Of course, we do have individuals who will come, but not as frequently. So we do

recognise the term medically unexplained symptoms....I don't know what that is, so what is FND.

(Claire, Doctor)

These perspectives shared by participants collectively illustrate the dynamic nature of terminology and its role in shaping professional-patient interaction and understanding. It becomes clear that the choice of language is not a one-size-fits-all approach; rather, it is a nuanced, context-specific decision guided by the healthcare professionals intended message. An example is the practice of Lisa, a nurse and Sheena, a doctor, who tailor their language to suit their audience, so that communication is more relatable and straightforward. This pragmatic approach further highlights the contextual nature of terminology selection. David's, a nurse, discussions add another layer to this adaptability, highlighting how he strategically deploys specific terminology when faced with terms that may carry potential stigma. This adaptability again demonstrates the nuanced and flexible nature of language choice among healthcare professionals:

When I'm speaking to professionals or colleagues, I probably would have said FND...but, I'd probably say medically unexplained. I think it makes a bit more sense to people. I think it's a bit more plain speaking.

(Lisa, Nurse)

With professionals, I use multiple terms so that they understand what we're talking about. So like when I've done presentations, I use different terms FND, MUS, Somatic form Disorder, Conversion Disorder. So I use different terms and I sort of explain that they all mean this kind of same thing, but maybe for the presentation I will use MUS because everybody just knows the term.

(Sheena, Doctor)

In emails if paramedics refer saying they're sort of pseudo seizures, I'll not correct them, but obviously say you know the impression is that they're it's functional in nature, they could be called pseudo seizures, but I suppose it's the stigma that's attached to that then and then that feeds back to the patient.

(David, Nurse)

The multitude of quotes presented in this discussion serves to emphasise the rich tapestry of subjective choices made by healthcare professionals' when it comes to selecting terminology. It drives home the point that terminology is not just a matter of semantics; it plays a pivotal role in conveying understanding, beliefs, connotations, and

encapsulates the implicit and explicit conceptualisation that healthcare professionals bring along to their work within the landscape of working with people living with or affected by MUS:

7.6. Theme 3: "Beyond the Fog: Envisioning Future Care for MUS"

This last theme encapsulates health professional's forward-thinking approach to care for people living with or affected by MUS. Participants explored innovative possibilities within current care, whilst envisioning a more efficient future in service provision and care.

Most participants spoke of active engagement in initiatives aimed at enhancing care for this patient group. For example, Benjamin, a doctor, shared his involvement in developing care pathways, stating, "We had our first meeting of a group to develop a pathway or a plan for MUS or functional neurology?... And today I've had some approaches from rheumatology about trying to sort out a complex regional pain pathway". The majority of participants displayed such creativity in developing strategies and making the most of limited resources within their services, to offer additional support and care. Throughout their discussions, all participants expressed a common desire for a fundamental shift to care for people living with or affected by MUS. They emphasised the importance of offering individualised, patient-led care, as noted by David, a nurse, who highlighted the need to "tailor your treatment for each person" unique needs, "because obviously everybody's different".

Claire, a doctor, echoed these efforts, creating and implementing individualised strategies and plans. Likewise, Sheena, a doctor, explained her endeavours towards a more holistic, patient-centred approach. She achieved this by modifying her referral forms to encourage clinicians in SBUHB to consider a broader range of factors to patient's symptoms in their practice:

I thought this is horrifying and I started the frequent service user group to try to develop individually based strategies for the individual, to say if this person presents with this, speak to a senior before you get him, get him investigations and look to see what's been done... I try to do as often as possible is meet with the patients GP...to try to address the gaps really for the individual and to individualise treatment processes.

(Claire, Doctor)

Since we formulated that referral template, where it asks for, associated disabilities, what are the psychosocial factors for the patient? Is there any history of trauma, what's the support like for the patient? So we are asking for a little bit more detailed information. I think clinicians are starting to think about, you know, these are not just physical symptoms that they are presenting with. There are other psychosocial factors around them. So I think the referral form itself has helped them to kind of think about those factors.

(Sheena, Doctor)

Amid these collective efforts committed to enhancing care for people living with or affected by MUS. All participants envisioned this care alongside Psychology. Despite some lingering uncertainty about the exact role Psychology could play in enhancing care, almost all participants were eager to make a case for its inclusion. Some participants, like Jean, an OT, felt that there was a need for "Concrete pointers which would necessitate the psychology referral". Many participants emphasised the importance of being well informed about the availability of psychological resources. They expressed their concerns about their lack of awareness in this regard, with comments like, "Can I speak directly to psychology?...I am glad you said that, I'm worried that I could. I could have referred all these patients".

Alex, a doctor, expanded this vision for the future of care for people living with or affected by MUS, to prominently feature Psychology. He expressed, that "in an ideal world, then I would refer everyone really...I'm a bit conscious that locally certainly access is limited and so I reserve it for someone who is doing badly." Nevertheless, all participants pitched for the integration of Psychology into the future care for people living with MUS. Sheena, a doctor particularly illustrated this commitment in her following pitch:

One is being part of the MDT really. Two is you know, helping with the assessments and you know taking on the patient on therapy. So there's both clinical and non-clinical. I think that psychology can help with this group of patients, as in clinical work, so taking on the clinical workload, I think we'll be able to see more patients, we'll be able to move, offer more support to a larger group of patients, less patients going down the mental health route down the line. So maybe in a couple of years there, you know mental health also starts to get affected so severely that they require secondary services. So to avoid that...I think it would help to have Psychology on the team, so I am pitching for why I need a psychologist basically...I think it will also improve the outcome for patients and for

professionals who work with these group of patients. So you know with that lack of uncertainty and to reassure, to reassure them that actually we know this condition.

(Sheena, Doctor)

Whilst participants were united in their vision of a future where clear care pathways were established, and Psychology played a central role in the care and treatment of people living with or affected by MUS. They also passionately advocated for a future where stigma and discrimination surrounding MUS are effectively addressed and minimised. These advocacy efforts were evident in participant's calls for a "need to do more" (Lisa and David). Most participants, like Jenny, a nurse, queried whether "maybe there is a bit more of an option for...more mandatory training in this area", advocating a need for teaching, in a quest to develop understanding and reduce stigma. There was a unanimous consensus among participants that educational initiatives could enhance colleague's awareness, knowledge, and referral practices, ultimately leading to improved care for people living with or affected by MUS. Again, this was particularly highlighted by Sheena, a doctor, who was particularly passionate about pushing for a transformative shift:

The approach becomes so much easier, when you're able to help the patient. I think the conflict is also in the mind of the professionals, to be honest, where one part of them, they're doing the investigations, they're not able to find anything and it's the unknown. So if they have, if there is that knowledge, which you can fill that gap in their knowledge. I think it becomes easier to support these group of patients. It's just like similarly with you know self-harm, if you don't know why people self-harm. Then the attitudes in, accident and emergency and different wards can be really unhelpful for the patient because you see them as a person who wastes time or who doesn't need to be here. So that's a similar kind of approach, isn't it? But once you understand mental health issues, once you understand the complexity of it, you're able to help the patient get a bit more access or help the person access services that can help the patient. But if you don't have that empathy, these patients might be dismissed. You know, the symptoms are dismissed.

(Sheena, Doctor)

Included in this shift, participants actively sought to foster collaborative relationships with colleagues as a broader shift in care for people living with or affected by MUS. They

recognised the importance of developing these connections despite the absence of a dedicated Multidisciplinary Team Framework. Collaborative relationships were deemed crucial for shared communication, understanding and insights in the care of people living with MUS. David, a nurse, illustrated this commitment stating, "I make a conscious effort to speak to the other teams that are involved with them... and as a health professional, could you have a look and see what you think? Is there merit for us to work together?" Nevertheless, despite these efforts to create interdisciplinary links, most participants envisioned a future characterised by the establishment of a dedicated MDT Framework. They acknowledged there was an existing division between disciplines, specialities and between mental health and general health sectors and advocated for future unity to address the issue of "Parity of Esteem". As illustrated by David, Sophie and Lisa below:

I think you've got a whopping great divide at the moment... I'm more aware of that sort of parity of esteem, in that mental health and physical health are going to be intertwined. I think the more you start to separate them out, the more you are going to get that divide.' I think in terms of delivery of services.

(David, Nurse)

"I guess from my point of view what these people probably need is a big MDT approach and there's a big sort of. I kind of feel like there's a lack of kind of together thinking maybe."

(Sophie, Occupational Therapist)

So, you know, in an ideal world, we would be more involved with an MDT. With all of the disciplines really isn't it, physiotherapy neurology, rheumatology, all these sorts of things where we could have a bigger impact"

(Lisa, Nurse)

Notably, participants generally found the interview process valuable, with many experiencing the questions asked as thought-provoking, or as an "interesting question". Additionally, some participants recognised the interview process as a valuable space for reflection. Sheena, a doctor, for instance, found it to be a useful platform to "reflect on my practice". Despite the challenges of working with people living with or affected by MUS, many participants had not given up. Their commitment to a better future in care for this patient group extended beyond aspirations for improved resources and care; as they also aimed to improve themselves as a healthcare professional. They sought to improve

the effectiveness of their practice, whether this was through self-learning as discussed in *Sub-theme 3.2: Barriers to services and bridging gap*, or through a future that provided "Consultation" (David, Benjamin) and "reflective practice" (Sheena, Jean, Lisa) to support them "address any difficult feelings of transference and countertransference", as advocated for by Sheena.

Despite its challenges, most participants spoke with passion about the topic and found unique value in working with people living with or affected by MUS. Lisa, a nurse, for instance, described that she "met some fascinating people". Benjamin, a doctor, particularly spoke of dedicated colleagues who "enjoy doing work with this client group" and that even though colleagues "pass the buck...every single one of them is fascinated and interested". There was a consensus that better future care for people living with or affected by MUS must start with fostering interest. Whilst, Jean, an OT, spoke of incidents where she encourages others to "Spread the word" and "get others on board", Claire, a doctor articulated a key perspective — the transformation of care for people living with MUS cannot rely solely on individual efforts. The responsibility should not rest solely on the shoulders of healthcare professionals. Instead, there is a need for a broader systemic transformation encompassing both service provision and attitudes towards people living with or affected by MUS:

I just think it's a huge area. I think it's actually really, really important area which we have to find solutions. You know, but solutions both on an individual but also on a service provision basis, because we simply don't have all the services, but we need to and sometimes it's about it's about working, you know almost utilising services to then prevent their use in the future. Do you know do you know what I mean? Its short term, short term, high load therapeutic intervention to help for the long term.

(Claire, Doctor)

8. Discussion:

8.1. Chapter Overview:

The aim of this research inquiry was to understand and explore health professionals' personal and professional implications towards their experiences of working with people living with or affected by MUS. Specifically, this research inquiry aimed to answer the following research question: 'How do health professionals in secondary care services within SBUHB, South Wales, experience working with people living with or affected by MUS?' Findings related to this research question and its extension questions; 'How does the experience of working with people living with or affected by MUS affect healthcare professionals both personally as individuals, and in their professional roles?' And 'Based on insights gained through this research inquiry, how the field of Counselling Psychology can contribute to support for both healthcare professionals and patients living with or affected by MUS, in SBUHB, South Wales', will be discussed within the context of the existing literature.

The chapter begins with a summary of the results section, where themes and subthemes were discussed grounded in healthcare professionals' discourse. The subsequent discussion contextualises the research questions within existing literature, exploring implications for Counselling Psychology and the broader healthcare system. In closing, within a critical-realism ontological framework, I will evaluate the study reflexively and reflectively, assessing its quality using guidelines from Kitto et al. (2008) and reviewed by Hammarberg, Kirkman, and de Lacey (2016). I will also reflect on my role as a researcher, particularly during analysis, and conclude by offering recommendations for future research on working with people living with or affected by MUS, as well as practice implications.

8.2. Summary of Key Findings in Healthcare Professionals' Discourse:

In the first theme ('Lost in the Fog of Uncertainty'), healthcare professionals highlight uncertainty as a fundamental experience when working with people living with or affected by MUS. Their combined narrative likened their experiences to navigating through a dense fog of uncertainty, where their usual diagnostic pathways and decision-making processes were obstructed. The 'finding a path' sub-theme highlights professionals' efforts to establish effective patient care despite the unexplainable nature

of these conditions. These healthcare professionals embarked on different journeys to provide 'effective care', displaying a multifaceted nature of responses. Within this theme, 'The emotional burden of professional helplessness' sub-theme offered a glimpse into how this emotional weight influences decision-making and creates a sense of helplessness when working with people living with or affected by MUS. For instance, Robert, a doctor, describes patients with MUS as 'heart sink patients,' illustrating the emotional toll of working with them. This emotional burden complicates the therapeutic relationship, shaping decisions about care in the absence of clear pathways.

In the second theme 'Healthcare Professionals' Subjective Journeys', subjectivity plays an important role in shaping healthcare professionals journeys when supporting people living with or affected by MUS. Within this theme, Sub-theme 1, demonstrated how 'intersectional identities' of healthcare professionals played a significant role in shaping their approach to practice, decision-making, and interactions when working with people living with or affected by MUS. It acknowledged that healthcare professionals' experiences extended beyond their professional roles. Their interactions shaped by the intersection of both their personal and professional identities, influencing their perceptions of patients, patients' responses to them and subsequently the care patients receive. For instance, some healthcare professionals chose to avoid contact with people living with or affected by MUS, due to difficult past experiences. As illustrated by Benjamin, a doctor, when recounting a colleague experience "I think she still bears the scars of it, but she will be skewed in a very, very negative light towards this whole thing. She tries to avoid it like the plaque now" (p72).

In sub-theme 2, "It's real for them" the diverse beliefs, assumptions and value frameworks of healthcare professionals, influenced their approach to understanding, communicating with, and providing care for people living or affected by MUS. This sub-theme discussed the specific language choices of healthcare professionals, which were intended to be validating and empathetic but instead inadvertently caused further uncertainty and scepticism. This sub-theme strongly acknowledged that language choice and approach of healthcare professionals in their communication with people living with or affected by MUS can have implicit meanings, and are all up for interpretation by the patient. As voiced by David, a nurse, "You may not be saying it, but they may pick up on

your body language the way you are talking, the way you are framing the questions, and they could think well, he did not believe this" (p80).

To conclude this section, the final theme 'Beyond the Fog: Envisioning future care for MUS' captured all healthcare professionals' forward-thinking approach to care for people living with or affected by MUS. All healthcare professionals, explored many innovative possibilities within current care, whilst envisioning a more efficient future in service provision and care. For instance, throughout their discussions, all healthcare professionals' emphasised the importance of offering individualised, patient-led care. David, for instance, emphasised this need to "tailor your treatment for each person" (p82) unique needs, "because obviously everybody's different" (p2).

8.3. Extracting meaning from the results of this research inquiry:

As detailed in Section 2.5. Philosophical assumptions, this study was conducted from a critical realist ontological stance; critical realism challenges the objectivity of knowledge and interrogates social, political, and cultural factors implicated in its construction. It takes a position that assumes a real and knowable world that sits behind the subjective and socially located knowledge that a researcher can access (Madill, Jordan & Shirley, 2000; Pilgrim, 2013). Parallel to RTA principles, critical realism goes beyond what is currently observable and acknowledges that context and values are embedded in a scientific inquiry, whereby I, as the researcher am fully part of the object of enquiry (Pilgrim, 2019). I hold a contextualised perspective on epistemology whereby a single reality is not assumed, but rather knowledge emerges from certain contexts and might hold true for those contexts, but not necessarily others. In any case, a contextualised epistemology embraces the subjectivity of the researcher and thus reflects my position(s) (Madill, Jordan & Shirley, 2000). Therefore, the subsequent key findings constructed from the RTA, offers one perspective into the personal and professional implications of healthcare professionals' experiences of working with people living with or affected by MUS, in secondary care services within SBUHB, South Wales.

8.4. 'How do health professionals in secondary care services within SBUHB, South Wales, experience working with people living with or affected by MUS?'

Current UK research has predominantly concentrated on the attitudes of General Practitioners (GPs) towards people living with or affected by MUS (Dowrick et al., 2008; Salmon et al., 2007; Shattock et al., 2013, Wileman et al., 2002; Yon et al., 2015). The experiences of secondary care medical doctors have been underexplored in research, with only one noteworthy study addressing this gap (Maatz et al., 2016). Moreover, the research around MUS has primarily centred on medical doctors, with a single study offering a broader perspective by encompassing all healthcare professionals. This particular study, however, focused on how culture influences the presentation and explanation of MUS (Kadir, 2022). None of these studies have thoroughly included the experiences of a broader perspective of all healthcare professionals in secondary care services, and none have specifically investigated health professionals' experiences in Wales. This is significant, as shaping decisions on how best to support healthcare professionals and patients in Wales, should be informed by local insights rather than relying solely on practices and experiences from other locations – beyond Wales. However, given this absence of Welsh literature on MUS, the current inquiry's findings will be contextualised within this existing literature, which predominantly features doctors, specifically GPs as the primary sample, and will draw data from locations outside of Wales.

8.4.1. Central Role of 'Uncertainty' in Healthcare Professionals' Work with MUS:

The findings from this current inquiry highlight that 'uncertainty' is not just a peripheral experience for healthcare professionals; rather, it stands as a central and inherent experience to their work with people living with or affected by MUS. This perhaps echoes the significant role uncertainty plays in the therapist-client interaction in the Counselling and psychotherapy literature (see Cononolly, 2022; Marshall, 2016; Willig, 2019).

The existing UK literature does acknowledge uncertainty in the landscape surrounding working with conditions that often defy traditional diagnosis and treatment

pathways. However, it does not explicitly identify it as a core feature and position to working with people living with or affected by MUS. Rather than it being directly expressed as central to the experience, uncertainty remains implicit or hinted at within the literature. Instances of this can be observed through diverse terminology and categorisation choices (Kinsella & Moya), the lack of consensus in conceptualisation (Marks & Hunter, 2015; Creed et al., 2011), understanding differing perspectives, and communicating them with patients (Crimslik et al., 2000), or the absence of guidelines for intervention and psychological therapies (Kaur et al., 2022). This lack of clarity in the literature may stem from scientists – which often includes psychologists – aligning themselves with ontological reductionism and a preference for quantitative approaches. Through this scientific lens, uncertainty is often overlooked as a valid position. As the search for a clear-cut, objective approach hinders embracing the inherent uncertainty of working with conditions that are often un-diagnosable or un-treatable.

Explicitly communicating 'uncertainty' as an inherent experience of working with people living with or affected by MUS may be beneficial or 'freeing'. In the sense that, it may assist healthcare professionals avoid the internalisation of working with conditions that often challenge diagnosis or treatment. Moreover, if uncertainty is framed as something that coexists with working with people living with or affected by MUS, than located 'in' the healthcare professional – emerging as an external factor, stemming from the context around MUS, or patient uncertainty – it can redefine the healthcare professional's role. Instead of internalising it and becoming overwhelmed by uncertainty, it reconceptualises its role as one of support and navigating uncertainty. A perspective that involves walking alongside the patients and their experiences, rather than one that feels more stifling and directive (See Voller, 2011; Mason, 2022).

8.4.2. Internalising Systemic Challenges: The Emotional Burden of Uncertainty on Healthcare Professionals

The existing literature appropriately acknowledges that people living with or affected by MUS often contend with feelings of blame, shame, and hopelessness (Lillrank, 2003; Rausch, 2021; Church, 2017). These current findings suggest that healthcare professionals might share a similar experience. Through their shared experience, healthcare

professionals revealed that they, too, feel the emotional burden of helplessness and uncertainty. One way of interpreting these feelings of helplessness that was grounded in the discourse of healthcare professionals is to suggest that healthcare professionals working with people living with or affected by MUS are perhaps, too, vulnerable to feeling shame.

"Shame is a powerful, primitive emotion that plays an important role in identity formulation" (Kaufman, 2004, p.568). It is "an emotional reaction to failing to live up to one's image of oneself" (Lazare, 1987, p.168). In light of this, the exploration of shame within the experiences of healthcare professionals working with people living with or affected by MUS remains an underexplored avenue in the existing literature. There is a small amount of research that found trainee doctors susceptible to feelings of shame, when they fail to live up to the values that they feel are essential to maintaining their professional identity (Bynum et al, 2014; Roberson & Long, 2019). Healthcare professionals' vulnerability to shame, stemming from repetitive feelings of a failure to fulfil the role of helper when supporting people living with or affected by MUS, deserves to be recognised. As healthcare professionals consistently encounter situations where interactions move away from their identity as professional helpers (Lazare, 1987; Kaufman, 2004), they may continue to internalise a system that lacks interest, clear support, and care pathways for people living with or affected by MUS. This shared emotional experience mirrors the challenges faced by patients, who might also internalise the absence of infrastructure and support from, and for healthcare professionals, as feelings of shame and hopelessness, as reported by Lillrank (2003).

This raises the question of whether these shared experiences of shame are interconnected, potentially a dynamic of projection within the therapeutic relationship, where the emotional challenges faced by both healthcare professionals and patients are reflected in each other (Holmes, 2002). For instance, the uncertainty of conditions that often have no clear diagnosis or treatment pathway, coupled with a lack of systemic support for healthcare professionals, may inadvertently lead to the projection of healthcare professionals' own anxieties of being made to feel "helpless" and "inadequate" into the experiences of their patients. Furthermore, this concept of projection works in both directions; patients, too, may project their feelings onto healthcare professionals. They might project frustration, blame, or hopelessness, driven

by expectations of clear answers and support from healthcare professionals. If patients feel let down by healthcare professional not knowing how to help, they might project these emotions onto the healthcare professional.

The current findings suggest that the emotional burden of helplessness, entwined with uncertainty, positions healthcare professionals and patients in a precarious position of jointly shouldering the weight of ambiguous conditions where clarity and solutions are often elusive. Healthcare professionals, in response to this, appeared to take on the responsibility, by aiming to do more and better, bearing the brunt of MUS's inherent uncertainty and tricky landscape. They actively engaged in neoliberal perspectives, where ideology encourages individuals to strive for self-actualisation, to do better and be responsible for their own personal growth and happiness (Adams, Estranda-Villalta, Sullivan & Markus, 2019). They appeared to navigate this landscape by adopting an intrapsychic approach towards their professional role and care, favouring an approach that positioned responsibility for success and well-being in the person. For instance, this was evident in healthcare professionals commitment to becoming more knowledgeable through "researching and researching", participating in "webinars" (p.62) "thinking outside the box" (p.62) and fostering ways to "be more creative" all aimed at finding solid ground to stand on and to provide effective care (See Steward & Zediker, 2000). Furthermore, this intrapsychic approach was projected onto patients, in the sense that they also viewed people living with or affected by MUS as needing more education and better coping strategies. As <u>all</u> healthcare professionals' consistently favoured psychoeducation and self-help strategies as their primary intervention, despite not knowing the problem to start with.

Notably, one healthcare professional expressed insightful concerns regarding this intrapsychic approach, foreseeing potential regret in the future for endorsing a strategy of self-resilience; "I do worry that in the future, you know, 10 years down the line, it'll be like, Oh my God, I can't believe people used to just tell them to, like, get on with it themselves. And I would feel bad because I'm part of that effectively." (Sophie, OT, p61). Despite, this awareness, it remains a part of her current care, highlighting a sense of powerlessness among healthcare professionals who find it challenging to question or alter the dominant discourse surrounding MUS. Consequently, the discourse continues to

repeat itself, and dominate in the routine care for people living with or affected by MUS (See Foucault, 1991). Perhaps these intrapsychic interventions are favoured when the only controllable factor appears to be the person in front of them.

Nevertheless, intrapsychic interventions, such as psycho-education and CBT, which focus on the 'problem' being within the psyche, mind, or personality, have been proven to help some people living with or affected by MUS (See Chalder et al., 2023; Seaton et al., 2023). However, it is important to acknowledge potential limitations. If healthcare services and professionals solely rely on a model of care that exclusively focuses on intrapsychic interventions, they may unintentionally reinforce the notion that the root cause of MUS resides within the person. Perhaps, this is why patients are made to feel, whether intentionally or not, that their experiences of MUS are often dismissed as "all in their head" (p.463) (See Lillirank, 2003). As broader systemic issues like inequalities in South Wales care, and support within the healthcare system are continued to be dismissed. Such a model risks contributing to the feelings of shame people living with or affected by MUS describe (See Raush, 2021; Lillirank, 2003) as they internalise not being favoured by the healthcare system. In recognising the emotional challenges of working in this complex and uncertain field, adopting an intrapsychic approach should not replace systemic improvements, but rather complement a comprehensive care approach (Rizg, 2013).

8.4.3. Risk of Potentially Moral Injurious Events (PMIE); the emotional burden of professional helplessness:

As detailed above, this current inquiry highlighted that healthcare professional's shoulder the emotional weight of working with often un-diagnosable and untreatable conditions. Although, working with uncertainty is considered a core part of working as a practitioner psychologist (BPS, 2017; HCPC, 2012). The capacity to be with uncertainty, and work alongside situations like MUS that are characterised by ambiguity, unpredictability and a lack of clear information or resolution, is not a comfortable or typical position for all healthcare professionals – *or all psychologists* (lannello et al., 2017; Milne, Lomax, & Freeston, 2019; Alam et al., 2017; Rizq, 2013). This is especially the case in healthcare settings, where scientists – which often include psychologists – see the world as

predictable, uniform, and controllable, confidently understood through scientific knowledge (Crossley, 1998; BPS, 2017; Horowitz, 2007).

The ability to manage such uncertainty is often considered essential for the wellbeing of healthcare professionals (Cooke, Doust & Steele, 2013) and, consequently, for the patients in their care (Simpkin at al., 2019). Working with any uncertainty, whether related to a medical condition, treatment options, or outcomes, will routinely create challenges for any healthcare professional (Cooke, Doust & Steele, 2013; Simkin et al.,2019). These challenges are exacerbated when solutions are elusive, and the nature of the problem is difficult to comprehend. Existing in this middle ground of uncertainty can create a reflective charge of helplessness for healthcare professionals, particularly when grappling with "inadequate" (p.64) feelings of not being able to provide solutions or not knowing "how to make people feel better" (p.61). This emotional burden of helplessness, becomes intricately woven into their trajectory of care for people living with or affected by MUS, as detailed in the results section. In such situations, this inquiry found that healthcare professionals were placed in situations where they often felt compelled to act in ways that challenge their professional ethics and values, such as "reaching for the pills again" (p.64). The persistent challenge of being unable to alleviate patients' suffering or provide definitive answers may give rise to what has been termed 'moral injury' among healthcare professionals (See Cartolovni, Stolt, Scott & Suhonen, 2021). While this perspective differs somewhat from traditional notions of moral injury, drawing parallels with other untreatable conditions, like Dementia or Cancer. The concept remains highly relevant for healthcare professionals who find themselves working in ways contrary to their preferences, possibly due to constraints in addressing the unique needs of patients with conditions that are often un-diagnosable or untreatable. It raises the question of whether these professionals, unable to fulfil their desired care roles, might experience a form of moral injury. Interestingly, there is a notable absence of existing literature exploring the intersections of the risk of moral injury when working with people living with or affected by MUS.

This current inquiry identifies this risk, suggesting that healthcare professionals working with people living with or affected by MUS may be at risk of exposure to potentially morally injurious events (PMIE). This vulnerability is particularly evident in the theme of being 'lost in the fog of uncertainty', particularly in instances where healthcare

professionals are unable to prevent or provide solutions, or where they follow a trajectory of care that contradicts their deeply held values or beliefs (See Griffin et al., 2019). A powerful expression of this struggle is captured in this statement, "You feel very helpless as a doctor… you start ending up reaching for the prescription again, cause maybe some pills will make him get better, better. And they often don't." (Benjamin, Doctor, p62).

While earlier research primarily explored moral injury and Potentially Morally Injurious Events (PMIEs) in a military context (William et al., 2021; Griffin et al, 2019), the recent COVID-19 pandemic brought attention to the risk of healthcare professionals exposed to PMIE (Mantelakis et al, 2021). Healthcare professionals working with people living with or affected by MUS, frequently navigate situations where providing effective care is hindered by uncertainty, resource and service limitations, and a lack of support and training. All of these are risk factors for PMIE and moral injury (Greenberg & Tracy, 2020; Williamson et al., 2020). Recognising healthcare professionals' susceptibility to moral injury is important, especially as cases of often un-diagnosable or untreatable conditions continue to increase (see Hunt, 2022), and re-present to services (Jadhakhan et al, 2022). Acknowledging and addressing these challenges externally can be protective, potentially minimising the internalisation of situations and fostering empathetic support for healthcare professionals and patients alike (Williamson et al., 2020).

8.5. How does the experience of working with people living with or affected by MUS affect healthcare professionals both personally as individuals, and in their professional roles?

The current inquiry showed diverse responses among healthcare professionals in their interactions with people living with or affected by MUS, reflecting the varied perspectives in the literature (Marks & Hunter, 2015; Creed, Barsky & Leiknes, 2011). This extends to how healthcare professionals articulate, diagnose, and conceptualise MUS (Crimlisk et al., 2000; van Ravenzwaii, 2010; Mewes, 2022; Lipowski, 1988). This section explores the personal and professional implications of their engagement with this patient group. Drawing on the insights from Counselling Psychology literature, it acknowledges that the way we experience our clients in therapeutic relationships — exchanging thoughts and emotions, both consciously and unconsciously — significantly influences both the

therapeutic relationship and our personal and professional responses. See Buirski, Haglund & Markley (2020)¹ and Kuchuck (2021).²

8.5.1. Healthcare Professionals' Stance to MUS:

The existing literature suggests that the majority of healthcare professionals adopt therapeutic orientations that align with their personality, personal values, personal and professional life experiences, and philosophical beliefs (Arthur, 2001; Buckman, 2006; Salter & Rhodes, 2018; Vasco et al., 1993). Consequently, how healthcare professionals approach their work with people living with or affected by MUS may differ. This research inquiry noted that this variance extended to how healthcare professionals constructed their relationship with this patient group and their chosen trajectory of care.

Healthcare professionals discussed many challenges along their pursuit for tangible answers and care pathways for conditions that are often un-diagnosable or un-treatable. These challenges presented a dilemma, when taking a realist perspective in healthcare, which posits an underlying 'truth' about the patient's condition (See Fleetwood, 2005). This perspective relies on evidence-based medicine, standardised diagnostic criteria, and measurable physiological markers (Alderson, 2021). Contrary to this realist perspective, the findings from this current inquiry challenge the notion of objectivity, finding that healthcare professionals exhibit subjectivity in both diagnosis and the trajectory of care; when having to rely on intrapsychic strategies such as "following my OT nose" (Jean, OT, p69) to find ways of working with this patient group. Consequently, subjectivity in diagnosis and treatment is particularly relevant when working with people living with or affected by MUS.

One way to interpret the discussed tensions is to see them as rising from an inherent challenge of applying a realist, objective model of diagnosis and treatment to conditions that do not fit neatly into such frameworks. Healthcare professionals, it seems, address these tensions by incorporating elements of subjectivity – which is specific to the person who devises, interprets, or applies it (Kuchuck, 2022). For instance, my theoretical

¹ Buirski, Haglund & Markley (2020)¹, *Making sense together: The intersubjective approach to psychotherapy*

² Kuchuck (2021), 'The relational Revolution in Psychoanalysis and Psychotherapy'.

stance, as detailed in section 3.4, is predominantly relational, drawing heavily on systemic and psychodynamic principles. These perspectives are intersecting with my personal identity and experiences, are undeniably shaping the lens through which I interpret and report these findings in this discussion. However, where I am able to acknowledge it as just 'one truth' among many, not all healthcare professionals are able or want to adopt this contextual lens.

8.5.2. Intersectional Identities

The findings of this study underscore the significant impact of healthcare professionals' intersectional identities on their approach to practice, decision-making, and interactions when working with people living with or affected by MUS. This recognition aligns with the principles of the Leventhal Self-Regulatory Model of Illness (Leventhal et al., 2001). Interestingly, while the Leventhal model traditionally focuses on patients' cognitive representations of health, goals, and coping behaviours, my research suggests that healthcare professionals will also have their own cognitive representations of MUS. These representations, shaped by their own personal and professional identities as well as socio-cultural contexts, play a significant role in influencing their interactions and the trajectory of care. This suggests that healthcare professionals' could also be considered and incorporated within the framework of the Leventhal Self-regulatory model of illness (Leventhal et al., 2001). In essence, applying the Leventhal model to both healthcare professional and patient, could potentially reveal a complex interplay of intersubjective dynamics (Gerson, 2004; Kuchuck, 2021). By acknowledging the reciprocal influence between healthcare professionals and patients' beliefs, emotions, and actions, healthcare professionals can gain deeper insights into the dynamics of the patient-professional interaction and their role within the patient's trajectory of care, promoting greater reflexivity and self-awareness in practice.

8.5.3. "It's real for them"

This section builds on the previous section, it recognises that the intricacies of non-verbal cues and language choice can inadvertently reveal a person's true thoughts and beliefs, i.e. what it means to be well or unwell. For example, as articulated by David, "They may not feel validated if you're internally thinking I don't believe what you saying. I don't

believe this is true disorder. You may not be. You may not be saying it, but they may pick up on your body language the way you're talking, the way you're framing the questions, and they could think well, he didn't believe this... It does come across in your encounters, albeit not necessarily through the word spoken, but through again body language phrases, values, judgments. They can. They can all be interpreted by the patient." (p.80)

The critical analysis of discourse holds an assumption that language is a social phenomenon, and seeks to explore ways in which relationships of dominance, discrimination, power, and control are manifested in language (Leitch & Palmer, 2010). The majority of Healthcare professionals spoke of cultivating a sincere belief in patients' experiences and their legitimacy. However, the repeated use of the phrase "it's real for them" (p78-79) inadvertently introduced an element of potential doubt or scepticism.

Drawing from Fairclough (1992) meta-positions for which to deconstruct discourse, the addition of "for them" introduces a relativism element, highlighting the subjective nature of reality. While intended to affirm the legitimacy of patients' experiences, this linguistic choice implied a level of scepticism or distancing. The repetitive use of this phrase, grounded in healthcare professionals' discourses in the findings of this inquiry creates a distinction between the subjective experience and an objective, shared reality. Linguistically, "for them" may subtly signal that the reality, while acknowledged, may not align with an objective or universally accepted truth. As a discursive practice, it becomes a tool for managing ambiguity and navigating the complexities of diagnosing and treating people living with or affected by MUS. It shapes the social practice by framing the patient's reality as individual and subjective, potentially distinct from an objective, measurable reality. This again, places the problem within the person, potentially providing a rational to why the existing literature demonstrates a high level of shame for people living with or affected by MUS. As healthcare professionals, whether blinding (or not) may be inadvertently portraying the message "it is all in your head" (p.463) (Lilrank, 2003) through linguistic choices such as "it's real for them". Consequently, framing patient's reality within a context of subjectivity and not in an entity in itself; language choices can inadvertently downplay patient experience and support, as they carry implicit meanings or tones that could diminish the significance of patient experiences.

8.5.4. Building the therapeutic bond in the shadows of uncertainty:

Building a therapeutic relationship is a formidable task, in and of itself (Smith & Smith, 2017). However, it is considered key to the patient-professional relationship across both general and mental healthcare services (Bolsinger et al, 2020), especially the therapist-patient encounter (See Mearns & Cooper, 2017; Clarkson, 2003). This inquiry identified that the therapeutic relationship between healthcare professionals and patients living with or affected by MUS is consistently vulnerable to breaking down, particularly in the face of uncertainty and healthcare professionals' sense of helplessness. This aligns with existing studies that highlight a strained relationship between healthcare professionals and people living with or affected by MUS (Lian & Nettleton, 2015).

Healthcare professionals displayed diverse strategies to maintain the therapeutic bonds, as they strived to find objectivity in their paths forward, which ultimately shaped the trajectory of care. This perhaps, provides a window into why the literature found healthcare professionals to respond in contradictory ways, such as offering reassurance whilst simultaneously making referrals just to be on the safe side (Salmon et al., 2004). One way of interpreting variation in the construction of the therapeutic relationship and trajectory of care may be through a psychodynamic lens. See, Michael Jacobs, (2012)³ and Patrick Casement, (2013)⁴. This perspective suggests an analysis of the therapeutic relationship through the lens of defence mechanisms and processes. The consideration of defence mechanisms as psychological strategies to cope with emotional distress, angst, and threats to self-esteem, parallels healthcare professionals' experiences of "helplessness" (p.66) and "inadequacy" (p66) (See Holmes, 2002).

Classical psychoanalysis would view these defences primarily from an intrapsychic perspective, as healthcare professionals internalise professional helplessness within a system of uncertainty, placing the tension and conflicts at the core of their experiences. These perspectives imply that conflict occurs for healthcare professionals between their desired working methods and the external reality, which produces inner tension and anxiety. This dynamic is not too dissimilar to the concept of risk to PMIE discussed in section 3.9.1 (Griffin et al., 2019). Adapting to these conflicts is made possible by defences (Holmes, 2002). However, while these unconscious and conscious defence

³ Michael Jacobs, The Presenting Past: The Core of Psychodynamic, (2012)

⁴ Patrick Casement, On Learning from the Patient' (2013).

mechanisms serve as adaptive coping strategies to the helplessness healthcare professionals describe, an excessive or inappropriate reliance on them can hinder effective patient care, communication, decision making and therapeutic relationships (Holmes, 2002; Kuchuck, 2021, Jacobs, 2012).

Internal defence mechanisms might be playing a role in healthcare professionals' encounters with people living with or affected by MUS, as identified uncertainty, shame and helplessness may pervade in the inter-subjectivity of the therapeutic relationship. This is perhaps demonstrated when healthcare professionals employ stark discursive contrasts between 'good patients' and 'difficult patients,' essentially categorising patients as either "cooperative, accepting or receptive" (p.69) or as presenting "challenges or disagreements" (p.69). One interpretation of this, drawing from analytical concepts, would suggest that such discursive contrasts resemble the psychoanalytic concept of splitting. In psychoanalysis, Melanie Klein (1976) introduced the concept of splitting—an act involving the division of an object into 'good' and 'bad' aspects. This mechanism serves to simplify categorisation, often aiding in the management of ambivalence and conflict within the therapeutic relationship. By unconsciously maintaining a separation between the 'good' and 'bad' aspects in their perception, healthcare professionals may inadvertently avoid confronting the complexity of both the patient's experience and their own emotions in response to the challenges presented in their work with individuals living with or affected by MUS. Further examples, included healthcare professionals holding on to patients, or desperately referring on. Psychoanalytically understanding these actions in terms of defence mechanisms provides insight into the emotional dynamics at play and how professionals navigate their subjective experiences in the context of uncertainty and helplessness. Although, I acknowledge that these interpretations are provisional and tentative.

8.6. Based on insights gained through this research inquiry, how can the field of Counselling Psychology contribute to support for both healthcare professionals and patients living with or affected by MUS, in SBUHB, South Wales.

In addressing this research question, a central point for consideration is the implications for 'what this means for Counselling Psychology'. Willig (2019) emphasises that effective therapists must possess a deep understanding of their own ontological and epistemological positions in their therapeutic work. Drawing parallels to my training as a counselling psychologist, which involved engaging in personal therapy to explore the influence of personal history on professional identity (McLeod, 1998). Similarly, as the researcher for this inquiry, I needed to cultivate reflexive awareness of my assumptions about what there is to know (ontology) and how I come to know about it (epistemology) (See Willig, 2019).

In both the roles of counselling psychologist and researcher, there exists a shared emphasis on recognising fundamental assumptions about human beings and the world (ontology), as well as beliefs concerning the understanding of clients and their experiences (epistemology) (Willig, 2019). Drawing from the findings of the research inquiry, it appears that, akin to therapists (Willig, 2019), healthcare professionals working with individuals affected by MUS tend to select their preferred practice model based on how well it aligns with their pre-existing understanding of human nature – their ontological commitments. This chosen model may resonate because it either conforms to existing beliefs or provides a framework to address questions and concerns related to the experiences of individuals affected by MUS. If Counselling Psychology can offer a supportive environment to facilitate reflexive practices among healthcare professionals, it has the potential to support them in several ways: a) understanding and processing their own emotional responses, such as shame or helplessness; b) clarifying their role within the broader system, including holding onto ontological positions such as a psychogenic model that may inadvertently make patients feel invisible; and c) collaborating with colleagues within the wider system to encourage reflexivity in their practice.

Healthcare professionals must recognise their own fundamental assumptions regarding the experiences of individuals living with or affected by MUS, understanding that their ontological and epistemological positions are subjective perspectives rather than indisputable truths. Counselling Psychology offers valuable support in cultivating this awareness through a reflexive approach. Adopting a reflexive approach to working with

individuals affected by MUS is crucial for two main reasons: Firstly, if clients do not share the therapist's assumptions, therapeutic progress and the development of a meaningful therapeutic relationship may be hindered. Secondly, without self-awareness, therapists risk imposing their own model of the person onto the client, raising ethical concerns regarding the trajectory of care (Willig, 2019). Moreover, the inherent fragility of the therapeutic relationship between healthcare professionals and patients affected by MUS may often stem from a lack of such awareness, underscoring the necessity of employing a reflexive approach when working with this patient group.

8.7. Considerations for Future Research:

This study explored the experiences of healthcare professionals working with people living with or affected by MUS in South Wales secondary care services. While the findings from this research add value to the existing literature, they also underscore the urgent necessity for more extensive exploration in Wales. The challenges identified for both healthcare professionals and people living affected by MUS highlight the critical need for increased research and attention to this underserved area.

Importantly, this study did not incorporate the perspectives of people living with or affected by MUS, indicating another under-researched area in Wales. The shortage of existing research in this domain may convey a message of insufficient importance or care. Therefore, cultivating interest in this area is imperative, as the scarcity of research and resources complicates efforts to comprehensively understand how to best support healthcare professionals in their care for individuals living with or affected by MUS in Wales .To address this gap, gaining a deeper understanding of people's lived experiences with MUS may inform the development of a future care model. This approach may provide valuable insights into their interactions with healthcare professionals, contributing to the formulation of a tailored care model for this patient group in South Wales.

Furthermore, the opportunity to explore perspectives of healthcare professionals through impactful quotes such as the recurrent message, "it's real for them", could offer a unique experience into patients' interpretation of this communication. For instance, understanding whether patients seek answers aligned with healthcare professionals' expectations or if they prefer a more collaborative, relational approach. This is important,

given that some models of care, particularly in England, and across other services in Welsh healthcare use CBT as routine practice, such as Government initiatives, like 'Improving Access to Psychological Therapies' (IAPT) in England and 'Matrics Cymru' in Wales (2017). However, such standardised practices may not best align with patients diverse needs and may inadvertently undermine their experiences by categorising them as 'real for them', rather than objectively true. Recognising this distinction may highlight future training opportunities for professionals working with this patient group and could potentially lead to the development of a care model that differs from those employed in different geographical locations.

Expanding on findings that healthcare professionals are vulnerable to moral injury and shame in their interactions with people living with or affected by MUS, future research could explore these specific factors further. Exploring the role of institutional structures, societal attitudes, and organisational support in shaping healthcare professionals' moral experiences could provide valuable insights. Furthermore, exploring potential interventions or support mechanisms to mitigate the risk of moral injury and shame in this context could be an important avenue for inquiry. This research could inform the development of tailored strategies, training programs, or policy changes aimed at safeguarding the well-being of healthcare professionals and, by extension, improving the quality of care for people living with or affected by MUS.

8.8. Reflexive and Reflective Evaluation:

8.8.1. Quality of Research:

Qualitative inquiries, like this one typically deviate from traditional 'quality' criteria that looks for generalisability, objectivity and validity (Lincoln & Guba, 2011). However, this research inquiry will remain committed to assessing the robustness and integrity of the research (Hammarberg et al., 2016). It will lean away from making reference to bias and other positivist considerations of research rigour, replacing them with comments within qualitative research that are complementary with Braun and Clarke (2021) Reflexive Thematic Analysis. To achieve this, I will follow the generic guidelines outlined by Kitto et al (2008) and reviewed by Hammarberg, Kirkman and de Lacey (2016), which instead

prioritise qualitative aspects such as Trustworthiness, credibility, applicability and consistency.

The 'trustworthiness' of this study is upheld by comprehensive procedural descriptions and decision-making, ensuring transparency and clarity throughout the research process. As recommended by Hammarberg et al, (2016), robustness of the study is evident in the detailed appendices provided. For example, Appendix A offers insight into the reflexive engagement with research material, while Appendix L provides a detailed account of data analysis. Furthermore, Appendix N illustrates the meticulous note-taking process, and Appendix O showcases the refinement of codes. These appendices collectively underscored my commitment to transparency and reflexivity, thereby enhancing the trustworthiness and overall quality of the study.

In defending the 'credibility' of this research inquiry, reflexivity was prioritised throughout (Hammarberg et al., 2016). This commitment is evident in several aspects. Firstly, comprehensive information about myself, as the researcher (see section 5.2.1) and my theoretical positions (see section 5.2) are clearly provided. Additionally, a research journal, as documented in Appendix A, recorded my thoughts and decision-making processes throughout. Moreover, the upcoming reflexive section (see section 8.8.3.) probes further into my reflections on how my reactions and influences developed throughout the research process. In accordance with Sandelowski (1986), verbatim quotations from the data were included to support interpretations. These measures collectively enhance the credibility of the study by demonstrating a detailed and transparent approach to data collection and analysis.

The 'applicability' of the research findings evaluates the external validity of the research (Hammarberg et al., 2016). Applicability in qualitative research relates primarily to case-to-case transferability (Tobin & Begley, 2004), enabling the potential transfer of findings to contexts beyond the immediate study setting. While I cannot predict which sites may seek to transfer findings, I took full responsibility for ensuring that I provided thick descriptions to facilitate judgments of transferability (Lincoln & Guba, 1985). By providing detailed participant and contextual descriptions, coupled with capturing diverse

perspectives in research interviews, this study aimed to equip readers with the necessary information to assess the applicability of its findings to their respective contexts.

'Consistency' in this study serves as a measure of reliability in research methodology (Hammarberg et al., 2016). To ensure consistency, I thoroughly detailed and justified the chosen methods, providing complete transparency into the data collection and analysis processes throughout the methodology (See Appendix A, Appendix L). A clear outline of research materials along with any adaptations made are supplied in appendices, ensuring a systematic approach to the study. Through these measures, the study upheld consistency in methodology, bolstering the trustworthiness and reliability of its findings.

8.8.2. Limitations:

One limitation of this research is the lack of co-production with both patients and a wider range of healthcare professionals involved in managing MUS. While developing the interview schedule, collaboration with only two trainee Counselling Psychologists may have limited the perspectives reflected in the questions. This oversight could impact future research efforts, potentially hindering equal understanding across diverse healthcare contexts and roles. To mitigate this, piloting the interview schedule with a more diverse range of healthcare roles could have been beneficial for gathering feedback and ensuring a shared understanding of the questions.

Treating all healthcare professionals as a homogeneous group overlooks the diversity within this population, including variations in training, experience, and perspectives. This approach may have overlooked nuanced differences in how different professionals experience and interact with people living with or affected by MUS, potentially limiting the depth of insights gained from the study.

It is important to recognise the limitations of self-selecting samples (Neuman, 2014). This sampling method can often fail to capture important perspectives, therefore restricting the applicability of research findings to broader contexts (Beedell, 2021; Neuman, 2014). Self-selecting samples frequently overlook voices from underrepresented groups, as participants tend to be drawn from specific segments of the workforce (Kvale &

Brinkmann, 2009). A stratified or purposive sampling approach could have facilitated a more intentional selection of participants, ensuring representation from diverse backgrounds and demographics (Guest et al, 2006; Patton, 2002; Creswell, 2013). This methodological approach might have resulted in more comprehensive and nuanced findings, thereby mitigating the risk of marginalising certain voices and enhancing the sample's representativeness within the context of healthcare professionals working with people living with or affected by MUS in secondary care in SBUHB.

This study sampled healthcare professionals who were actively working with patients living with or affected by MUS and interested in the topic. However, this approach may have excluded perspectives of those unaware or disinterested in their involvement with MUS. Therefore, the sample may not fully represent all healthcare professionals working with this patient group. To address this limitation, future research could adopt a more inclusive approach, such as conducting interviews with staff during their daily practice on a ward, capturing a broader range of perspectives.

While the discussion has focused on healthcare professionals' exposure to Potential Moral Injury Events (PMIEs) and associated shame, the study did not directly assess the immediate impact, frequency, or severity of these events. Comments regarding the risk of Moral Injury are speculative, though supported by exposure to PMIEs. Whether these events caused moral injury remains unknown, yet it's clear that emotional burden and shame affect healthcare professionals to some extent. Exploring the potential link between shame, moral injury, and working with people affected by MUS could be a fruitful area for future research.

It feels important to also acknowledge the significant variation in interview duration, ranging from 44 minutes to 1 hour and 34 minutes. This discrepancy may have introduced a limitation, as longer interviews could have potentially gathered more in-depth data. This variation in interview duration was influenced by the participant's contribution and the flexibility allowed by the researcher during the interviews, which should be considered when interpreting the study findings.

8.8.3. My reflections on my reaction to research:

This section reflects on my journey with MUS and my identity as a healthcare professional within SBUHB, and how these experiences influenced my research. It is crucial to acknowledge my identities, as they inevitably shaped my interpretation and engagement with the research process, particularly during the analysis (See Cohen, 2014; Doucet, 2008, Willig, 2019).

Initially, I focused primarily on my role as a healthcare professional, empathising with participants' challenges in providing patient support amidst uncertainty. However, I gradually became aware of my own experiences with MUS, such as my search for organic answers to dysmenorrhea, and how they influenced my choice of research topic. While I recognised my subjective experiences will play out, I attempted to maintain some neutrality in my analysis process.

The shift in my perspective - from an outsider, to an insider of living with the experience of MUS - is eloquently articulated in Doucet's (2008) paper 'Her Side of the Gossamer Wall(s)": Reflexivity and Relational Knowing', where she uses the concept of 'ghosts' sitting behind us to illustrate how our unconscious biases influence our research journey. Doucet (2008) suggests that in reflexive research, psychologists become increasingly figural—attaining a heightened awareness where patterns, meanings, and connections become more pronounced. Throughout the research process, as demonstrated through my shift in positions, I experienced this transition first-hand. This transition emphasises the quality of my research inquiry, as it signifies that I was genuinely reflexive throughout as I ended with a deeper self-awareness and understanding of the research area.

8.9. Implications for practice: How can Counselling Psychology contribute to service frameworks?

Counselling Psychology can play an important role in shaping service frameworks for people living with or affected by MUS. By actively contributing to the development of healthcare delivery models and implementing training programs that promote awareness of diverse perspectives, Counselling Psychology can help foster a broadened perspective. This perspective advocating for a holistic, patient-centred approach to care.

Counselling Psychology can drive discussions and generate interest in the field of MUS in Wales, ensuring the voices of people living with or affected by MUS are heard. They can advocate for the integration of psychological practice into health and MUS care, aligning with recommendations from authoritative sources such as the Psychological Professions Network's (2020) paper on 'Maximising the Impact of Psychological Practice in Physical Healthcare.' This integration aims to achieve parity between physical and psychological healthcare, establish multidisciplinary teams, and enhance coordination across care boundaries. By implementing these recommendations, Counselling Psychology emphasises psychologists' role in training healthcare staff and advocating for their representation in healthcare management. Integrating psychological support into MUS service models can facilitate early intervention and holistic care, contributing to improved patient outcomes and supporting a 'Healthier Wales' (Welsh Government, 2018) and the 'Well-being of Future Generations (Wales)' (Welsh Government, 2015).

9. Conclusions:

In conclusion, this study addresses gaps in research concerning healthcare professionals' experiences in secondary care services in Wales, when working with people living with or affected by MUS. It underscores the significance of uncertainty in these interactions. Embracing uncertainty as inherent in MUS, healthcare professionals can shift from a directive, solution-focused approach to one focused on support and guidance, thus better aligning with patient-centred perspectives.

This study identified shared feelings of helplessness and shame among healthcare professionals and people living with or affected by MUS. The experience of shame among health professionals is understudied, and the interconnectedness of these experiences suggests a dynamic of projection within the therapeutic relationship, potentially leading to internalised feelings of inadequacy and helplessness among both healthcare professional and patient, exacerbated by limited resources and interest in this patient group. Moreover, the study illuminated the vulnerability of the therapeutic relationship between healthcare professionals and people living with or affected by MUS. This

vulnerability prompted the implementation of various strategies to uphold therapeutic bonds. Nevertheless, these strategies inadvertently influenced the trajectory of care.

The risk of exposure to Potentially Morally Injurious Events (PMIE) was identified, particularly in situations where effective care is hindered by the uncertainty of how to work with often unexplainable and untreatable conditions. This is considered in the backdrop of resource limitation, and a lack of support and training. Recognising healthcare professionals' vulnerability to moral injury is important, necessitating external acknowledgment and support to prevent internalisation of systemic challenges by both professionals and patients.

Navigating the conflict between a realist, objective diagnostic model and the elusive nature of MUS, healthcare professionals often incorporate subjective elements into the construction of the therapeutic relationship and trajectory of care. This inquiry highlighted the complex interplay between healthcare professionals' personal and professional identities, emphasising how these intersecting identities can shape perceptions of patients, influence patient responses, and ultimately impact care provided. Furthermore, the specific wording, phrases, and expressions they employ carry implicit meanings and tones that significantly shape the perception of patient experiences. It is crucial to critically examine these linguistic choices to avoid unintentional dismissiveness or the inadvertent undermining of the validity of patient narratives

Counselling Psychology can play an important role in shaping service frameworks for people living with or affected by MUS. By actively contributing to the development of healthcare delivery models and implementing training programs that promote awareness of diverse perspectives, Counselling Psychology can help foster a broadened outlook. If Counselling Psychology can support healthcare professionals in a) aiding them in understanding and processing their own emotional responses, including feelings of shame or helplessness; b) enabling the recognition of their role within the broader system, i.e. considering the impact of specific ontological positions, such as a psychogenic model, which may inadvertently make patients less visible; and c) fostering collaborative and reflexive practices among colleagues within the wider healthcare system. They can lead in

encouraging the healthcare community to pause, reflect, and transform its approach to caring for people living with or affected by MUS. Leading a paradigm shift towards a holistic, patient-centred approach to care.

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11.Appendices

Appendix A - Research Diary Excerpt

21st September, 2022.

Today's reflection was about a particular moment during my research interview with a consultant doctor. As I revisited the recorded conversation, I discovered a subtle yet impactful comment that had initially shaped my perception of the interaction.

During the interview, the doctor made a remark about my age, stating that I was "clearly a lot younger" than him. At the time, I internalised this comment in a way that left me feeling somewhat diminished, as if I was perceived as less knowledgeable or experienced. The power dynamic seemed to shift, and I found myself in a position where I questioned my own expertise, especially in comparison to this experienced consultant neurologist.

Upon reviewing the recording, I was struck by the realisation that my initial interpretation was misguided. The doctor had been discussing the aging process and our brains' susceptibility to atrophy, drawing a comparison between different age groups. He wasn't commenting on my competence or experience but rather using a relatable analogy to convey a complex concept.

This stark revelation prompted a shift in my perspective. Instead of feeling small or unknowledgeable, I now recognised that our conversation had explored into the intricacies of age-related brain changes. The doctor, being older than me, was offering insights from his own experiences and drawing on a metaphor that inadvertently resonated with our age difference. However, I do wonder how much this emotional response to power in the interview, influenced the rest of the interview.

This reflection highlighted the importance of revisiting moments that trigger emotional responses in interviews. It highlights the potential for misinterpretation of the data. The experience serves as a valuable reminder to approach interactions with an open mind and to consider alternative perspectives, even when the initial emotional impact seems clear.

Appendix B - Initial Topics of interest for development of the interview schedule

Topic guides for participants:

This study involves collecting the views of health professionals who have been involved in the care of patients experiencing medically unexplained symptoms (MUS). I will be looking at:

- How health professionals conceptualise MUS.
- Health professionals' understandings and experiences of the assessment and treatment process of MUS.
- How psychology can be positioned to both the patient and professional in the care of MUS.
- Factors that may facilitate or hinder the effectiveness of care for patients with MUS.
- The impact of practitioner compassionate fatigue



Appendix D -	Participant	Information	Sheet for	Qualtrics
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Appendix E- Participant Recruitment Fl
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Appendix F - Demographic Information Form for Qualtrics

Version 3.0 - 03/10/2021





Please could you provide	details for the following:
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Date of Interview:	5
Name:	<u> </u>
Age:	<u> </u>
Gender:	(-
Ethnicity:	\$ <u></u> -
Job title:	
Department:	

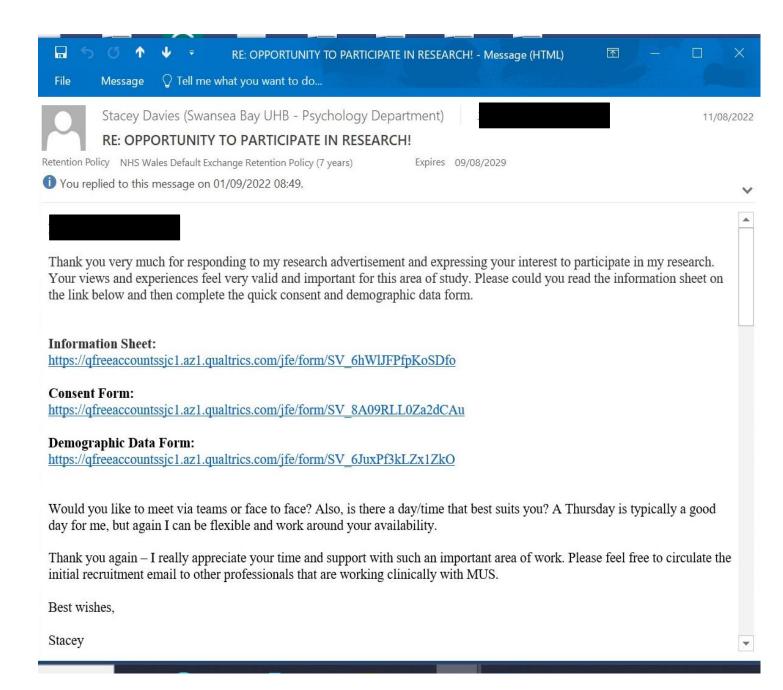
Appendix G - UWE Etl	hical Approval

Appendix H - Health Research Authority (HRA) and Health and Care Research Wales (HCRW) approvals.

Appendix I - Approvals	from SBUHB	management
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Appendix J - Consent Form for Qualtrics

Appendix K - Email for potential participants containing links to Qualtrics Form



Appendix L - Detailed Reflective Description of the data analysis

Phase 1: Data Familiarisation:

I conducted the semi-structured interviews and made brief notes of my processes and reflections after each interview. Consequently, upon reaching the familiarisation stage, I naturally possessed some understanding and initial interpretations of the data, see **Appendix N** Examples of my brief notes at the familiarisation phase. Consistent with the first aspect of familiarisation – *immersion* -, given that all 10 interviews were conducted via online team software, I initiated the process by re-watching all interviews while reading alongside the transcripts generated by Teams. This allowed me to identify and rectify any errors in the transcripts. Furthermore, I read and re-read through the transcripts to cultivate intimacy and familiarity with the data. I aimed to reach a point where, as Braun and Clarke (2021) suggest "where if suddenly your data got stolen, you'd be able to describe the broad content fairly well, even if precise detail was gone" (p43).

In line with the second practice of familiarisation, whilst immersed, I also critically engaged with the data; "actively making sense, contesting and challenging, critiquing and imagining how things could be different" (Braun & Clarke, 2021, p43). All in pursuit of identifying potential patterns of meaning. I carried out these two practices of familiarisation concurrently with the third practice – not making thoughts – rather than following a strictly sequential approach. I found this method more intuitive, as critically engaging and interpreting while reading to uncover deeper layers of meaning came more naturally to me. Note-making of thoughts also happened in a more focused way at the end of this phase.

Phase 2: Data Coding:

After immersing myself in the data during the familiarisation phase and making initial observations about what things are like, I reflected on my impressions, both overall and in specific aspects I encountered. I moved on to the next step outlined by Braun and Clarke (2001) as "the time for a more detailed and systematic exploration" — coding. It was clear to me that these little codes would serve as the fundamental building blocks for my analysis, shaping the development of my themes.

With this perspective in mind, I decided to employ a discursive, critical psychology approach to coding, favouring a manual, low-technology method. I chose this approach because it aligned with my preferences and allowed me to stay closely connected to the narrative within the data (See **Appendix U:** Example of coded transcription). Although, I contemplated using NVivo Software, which provides tools for organising, coding, and analysing qualitative data; I decided to embrace the messiness inherent in qualitative analysis, something I felt a technical approach might hinder. Methodically, I worked through the data line by line, using both semantic and latent codes to capture specific meanings relevant to my research question. Throughout this coding process, I adhered to an inductive approach, prioritising the data's guidance as opposed to imposing preconceived notions of knowledge and theory (Braun and Clarke, 2021). I remained aware of reflexivity and that my subjectivity was playing a role in shaping the coding process.

The coding process generated numerous codes – over 2000 to be honest. However, I was very aware that some were overly general while others failed to distinguish between nuanced meanings. For me, this signalled the shift from the familiarisation phase to coding, and I was now fully engaged with the data "as material that we are grappling with to make sense of, to address a specific question" (Braun & Clarke, 2021). As I engaged further with the data – I got completely lost. Information that initially appeared clear and straightforward became deeper and more fluid, and the volume of my analysis grew significantly. Despite moments of feeling lost and the temptation to jump ahead to potential themes, I consciously resisted this urge, recognising that such unconscious processes were common in qualitative research. Analysis might unconsciously select patterns in the data to align with their preconceived ideas (Braun and Clarke, 2021). Consequently, I redirected my focus away from prematurely identifying themes and continued to engage systematically with the data, ensuring a rigorous and thorough interrogation.

Given my natural broad thinking, the coding process naturally extended to encompass a broad range of codes. On average, each transcript received an initial coding of approximately 200-250 codes. These codes were both semantic and latent, and in many places included unprocessed thoughts. Nonetheless, for me as a qualitative analyst,

it felt important to capture every aspect of my initial thinking as I engaged with the data. As I am a visual thinker, I printed and physically cut out all potential codes. This hands-on process allowed me to evolve, redefine, and eliminate many duplicated codes (See **Appendix O,** Photographs of coding stage). Although, time-consuming I now appreciate this process, as it ultimately led to the development of a final set of 60 robust codes that effectively captured "both the diversity of perspectives...and the pattern of meaning" across the dataset (Braun &Clarke, 2021a). A comprehensive list of the final codes, alongside their corresponding narratives, can be found in **Appendix P** - List of final evolved codes and their narratives.

Phase 3: Initial Theme Generation:

Once all data had been coded, I transitioned into the phase of generating initial themes. My focus shifted from interpreting individual data within the dataset to exploring shared meanings across the entire dataset (Braun & Clarke, 2021). To facilitate this process, I printed and cut out all 60 codes, which allowed me to physically review and analyse them for potential shared meanings that may create themes or sub-themes, see **Appendix S**, for a visual representation.

I spent a lot of time actively engaging with my codes, construing the relationship between different codes and thinking about how these relationships might contribute to the narrative of potential themes. Throughout this phase, I maintained the perspective that "what is important is that the pattern of the codes or data items communicated something meaningful that helps answer the research question(s)" (Braun & Clarke, 2013). Some themes stayed the same as my initial clusters, whilst others collapsed and amalgamated based on shared meaning. The most challenging aspect of this phase was the need to let go of certain codes or ideas that didn't align with the overarching narrative of the data. Nevertheless, I set these aside in case they evolved into standalone themes in their own right. I knew I had reached the end of this stage, as I felt that I could produce an initial thematic map that collated initial themes and sub-themes, relative to their respective codes (See **Appendix R** - Evolving Thematic Map of Initial Themes).

Phase 4: Developing and Reviewing Themes:

During this phase, I reviewed the initial themes in the context of the coded data items and their interview transcripts (Braun and Clarke, 2020). As I outlined my themes I had a vision. My aim was to detail a comprehensive and engaging storytelling approach to my data. I wanted themes to create a compelling narrative of the data about health professionals' experiences when working with people experiencing or living with MUS (Braun and Clarke, 2021). To guide my review of these themes, I employed Braun and Clarke's (2012, p.65) series of key questions. The questions that were most relevant to me and helped me further refine my themes were, is this a theme? (It could be just a code)? Are there enough (meaningful) data to support this theme? Is the data too diverse and wide ranging (does the theme lack coherence)? These questions allowed me to consolidate themes that were essentially codes and integrate a final theme drawn from the initially set aside codes, i.e. see section 7.6. Theme 4: Beyond the Horizon: Envisioning Future Care for MUS. This theme completed and brought my narrative of the data set to a rich and meaningful ending (See Appendix S- Final Thematic Map)

Phase 5: Refining, Defining and Naming Themes:

At this stage, I found it useful to spend time detailing the narrative for each developed theme and sub-theme. My goal was to articulate each theme and sub-theme in relation to the dataset and research questions (See **Appendix** T –Refining, defining and naming themes phase: Drafted narrative of developing theme and sub-themes). I shared these narratives with my research supervisory team, which allowed for feedback and in-depth discussions regarding my themes, sub-themes, and selected quotes from the data. This collaborative process enabled me to refine and solidify the overarching meaning across the dataset in alignment with the research questions, and in preparation for the write-up of results. In this phase, I revisited the dataset once more, collecting and organising quotes that supported themes and sub-themes. I also reviewed the names of the themes and sub-themes, spending time examining the language employed in each theme and sub-theme, and making adjustments based on supervisory feedback.

Phase 6: Writing up Reflexive Thematic Analysis:

This final phase of this analysis was an ongoing thread woven throughout the entire research analysis process. This phase signified the completion and final inspection of the

data analysis. By this stage, I had already determined the sequence in which the themes would be reported. I wanted them to flow logically and meaningfully, building on a congruent narrative of the data (Braun & Clarke, 2021). I felt confident that my themes and sub-themes were robust, rich and detailed, representing the dataset and closely aligned with the research questions. A detailed presentation of my results is provided in the subsequent chapter.

Appendix M - Interview Schedule

Interview Schedule (Version 1.0/ 20.07.2022)



A qualitative examination of health professionals' experiences of working clinically with medically unexplained symptoms (MUS) in secondary care services

- 1. What terminology do you choose to use to describe physical symptoms that continue to find no organic cause?
 - a. Why do you choose to use this terminology?
 - b. Do you find that there are any strengths/weaknesses to using this terminology, rather than alternatives?

Statement: The National Health Service describes MUS an umbrella term constructed to describe a heterogeneous group of conditions of 'persistent physical complaints that do not appear to be symptoms of a medical condition' (NHS, 2021).

- The term MUS is a broad description used across various specialties in NHS Secondary Care Services, what does MUS mean to you? And your work?
- 3. Factual Questions;
 - a. How long have you worked in the NHS?
 - b. How long have you worked with MUS?
 - c. Roughly how many people do you see with this diagnostic label?
 - d. How is MUS described in your specialty?
- 4. What is your experience of current service provision of MUS services in South Wales?
 - a. Are there any factors that are facilitating or hindering the effectiveness of care offered to patients living with MUS across South Wales?
 - b. What is your experience of current service provision of MUS Services in South Wales?
- What is your role in making and receiving referrals for patients with MUS?
 - a. What was your experience in doing this? Were there difficulties?
 - b. Were there any alternative ways of working you considered?
 - c. What was your understanding of this process?

Page 1 of 2

I am now going to read you a vignette of Mrs Williams and ask you a few questions on how you are experiencing and conceptualising Mrs Williams:

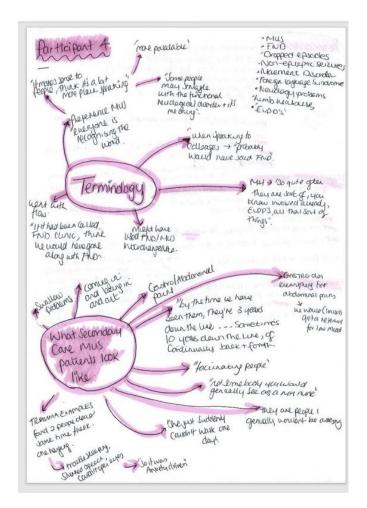
"Mrs Williams is a 59-year-old Lady who at different points in her life has received a diagnosis of Crohn's Disease, depression, anxiety and chronic fatigue syndrome. She has recently been bereaved after losing her husband. She is the main carer for her daughter who has cerebral palsy. There is no information on Mrs Williams' childhood or upbringing in her medical record. She presented to A&E after a sudden onset of headaches and neck pain; she re-presented a week later after developing some blurred vision along with left arm and leg weakness and numbness. Initially she was admitted with a suspected stroke, however investigations which included a CT Brain, MRI and CT angiogram, did not reveal any acute abnormalities that could explain her symptoms.

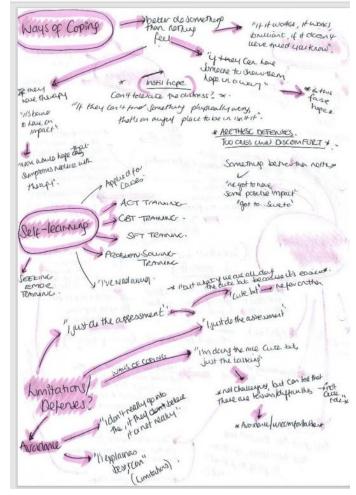
- a. What are your first thoughts about Mrs Williams symptoms?
- b. Are there any theoretical models/ guidelines that you may draw upon during assessment and treatment of this patient?
- c. What direction of care and treatment might you consider recommending going forward and why?
- d. What types of explanation might you offer Mrs Williams to describe the cause of her problems during the clinical encounter?
- e. Do you feel comfortable and prepared for working with this client?
- 7. What are your personal feelings of working with MUS?
 - a. How does working with people with MUS make you feel?
 - b. Does these feelings impact on your clinical work with someone with MUS?
- 8. What is your experience of the therapeutic relationship or therapeutic engagement with people who experience MUS?
 - a. What facilitates/hinders your therapeutic encounter with people who experience MUS?
 - b. What does a professional encounter look like with this patient group? Is there any conflict or differences of opinions?
- 9. Psychologists are increasingly being referred cases of MUS across all service, how do you think Psychologists can help?
 - a. Do you refer patients like Mrs Williams to Psychology?
 - b. Why might you/ or might not refer to Psychology for MUS?
 - c. What do you think would be the best role for Psychology?
 - d. How could Psychology complement your practice?

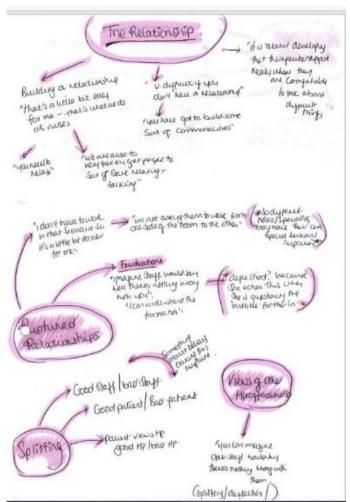
End of interview schedule.

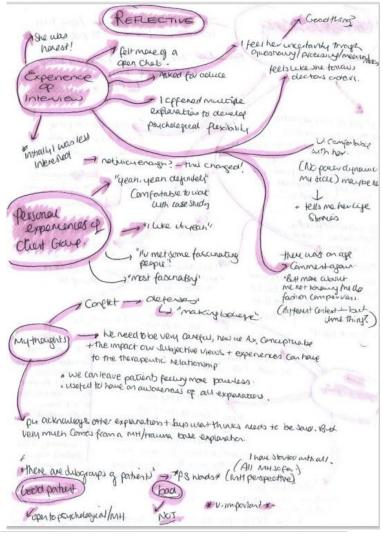
Page 2 of 2

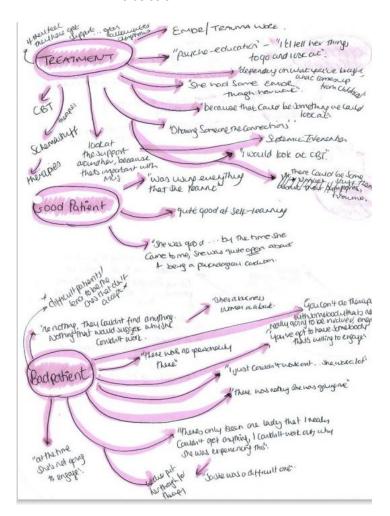
Appendix N - Example of note-taking during data familiarisation phase

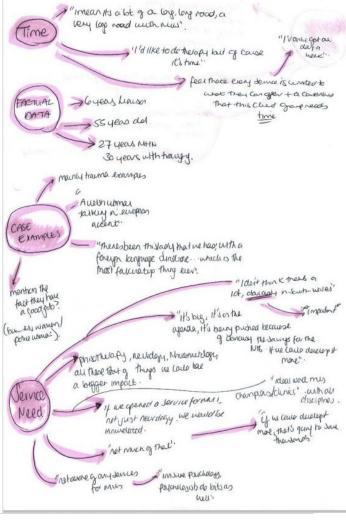












Appendix O - Photographs of data coding phase





Appendix P - Details of final 60 codes

- **1.** The Guru The guiding mentor of discipline/area of work. Signifying an unwritten election of an individual to serve as a mentor, provide guidance and wisdom this recognition can be attributed to their high confidence, successful approaches, and the support and advice sought by their colleagues.
- 2. Expert Discourse The professional-patient dominant discourse and its consequences. This code reflects the ways in which patients and healthcare professionals perceive expertise and specialized knowledge in the context of medically unexplained symptoms (MUS). As well as the recognition that understanding MUS may come with experience, align with the concept of expert discourse.
- 3. Authenticity vs. Falsehood: The impact of Beliefs of MUS Care This code captures a focus on health professionals' beliefs about the authenticity of MUS symptoms and how these beliefs influence patient care and outcomes. This title highlights the contrast between believing in the authenticity of the symptoms and potentially dismissing them as false, and how these contrasting perspectives can shape the overall care approach.
- **4. Influence of Clinician Traits on Patient Care:** This code reflects how the personal characteristics and attributes of healthcare professionals play a significant role in shaping their approach, decision-making, and interactions when providing care for patients with MUS.
- 5. Health Professionals' Assumptions and Biases: This code highlights the role of healthcare professionals' personal beliefs and biases in shaping their approach to MUS patients, including how they communicate diagnoses and hypotheses, and how they consider psychological factors from the start. It emphasizes the need for self-awareness and reflexivity to minimize the impact of assumptions and judgments on patient care.
- **6. Intrigued by MUS Complexity:** This code encompasses the participant's genuine interest, fascination, and passion for working with MUS patients due to the intricate nature of their cases, the challenge of the unknown, and the uniqueness of their experiences. It reflects the participant's engagement and enthusiasm for understanding and addressing the complexities associated with MUS.
- 7. Emotional Responses and Challenges in Working with MUS. This code reflects the varied emotional reactions, frustrations, concerns, and internal conflicts that healthcare professionals may experience when providing care for patients with medically unexplained symptoms (MUS). It highlights the complex and challenging nature of working with this patient group and the impact it can have on professionals' well-being and sense of efficacy.
- **8. Self-learning-** This code highlights the participants proactive approach to self-learn. It highlights their quest for knowledge, understanding, and coping strategies through self-directed learning. The participant actively seeks information to navigate through uncertain situations. By embracing self-learning, they empower themselves to take charge of their own learning journey, fostering resilience and

- adaptability in the process. This theme underscores the importance of self-directed learning as a catalyst for personal empowerment and continual growth
- 9. Balancing Risk and Care with MUS patients: This code explores the delicate balance between taking calculated risks and ensuring careful evaluation when dealing with medically unexplained symptoms (MUS). It highlights the importance of approaching MUS with a proactive mind-set while also being mindful of the potential risks, such as misdiagnosis.
- **10. Professionals chosen terminology:** Participants have their preferred terminology. This code highlights that health professionals all have their own subjective preferred terminology for referring to a group of people who experience physical symptoms with no organic cause. It reflects individual perspectives on the most appropriate language to use in the context of their work.
- 11. Variability and Uncertainty in Terminology: This codes acknowledges the diversity of terminologies used to describe physical symptoms that continue to provide persistent difficulties but have no organic cause. Indicating the lack of standardised terminology in this area of work. The code also encompasses the uncertainty surrounding what is the most appropriate and accurate terminology to use when discussing MUS. It underscores the dynamic nature of language choices in describing MUS.
- **12. Shifts in terminology:** This codes signifies how professionals may shift their language choices depending on the audience they are addressing, such as patients, colleagues, researchers, mental health, written format to ensure effective communication and understanding. It also accounts for systemic shifts in terminology. Shifts can be down to cultural sensitivity, patient sensitivity, to reduce stigma.
- **13. Terminology connotations:** This codes that certain terminologies used to define MUS can carry associated stigma impacting on how the patient, professional and society views their condition. It suggests more positive and empowering terminology that is subjective to participant. The code underscores that the choice of terminology matters and can influence perceptions and experiences of patients.
- 14. Patient's perception of Terminology: Patients may have a preferred terminology to describe their experiences. They may have their own autonomy and sense of identity in how they perceive and discuss their health experiences. This code includes that some patients may reject certain terminologies of health professionals. Patient preferences and acceptance of specific terms are considered, and some terminologies, like "MUS," are seen as potentially complex and confusing. This code also touches on the provider's perspective, highlighting the challenges and implications associated with selecting appropriate language to communicate about MUS.
- **15. Diverse Explanatory Frameworks for MUS:** This code illuminates the various interpretive lenses that healthcare professionals employ to understand and address medically unexplained symptoms (MUS). Professionals consider a range of explanatory frameworks, encompassing trauma, biology, mental health, and the limits of scientific understanding.

- 16. Embracing Professional Limitations: This codes includes the concepts of professionals recognising and accepting their limitations within their job roles and therapeutic practice with honesty and integrity. An acknowledgement that no professional can be all knowing or all capable. The code underscores a level of self-awareness and humility within the scope of one's own expertise and one's reluctance towards uncertainty.
- 17. The do-do effect- Regardless of the causal factors or specific interventions, the emphasis remains on delivering support that leads to meaningful improvements. Professionals prioritize offering interventions, as they firmly believe that any form of assistance can yield positive outcomes. Can be related to the psychological concept known as the "do-something, do-anything" effect. This effect refers to the tendency for people to believe that taking any action, even if it may not be the most effective or rational, is better than doing nothing at all. In the context of the theme, healthcare professionals prioritize offering interventions or support for patients with medically unexplained symptoms (MUS) based on the belief that providing some form of assistance, no matter the cause or approach, is more beneficial than not taking any action.
- **18. Avoidance and Distancing in MUS Care:** This code delves into the psychological dynamics surrounding the tendency of health professionals to avoid or distance themselves from patients with medically unexplained symptoms (MUS). Overall, the theme emphasizes the intricate interplay of unconscious processes, fears, and dynamics that influence the interactions and decisions of health professionals when faced with MUS cases.
- 19. Holding on: Professionals might feel the need to hold onto MUS patients, provide ongoing care, and intervene frequently to prevent them from being passed through the system or to ensure they receive the care they need. It delves into the complex interplay of transference, countertransference, and unconscious motivations that impact how professionals handle MUS cases. The theme highlights the challenges, dilemmas, and emotional aspects involved in deciding whether to hold on to MUS patients or discharge them from care. It also sheds light on the matriarchic approach adopted by some paediatric services and the potential disempowerment of patients due to professionals taking excessive responsibility for their care.
- 20. Precautionary prescribing: This code highlights the motivations behind prescribing medication out of pity or to alleviate health professionals' own anxiety, leading to precautionary prescribing. The theme also examines the implications of such prescribing, including the potential for polypharmacy and mixed messages conveyed to MUS patients. The tension between acknowledging the limitations of medication while still resorting to it, as well as the potential negative effects on patients, is highlighted.
- **21. Managing Uncertainty in Clinical Practice:** This code delves into the strategies and behaviours that healthcare professionals employ to manage uncertainty and seek reassurance in their clinical practice. Participants express a willingness to conduct further investigations or assessments to ensure a higher level of certainty in their decision-making. This may involve seeking additional opinions from colleagues or

- re-admitting patients to follow established protocols, which can serve as protective measures. Overall, the theme emphasizes the professionals' efforts to mitigate uncertainty and enhance confidence in their clinical decisions through various means.
- 22. Reverting to Familiar during uncertainty: This code considers how healthcare professionals cope with uncertainty in the context of medically unexplained symptoms (MUS). When confronted with complex and uncertain situations, they tend to rely on their familiar professional lens, knowledge, and expertise to navigate and manage these challenges. For example, occupational therapists (OTs) may revert to their occupational therapy lens, and healthcare professionals, in general, may stick to what they know best. This coping mechanism provides them with a sense of stability and guidance in dealing with the complexities of MUS, allowing them to draw on their expertise to provide care and support for their patients.
- 23. Managing Relational Dynamics and Challenges: This code looks into the intricacies of the relationships between healthcare professionals and patients with MUS, focusing on the challenges and strategies employed to navigate communication and relational dynamics. Participants highlight the fragility of these relationships and the potential for ruptures, which can be influenced by various factors such as dominant medical discourse, patient expectations, and lack of understanding. It emphasizes the significance of maintaining and navigating through these relationships, even in the face of challenges, to provide effective care and support for patients with MUS. These actions, such as backing down to avoid discomfort, giving in to patient demands, offering apologies for uncertainties, and finding ways to manage potential ruptures, contribute to the overall theme of managing communication challenges and maintaining the patient-professional relationship in the context of MUS care.
- 24. Evolution of terminology: This code focuses on the dynamic nature of terminology used to describe MUS within the healthcare context. It recognises that healthcare professionals' choice of language and terminology may evolve over time as they gain more experience and insights into managing MUS. Additionally, acknowledges that the term "MUS" itself has historical significance and has been used over time to refer to this category of symptoms. It emphasizes the importance of understanding how terminology can change and adapt based on evolving perspectives, experiences, and knowledge.
- **25.** The Pros and cons of a diagnosis: This code revolves around the intricate role of diagnosis in the context of MUS, exploring how it affects both patients and healthcare professionals. The theme underscores the significance of a clear diagnosis and labels, which empower patients by validating their experiences and providing a means of communication. Overall, it sheds light on the complex interplay between diagnosis, patient empowerment, and the approaches of healthcare professionals in the realm of MUS.
- **26. Evolving care for MUS**: This code encapsulates the dynamic and ongoing process of growth, learning, and improvements within the realm of medically unexplained

- symptoms, where understanding, approaches, and confidence are very slowly evolving among healthcare professionals.
- 27. Lack of Awareness and Knowledge about MUS: This code centres on the crucial issue of inadequate awareness and understanding of medically unexplained symptoms (MUS) among healthcare professionals. It highlights that MUS is not well-known or recognised within various healthcare contexts, including specific teams, disciplines, and the broader healthcare community. The lack of awareness poses challenges in early diagnosis, appropriate treatment, and the provision of comprehensive care for MUS patients.
- 28. Balancing patient hopes and professional realism: This code explores the dynamic between patient expectations and the role of healthcare professionals in managing these expectations. Patients often enter healthcare encounters with preconceived notions and hopes for solutions. The theme highlights the challenge professional's face in aligning patient expectations with realistic outcomes. It delves into the complexities of managing patient hopes while avoiding the potential pitfalls of raising false expectations. The interplay between optimism and realism is a key consideration in interactions with MUS patients, with healthcare professionals striving to provide meaningful support without misleading patients. The theme underscores the importance of striking a delicate balance between addressing patient expectations, fostering hope, and ensuring realistic understanding of the care and outcomes that can be offered
- 29. Time constraints and patient care for MUS: This code explores the significant impact of time limitations on healthcare professionals when working with patients experiencing MUS. It encompasses the challenges posed by the time-consuming nature of addressing MUS, the struggle to provide sufficient time for comprehensive care, and the need for a balance between dedicating time to MUS patients while managing overall workload. The theme underscores the importance of allocating adequate time to build relationships, engage in thorough assessments, and offer meaningful support to MUS patients within the constraints of a busy healthcare environment.
- **30. Advocacy and education:** Advocacy efforts by healthcare professionals aim to reduce stigma associated with MUS and promote a more empathetic approach to patient care. The need for staff training and engaging other health professionals is emphasized. This code also includes the role of teaching and education in the effective management of MUS. Through teaching initiatives and educational efforts, healthcare professionals gain a deeper understanding of MUS, leading to improvements in awareness, knowledge, and referral practices
- **31. MUS stigma in Healthcare services:** This code addresses the presence of stigma and negative perceptions surrounding patients with MUS within healthcare services. The theme highlights the impact of stigma on the care and treatment of MUS patients, including instances where professionals may belittle or stigmatize their experiences. It also explores how biases and lack of understanding among health professionals can contribute to the stigma, affecting the quality of care provided to MUS patients. Stigma's influence on treatment options and its potential to overshadow patient experiences are also discussed within this theme.

- **32. Overlooked and under recognised:** This code sheds light on the tendency within healthcare settings to prioritize emergency patients over those with MUS. It highlights how MUS patients often receive less attention and recognition compared to emergency cases. The code underscores the retrospective nature of identifying MUS patients, where their condition might only be recognised after the fact or upon reflection. It points out the lack of sufficient interest and awareness surrounding MUS, which leads to these patients being overlooked and neglected. The code also emphasizes the disparity in support between organic and nonorganic illnesses and highlights the challenge of identifying MUS patients across various medical specialties.
- 33. Reassurance through Exclusion: This code focuses on the diagnostic process for patients with MUS, highlighting the emphasis on ruling out potential causes. Healthcare professionals use assessments and investigations to systematically exclude possible underlying conditions and provide reassurance to the patient by eliminating specific diagnoses. The code underscores the use of exclusionary methods to arrive at a diagnosis, describing how MUS assessment involves a process of elimination and negation. It also reflects the importance of clear and precise diagnosis, while acknowledging the need for a proactive diagnostic approach. The theme emphasizes the potential shift from solely viewing MUS as a diagnostic exclusion to considering it as a primary diagnosis in its own right.
- **34. Patient Engagement and Professional Dynamics:** This code revolves around the diverse dynamics that arise in patient-professional interactions within the realm of MUS. It delves into the distinctions between patients who exhibit a cooperative and receptive attitude towards MUS diagnoses, often referred to as "good patients," and those who may present challenges or disagreements, sometimes termed "difficult patients." The theme explores the complexities of communication and rapport-building, particularly when patients hold differing perspectives on the origin and nature of their symptoms.
- **35.** Interdisciplinary Collaboration for Comprehensive MUS Management: This code encompasses the importance, benefits, challenges, and necessity of collaborative efforts among healthcare professionals to provide holistic care for patients with Medically Unexplained Symptoms (MUS). It highlights the need for cohesive teamwork, shared communication, and coordinated approaches to address the complex and multifaceted aspects of MUS, both in terms of patient care, diagnosis and professional support.
- **36. Need for MDT:** This cod highlights the significance of a MDT approach in managing and addressing MUS. It emphasizes the benefits of collaborative teamwork, effective communication, and shared insights among various healthcare professionals. The MDT framework is underscored as essential for identifying and addressing challenging feelings towards MUS patients, reducing unnecessary investigations, and providing comprehensive explanations and care. The theme underscores the need for an MDT approach and advocates for its implementation as a valuable strategy to enhance the quality of care for individuals with MUS.
- **37. Individualised and Patient-Led Care:** This theme emphasizes the importance of providing individualised and patient-centred care for individuals with medically

- unexplained symptoms (MUS). Healthcare interventions and care plans should be tailored to meet the unique needs of each patient. The approach to care is collaborative, involving the active participation of the patient, and respects the patient's preferences and input in decision-making. It emphasizes the practice of adapting therapeutic interventions, explanations, and support strategies to align with each patient's unique circumstances. By prioritizing patient preferences, the theme aims to enhance patient wellbeing, improve overall functioning, and cultivate a patient-centred approach to MUS care.
- **38.** Uncertainty and Awareness of Service Availability and Coverage: This code centres on the uncertainties and awareness gaps surrounding the availability and coverage of healthcare services for MUS. Healthcare professionals express uncertainties about the extent of services across their region, including doubts about the contributions of other services and the scope of primary mental health services. There is doubt in whether referrals are picked up and lack of follow-up.
- **39. Psychological and Emotional Dynamics for MUS patients:** Psychological and emotional impact of MUS on the patient: The intricate interplay of psychological and emotional factors is recognised. MUS patients can experience trauma through being passed through services: Navigating complex healthcare systems can lead to traumatic experiences for MUS patients, underscoring the importance of traumainformed care and support. These reflexive thematic themes collectively emphasize the nuanced emotional experiences of MUS patients.
- **40. Insufficient support and Service:** This code addresses the challenges posed by the lack of adequate support and services for individuals with Medically Unexplained Symptoms (MUS). It highlights the limitations and gaps in available resources, leading to difficulties in effectively managing and addressing the needs of MUS patients. Professionals often face barriers when trying to refer patients to appropriate services, and the absence of specialized care pathways and support systems can impact the quality of care provided. The code also underscores regional disparities in the availability of services and research, emphasising the need for greater focus, research, and resources to better support MUS patients and address their unique healthcare requirements
- 41. A strained healthcare-system: This code highlights the challenges and strains that healthcare professionals face within the healthcare system, particularly in relation to managing patients with MUS. It underscores the impact of resource limitations, high patient demand, and time constraints on the ability of healthcare providers to effectively care for MUS patients. Professionals often grapple with heavy workloads, tight criteria for service provision, and overwhelming pressures in emergency departments. The strained healthcare environment not only affects the quality of care that MUS patients receive but also hinders professionals' capacity to build relationships and offer comprehensive support. This theme sheds light on the complex interplay between healthcare system pressures, resource availability, and patient care, underscoring the need for strategies to address these challenges and improve care for MUS patients.
- **42. Theme: Continuity of Care and Communication:** This code emphasizes the crucial role of continuity of care and effective communication in managing patients with

- MUS. It highlights the challenges that arise when patient histories are lost or fragmented due to repetitive attendance or lack of follow-up. Professionals stress the importance of ongoing communication with patients throughout the referral process to ensure that their history and needs are adequately addressed. Additionally, the theme reveals the limitations and implications of not having continuity of care, such as the potential for unnecessary retesting and investigations.
- 43. Challenges of introducing "Psychiatric term": This code highlights the complex dynamics related to patient receptivity and stigma when considering referrals to mental health services for individuals with Medically Unexplained Symptoms (MUS). Professionals recognise the challenges associated with introducing the term "psychiatric" due to potential patient resistance and defensiveness. Stigma surrounding mental health care, particularly in the context of MUS, can deter patients from engaging with mental health services. The code emphasizes the importance of patient choice and receptivity when considering referrals to psychological therapies or community mental health teams.
- **44. Pitching for Psychology:** This code highlights how Participants envision psychology alongside their practice and how they can help patients and their teams. Participants stress the importance of clear criteria for Psychology referral, express uncertainty in referrals, actively pitch for Psychology involvement, and underscore the need for Psychology services within the healthcare team.
- **45.** The Role of Psychology with MUS patient: It emphasizes the diverse role of psychologists as experts in trauma. The theme highlights the need for psychological support for patients with complex physical health conditions and how therapy can help patients connect their mind and body to better understand MUS. It underscores the adaptability and flexibility of therapies for MUS, allowing psychologists to address the complexities of pain and mental health issues in these cases. The theme also discusses the role of psychology as a crucial resource when other approaches have failed, reaching the limits of expertise, or when more intensive interventions are required. It emphasizes the importance of identifying the most suitable psychological modalities for individual patients to ensure effective and patient-centred care.
- 46. Challenges in Accessing Psychological Support for MUS Patients: This code emphasizes the difficulties and barriers faced by both healthcare professionals and patients in accessing psychological support for individuals with Medically Unexplained Symptoms (MUS). It highlights the limitations, waiting lists, and insufficient resources that hinder the availability of adequate psychological therapies for this specific client group. The theme underscores the importance of addressing these challenges to ensure that MUS patients can access the appropriate psychological interventions they may need to effectively manage their conditions.
- **47. Limited Intervention after Exclusion of Organic Causes:** This code revolves around the challenges faced by healthcare professionals when there are no clear organic causes found for patients with MUS. After exhausting all investigations and ruling out red flag symptoms, health staff may conclude that there is nothing physically

- wrong with the patient, leading to limited intervention options. This code highlights the difficulties in managing and providing further care for patients once organic causes have been excluded, and it underscores the need for alternative approaches to address the complexities of MUS cases when clear organic explanations are lacking.
- 48. Thinking outside the Box in Managing MUS: This code emphasizes the need for healthcare professionals to adopt innovative and flexible approaches when dealing with MUS. Standard medical guidelines and protocols may not be effective in addressing the complexities of MUS, leading professionals to seek alternative methods and solutions. Creativity and initiative are crucial in tailoring services to meet the unique needs of MUS patients, as they may not fit neatly into existing diagnostic categories. Professionals recognise the limitations of the medical model and advocate for individualised, out-of-the-box approaches to support and treat MUS patients effectively.
- 49. Self-Reflection and Growth in Managing MUS: This code highlights the importance of self-awareness and ongoing reflection for healthcare professionals working with MUS. Professionals recognise the need to acknowledge their own knowledge gaps, biases, and discomfort when interacting with MUS patients. Through self-reflection, they can address difficult feelings, transference, and countertransference, enabling them to remain compassionate and effective in their care. Over time, professionals' perspectives on MUS may evolve, leading to a better understanding and acceptance of the reality of MUS as a legitimate condition. Reflecting on past experiences also allows for personal growth, leading to improved decision-making and the establishment of boundaries when working with MUS patients.
- 50. Diverse Approaches in MUS Intervention: This code highlights the wide range of interventions and approaches utilized by healthcare professionals when dealing with MUS patients. Professionals vary in their treatment strategies, including psychological therapies, lifestyle advice, emotional regulation techniques, attention switching, psychoeducation, and self-management. Some professionals focus on symptom management and reducing the impact of symptoms on the patient's life, while others emphasize empowering patients to take control of their own symptoms through self-help and goal-oriented interventions. The interventions employed may include cognitive-behavioural therapy (CBT), teaching stress management techniques, providing psychoeducation, using attention theory, and utilizing various tools and worksheets to help patients understand and manage their symptoms. The diversity in intervention approaches reflects the individual perspectives and expertise of healthcare professionals, acknowledging that there is no one-size-fits-all to patient centred intervention or professional's subjective choice of intervention.
- **51. Intrapsychic strategies as MUS care:** This code can be considered as an intrapsychic code. Intrapsychic refers to the individual's internal psychological processes and how they cope with and manage their own symptoms. The code captures aspects of treatment, such as empowering patients with selfmanagement techniques and providing psychoeducation to enhance their

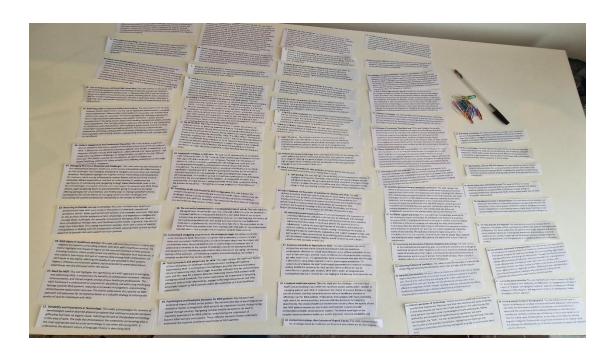
- understanding of MUS and its management. The aim is to promote patient autonomy, self-efficacy and emotional regulation in dealing with MUS. While intrapsychic interventions can be valuable in empowering patients to take ownership of their psychological well-being and self-management, it is equally important for healthcare professionals to acknowledge and address the physical aspects of the condition. As intrapsychic strategies are a positivist way of seeing the world taking ownership off the wider system and placing the problem in the person. Sometimes a strategy employed during professional angst.
- **52.** Building a Positive Therapeutic Relationship with MUS Patients: This code encompasses various aspects of building a strong and supportive professional-patient relationship when working with patients with Medically Unexplained Symptoms (MUS). It includes validation and empathy, effective communication and listening, patience, perseverance, and a patient-centred approach. Additionally, the code emphasizes the importance of understanding the patient's perspective, empowering them, and fostering trust and a sense of being heard and believed. Professionals use their skills, humour, and compassion to create an open and supportive environment, where patients feel comfortable expressing themselves and engaging in open communication. Overall, this theme reflects the essential components that contribute to a positive therapeutic relationship with MUS patients.
- 53. Personal Experiences Shaping Perspective and Practice: This code highlights the impact of personal experiences on healthcare professionals' attitudes and practices regarding MUS. Professionals' own experiences with illness, including MUS, influence their understanding and empathy towards patients. Personal encounters with health challenges have led to a more patient-centred approach, openness to alternative treatments, and increased receptiveness to the complexities of MUS. These experiences shape how professionals work with MUS patients, promoting a more empathetic and comprehensive care approach. Additionally, experiences during previous placements and interactions with mentors have also influenced professionals' perspectives and practices when working with MUS patients.
- 54. Subjective Variability in Approaches to MUS: This code emphasizes the varied perspectives and approaches towards MUS between different healthcare professionals. Observations reveal that colleagues across different specialties do not work in the same ways, and their views on MUS can be influenced by their exposure, job roles, experiences, and opportunities. Some professionals may view MUS through a physical lens, while others approach it with a psychological perspective. The subjectivity of clinicians can significantly impact assessment and treatment decisions, leading to different outcomes for MUS patients. Some professionals may be committed to a specific path of action, while others prefer an integrative and individualised approach. Overall, the code highlights the diversity of perspectives and approaches that healthcare professionals have towards MUS, which can significantly impact the care and management of patients with this condition.
- **55.** The non-verbal communication of professional's implicit beliefs: This code highlights the significance of non-verbal communication and subtle actions in the

interactions between healthcare professionals and patients with MUS. Patients can discern whether they are believed and listened to based on the body language and actions of the healthcare professionals. Non-verbal cues can reveal the true beliefs and frustrations of professionals, even if they try to hide them. The expressions on the faces of healthcare professionals when working with MUS patients can communicate volumes about their attitudes and perceptions towards these patients.

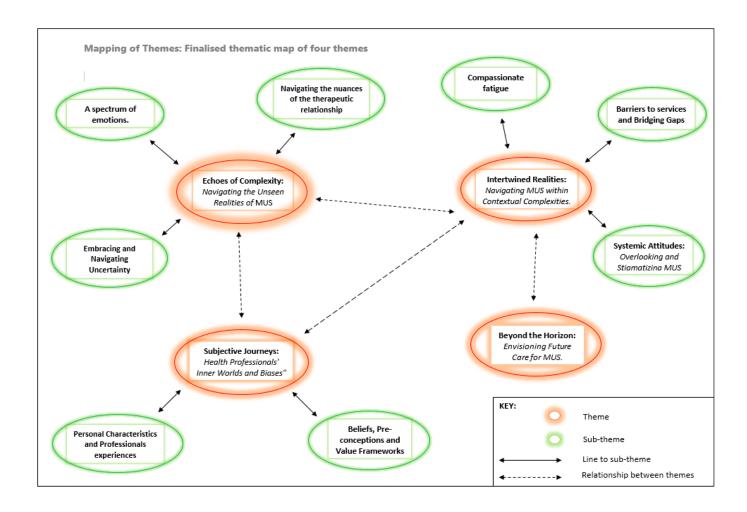
- 56. Embracing & navigating uncertainty in the therapeutic dyad: Admitting uncertainty in the therapeutic dyad: This theme recognises that uncertainty is inherent in MUS cases and encourages healthcare professionals to be open about their limitations and uncertainties when discussing patient care. It acknowledges the complex task of addressing uncertainty in the context of medically unexplained symptoms (MUS) during patient care. Healthcare professionals play a vital role in managing minimizing feelings of the unknown, and conveying empathy and understanding even when a complete explanation may not be available
- **57. Holistic Approach to MUS care:** This code highlight the importance of taking a holistic approach to patient care when dealing with MUS. Professionals need to consider the broader context and systemic factors that may contribute to the patient's condition. It acknowledges that professionals aim to understand the whole picture, but mainly focus on their own discipline. Advocating for a comprehensive bio-psycho-social assessment and intervention can lead to better outcomes for patients experiencing medically unexplained symptoms.
- **58. Balancing comfort and challenges:** This theme recognises that despite facing emotional challenges, participants still find comfort in working with patients with MUS. It underscores their commitment to providing care and support to this patient population despite the difficulties they encounter. The overall emotional impact of working with MUS patients is a multifaceted experience, with participants navigating both the challenges and rewards of their profession.
- **59. Integration of MH and Physical for MUS management;** This code highlight the complex interactions between physical and mental health aspects in MUS cases, the challenges related to parity of esteem, and the varying approaches of healthcare professionals from different disciplines. They emphasize the importance of integrated care and understanding patients' holistic needs.
- 60. Lack of Guidance and Awareness of Guidelines for Working with MUS: This code revolves around the challenges faced by professionals when dealing with MUS due to the absence of clear guidelines and limited awareness of existing guidelines and theoretical frameworks. Professionals express uncertainty and lack of familiarity with specific models or evidence-based recommendations for working with MUS conditions like Functional Neurological Disorder (FND), fibromyalgia, and Chronic Fatigue Syndrome/Myalgia Encephalomyelitis (CFS/ME). The absence of clear guidance and awareness creates difficulties in effectively managing and treating patients with MUS, leading to potential variations in clinical practice and outcomes.

Appendix Q - Photographs of Initial Theme Generation

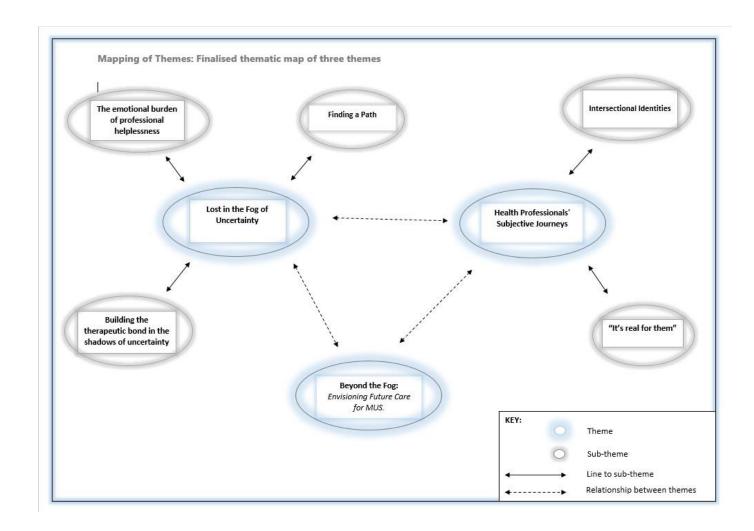




Appendix R - First draft of thematic Map



Appendix S - Developing and Reviewing Themes: Final Thematic Map



Appendix T- Refining, Defining and Naming Themes Phase: Example of a drafted narrative of developing theme and sub-themes.

Theme 1: Subjective Dimensions of Health Professionals' Reality (not sure this will be the first theme – might need to lead on from something)

"Subjective Dimensions of Health Professionals' Reality" refers to the personal and individualised aspects that contribute to how healthcare professionals perceive and experience their roles, interactions, and environments within the healthcare system. This concept acknowledges that each health practitioner brings their own unique perspectives, emotions, beliefs, and personal experiences to their profession, which in turn shapes their understanding of their work and the context in which they operate. This theme reveals that no professional works in the same way, and their emotional response and mechanisms of defence to the complexity of MUS, may be influenced by their exposure, experiences, individual profiles and beliefs. The subjectivity of clinicians can significantly impact assessment and treatment decisions, leading to different outcomes for MUS patients. Where some professionals may be committed to a specific path of action, others may prefer a different approach. Overall, the code highlights the diversity of perspectives and approaches that healthcare professionals have towards MUS, which can significantly impact the care and management of patients with this condition.

Subtheme 1: Defence mechanisms to Emotional Response:

Mechanisms of defence, are psychological strategies that individuals unconsciously employ to cope with emotional or psychological distress, anxiety, and threats to their self-esteem or well-being. These defence mechanisms serve as protective strategies that help individuals manage difficult feelings, thoughts, or situations, often by distorting, denying, or displacing the perceived threat or discomfort. The data acknowledged that health professionals did have different ways of approaching MUS and it appeared that this could be influenced by how they experienced MUS and the emotional response they illicit in individual health professionals. While defence mechanisms serve as adaptive coping strategies in certain situations, relying on them excessively or inappropriately can hinder effective patient care, communication, decision-making, and professional relationships.

Here are some ways in which defence mechanisms were seen to be impacting health professional practice:

Avoidance and Distancing in MUS Care: Some Health professionals talked explicitly about avoiding and distancing from MUS due to the emotional response and complexity MUS can elicit (See theme 1). Whereas others more implicitly – how other health professionals may avoid MUS- a potential projection of their own thoughts and experiences of working with MUS. (1 or 2 quotes)

Intellectualization: Another avoidance mechanism of defence felt in the data was 'intellectualisation'. A substantial amount – *if not all* – participants took a proactive approach to self-learning; highlighting their quest for knowledge, understanding – *and coping*- through self-directed learning. Participants demonstrated a need to seek information to navigate through the uncertainty that can arise working with MUS. It promotes self-directed learning as a catalyst for personal empowerment. Nevertheless, focusing on abstract or intellectual aspects of a situation can help avoid the emotional content, as it helps the person distance themselves from any overwhelming emotions working with MUS may illicit. (1 or 2 quotes)

Holding on: Some health professionals talked about holding on to MUS patients, whether this was through the avoidance of discharge or "offering more follow-up appointments than not". They spoke about a need to intervene – *a potential rescuer*- to prevent patients being passed through the system or to ensure they received some care. This delves into the complex interplay of transference, countertransference and unconscious motivations that can impact how professionals work with MUS. Whilst some favoured this approach, others felt that holding onto patients offers false hope, disempowerment and a unhelpful matriarchic approach to the care of MUS. (1 or 2 quotes).

Splitting: There were observations of Health professionals employing 'splitting' in the context of patient engagement and professional dynamics, as a response to the complexity of MUS. There were distinctions between "good patients" and "difficult patients" and extreme language used to categorize patients ("cooperative, accepting and receptive" vs. "challenges or disagreements") can be indicative of splitting. In this case,

the division between "good patients" and "difficult patients" suggests a black-and-white view of patient behaviour and attitudes, which is characteristic of splitting. The passage implies that patients are either entirely cooperative or entirely challenging, without accounting for the multiple factors that might influence patient behaviour. Splitting is a subjective perception of an individual's situation, it involves perceiving people, situations, or experiences in an extreme, black-and-white manner, without acknowledging the complexities or nuances that usually exist. In the context of working with MUS, splitting could potentially be relevant in how health professionals perceive and respond to the complexity of these cases.

Subtheme 2: Intersectional Identities:

This subthemes reflects how the personal characteristics and professional experiences of healthcare professionals can play a significant role in shaping their approach, decision making and interaction when providing care to MUS patients. Some health professionals spoke implicitly about their characteristics, through their confidence in their approach and success rates working with MUS, whereas others spoke more explicitly about their personal characteristics and how this influences working with MUS. i.e.

"Yeah. So I guess my feelings of uncertainty. Sometimes worry...and I think it's all to do with, like myself and my personality type as well. So I guess I think that can get in, in the way maybe. But I guess what? Yeah. What was the question? What do my feelings sort of? Yeah. Get in the way.

Precautionary prescribing/investigating: It was suggestive that there were personal characteristics of the health professional at play in the precautionary prescribing and investigating. Some health professionals spoke about prescribing out of pity, treating what is potentially visible and treating to alleviate both professional and patient angst of the experience of MUS. The tension between acknowledging the limitations of medication whilst also resorting to it was highlighted. The do-do-effect comes to mind; professionals prioritising offering – some sort of – intervention, as they firmly believed that any form of assistance can yield positive outcomes. This is related to the do-do effect, which is a psychological concept known as "do something, do-anything" effect. Some health professionals showed the tendency to believe that taking any action, even if it may not be the most effective or rational, is better than doing nothing at all.

"We need to departure from the notion that nothing can be done for this patient, we all have something we can offer"...."we need to do anything to help, we need to help as much as we can".... Whatever we do right, we got to have some positive impact, it's gotta, gotta have some benefit".

Personal and professional experiences: This subtheme will also provide quotes to show how health professional's personal and professional experience can shape their perspective and ways of working with MUS. Where some health professionals identified as an 'insider' having experienced physical illness, this appeared to influence their understanding of MUS- as "this could happen to any of us". Although, health professionals could identify with ill health I was unsure they would truly know they experience of an 'insider' with MUS that has no organic cause. Nevertheless, professionals own experiences with illness appeared to influence their understanding of MUS as "this could happen to any of us". Personal challenges led to more empathy in the therapeutic dyad, openness to alternative treatments and increased receptiveness to the complexity of MUS. Therefore, their experiences shaped how they worked with MUS, promoting a more emphatic and comprehensive care approach.

Learning through the patient: Health professionals spoke about how they learn from each MUS patient and this helps form their assessment and conceptualisation of the next MUS patient.

Mentors/Significant others: There was also talk of how significant others in their career journey influenced their approach to MUS – whether this was in terms of how they wanted to practice or how they were not going to practice..

Subtheme 3: Beliefs, Pre-conceptions and Value Frameworks:

This subtheme encapsulate the various ways in which health professionals' beliefs, assumptions, and value frameworks shape their approach to understanding, communicating about, and providing care for patients with MUS. It highlights the subjective dimensions that influence how health professionals perceive, diagnose, treat, and interact with patients who present with MUS.

Authenticity V Falsehood: Health professionals spoke about the authenticity of MUS, this was sometimes communicated explicitly or implicitly amongst health professional's

uncertainty. There was a contrast between believing in MUS or potentially dismissing the patient if you didn't implicitly and explicitly believe MUS was "real for them" but also real for you as a health professional – and how these contrasting perspectives could shape the overall care approach.

P4: "Hmm. Hmmm. Yeah, sometimes because. Generally, like like some people I've seen. They have dropped episodes in or they have dropped drop episodes or or or non-epileptic seizures. But never when I've been with them, which is strange. So if it can happen anytime, why doesn't it happen then when it's a stressful situation? You know, it's like hmmm. Ohh yeah. You know, that's really strange to me. I think. Well, that would be a stressful situation meeting me for the first time. I know we're on on teams or on attend anywhere, so that bothered... Sometimes I do think, Oh well... so I say, you know, I'll say, how often do you have them, you know and its every other day or today or yesterday and maybe twice in three days. You know that sort of thing. And I think well, but never, it hasn't happened when I have been with you. I don't say that!! Obviously!! [Lots of Laughter's]yeah I do wonder it. I do wonder [Nods like it is ok]. There are certain people that may...BUT that's not really for me as a therapist, I wouldn't really worry about that. I would just do what I could. Isn't it, psychologically?

P3: "Once a patient feels that the clinician is listening to them and it's taking them seriously and believes in their symptoms. So I think believing in their symptoms that their symptoms are really so very important in that interaction... Yeah. I think the key one of the key parts of that relationship is actually believing in the patient's symptoms. I think if you you believe in the patient's symptoms, you'll actually be able to empathize in the true sense of what this person is experiencing, the effect it has on them, their family, their children...I I think because the nature of the diagnosis, the term functional, the professionals themselves think well, there's nothing wrong with them. What else can we offer, isn't it? Whereas if you start believing in their symptoms, start believing that they are actually pain, they're not able to move their limbs and they need that support. We were able to provide that support better, I think. I think believing, yeah, believing their symptoms is important.

This was also discussed in the context of non-verbal communication, of subtle actions revealing health professionals true implicit beliefs about authenticity and falsehood. It suggested that patients can discern whether they are believed and listened to base on the body language and actions of health professionals. Non-verbal cues could reveal the true beliefs and frustrations of health professionals, although some spoke of hiding them.

P2 "I think that, that can. It can. It can sort of [talking about personal feelings]...Yeah, it it can cover it. It can can cause you to be. Yeah, cloud your judgment a little bit, maybe you may be not dismissive, but I I think you may not, it may at times cause you to not take, give the patient or may not allow you to, for the patient to appreciate that you understand. You know you can sort of validation, they they may not feel validated if you're internally thinking I don't believe what you saying. I don't believe this is true disorder. You may not be. You may not be saying it, but they may pick up on your body language the way you're talking, the way you're framing the questions, and they could think well, he didn't believe this. So I think it can. And it does come across in your encounters, albeit not necessarily through the word spoken, but through again body language phrases, values, judgments. They can. They can all be interpreted by the patient."

Diversity and choice of Terminology: Health professionals' preferred terminology for referring to MUS can impact how they communicate with patients. The language used can either validate patients' experiences or inadvertently stigmatize and marginalize them. It was acknowledged that all participants had their own preferred terminology; a subjective preferred way of referring to a group of people who have experienced physical symptoms with no organic cause. This preferred terminology would shift depending on their audience; i.e. patient, professional, mental health specialist, family member, written reports. The rational for shift of terminology was to allow for understanding and effective communication between patient-professional. Shifts were also considered down to cultural sensitivity, patient sensitivity and reducing stigma of MUS across services — as each professional had subjective opinions of what terminology carried associated stigma and what terminology was more empowering for the patient; underscoring that the choice of terminology matters as it can significantly influence patient care.

Diversity in understanding and intervention: This diversity in terminology preference also spread across participants preferred framework for understanding and working with MUS. Health professionals approach MUS with a variety of interpretive lenses, encompassing trauma, biology, mental health, and the limits of scientific understanding. Depending on their chosen framework, health professionals might prioritize different aspects of the patient's experience during assessment and treatment. Their unique perspectives led to varied lines of questioning, diagnostic considerations, and treatment directions. For instance, a professional focusing on mental health explored emotional triggers and psychiatric medication, while another emphasising biology prioritized physiological factors and regaining functioning.

Whilst there was also a diversity across intervention strategies offered to MUS in the patient-professional interaction; i.e. some professionals prioritize symptom management and minimizing symptom impact on patients' lives. Others focus on empowering patients to take control of their symptoms through self-help and goal-oriented interventions. The understanding didn't always correspond with the intervention offered and health professionals offered a wide array of intervention approaches – it felt like an anything goes vibe – or maybe thought to be holistic. Nevertheless, the focus of intervention did typically reflect individual perspectives, expertise and values.

Appendix U – UWE Risk Assessment.

University of the West of England BRISTOL University of the GENERAL RISK ASSE	GENERAL RISK ASSESSMENT FORM					
Describe the activity being assessed:	Assessed by:	Endorsed by:				
Conducting face-to-face or virtual interviews with health profesionsals about their experiences o working clinically with medically unexplained symptoms.	Professor Richard Cheston.	Dr Zoe Thomas				
Who might be harmed:	Date of Assessment: 03/11/2021	Review date(s):				
The researcher is offering participants the choice of face to face interviews or virtual interviews.		03/11/2021				
Face-to-face interviews will be on hospital site. Therefore, there is the risk of lone working away						
from UWE and there is also the risk of exposure to COVID-19.						
How many exposed to risk:						

Hazards Identified (state the potential harm)	Existing Control Measures	S	L	Risk Level	Additional Control Measures	S	L	Risk Level	By whom and by when	Date completed
Interviews are being offered virtually or face to face. Usually computer use would not pose a significant risk. However, researcher suffers with migraines and continuous computer use puts the researcher at risk of experiencing a migraine.	Researcher has purchased blue light glasses and understands the important of self-care and laptop breaks. Researcher will aim to do 1 interview a day to minimise excessive screen use. If migraines increased will contact Occupational Health for further support.	1	3	3						
If participant chooses to conduct interview face-to-face. There is the risk to researcher of lone working away from UWE premesis.	The researcher will use a safety buddy procedure. She will inform her clinical and research supervisor where and when she is conducting the interview, and will notify them when the Interview is finished and she is safe. Interviews will take place in a healthboard office, where there are lots of staff on the premesis if needed.	1	1	1						

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It is possible that participants might become distressed talking about feelings and perceptions linked to their professional judgement or lack of knowledge in a complex topic.	If this were to occur during a semi-structured interview, the researcher will speak with the participant and details of supervising Psychologist will be given, with the anticipation that they are free to arrange a time to speak with them. This has been agreed and put in place with supervising psychologist; who is an experienced psychotherapist and Clinical Psychologist of 30 years within the NHS. Participants will also be reminded that they can contact occupational health for further support and advice.	1	3	3			
Risk of transmision and exposure to COVID-19. Health professionals targeted will be working in secondary services, i.e. hospitals with face to face contact with members of the public	Social distancing guidelines required by Swansea Bay Healthboard will be followed. This includes A room with increased ventiliation will be utilised, where windows will be open. If the interview happens face to face the researcher will contact the participant the day before to check whether they are or have recently experienced any symptoms associated with COVID-19. If the participant has recently or currently experiencing symptoms the researcher will cancel the interview and re-arrange the interview for a later date. A mask will be worn by both researcher and participant and 2 meter guidelines will be adered to. Santisation of hands wil be encouraged. Researcher is also employed in Swansea Bay Healthboard and completes regular lateral flows. This will be completed prior to the interview and researcher will request to see participants' recent lateral flow results; which all NHS staff are required to complete and upload on the NHS App.	3	2	6			

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	professionals of Swansea Bay Health Board. Researcher is fully vaccinated. Particiapnts are health professionals, therefore it is highly likely that they are also fully vaccinated.					
						Ì

RISK MATRIX: (To generate the risk level).

Very likely	5	10	15	20	25
5					
Likely	4	8	12	16	20
4					
Possible	3	6	9	12	15
3					
Unlikely	2	4	6	8	10
2					
Extremely unlikely	1	2	3	4	5
1					
Likelihood (L)	Minor injury – No first aid	Minor injury – Requires First	Injury - requires GP treatment	Major Injury	Fatality
1	treatment required	Aid Treatment	or Hospital attendance		
Severity (S)	1	2	3	4	5

ACTION LEVEL: (To identify what action needs to be taken).

POINTS:	RISK LEVEL:	ACTION:			
1-2	NEGLIGIBLE	No further action is necessary.			
3 – 5	TOLERABLE	here possible, reduce the risk further			

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6 - 12	MODERATE	Additional control measures are required
15 – 16	HIGH	Immediate action is necessary
20 - 25	INTOLERABLE	Stop the activity/ do not start the activity

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Appendix V – Journal Article

Part 2 - Journal Article

How do Healthcare Professionals experience working with people living with or affected by Medically Unexplained Symptoms (MUS) in South Wales Secondary Care Services?

An exploration using reflexive thematic analysis

Stacey Davies

Journal article submitted in partial completion of the requirements of the award of Professional Doctorate in Counselling Psychology

Word Count: 4836

(Excluding title page, abstract and references)

Department of Psychology

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How do Healthcare Professionals experience working with people living with or affected by Medically Unexplained Symptoms (MUS) in South Wales Secondary Care Services? An exploration using reflexive thematic analysis

Abstract:

Background: Medically Unexplained Symptoms (MUS) present persistent challenges for people living with or affected by MUS that are marked by uncertainty and stigmatisation. Healthcare professionals face complex diagnostic and treatment dilemmas when working with this patient group. Despite these challenges, research in this area has to date been limited in Wales, particularly within the Swansea Bay University Health Board (SBUHB) region. This lack of research and resources, complicates efforts to understand how best to support healthcare professionals in their care for people living with or affected by MUS. Aims: The aim of this research was to explore the experiences of healthcare professionals working with people living with or affected by MUS within SBUHB. Methods: Ten healthcare professionals across secondary care services were interviewed using semi-structured interviews. Results: Interviews were analysed using a critical realist orientated Reflexive Thematic Analysis (RTA), and one theme is discussed 'lost in the fog of uncertainty': Conclusions: This is the first known inquiry that asks health professionals in Wales about their experiences of working with people living with or affected by MUS, addressing critical gaps in the existing literature. It highlights the role of uncertainty, shared emotional burdens, vulnerability to Potential Morally Injurious Events (PMIE), and the fragility of the therapeutic relationship. Implications for Counselling Psychology: The findings highlight the importance of fostering reflexivity when working with people living with or affected by MUS. By highlighting the importance of self-awareness and reflective practices, Counselling Psychology can aid healthcare professionals in navigating their ontological positions, thereby deepening their understanding of their role in the therapeutic relationship and trajectory of care when supporting people living with or affected by MUS.

Introduction:

Medically Unexplained Symptoms (MUS) is an umbrella term to describe a heterogeneous group of conditions of 'persistent physical complaints that do not appear to be symptoms of a medical condition' (NHS, 2021). The literature offers various definitions and categorisations of these experiences (Kinsella & Moya, 2022). MUS covers a wide spectrum of physical complaints that vary in nature, site, severity and chronicity (Jadhakhan et al, 2022). In the UK National Healthcare Service (NHS), amongst the conditions that fall into this category include Fibromyalgia, Irritable Bowel Syndrome (IBS), Functional Neurological Disorder (FND) and Non-Epileptic Seizures, to name a few. Moreover, there is an on-going debate around the status of an additional illness, namely myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) (See ME/CFS Association, 2022, Scott et al, 2020)

MUS is highly prevalent across various UK healthcare settings, constituting approximately 45% of general practice cases (Haller, Cramer & Lauche, 2015; Jadhakhan et al, 2022). This high prevalence rate often results in repeated visits to different secondary care settings, including A&E, outpatient clinics, general wards, rehabilitation, stroke services, and mental health services. Previous UK literature indicates that people living with or affected

by MUS can represent up to one in five primary care presentations (De Waal et al., 2004), with an even higher prevalence rate suspected in certain secondary care clinics (Nimnuan, Hotopf & Wessely, 2001). The financial burden on the NHS is considerable, impacting both physical and mental health services and constituting up to 10% of the total NHS expenditure (Bermingham et al., 2010). Furthermore, the aftermath of COVID-19 has led to a surge in non-organic cases linked to long COVID and COVID-19 vaccinations across healthcare services (see Hunt, 2022).

The high prevalence rates of MUS across the UK, suggests that healthcare professionals in the NHS are routinely engaging in clinical interactions with people living with or affected by MUS - interactions marked by uncertainty (Meyer, Giardina, Khawaja & Singh, 2021). Although, there are a few studies that have acknowledged the doctor-patient relationship (Stone, 2014) and doctors' attitudes towards people living with or affected by MUS (Kadir, 2022). Gaining a better understanding into experiences of healthcare professionals with this patient group, is important for developing effective support systems. This is particularly pertinent given the absence of comprehensive research in Wales.

Addressing the MUS Research Gap in South Wales:

This research inquiry takes on added significance, as it is centred in Wales. Research and interest in MUS in Wales is notably limited. The academic literature on this subject is scarce, with only two notable papers as exceptions (See Yon et al., 2017; Downes, 2022). It is evident that MUS, is an under-represented area in research across Wales. It is hoped that this research inquiry will make a meaningful contribution to the limited literature. Understanding the experiences of healthcare professionals in Wales will be essential towards thinking of ways towards improving healthcare practices for people living with or affected by MUS.

Study aims:

The aim of this research was to answer the following research question: 'How do health professionals in secondary care services within SBUHB, South Wales, experience working with people living with or affected by MUS?'

Methodology:

Study Design & Participants

A qualitative research design, using semi-structured interviews was used to explore the experiences of healthcare professionals working with people living with or affected by MUS in Swansea Bay University Health board (SBUHB), secondary care services, South Wales.

A total of ten healthcare professionals were recruited representing both Mental Health and General specialties. These participants were identified as gatekeepers to services, possessing direct clinical experiences of working with this patient group. The study excluded temporary or 'in-training staff' from the study sample to ensure a focused experienced sample.

To safeguard participant anonymity, pseudo-names and aggregated demographics were employed. Recognising concerns about confidentiality, especially given the limited focus on MUS in Wales, participant demographics were further aggregated following the recommendations of Morse and Coulehan (2015). The diverse participant group comprised four males and six females, with three participants below 40 years of age and six in the 40-65 age range. The participants included two occupational therapists, three nurses, and five consultant doctors, offering a well-rounded representation across secondary care.

Ethical Considerations:

Full ethical approval was granted from the University of West England (UWE), Health Research Authority (HRA) and Health and Care Research Wales (HCRW). This included gaining informed consent from all participants prior to their involvement in the study and coherence to data quality and protection protocols regarding confidentiality, data use and data storage.

Data Collection:

All 10 participants opted for the convenience of online semi-structured interviews via Microsoft Teams software. At the outset of each interview, participants received reminders about the inquiry's aims and objectives, confidentiality, and data management. Subsequently, all interview materials underwent transcription, with any identifiable information removed to uphold confidentiality.

Data Analysis:

All transcribed data was analysed using Braun and Clarke's (2021) six phases of Reflexive Thematic Analysis (RTA), as detailed in 'Thematic Analysis: A Practical Guide'. As Braun and Clarke (2021) describe RTA is "typically messy and organic, complex and contested', which involves a reflexive approach of consciously engaging with each phase, incorporating subjectivity as a valuable aspect.

Results:

The results presented formed part of a wider study in which a total of three themes were identified. However, in order to capture the richness and depth of healthcare professionals' experiences of working with people living with or affected by MUS, only one theme will be presented in the paper; 'Lost in the Fog of Uncertainty'.

Theme 1: Lost in the Fog of Uncertainty

Participants spoke about the challenges of working with people living with or affected by MUS. Their combined narrative likened their experiences, to navigating through an obstructing fog of uncertainty. The first sub-theme, 'Finding a path' highlights the experiences of healthcare professionals' as they seek a path forward, to establish a solid foundation for effective patient care. The second sub-theme looks into the 'The Emotional Burden of professional helplessness', and its impact on clinical practice as health professionals' grapple with the personal and professional implications of being unable to 'fix' or diagnose effectively when their usual pathways are clouded. Finally, the

third sub-theme 'Building the therapeutic bond in the shadows of uncertainty' discusses the formidable task of forging therapeutic bonds with people living with or affected by MUS, when the path ahead remains unclear.

Sub-theme 1: Finding a path:

Some health professionals chose to walk along the path of uncertainty with their patients, embracing it as an integral part of their practice. For instance, Jean, an Occupational Therapist, emphasised the importance of openly admitting professional limitations when confronted with questions to which there are no clear answers. She exemplifies this by frequently stating, "I don't know". Robert, a doctor, echoed this sentiment, highlighting the necessity of "making sure our patients are on board with this level of uncertainty":

They looking to you for answers and it be lovely to provide all those answers, but you don't want them to believe you are this expert and you have the answers when you don't, it's not fair to make those false promises, is it?

(Jean, Occupational Therapist)

On the other hand, there were a group of participants that opted for a different strategy to confront the uncertainty, focusing on projecting an aura of expertise to instil patients with confidence in them as a health professional. Sheena, a doctor, in particular, demonstrated this approach by discussing the necessity for health professionals to carve a path forward that reflects and maintains assurance, even in the face of uncertainty:

What we want to say is that actually we understand, we actually understand this condition. Although we may not know entirely... giving the patients the confidence that the clinicians are able to manage or help them manage, because many of times you see that clinicians themselves are not able to, they don't have that understanding, so may give that feeling that we don't know what we are doing here and you know ... I think one thing that patients would like to see is the confidence that the clinician knows what they're dealing with.

(Sheena, Doctor)

Within these narratives, uncertainty appeared to significantly shape how professionals' approached their practice when working with people living with or affected by MUS. Some participants, were inclined to taking action, even when such actions didn't promise definite solutions. Sheena particularly, emphasised a need to move away from the notion that nothing can be done for this patient group, a sentiment echoed by Lisa, a nurse. They both emphasised that there are many ways to make a positive difference in the lives of people living with or affected by MUS, even when the path ahead remains obstructed and murky.

We need to departure from the notion that nothing can be done for this patient, we all have something we can offer ...we need to do anything to help, we need to help as much as we can.

(Sheena, Doctor)

Whatever we do right, we got to have some positive impact, it's got to have some benefit ... if it works, it works. Brilliant. If it doesn't really. We've tried, you know.

(Lisa, Nurse)

However, there was a counter-narrative, some participants stressed the importance of navigating the unknown terrain of uncertainty with caution. These participants highlighted that not all interventions are akin to well-trodden paths, particularly when driven by approaches that are lacking strong evidence base. David, a nurse, and Clare, a doctor accentuated the potential harm associated with the notion of "doing anything to help" (Sheena):

Pharmacology is a big hindrance for these people. I think we often end up turning to drugs and just make people worse rather than better. And you know, we often give some sort of neurological numbing pills, whether that's Amitriptyline, Gabapentin or Pregablin, and they have quite significant amount of side effects. I think they're using that almost as precautionary prescribing.

(David, Nurse)

There are no new or sinister findings clinically, then, by commissioning more blood tests, more X-rays and re-referring the patient, actually we're causing patient harm. By taking yet more blood and investigating the person further. That's another needle stick. By doing more X-rays, that's more radiation ... and that's actually clinically negligent.

(Claire, Doctor)

<u>All</u> health professionals empathised with self-management and psycho-education as a primary intervention. Secondly, all health professionals discussed their own self-learning and management experiences. This parallel process demonstrates an intrapsychic dynamic at play (See Adams, Estranda-Villalta, Sullivan & Markus, 2019), where the challenges of MUS are placed on the patient by the health professional and, reciprocally on the health professional by the surrounding healthcare system. This is demonstrated by participants desire to deepen their understanding, whether this was through "reading and reading" (David), "seeking out webinars", or "following experts in the field" (Benjamin and Alex). This intrapsychic approach was also projected onto patients, as <u>all</u> participants expressed their desire to deepen their patients understanding by advocating for "self-management" (Sophie, Benjamin, David) or "psycho-education" (all participants) as the primary intervention for people living with MUS. The following excerpts from David illustrates one of many examples of this parallel process:

"It's only for the fact that I've spent time going over and over it and having to read about it and read about it, that I've got a bit more of an interest in it. I know a lot more about it now...there was an article in the Telegraph about seven or eight months ago talking about FND because I think it was at the time when I was first seeing that patient and I sort of brought it up on the screen and I talked it through and it was a really interesting article."

(David, Nurse)

"I think, it's that patient education, empowering them to know more about the diagnosis because I didn't know much about it. And I think patients probably know even less. So they're probably feeling worried, scared. But by empowering them, teaching them, learning about their illness, I think we're better able to process why

they've got these symptoms. So I think at a low level, it's just going to be patient education."

(David, Nurse)

Sub –theme 2: The Emotional Burden of professional helplessness:

Health professionals' narratives offered a window into the emotional burden they shoulder. In doing so, they illustrated how this emotional weight impacts their professional decision making, as they cope with the consequences of often undiagnosable and untreatable conditions. Robert, a doctor, vividly depicts patients living with or affected by MUS as, "heart sink patients", exposing the emotional burden that healthcare professionals can shoulder when working with this patient group. This phase carries powerful negative connotations. Jenny, a nurse, alludes to how the emotional strain can manifest in health professionals through their non-verbal cues and expressions, when encountering people living with or affected by MUS. The "look on their face" conveys this inner emotional turmoil of helplessness. If Jenny can discern this emotional turbulence in her colleagues, it is conceivable that this may play a role in the patient-professional encounter:

We see them as heart sink patients, don't we? And they come through your door, you've seen them twenty times with the same issue. You haven't been able to fix it and therefore, yeah, your heart sinks when they walk through the door, 'it's frustrating, isn't it? Cause us as doctors we like making people better. And if we 'don't know how to make people better, we feel bad.

(Robert, Doctor)

It's very, very frustrating. And you know, people do the look on their face, says it all, and with the greatest will in the world, isn't it? You know, there are patients and you go ohh, you're not back again.

(Jenny, Nurse)

There was a shared fear of "missing something" (Lisa), as health professionals walk the fine line between holistic patient care and the potential risk of overlooking underlying medical conditions. Sheena, a doctor, was one of three professionals' that discussed diagnostic overshadowing, shedding light on the challenging balance healthcare professionals must maintain. This concept highlights the risk that "functional symptoms" might mask serious medical issues, further intensifying the fear of overlooking critical details in their patient assessments. These fears were further compounded by an awareness of "horror stories" (Jenny) that could haunt health professionals' decision-making.

You think that it's just part of the FND, but actually when you investigate the person has a fracture you know. There HAVE been cases. So the person ACTUALLY has a fracture and people have left it out because the person is known with a lot of functional symptoms. I am involved with a patient with eating disorder who's always been obsessed about her gut and she's been diagnosed with functional gut by the gastro consultant. But this year she was diagnosed with cancer in her bowel.

(Sheena, Doctor)

Robert and Sheena, both doctors, described coping with a sense of professional helplessness when working with people living with or affected by MUS, at times contemplating pharmaceutical intervention, even in the face of uncertainty about their efficiency. This decision to prescribe medication can pose as significant emotional challenge, as it may conflict with their preference to address underlying causes to provide non-pharmacological treatments:

So you kind of feel very helpless. You feel very helpless as a doctor for all these kind of patients. And you wonder, you start ending up reaching for the prescription again, cause maybe some pills will make him get better, better. And they often don't.

(Robert, Doctor)

When we see so many patients with FND, we're not able to give a good explanation. ... Or having that feeling of inadequate, inadequate feeling of how you know, you know we won't be able to provide anything.

(Sheena, Doctor)

The majority of participant narratives, lacked emotional fulfilment and satisfaction in working with people living with or affected by MUS. This underlines the significant emotional burden that health professionals experience, towards the burden of not being able to 'fix' or diagnose. Robert's experience serves as an illustrative example of this contrast. He points out those cases with well-defined diagnoses typically provide an emotional response of a sense of accomplishment and professional's satisfaction, a sentiment rarely found when working with people living with or experiencing MUS:

They're not the kind of patients that you that, that that make you feel really kind of satisfied afterwards...sometimes you kind of make a difficult diagnosis and you feel great that you found that out, but that never tends to happen this with this kind of, it often kind of leaves you feeling sad you kind of feel like you know. And often I feel bad...I feel a bit lost in kind of offering further support with regards to that [MUS] which is completely different with someone who's got type 2 diabetes for example, who has got lots of options available to them you know.

(Robert, Doctor)

Sub-theme 3: Building the therapeutic bond in the shadows of uncertainty:

Health professionals discussed the formidable task of forging therapeutic relationships with people living with or affected by MUS. The nature of the relationship between health professionals and their patient could influence the direction of care. David, a nurse, among others, offered stories into the nuances of these relationships, sharing encounters with particularly challenging cases of people living with or affected by MUS. Jean, an OT, echoed this discomfort and unease experienced when faced with patients in distress or frustration. The therapeutic relationship hung in the balance, especially when patients expressed disagreement or dissatisfaction with the limited resources and explanations offered:

I don't like seeing patients get upset, get frustrated with you and have a negative experience of an interaction with you...anyone that I see and they get frustrated or don't agree with me, that can knock you a bit and knock your confidence.

(David, Nurse)

"She is very draining. I have snapped at her in the past, you put the phone down after 30 minutes of going around the loop and people in the office say God you've got the patience of job and you think ahhhhh, but I keep reminding myself that she is desperately unhappy... And to her, obviously it's all real and she is desperately worried. And I just have to keep putting myself in her shoes. And then, you know, you can get that compassion back"

(Jean, Occupational Therapist)

The challenge of working with MUS appeared to strain the therapeutic relationship, further impacting the well-being of both professional and patients. For most, the crux of this challenge often lied in the misalignment between patients' expectations and the reality of available care and options for people living with or affected by MUS. These perspectives were around the anticipation of clear diagnoses and straightforward solutions. Alex's perspective, particularly captures this discourse "patients expect you to say what's wrong, give you something and your problems fixed". Patients may arrive with the hope of receiving definitive answers and treatment, as poignantly echoed by Sophie, only to be confronted with the reality of the uncertainty surrounding MUS. This stark dissonance between patient expectations, and the reality of the situation, creates fertile ground for patient frustration and dissatisfaction, further straining the delicate threads of the therapeutic relationship, as vividly demonstrated by Jenny:

Patients or services tend to think... that there's someone that's going to like, understand what's going on for them and their body and diagnose and provide treatment. And I think that's a part of it, realising that...I think a lot of people don't know or don't understand.

(Sophie, Occupational Therapist)

I think lots of people have the perception that, especially when you're seeing doctors that they should be able to give you the answers for everything. And I think sometimes they do get frustrated. [Puts on an angry voice] Well what do you mean? They medically unexplained! You have done an X-ray! Done my blood!! Why can't you explain it?

(Jenny, Nurse)

In these discussions, most participants acknowledged the delicate balance they faced when attempting to incorporate any psychological or psychiatric aspects into the therapeutic encounter. They recognised that their word choices and communication styles held a profound influence on potentially "muddy the waters" (Benjamin) of the therapeutic relationship. Alex, a doctor, particularly shared an example that highlighted the nuanced challenges faced through communicating their explanations, when working with an unexplained or untreatable condition. He emphasised how specific terminology could inadvertently unsettle patients and disrupt the therapeutic bond. He noted that certain terminology can get patients "hackles up":

I think if you use the word psychological or psychiatric, it immediately upsets them... I never used the term psychiatric because it tends to put people's hackles up.

(Alex, Doctor).

Most participants elaborated further on the fragility of the therapeutic relationship, discussing the strategies they employed when faced with the looming presence of ruptures in the therapeutic bond. For instance, Jean, an OT recounted a scenario where she would "back down" from discomfort to salvage the remnants of the relationship, often retreating from explanations or language rooted in psychological or psychiatric discourse. Similarly, Alex, a doctor, exercised caution in introducing his favourable perspective for explaining MUS, The Attention Model (See Rief & Broadbent, 2007), as he didn't want to "set off their antibodies against me."

These narratives emphasised the adaptions participants made to their communication strategies when they sensed the potential rupture in the therapeutic bond. For instance, Jenny particularly spoke of how some colleagues result to "giving in...just bring them in, refer them to the team" for further investigations, to avoid discomfort and maintain the therapeutic bond. In contrast, other participants took a very different approach, opting to confront the emotions brewing in the therapeutic relationship and lean into the potential ruptures. This approach was illustrated by Sheena and Benjamin, both doctors, whom rooted their therapeutic relationship on honesty:

I think being really honest within that relationship is important. I'm lucky to have that relationship with many patients. So for example, when they don't turn up for appointments or when they switch off the video. I'm able to have that Conversation.... And, you know, we can talk. And that's more important. So, yeah. So having that good therapeutic relationship is vital, I think as well.

(Sheena, Doctor)

I will also try and build their empathy with me or their trust, and I will do that by explaining my thought process, so I can be as transparent as possible in terms of decision making.

(Benjamin, Doctor)

Throughout these interactions, a noticeable divergence in how participants talked about patients could be seen. Some participants used terms such as "cooperative" (Sheena), "accepting" (Jean, Sheena & Jenny), and "receptive" (Jean) to depict certain patients, while others label them as "challenging" (Jean) or "disagreeing" (David). These characterisations stemmed from health professionals' attempts to establish a foundation for broader perspectives within the therapeutic relationship. Jean, an OT, commented "she's not on board yet", this encapsulates this tension that healthcare professionals face as they attempt to integrate alternative hypotheses to medical solutions. This tension feels rooted in the spoken and unspoken beliefs of MUS origin. Sheena and Robert, both doctors, explored further into this concept of categorising patients within the therapeutic

relationship and how the clash of differing perspectives on the origins of MUS, can greatly influence how healthcare professionals experience and interact with their patients:

I mean there will be some patients in spite of all the help...they will keep on going. So you do have that subgroup, but on the other hand, you do have patients who when you provide a reasonably good explanation of what's happening, they seem to be able to take that on board and work on how other ways to improve.

(Sheena, Doctor)

"It depends if you're patients receptive to that, isn't it? There's a lot of patients that are not willing to accept that, that might be a cause of why they're having these kind of functional symptoms. If they're not accepting that, and I think they're not ready to be referred on to, for that. So they have got to have some sort of insight and be willing to be referred because they are not going to engage and there's no point is there."

(Robert, Doctor)

Discussion:

Central Role of 'Uncertainty' in Healthcare Professionals' Work with MUS:

Uncertainty is a central aspect of healthcare professionals' engagement with people living with or affected by MUS, akin to its role in therapist-client dynamics (Cononolly, 2022; Marshall, 2016; Willig, 2019). While UK literature acknowledges uncertainty in managing conditions defying traditional pathways, it doesn't explicitly recognise it as a core feature, but rather hints at it (Kinsella & Moya, 2021; Marks & Hunter, 2015; Creed et al., 2011; Crimslik et al., 2000; Kaur et al., 2022). Communicating 'uncertainty' as inherent in working with MUS could liberate professionals from internalising challenges in diagnosis or treatment. Framing uncertainty as an external factor redefines the healthcare professional's role as one of support and navigation, rather than directive and solution focused, aligning with perspectives that involve walking alongside patients (Voller, 2011; Mason, 2022).

Internalising Systemic Challenges: The Emotional Burden of Uncertainty on Healthcare Professionals:

Healthcare professionals, akin to individuals affected by MUS, share the emotional burden of helplessness and shame (Lillrank, 2003; Rausch, 2021; Church, 2017). The unexplored experience of shame in healthcare professionals working with MUS patients prompts exploration into the interconnectedness of shared experiences, suggesting a dynamic of projection within the therapeutic relationship (Holmes, 2002). The uncertainty surrounding conditions with no clear diagnosis or treatment pathway, coupled with a lack of systemic support, may lead to healthcare professionals projecting anxieties and feelings of being made to feel "helpless" and "inadequate" onto their patients and vice versa. Patients, feeling let down by healthcare professionals, might project emotions of frustration, blame, or hopelessness onto them (Lazare, 1987; Kaufman, 2004).

Responding to the uncertainty of working with often unexplainable and untreatable conditions, healthcare professionals embrace neoliberal perspectives, advocating for self-

actualisation and personal growth (Adams et al., 2019). This intrapsychic approach, is experienced by health professionals and is projected onto patients, emphasising education and coping strategies as a solution. While intrapsychic interventions like psycho-education and CBT are favoured, acknowledging potential limitations is crucial, as exclusive reliance may reinforce the perception that the root cause lies within the individual (Rausch, 2021; Lillrank, 2003). Adopting an intrapsychic approach should complement systemic improvements, not replace them, for a comprehensive care approach (Rizq, 2013).

Risk of Potentially Moral Injurious Events (PMIE); the emotional burden of professional helplessness:

Working with uncertainty, a core aspect of being a practitioner psychologist (BPS, 2017; HCPC, 2012), is not universally comfortable, especially in healthcare settings where professionals often perceive the world as predictable and controllable through scientific knowledge (Crossley, 1998; BPS, 2017; Horowitz, 2007). In working with people living with or affected by MUS, health professionals may act against their ethical values, leading to a unique emotional burden and a potential risk of exposure to Potentially Morally Injurious Events (PMIE). The theme of being "lost in the fog of uncertainty" highlights instances where professionals struggle to provide solutions, conflicting with their values (Griffin et al., 2019). The risk of moral injury is noticeable in situations hindered by uncertainty, resource limitations, and a lack of support and training. While prior research focused on moral injury in military and COVID-19 contexts (Griffin et al., 2019; Mantelakis et al., 2021), the vulnerability of health professionals dealing with MUS requires external acknowledgment and support to prevent internalisation of systemic challenges by both professionals and patients (Williamson et al., 2020).

Building the therapeutic bond in the shadows of uncertainty:

The therapeutic relationship is crucial in healthcare services (Bolsinger et al., 2020). Findings showed its consistent vulnerability in the context of healthcare professionals working with MUS patients, echoing previous findings (Lian & Nettleton, 2015). Health professionals employ diverse strategies to maintain therapeutic bonds, influencing the trajectory of care and occasionally leading to seemingly contradictory responses (Salmon et al., 2009). I.e. precautionary prescribing, referring patient on, "giving in", "backing down". From a classical psychoanalytic perspective, these strategies are seen as defences, with healthcare professionals internalising professional helplessness amid uncertainty, placing tension and conflicts at the core of their experiences. This suggests a conflict between desired working methods and external reality, leading to inner tension and anxiety. While defences adapt to these conflicts, an excessive reliance on them, whether unconscious or conscious, can impede effective patient care, communication, decision-making, and therapeutic relationships (Holmes, 2002; Kuchuck, 2021; Jacobs, 2012).

Conclusion: How Counselling Psychology can help?

In the context of Counselling Psychology, this study proposes that nurturing self-awareness among healthcare professionals can be effectively achieved through a

reflexive approach. If Counselling Psychology integrates reflexive practices, it holds the potential to support healthcare professionals in various ways: a) by aiding them in understanding and processing their own emotional responses, including feelings of shame or helplessness; b) by enabling the recognition of their role within the broader system, i.e. considering the impact of specific ontological positions, which may inadvertently make patients less visible; and c) by fostering collaborative and reflexive practices among colleagues within the wider healthcare system.

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