

**Paediatricians' experiences of managing medically unexplained symptoms (MUS) and fabricated or induced illness (FII) in children and families:
a qualitative study**

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Thesis Declaration Form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Overview

Medically unexplained symptoms (MUS) are common in children and can be complex for doctors to manage. Fabricated or induced illness (FII) is less common, but can be particularly challenging to recognise and manage. Paediatricians play a central role in identifying and managing MUS and FII in children, but currently very little is known about their experiences of working with these presentations. This project aimed to explore paediatricians' views and experiences of managing MUS and FII, and to identify any gaps in training and service provision in these areas.

Part one presents a conceptual introduction outlining the definitions of MUS and FII, theories about their causes, current prevalence rates, an overview of the services available to address these presentations, and a summary of the existing literature highlighting doctors' experiences of managing MUS and FII in adult and child populations. It concludes with a brief rationale for the present study.

Part two comprises an empirical paper presenting the current qualitative study which aimed to explore paediatricians' experiences of managing MUS and FII. Twenty London-based trainee and consultant paediatricians took part in qualitative interviews, and the results were analysed using thematic analysis. Findings showed paediatricians' varying conceptualisations of MUS and FII, the role parents and doctors can play in maintaining symptoms, the challenging nature of the work, issues around service design, and requests for improved services and further training.

Part three presents a critical appraisal offering personal and epistemological reflections on the research, a discussion of some of the methodological considerations that arose, and an extended discussion of the clinical, educational and research implications of the work.

Impact Statement

Given the prevalence of medically unexplained symptoms (MUS), the serious and harmful impact of fabricated or induced illness (FII) and the risk of iatrogenic harm in both presentations, it is important that children affected by MUS and FII are identified early by paediatricians in order to facilitate optimal care and reduce risk of harm. Trainee and consultant paediatricians in this qualitative interview study reported that MUS and FII can be challenging to identify and manage. Participants discussed the issue of over-investigation in cases of MUS and FII, delayed identification of FII, and concerns about limited service provision for children and families. Participants also reported having had little training about these topics, and many said they felt under-confident when managing these presentations.

These findings have significant implications for clinical practice, medical education and research. Paediatricians in the current study discussed cases where erroneous health beliefs held by anxious parents were perceived to contribute in some way to a child's symptoms. These types of presentations fall under the official definition of FII given in the literature (e.g. Royal College of Paediatrics and Child Health, 2009), but interestingly they were categorised differently by participants, with some considering them to be FII, and others viewing them as MUS or falling into a 'grey area' somewhere 'in between'. This confusion over categorising FII emphasises the need for guidance to more explicitly outline the defining features of this presentation. It also demonstrates the urgent need for more comprehensive training about MUS and FII for both trainee and consultant paediatricians. This would prevent cases of FII being overlooked or missed, and reduce risk of harm to children. It is essential for training programmes and future guidance directed towards paediatricians to clearly outline the definitions of these presentations and their alerting features in

order to assist with early identification. Outlining appropriate management approaches and options for onward referral would also be of importance. In addition to this, more research is needed to understand paediatricians' conceptualisations of presentations falling into this 'grey area', and to identify which features of a presentation might prompt onward referral to psychological services or social care.

Participants identified barriers faced by children and families affected by MUS and FII when accessing support via services such as child and adolescent mental health services (CAMHS) and social care, and indicated a strong need for more accessible and integrated services tailored to the needs of these client groups. Participants valued the role of psychological input, and said that ideal service provision would take place in a multi-agency, multi-disciplinary format and address the physical, mental and social care needs of children and families in a single location. This configuration would facilitate more effective and timely communication amongst professionals and prevent cases of FII being overlooked or missed.

This study draws attention to the significant emotional impact on professionals working with MUS and, in particular, FII. Currently, little is known about the amount and type of support provided for doctors and other involved professionals following involvement in cases of FII. Given the potentially devastating effects of FII on families and professionals, and the increasing awareness about doctors' mental health, it seems imperative to investigate further the emotional impact of the work on those involved in managing these complex presentations.

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Abbreviations

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Part 1: Conceptual Introduction

**Paediatricians' experiences of managing medically unexplained symptoms (MUS) and fabricated or induced illness (FII) in children and families:
a qualitative study**

Abstract

This Conceptual Introduction provides an overview of medically unexplained symptoms (MUS) and fabricated or induced illness (FII), and a background summary of the research carried out in these areas to date. Following a brief introduction to the main qualitative research study, section one begins with an overview of the definitions of MUS and FII and a theoretical discussion of some of the factors associated with the development of these presentations. Section two outlines prevalence rates, and gives an overview of the clinical pathway for MUS and FII for adults and children within the current UK National Health Service (NHS). Section three explores existing research looking at adult patients' experiences of healthcare, and doctors' experiences of managing MUS and FII in adults. Section four gives a more detailed account of existing research, and specifically focuses on doctors' and other healthcare professionals' experiences of managing MUS and FII in children and families. Section five concludes with an overview of the rationale for the main research study.

Introduction

Medically unexplained symptoms (MUS) are common in children and young people and can be complex for doctors to manage. Fabricated or induced illness (FII) is less common, but is particularly challenging to identify and manage. Currently, very little is known about paediatricians' views and experiences of managing MUS and FII, and their approach to cases in practice. This study proposes to go beyond previous research by looking at these unexplored areas in depth via the use of qualitative interview methods. Individual interviews will be conducted with paediatricians of varying levels of seniority working in hospital and community posts

in North Central London. Qualitative interviews will provide an opportunity to gather rich information about paediatricians' unique experiences of managing MUS and FII, the ways in which cases are conceptualised and approached in practice, and any potential gaps in paediatric training. It is anticipated that the findings of this research will provide insight into the ways that children and families presenting with MUS and FII are approached in practice, and inform future training and service developments in these important areas.

This conceptual introduction aims to provide a comprehensive overview of the literature pertaining to the topics of MUS and FII and the ways these presentations are addressed in practice. It also provides a summary of the research looking at doctors' experiences of managing MUS, with close attention to selected papers looking at paediatricians' and healthcare professionals' experiences of managing MUS. No previous studies examining doctors' experiences of managing FII have been identified. It is intended that this background information will provide a rationale for the current research study which aims to investigate paediatricians' views and experiences of managing MUS and FII in children and families.

1.0 Definitions and Associated Factors

1.1. Definition of MUS. Medically unexplained symptoms (MUS) can be described as symptoms not clearly linked to organic pathology or disease (Henningsen, Zipfel & Herzog, 2007). Similar terms used in the literature include 'functional somatic symptoms', 'functional syndromes', 'somatisation', 'psychosomatic symptoms' and 'persistent physical symptoms'. MUS encompass a range of symptoms affecting various bodily systems. Symptoms can include pain, such as headaches, migraines, musculoskeletal pain, abdominal pain, back pain or non-cardiac chest pain.

Gastrointestinal symptoms such as diarrhoea, constipation and bloating can also fall into the category of MUS, as well as neurological symptoms like blurred vision, flashing lights, tremors, weakness, paralysis, numbness, tingling, collapsing and seizures. Other MUS can include fatigue, dizziness, heart palpitations, breathlessness without exertion, concentration difficulties and feeling faint. MUS can also refer to symptom clusters or ‘syndromes’ including irritable bowel syndrome (IBS), chronic fatigue syndrome (CFS) and chronic pelvic pain syndrome, and other presentations such as fibromyalgia (a long-term condition causing widespread bodily pain).

The term ‘medically unexplained symptoms’ has been criticised by some patients as a frustrating term that implies symptoms have no medical cause and therefore are psychological in nature. For some, the term also implies that there is nothing medical science can do to treat the symptoms (Marks & Hunter, 2015). In an attempt to define persistent MUS, the revised fourth version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) (American Psychiatric Association, 2000) put forward a diagnosis of somatoform disorder, defined as a chronic condition where the person presents repeatedly with MUS affecting a range of bodily symptoms. In a move to simplify this and shift away from the need for symptoms to be ‘medically unexplained’, the DSM-5 (American Psychiatric Association, 2013) defines a new diagnosis of somatic symptom disorder (SDD) as organic or non-organic physical symptoms that affect functioning or are distressing for the individual and persist for 6 months or more.

MUS has also been linked to increased rates of anxiety and depression (Henningsen, Zimmermann & Sattel, 2003; van Eck van der Sluijs, ten Have, Rijnders, van Marwijk, de Graaf, & van der Feltz-Cornelis, 2015). As Henningsen et

al. (2003) outline, it remains unclear as to whether this association represents a reactive increase in mental health problems in patients experiencing MUS (Nielson & Merskey, 2001), or if the physical symptoms emerge as a consequence of anxiety or depression (Gillespie, Kirk, Heath, Martin, & Hickie, 1999). Alternatively, the psychological and bodily symptoms might be expressions of an underlying common distress (Sharpe & Carson, 2001).

1.2 Definition of FII. Fabricated or induced illness, formerly known as Munchausen syndrome by proxy (Meadow, 1977), occurs when a parent or carer exaggerates, fabricates or deliberately causes symptoms of illness in a child. The caregiver's behaviour leads to both direct and indirect harm to the child, and for this reason, FII is seen as a form of child maltreatment, even though the caregiver rarely intends to harm the child. It can occur either when a caregiver is motivated by their own personal gain and acts deceptively, or when a caregiver is highly anxious and believes the child is more unwell than indicated by medical teams or investigation; a presentation seen more commonly (Davis, Murtagh & Glaser, 2019). FII can range from the exaggeration of, or the selective or false reporting of the child's presenting history, symptoms or signs with or without deception; to clear deceptive actions involving the falsification of records, interference with investigations and specimens, or actually inducing symptoms or signs of illness in the child, which are more rare (Bass & Glaser, 2014; London Safeguarding Children Board, 2017; Royal College of Paediatrics & Child Health [RCPCH], 2009). Methods of inducing illness might include overmedication, suffocation, poisoning or starving. For example, in a case report of 41 children treated at Great Ormond Street Hospital (GOSH) in London with FII, one of the most common presentations noted in 17 of the children included failure to thrive due to the active withholding of food in the context of high maternal anxiety

(Gray & Bentovim, 1996). In cases of FII, the caregiver's actions are understood as attempts to convince health professionals that the child is more unwell than the child actually is (Glaser & Davis, 2019).

The serious implications of FII include iatrogenic harm in the form of frequent and invasive medical investigations and unnecessary treatments, and direct harm from the caregiver including missed education and social isolation, the adoption of the 'sick role' or lifestyle of a person with a disability, developmental implications including profound impacts on a child's psychological and emotional wellbeing, and rarely, illness induction (Glaser & Davis, 2019; RCPCH, 2009).

1.3 MUS, FII and related concepts. Figure 1 gives an overview of MUS, FII and related concepts. MUS are not produced deliberately, and the person is usually unaware of any psychological causes for their symptoms. For example, a child might develop abdominal pain due to underlying anxiety about being bullied at school, but with support and guidance, they can be helped to develop an understanding of why their symptom has developed, such as when a parent may assist their child in making the link between bullying, anxiety and their abdominal symptoms. FII differs from MUS in that the child's symptoms are fabricated or induced, and come about partly or solely as a result of input from the parent or carer. In some cases the child themselves experiences symptoms, but it is the caregiver's insistence that these have an organic cause and their reluctance to pursue treatment options for MUS which categorises the presentation as FII.

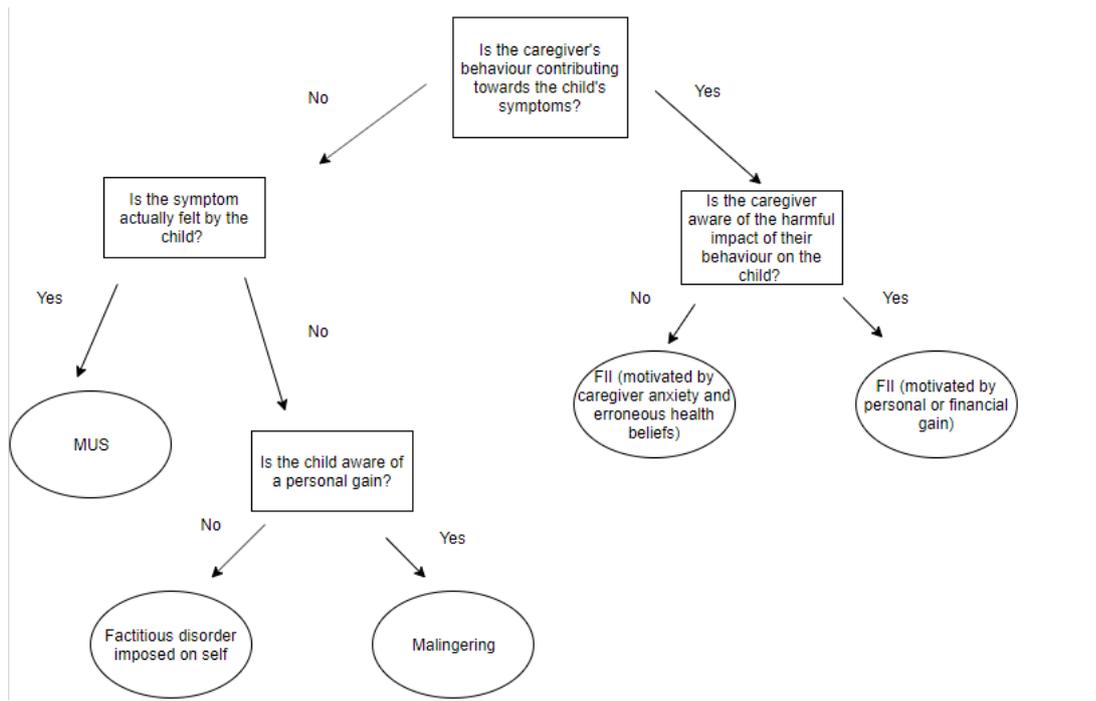


Figure 1. MUS, FII and related concepts.

In some cases, the caregiver is aware that they are inducing or exaggerating a child's symptoms, whilst in others, the caregiver's behaviour and actions are based only or additionally on caregiver anxiety and genuine but erroneous beliefs that the child is more unwell than they are (Davis et al., 2019). In cases where the caregiver has a personal gain the motivation is conscious, meaning that the caregiver is aware of the reasons for their behaviour. However, in most cases it is the caregiver's own anxiety and erroneous beliefs about the child's health which are driving their behaviour, and there is less awareness of the harmful impact on the child.

Malingering and factitious disorder imposed on self are separate concepts. Malingering is defined as the deliberate feigning, simulation or production of physical symptoms in pursuit of a conscious incentive, such as avoidance of punishment or financial gain (Geist, Weinstein, Walker & Campo, 2008). Factitious

disorder imposed on self, formerly known as Munchausen Syndrome, is defined as a falsification of one's own symptoms without an obvious external incentive. These concepts are more commonly referred to in the adult literature, and are terms that should be used with caution in reference to child and adolescent populations.

1.4 Definitions: Critical Reflection. The definitions of MUS and FII are situated within the medical model, a model which adapts a nosological approach to diagnosis involving concrete categories and definitions. As is often the case with diagnostic categories, the categories might not capture the full extent of a person's difficulties, and many individuals do not fit neatly into the definitions provided. Furthermore, the categories are based on Western approaches, and do not take account of the various ways individuals might express distress across different cultures. These factors might explain some of the understandable confusion around the term MUS found in other studies (e.g. Yon et al., 2015), and are important to hold in mind when interpreting the findings of the current study.

The term 'perpetrator' is commonly used to refer to the caregivers involved in cases of FII. It is important to reflect on the connotations associated with this term, such as criminalisation and intent, and how this use of language might position caregivers in the minds of professionals. Associations between FII and perpetrators might raise questions as to whether cases of FII which do not involve deliberate intent to harm should be placed in the same 'category', and whether separating the two main FII presentations by using different definitions might influence professionals' willingness to consider cases as FII, as well as their subsequent management approaches.

As an alternative perspective to the nosological approach, the sociological perspective acknowledges how ‘medical uncertainties’ can be difficult for clinicians to tolerate, and can lead to an increased urge to assign categories to symptoms in an effort to understand them (e.g. Nettleton, 2006). Instead of giving experiences the discrete label of ‘MUS’ or ‘FII’, the sociological approach might pay more attention to a person’s context and the multiple factors at play over time, viewing MUS and FII as more nuanced phenomena which do not fit so neatly into diagnostic boxes.

1.5 MUS: Theories and causes. MUS are common in the general population, but there are theories as to why some individuals experience more persistent unexplained symptoms than others. The theories discussed in this section refer to MUS in adults, unless otherwise specified.

According to the biopsychosocial perspective, MUS are thought to emerge as a result of a complex interplay between biological, psychological and social factors (Engel, 1977). From a biological angle, some people might have a genetic predisposition which leaves them more vulnerable to developing MUS. Furthermore, the sensitisation theory of MUS suggests that physical experiences of symptoms such as pain can lead to memory traces at a neuronal level, which increases sensitivity and lowers the threshold for a sensation to be experienced as painful. This means that subsequent sensations, and even neutral stimulation, can be experienced as painful (Rief & Broadbent, 2007). Research into the role of the hypothalamic-pituitary-adrenal (HPA) axis in MUS also suggests that prolonged stress can result in down-regulation of the HPA axis and decreased amounts of the hormone cortisol, leading to fatigue, pain and sensitivity associated with hypocortisolism (Cleare, 2004; Fries, Hesse, Hellhammer & Hellhammer, 2005).

As well as these possible neural and sensory components, a number of psychological and social factors can affect a person's experience of MUS. MUS have been linked to insecure attachment styles, with a recent study identifying reduced mentalization abilities (the ability to reflect on and understand one's emotions) and alexithymia (difficulties in identifying and describing one's emotions) as mediating factors (Riem, Doedée, Broekhuizen-Dijksman & Beijer, 2018). Furthermore, introspective individuals who focus more closely on bodily sensations are thought to be more likely to experience physical symptoms, and being in an environment with little stimulation might lead some individuals to focus their attention inwards (Fillingim & Fine, 1986). Illness worry and rumination, i.e. the process of focusing intensely on symptoms and repetitively going over thoughts about the symptoms, can further reinforce the belief about a serious underlying cause and increase self-focused attention and monitoring of the body for information that fits with these beliefs (Wells, 2000). Unhelpful beliefs that symptoms indicate underlying pathology and that a healthy person does not experience physical symptoms are common amongst people with MUS, and beliefs of this nature have been observed in children reporting multiple physical symptoms in the general population (Eminson, Benjamin, Shortall, Woods & Faragher, 1996).

When considering MUS occurring in childhood, the context around a child is seen to be important in contributing to the development of MUS, and any unhelpful beliefs are likely to be influenced by those held by caregivers and the wider family (Hotopf, Mayou, Wadsworth, Wessely & Thomas, 1999). For instance, in one study of children with chronic fatigue syndrome (CFS), families were found to have strong beliefs that the cause of the child's illness was biological or disease-related, even after negative investigations and multiple medical opinions indicated otherwise, and even

after the child had recovered (Garralda & Rangel, 2001). Parents may also unintentionally reinforce symptoms by providing attention, rewards or opportunities to avoid school or other activities the child sees as unpleasant (Walker & Zeman, 1992). Alongside this, unhelpful beliefs that unexplained symptoms indicate a serious underlying cause can often be inadvertently reinforced by healthcare professionals through a process of over-investigation in search of an organic cause (Salmon, Humphris, Ring, Davies & Dowrick, 2007).

Some studies have suggested that MUS could be influenced by factors like parental illness during childhood (Hotopf, 2003), disproportionate parental concern about benign symptoms (Benjamin & Eminson, 1992) and overprotective parenting styles (Lackner, 2005). Adverse childhood experiences, including sexual and physical abuse, have also been identified as risk factors for developing MUS (Fiddler, Phil, Jackson, Kapur, Wells & Psych, 2004). In a study of children with MUS, parents and doctors identified symptoms of anxiety in a significant proportion of the children, which included general worries, separation fears and anxiety about novel situations (Campo, Jansen-McWilliams, Comer & Kelleher, 1999). Another study of children with unexplained symptoms identified psychosocial difficulties in about a quarter of the children, whereas difficulties of this nature were only present in around a tenth of children without MUS. These included emotional difficulties such as chronic unhappiness, and relationship difficulties such as problems with teachers or bullying (Garralda & Bailey, 1990).

In summary, MUS is thought to emerge as a result of a complex interaction between a range of physiological, psychological and social factors, and one domain alone cannot account fully for the emergence of symptoms in all individuals.

1.6 FII: Theories and causes. FII is usually perpetrated by a child's biological mother; however, fathers, carers and healthcare professionals can also be perpetrators of FII. In one study of 28 mothers who were perpetrators of FII, the majority were themselves found to meet criteria for significant disorders such as somatoform disorder, factitious disorders characterised by the fabrication of one's own illness, or both (Bass & Jones, 2011). Evidence of pathological lying (*pseudologia fantastica*) was also found in 61% of the study participants. Loss or separation from their own parent before the age of 11 years had occurred for 86% of the participants, and 54% had experienced severe abuse themselves as a child. Childhood sexual abuse (CSA) was reported by 43% of the sample, and 25% reported severe physical abuse. Some of the mothers reported that from a young age they had begun to feign symptoms to avoid abuse or contact visits with abusive parents. Over half had themselves been referred to child and adolescent services for psychiatric input, and over three quarters accessed mental health services as adults. Based on the results of this study, the authors compiled a list of risk factors for fabricating or inducing abnormal illness behaviours in children. This includes a history of loss or separation from a parent, abuse or neglect, history of lying in adolescence, current somatoform or factitious disorder, and frequent visits to the doctor with unexplained symptoms (Bass & Jones, 2011). These findings illustrate the traumatic backgrounds of many perpetrators of FII, with common narratives of early family disruption and loss.

In another study of 47 perpetrators of FII, 89% were found to have a personality disorder, with high rates of borderline personality disorder (BPD) in particular (Bools, Neale & Meadow, 1994). Of course, it is important to recognise that many mothers with a diagnosis of BPD (now known as emotionally unstable personality disorder, or EUPD) do not abuse their children in this way, so the presence of a personality disorder

or any other mental health difficulty alone is not enough to indicate FII (Adshead, Faklov & Gopfert, 2004). FII has instead been formulated as a type of complex deceptive behaviour which has its roots in a disturbed mother-child attachment bond, which in turn is likely to be influenced by the mother's own attachment experience (Bass & Adshead, 2007; Kozłowska, Foley, & Crittenden, 2006). High levels of insecure attachment and unresolved bereavement have been found in mothers who perpetrate FII (Adshead & Bluglass, 2005). One theory is that a parent's unresolved bereavement might result in anxieties about death, leading to the view that their own children are more unwell than they actually are, or a fear that a potentially fatal illness might be missed (Bass & Adshead, 2007).

Theories outlined on the official NHS website (NHS, 2016) add further suggestions, including the idea that mothers might create a permanent crisis situation surrounding their child as a form of 'escapism' from their own distress. Focusing energy on the child might enable mothers to avoid their own negative feelings and unpleasant emotions, or might satisfy an unmet psychological need in the mother, such as a need for care and attention. In summary, there are several theories as to why a parent or carer may fabricate, exaggerate or induce illness in a child, but as yet the phenomenon is not fully understood.

2.0 Prevalence and Clinical Pathway

2.1 Prevalence of MUS. It is estimated that between 15-50% of all cases seen by GPs in primary care involve MUS, and up to 50% across various specialties in adult secondary care (Aggarwal, McBeth, Zakrzewska, Lunt & Macfarlane, 2005; Haller, Cramer, Lauche & Dobos, 2015; Nimnuan, Hotopf & Wessely, 2001). In a study looking at self-report data from 91,000 adults in the general population, 9.7%

of participants reported a diagnosis of IBS and 3% a diagnosis of fibromyalgia (Janssens, Zijlema, Joustra & Rosmalen, 2015). As noted earlier, given that these diagnostic labels are not always favoured by individuals who experience symptoms, these figures could be an underrepresentation of the true prevalence rates in the population.

Fewer studies have been conducted regarding the prevalence rates of MUS in child populations. Amongst clinical outpatient paediatric patients in the USA and Ireland, it has been found that around a third of children report unexplained physical symptoms associated with emotional and functional impairment (Andresen, Woolfolk, Allen, Fragoso, Youngerman, Patrick-Miller & Gara, 2011; Campo et al., 1999; Kelly, Molcho, Doyle & Gabhainn, 2010). In terms of prevalence rates in the general child population, a questionnaire survey involving the parents of a representative sample of 3760 Nordic children aged 7-12 years found that 24% of children and adolescents reported weekly or bi-weekly MUS, with headaches, stomach complaints and loss of appetite being the most common (Berntsson & Kohler, 2001). Similar prevalence rates were reported by more recent studies conducted with adolescents of an average age of 16 in Sweden (van Geelan, Rydelius & Hagquist, 2015), children aged 11-12 years in the USA (Saps, Seshadri, Sztainberg, Schaffer, Marshall & DiLorenzo, 2009), children aged 5-7 years in Denmark (Rask, Olsen & Fink, 2009) and toddlers aged 18 months in the Netherlands (Wolff, Darlington, Hunfeld, Verhulst, Jaddoe, Hofman & Tiemeier, 2009). Symptoms most commonly reported by children and adolescents were headaches, recurrent abdominal pain, fatigue, musculoskeletal pain, dizziness and loss of appetite (Schulte, Petermann, McNeil, Hawkins, Moore & Wiles, 2011). In a longitudinal study conducted in the USA, the most common symptoms reported by

children aged 9-13 years were headaches (reported by 10%), stomach aches (2.8%) and musculoskeletal pains (2.2%) (Egger, Costello, Erkani & Angold, 1999). For the majority of children, symptoms are usually transient, but it is estimated that in around a third of cases they can become persistent and may be associated with behavioural difficulties, poor school attendance and psychological problems such as anxiety and depression (Eminson, 2007). However, it is important to note that often information about the symptoms experienced by younger children is provided by the parents, meaning the findings might not accurately represent actual prevalence rates.

2.2 Prevalence of FII. FII is less common than MUS. In their guidance, RCPCH (2009) reported an estimated prevalence rate suggested by Watson, Eminson & Coupe (2000) of 89 per 100,000 children over a two-year period. However, the RCPCH guidance is due to be updated in September 2019, and it has been suggested that actual prevalence rates in the population are likely to be much higher than indicated in the literature. This could be due to difficulties in identifying FII, the lack of existing studies, and the fact that many existing studies of prevalence focus on the less-common illness induction as opposed to the more commonly seen erroneous reporting by a carer (Davis et al., 2019).

Most children affected by FII are infants and toddlers, although approximately 25% of cases involve children over 6 years (McClure, Davis, Meadow & Sibert, 1996). Although FII in the form of illness induction is rare, it is estimated that health professionals will likely encounter at least one case of FII over the course of their career, and that paediatricians will see many more (The Lancet, 2010).

2.3 Organisational structure of services. It is estimated that the NHS in England spends around £3 billion per year attempting to diagnose and treat MUS in adults (Bermingham, Cohen, Hague & Parsonage, 2010). However, much of this expenditure has little benefit for patients experiencing MUS, as investigating symptoms in search of a treatable organic disease can cause iatrogenic harm to patients and lead to repeated presentations (Naylor, Das, Ross, Honeyman, Thompson & Gilbert, 2016; Ring, Dowrick, Humphris & Salmon, 2004).

As with most NHS services in the UK, provision varies depending on a number of factors including location, funds, demand, service performance, local demographics, commissioner preference, interpretation of the evidence base and availability of resources. The majority of services (including mental health services and most primary and secondary care services) are commissioned by local Clinical Commissioning Groups (CCGs), and most other services are commissioned by NHS England (The King's Fund, 2016).

2.3.1 Services for adults. Mental and physical health are closely interlinked, and MUS, like many other health problems, concerns both the mind and body. As previously outlined, MUS can be associated with difficulties including anxiety and depression in both adults (Henningesen et al., 2003; van Eck van der Sluijs et al., 2015) and children (Lieb, Pfister, Mastaler & Wittchen, 2000; Taylor & Garralda, 2003). Patients with MUS tend to fall into a service gap, as they often require input that covers both physical and mental health (Cooper, Abbass, Zed, Bedford, Sampalli & Town, 2017). Since the NHS was founded in 1948, mental health and physical health services in the UK have been largely disconnected. The need to move towards integrated mental and physical health services is evident, and this aim formed part of

the NHS *Five Year Forward View* agenda for change (NHS England, 2014). The King's Fund report *Bringing Together Physical and Mental Health: A New Frontier for Integrated Care* also calls for more joined-up care for people with MUS, and for mental health support to be more integrated into primary care (Naylor et al., 2016).

Most adults who present to their GP looking for psychological as opposed to psychiatric support are referred to local primary care mental health services called Improving Access to Psychological Therapies (IAPT). In their report *Implementing the Five Year Forward View for Mental Health*, NHS England (2016) acknowledges that a large proportion of adults seen in IAPT have comorbid physical health problems including MUS, and a later report outlines a new pathway within IAPT which aimed to expand adult services to focus on people with 'long term physical health conditions' and 'persistent medically unexplained symptoms' (NHS England, 2018).

Aside from the IAPT initiative, there have been further service developments in Central London over the last few years which aimed to address the physical and mental health needs of adults experiencing MUS in a primary care setting (e.g. Parsonage, Hard & Rock, 2014; Stern, Yon & Kent, 2016). However, these services are rare, and unfortunately most adults with persistent MUS seen clinically will not receive this form of holistic care. In some areas, mental health practitioners are integrated into secondary care teams in an inpatient or outpatient hospital setting. For example, psychologists, psychiatrists or psychotherapists might form part of a multi-disciplinary adult pain management service or chronic fatigue service and see adult patients experiencing MUS. However, therapeutic interventions are usually brief and time-limited, and many adults will be referred onwards to their local IAPT service or

community mental health team (CMHT), depending on the severity and complexity of their difficulties.

2.3.2 Services for children and young people. For children and young people, service provision also differs depending on location. In most parts of the UK, children presenting to their GP with mental health difficulties can be referred to Tier 3 community child and adolescent mental health services (CAMHS) (NHS England, 2015). Most Tier 3 CAMHS provide generic mental health support for children and young people with a wide range of presenting problems; primarily anxiety, depression, conduct disorders and neurodevelopmental disorders such as attention deficit hyperactivity disorder (ADHD) (Office for National Statistics, 2005). CAMHS also provide highly specialist services at Tier 4 level (NHS England, 2015). These differ nationwide depending on local requirements, and can include services like CAMHS specialist eating disorder teams. The *Implementing the Five Year Forward View for Mental Health* report (NHS England, 2016) suggested several improvements to CAMHS services. However, although MUS was highlighted in the section of the report outlining the objectives for adult IAPT services, there is no mention of a similar initiative in relation to children and young people. The report does not address the need to integrate physical and mental healthcare for children in the same manner as it does for adult services, and instead focuses on other objectives such as improving the transition from CAMHS to adult mental health services.

Some inpatient and outpatient hospital settings house CAMHS specialist paediatric liaison teams which provide psychological interventions for children and families with complex needs. For example, King's College Hospital in Central London provides a paediatric liaison service specialising in MUS and FII which is

comprised of consultant child and adolescent psychiatrists, a consultant clinical psychologist and a clinical nurse specialist (SLaM National Services, 2015). However, these types of services appear to be quite rare. Research shows that paediatric liaison provision is largely scarce and insufficient in meeting the needs of the child and adolescent population (Bradley, Kramer, Garralda, Bower, Macdonald, Sibbald & Harrington, 2003; Garralda, 2001). Surveys conducted in Greater London with CAMHS teams and paediatricians showed that only a third of London hospitals had access to a paediatric liaison service, and only 15% had dedicated liaison teams (Woodgate & Garralda, 2006). The CAMHS teams who provided these services reported that 43% of inpatients and 78% of outpatients treated by the service presented with somatoform disorders, highlighting the demand for CAMHS input in the management of MUS. However, it is important to note that these studies were conducted over ten years ago, so it is likely that provision has since changed.

3.0 Identification, Treatment and Management

3.1 Identification of MUS and FII in children and young people. MUS are common in childhood (e.g. Rask et al., 2009; Saps et al., 2009), and the majority of children experiencing MUS are unlikely to come into contact with healthcare services. Some children are seen in primary care by a GP for mild to moderate symptoms, the majority of whom are reassured following examination or limited investigations. Some are referred onto a paediatric setting and might see members of a multi-disciplinary team including paediatricians, physiotherapists, occupational therapists and psychologists. A smaller percentage with persistent and severe MUS might come into contact with CAMHS services (Tøt-Strate, Dehlholm-Lambertsen,

Lassen & Rask, 2016; Woodgate & Garralda, 2006) or be admitted to a paediatric inpatient unit for closer monitoring and rehabilitation.

MUS can be challenging to identify, particularly for doctors who are accustomed to working within a medical model promoting clear and accurate diagnosis. The process of identification risks causing iatrogenic harm to the child, particularly if MUS are approached as a 'diagnosis of exclusion' (i.e. only considered after ruling out other possible options). Depending on the nature of the symptoms and the orientation of the GP or treating clinical team, children might undergo extensive investigations in an attempt to identify an organic cause for their symptoms, and some may remain in hospital for several weeks or months (Gill, Dosen & Ziegler, 2004; Rangel, Garralda, Levin & Roberts, 2000). For some conditions such as chronic fatigue syndrome, studies report long delays in recognition and treatment, which can have a significant impact on multiple aspects of a child's development (Sankey, Atherine, Hill, Brown, Quinn & Fletcher, 2006).

FII may be identified in a medical setting, or following repeated presentations in a number of settings such as primary care, secondary care and school. It is difficult to recognise due to its complex presentation and the difficulty in distinguishing between anxious carers who are responding reasonably to their child's organic problem, and carers whose behaviour is causing harm to their child (RCPCH, 2009). A number of factors might indicate FII, including the reporting of symptoms which are not explained by a known medical condition, results of physical examinations or investigations which do not correspond with the symptoms reported by the carer, acute symptoms that are observed mostly or only when in the presence of the carer, an inexplicably poor response to treatment or medication, or incoherent history

reports. As well as this, school attendance is often poor, and other areas of functioning are often impaired to such a degree that is not readily explained by any diagnosed illness (RCPCH, 2009).

Multiple guidance for managing FII exists for professionals (e.g. HM Government, 2008; London Safeguarding Children Board, 2017; RCPCH, 2009), and the RCPCH guidance is due to be updated in September 2019. Signs of FII should be treated as a safeguarding concern, and information should be coordinated and discussed within a multi-disciplinary team (MDT). Guidance outlines that the consultant paediatrician responsible for the child's health should take the lead clinical role in case management, and equal effort should be put into confirming or excluding a diagnosis of FII, with care taken not to treat FII as a 'diagnosis of exclusion'. Where FII is suspected, clinicians have a duty to report concerns to children's social care (HM Government, 2008). Children's social care hold lead responsibility for undertaking an initial assessment of a child where FII is suspected, and must co-ordinate the gathering of information across multiple agencies and sources. Specialist assessments conducted by CAMHS, adult mental health services, paediatrics and various other agencies are used to inform the assessment, and historic accounts are gathered from any agencies with whom the family have had contact (such as school). Ultimately, the investigation aims to determine whether the parents in question have the capacity to meet the developmental needs of the child, and whether authorities need to take any action to safeguard and promote the child's welfare. This may include putting a multi-agency child protection plan in place, or making an application for a Care Order or Emergency Protection Order if it is felt that the child is not safe under the care of their parents (HM Government, 2008).

3.2 Treatment and management of MUS. Guidance provided by the Royal College of Psychiatrists (RCPsych) and Royal College of General Practitioners (RCGP) explains the doctor's role in identifying and managing MUS in adults (Chitnis, Dowrick, Byng, Turner & Shiers, 2014). The guidance emphasises that GPs should take symptoms seriously and focus more on the impact of the symptoms, rather than seeking a diagnosis and cure. The importance of the doctor-patient relationship is highlighted, as doctors are advised to 'just be there' for patients and where possible give explanations for symptoms that make sense to the patient, rather than brushing the symptoms off as 'normal'. Removing any blame from the patient and generating ideas about how to manage their symptoms is important, as is discussing the likely outcome of non-pathological tests results and the implications of this (Hatcher & Arroll, 2008; Salmon, Peters & Stanley, 1999).

The guidance for paediatricians covers much of the same principles, with a focus on the engagement of children and families whilst conducting a thorough clinical assessment and ruling out organic disease using the minimal number of investigations necessary (Cottrell, 2016; Geist et al., 2008). Acknowledging the reality of symptoms and their impact on the child's or young person's functioning is key, as well as developing a full account of the family's psychosocial context, history and any potential stressors. Giving a rationale for the symptoms in absence of an organic cause is suggested, such as by giving examples of how common everyday stressors (e.g. examinations and job interviews) might lead to common physical symptoms (e.g. 'butterflies in the stomach' and a racing heart) (Cottrell, 2016). These steps can be difficult or even impossible to achieve in busy settings like A&E where children are usually seen briefly by the attending paediatrician. It is therefore important for children experiencing persistent MUS to be seen by paediatricians in

an outpatient setting, where more time can be given to exploring their context and symptoms, and for GPs to be on board with a management plan (Cottrell, 2016).

Encouraging the child to continue with everyday activities, such as attending school and seeing friends is an important part of a plan, and it is important to ensure that all parties are on board, including parents, schools and the GP. Referral to CAMHS for treatment of comorbid mental health difficulties like anxiety and depression is suggested (Cottrell, 2016; Geist et al., 2008), although this suggestion could be seen as reinforcing the idea that mental and physical health are separate and require separate treatment plans.

Various psychological interventions exist for adults experiencing MUS, but studies evaluating psychological treatments for MUS in child and adolescent populations are limited. In the adult literature, recent systematic reviews and meta-analyses provide moderate evidence for the effectiveness of cognitive behaviour therapy (CBT) as an intervention for general MUS (Menon, Rajan, Kuppli & Sarkar, 2017), IBS (Li, Xiong, Zhang, Yu & Chen, 2014), fibromyalgia (Bennett & Nelson, 2006) and somatoform disorders (Kroenke, 2007). There is also evidence for the positive effects of various short-term psychotherapy interventions for adults (Kleinstäuber, Witthöft & Hiller, 2010) and other approaches including mindfulness-based cognitive therapy (MBCT) (Lakhan & Schofield, 2013), short-term dynamic psychotherapy (ISTDP) (Abbass, Kisely, Rasic, Town & Johansson, 2015), and self-help interventions (van Gils, Schoevers, Bonvanie, Gelauff, Roest & Rosmalen, 2017). In terms of treatments for children, a recent systematic review gives an overview of various family-based interventions available for children and families (Hulgaard, Dehlholm-Lambertsen & Ulrikka Rask, 2019). Studies examining the effectiveness of treatments show mixed results for the effectiveness of CBT as a

treatment for abdominal pain in children and adolescents (Humphreys & Gevirtz, 2000; Sanders, Shepherd, Cleghorn & Woolford, 1994) and more positive results for the use of CBT in treating headache (Griffiths & Martin, 1996), chronic fatigue syndrome (Knoop, Stulemeijer, de Jong, Fiselier & Bleijenberg, 2008) and general somatic complaints (Masia Warner, Reigada, Fisher, Saborsky & Benkov, 2009). There is also evidence that relaxation, and relaxation with bio-feedback, improve headache (Larsson & Melin, 1986). However, many studies within the child and adolescent literature looking at CBT approaches are outdated and lack effective control groups or adequately sized samples, limiting the conclusions that can be drawn about the overall effectiveness of interventions in paediatric populations.

3.3 Treatment and management of FII. In cases where FII is strongly suspected, the consultant paediatrician acting as the clinical lead for the case is responsible for all decisions regarding the child's healthcare and, as previously outlined, must make a referral to children's social care as early as possible (London Safeguarding Children Board, 2017; RCPCH, 2009). In collaboration with treating clinical teams, a detailed health chronology should be compiled and used to inform decisions made by both clinical and social care teams. Appropriate tertiary care specialists may need to become involved to aid with the process of FII diagnosis. Effective and timely communication amongst colleagues is essential to ensure the best possible outcome for the child. If a diagnosis is confirmed, CAMHS should support the child with the psychological and emotional consequences of FII. If a child remains in hospital, ongoing observation and supervision of the child is important, and police involvement may be necessary if Covert Video Surveillance (CVS) is required (RCPCH, 2009).

Guidance indicates that a strategy discussion should take place with all involved professionals and, following this, social care (in collaboration with the lead paediatrician) must disclose the possibility of FII to the carers (RCPCH, 2009). Ongoing monitoring of the child's health is usually required by the paediatric team. Other individuals from various teams such as adult psychiatry, psychology and social work may work with the child and family, and recommendations may be made for rehabilitation, reunification and treatment. Guidance emphasises that staff involved with cases of FII should receive support and supervision due to the complex nature of managing such cases, and that de-briefing sessions should take place within the team (RCPCH, 2009). It is unclear how often this occurs in practice.

There is little research about treatments available for children affected by FII and their families. Treatments involving the parent tend to focus on helping them to acknowledge that fabrication or induction of illness has taken place. The intention here is to improve parental competence and sensitivity to the child's needs, and facilitate a resolution phase, which involves putting in place a safety plan for the child, ideally including extended family members (Klepper, Heringhaus, Wurthmann & Voit, 2008). A study looking at case reports of 41 children at GOSH found evidence of good outcomes for children where the child's safety had been addressed in the context of a child protection framework, and the families had undertaken long-term therapy with a focus on the protection of the child (Gray & Bentovim, 1996). Another more recent study of case reports indicated more successful outcomes where early intervention had taken place, with mothers who acknowledged their deception and the psychosocial context in which it occurred, and agreed to participate in long-term therapeutic treatment (Klepper et al., 2008).

3.4 Training and support for medical doctors. Somewhat surprisingly given its prevalence and complexity, training about MUS for doctors at undergraduate (Howman, Walters, Rosenthal, Ajjawi & Buszewicz, 2012; Shattock, Williamson, Caldwell, Anderson, Peters & Schwartzstein, 2013) and postgraduate levels (Yon, Habermann, Rosenthal, Walters, Nettleton, Warner, Lamahewa & Buszewicz, 2017; Yon, Nettleton, Walters, Lamahewa & Buszewicz, 2015) is very limited, and training about the topic of MUS or FII does not appear to feature in the formal UK undergraduate or postgraduate foundation year curricula. Foundation training programme directors (FTPDs) organise postgraduate training for junior doctors in their first two years post-qualifying in the UK. In a survey study, FTPDs were asked to give recommendations for future training on the topic of MUS (Yon et al., 2017). Of the third who responded, the FTPDs recommended case-based group discussions as the most feasible method of teaching, followed by lectures and GP or outpatient-based teaching, and suggested two to three hours of teaching on the topic of MUS for each of the two foundation years. In a more recent qualitative study examining the reasons for the lack of teaching in this area at undergraduate level, medical educators reported that MUS is a complex subject and is usually seen as a low priority, largely because it is a non-essential, non-life-threatening topic amongst an already ‘packed’ curriculum. Instead of formal teaching slots, they recommended learning through ‘managed patient exposure’ and acknowledged that the negative attitudes of tutors should somehow be addressed (Joyce, Cowing, Lazarus, Smith, Zenzuck & Peters, 2018).

MUS and FII are not mentioned in the General Medical Council (GMC) approved curriculum for doctors specialising in general paediatrics in the UK provided by the RCPCH (2018). These topics also do not feature in other specialty

curricula like paediatric and perinatal pathology, or in other sub-specialty curricula including community child health, neonatal medicine or paediatric emergency medicine. The only curriculum that mentions both these topics is the paediatrics sub-specialty curriculum for child mental health (RCPCH, 2018). This states that paediatricians should ‘demonstrate expertise in psychological aspects of safeguarding, particularly emotional abuse and fabricated or induced illness’ and should ‘demonstrate an ability to recognise and manage competently a range of mental health difficulties and disorders such as... medically unexplained symptoms and somatoform disorders’ (pp11). The fact that these topics are categorised under child mental health implies that MUS and FII are perceived as mental health problems, which again highlights the ongoing divide between physical and mental health in the way these difficulties are conceptualised.

In a study of paediatric liaison work provided by CAMHS in Greater London, it was found that most CAMHS offered formal teaching on various subjects to doctors, medical students and nurses (Woodgate & Garralda, 2006). However, these took place infrequently and mostly on an ad-hoc basis, and it is unclear whether this teaching included the topics of MUS and/or FII. Two thirds of the services offered paediatric liaison support to general paediatrics and a third to the paediatric intensive care unit (PICU), with most support offered by psychiatry and some by psychology and nursing. Improvements to paediatric training programmes are needed to increase the recognition of MUS and equip clinicians with the necessary skills to address the needs of children and families and adequately explain the role of mental health services as part of the treatment plan (Canavera, Allen & Johnson, 2018; Cooper et al., 2017).

4.0 Patient and Doctor Experience

4.1 Patients' experiences of healthcare. Adult patients experiencing MUS report frustration with the lack of a definitive diagnosis (Dow, Roche & Ziebland, 2012; Nettleton, 2006). A qualitative study examining the experiences of 18 neurology outpatients with an 'MUS' label found that patients were anxious about being seen as a 'fraud' or 'hypochondriac' and that they mostly wanted their symptoms to be acknowledged as genuine by friends, family and healthcare professionals (Nettleton, 2006). Most had been through countless consultations and had multiple tests and referrals, so much so that they were unable to recall all the details. Another study reported how people with unexplained chronic back pain felt that the invisibility of their symptoms challenged the credibility of their illness and, although psychosocial factors were acknowledged, patients felt that psychosocial explanations contradicted medical explanations and implied that symptoms might be 'imagined', which left them doubting their own experiences (Toye & Barker, 2010). Patients also report dissatisfaction with medical professionals who can be experienced as dismissive and non-believing (Peters, Rogers, Salmon, Gask, Dowrick, Towey & Morriss, 2009), with some patients recalling being told that their symptoms were 'all in their mind' (Kouyanou, Pither, Rabe-Hesketh & Wessely, 1998). Indeed, the 2015 award-winning book by consultant neurologist Suzanne O'Sullivan containing anonymised case studies about her patients with 'psychosomatic illnesses' was given the title *It's All in Your Head* in reference to the unhelpful way MUS are often conceptualised within the medical profession.

A recent study examining adult patients' preferred term for MUS found an overarching preference for 'persistent physical symptoms', and in second place

‘functional symptoms’. A term less preferable than MUS was ‘bodily distress disorder’, and the least favourite term ‘complex physical symptoms’ (Marks & Hunter, 2015). This study highlights the importance of considering the language used to explain patients’ experiences. A further study by Ding & Kanaan (2016) examining patients’ views of the term ‘unexplained neurological symptoms’ emphasises how it is the meaning behind the terms which are used, rather than the terms themselves, that is often seen as more important to patients because of the potential stigma associated with the terms.

There do not appear to be any published studies examining the views or experiences of children, adolescents or parents in relation to MUS or FII.

4.2 Doctors’ experiences of managing MUS in adults. Consultations involving MUS are often reported as frustrating and unsatisfying by both doctors and patients (e.g. Salmon et al., 1999; Wileman, May & Chew-Graham, 2002), and doctors have been reported as describing patients using terms such as ‘difficult’ and ‘heart-sink’ (Hartz, Noyes, Bentler, Damiano, Willard & Momany, 2000; O’Dowd, 1988). In a more recent UK study, junior doctors expressed feelings of anxiety and frustration when managing such patients, and reported a lack of confidence and difficulty negotiating the uncertainty surrounding MUS (Yon et al., 2015). GPs have also reported experiencing negative and uncomfortable feelings towards patients (Stone, 2014), and difficulties in providing satisfactory explanations for patients’ symptoms (Howman, Walters, Rosenthal, Ajjawi & Buszewicz, 2016). Studies examining GP consultations indicate that patients often attend appointments with a psychosocial explanation for their symptoms in mind, but that GPs have difficulty exploring possible psychological links to patients’ symptoms (Henningsen, Jakobsen,

Schiltewolf, Hiller, Cebulla, Korn, Leibbrand, Röers, Nilges & Nilges, 2010; Weiss & Weiss, 2005). This could be related to fears of offending patients by implying that their symptoms are ‘put on’ or ‘imagined’ (e.g. Stone, Wojcik, Durrance, Carson, Lewis, MacKenzie & Sharpe, 2002).

It has also been suggested that adult patients with MUS approach GPs seeking emotional support and reassurance more so than patients with straightforward physiological diagnoses, but that GPs report feeling insecure about meeting patients’ need for emotional support (Henningson et al., 2007; Salmon, Ring, Dowrick & Humphris, 2005; Salmon, Ring, Humphris, Davies & Dowrick, 2009; Wileman et al., 2002). Instead, secondary care referrals or over-investigation of symptoms in search of an organic cause are common, both of which are costly approaches that risk causing iatrogenic harm to the patient (Konopka, Schaefer & Heinrich, 2012; Nettleton, 2006). Sometimes medical professionals may collude with patients by attributing symptoms to an organic cause (Salmon, Peters & Stanley, 1999) or misdiagnose symptoms as pathological, with the paradoxical intention to ‘put the patient’s mind at rest’ by giving a diagnosis (Kouyanou et al., 1998). Some junior doctors have said that referring on for further investigations is the easier, more appealing option, as it allows them to ‘get rid’ of the patient more quickly, and can be preferable to the more challenging task of constructing explanations for ambiguous symptoms (Yon et al., 2015). Other participants in the same qualitative study spoke about a lingering fear of missing a serious underlying disease, with a fear of litigation driving them to make onward referrals for further investigation. Overall, the study concluded that the uncertainty associated with MUS can be challenging for doctors to manage, particularly as medical training focuses more on

dealing with straightforward diagnoses of organic disease, and less on complex presentations involving both physical and psychological factors.

4.3 Doctors' experiences of managing MUS & FII in children.

4.3.1 Search strategy. The databases PubMed and MEDLINE (Ovid version) were used to identify any relevant studies looking at paediatricians' and healthcare professionals' experiences of managing MUS and FII in children and families. The following search terms were used to search for relevant titles and abstracts: medically unexplained symptom* OR functional disorder* OR functional syndrome* OR unexplained symptom* OR unexplained physical symptom* OR medically unexplained physical symptom* OR functional somatic symptom* OR persistent physical symptom* psychosomatic OR somatoform OR somatisation OR irritable bowel syndrome OR chronic fatigue OR myalgic encephalomyelitis OR fibromyalgia OR chronic pain OR fabricated or induced illness OR Munchausen Syndrome by Proxy OR Munchausen* OR factitious OR doctor OR paediatric* OR pediatric* OR healthcare professional* OR nurse OR child* OR adoles* OR young people OR qual*. The search identified the studies outlined below.

4.3.2 Identified literature. Interestingly, little research has been carried out examining doctors' views and experiences of managing MUS in child and adolescent populations, and no identified studies appear to have explored paediatricians' experiences of managing FII. A recent literature review carried out by Hinton & Kirk in 2016 identified four studies looking at healthcare professionals' (HCPs) experiences of managing MUS in children and young people. In three of the studies, surveys were used to assess the views of HCPs. The earliest of these was

administered to 225 GPs in the UK to assess their experiences of managing chronic fatigue syndrome (CFS) in children and adolescents and their treatment preferences (Richards & Smith, 1998). The majority of respondents regarded CFS as a combined physiological and psychological disorder requiring onward referral and additional medical input beyond that offered by the GP.

The second study involved a survey of UK healthcare professionals' (HCPs) attitudes to caring for children experiencing MUS (Glazebrook, Furness, Tay, Abbas & Hollis, 2009). One hundred and twenty-eight HCPs responded, including doctors and nurses. The majority noted the 'demanding' nature of the work, with doctors reporting the care of this client group to be less rewarding than nurses. Doctors from paediatric teams in particular gave higher scores for the 'demanding' nature of the work and were also more likely to perceive the children as having unmet support needs, which the authors hypothesised could be due to the greater pressure on paediatricians to take responsibility for case management and confirm a clear diagnosis. All participants highlighted a need for further support from CAMHS. The third study was conducted in the Netherlands, and involved a survey of 16 paediatricians who were asked about the typical characteristics of children with unexplained chronic pain that were seen as diagnostically relevant for associated 'psychiatric morbidity' (Konijnenberg, de Graeff-Meeder, van der Hoeven, Kimpfen, Buitelaar & Uiterwaal, 2006). The study concluded that paediatricians were aware of the signals seen as important for detecting early 'psychiatric comorbidities', including social and familial issues, parental somatisation and difficulties at school.

The final study was conducted in the UK and involved 12 HCPs including consultant paediatricians, registrars, nurses, a healthcare assistant, an occupational

therapist and a play specialist (Furness, Glazebrook, Tay, Abbas & Slaveska-Hollis, 2009). It is unclear how many paediatricians took part. The study used qualitative methods, with three participants taking part in individual interviews and nine participating in focus groups. The study focused on the HCPs' experiences of MUS more generally, and reported on their views and experiences of providing care. The study reported that participants acknowledged the complexity of MUS and expressed anxiety about caring for children with unexplained symptoms. Nurses who took part in the focus groups talked about the role of the family, specifically the parents, in reinforcing some of the symptoms in the children under their care on the inpatient ward. They described unusual behaviours by some parents, which they felt evoked anxiety in children and contributed to their symptoms. They also said they had noticed themes of overprotectiveness and parents' resistance to their children receiving 'conventional' medical care (Furness et al., 2009). Interestingly, these described characteristics appear to fit more closely with official definitions of FII (e.g. Davis et al., 2019) rather than MUS. HCPs also expressed frustration as they often felt unable to satisfy families' concerns, and talked about feeling powerless and uncertain about how to manage situations with families. Participants talked about the complicated process of the 'transition' of care from 'physical to psychological', and how parents perceived this as meaning their child might be 'mad' or fabricating their symptoms, resulting in the parents sometimes expressing anger in the presence of their children. Paediatricians in the study talked about fears of missing cues that indicate organic disease, and one paediatrician spoke about the work being 'unsatisfactory' because of the challenging nature of the presentations.

In the above mentioned study HCPs requested further and 'better' training, and specifically asked for more teaching about the psychological aspects of MUS,

including more information about the clinical pathway undertaken by patients following a referral to psychological services. They made suggestions for improvements in care, such as by limiting investigations, and working more closely as a team through effective communication and information sharing.

5.0 The Present Study

5.1 Study rationale. The studies mentioned in section 4.3 indicate that healthcare professionals find MUS challenging to manage; however, beyond this little is known about the specific views of paediatricians working directly with these cases. Furthermore, no studies examining paediatricians' experiences of managing FII have been identified. Paediatricians play a key role in the direct management of MUS and FII, and usually hold responsibility for cases seen in secondary care hospital settings. Effective and safe case management is of utmost importance, as over-investigation of symptoms risks causing significant iatrogenic harm to the child. It is important that MUS and FII are recognised early and managed appropriately, as both can have serious implications in multiple areas of development, with many cases of FII leading to devastating consequences for children's overall health and wellbeing. It therefore seems imperative to gain a deeper understanding of paediatricians' knowledge and experiences of working with these presentations in practice, with the aim to improve healthcare for children affected by MUS and FII.

Although some of the studies described in section 4.3 involved paediatricians, the sample sizes were very small, and in the qualitative study by Furness et al. (2009) it is not clear which views were held by paediatricians and which views were held by the other health professionals. Furthermore, previous studies mainly used questionnaire surveys to explore participants' views and looked at specific types of

MUS such as chronic pain or chronic fatigue syndrome. There remains a great deal to explore and understand regarding paediatricians' views and experiences of managing MUS and FII. This current study proposes to go beyond previous research by looking at these unexplored areas in depth via the use of qualitative interview methods.

Individual interviews will be conducted with paediatricians of varying levels of seniority working at hospitals and in the community in North Central London, and analysed using thematic analysis (Braun & Clarke, 2006). Qualitative interviews will provide an opportunity to gather rich information about paediatricians' unique experiences of managing MUS and FII, in particular their views about the possible causes of MUS and FII, how these topics are conceptualised, typical approaches to managing cases, general attitudes towards parents and families, the emotional impact of being involved with such cases, and views about current service provision. It is anticipated that the findings will provide insight into the care currently being provided for children, and give an indication of any improvements that could be made to service provision and training for paediatricians in these important areas.

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Part 2: Empirical Paper

**Paediatricians' experiences of managing medically unexplained symptoms (MUS) and fabricated or induced illness (FII) in children and families:
a qualitative study**

Abstract

Aims: Currently, very little is known about paediatricians' understanding of medically unexplained symptoms (MUS) and fabricated or induced illness (FII), both of which can be challenging presentations to manage. This study used qualitative methods to explore how paediatricians conceptualise the topics of MUS and FII, their approach to cases in practice, and any gaps in service provision and training.

Methods: Twenty semi-structured interviews were carried out with trainee and consultant paediatricians based in hospital and community posts in North Central London. Data were analysed using thematic analysis.

Results: Participants reported varying amounts of exposure to MUS and FII, and identified a 'grey area' related to these topics, characterised by parents' inappropriate help-seeking behaviours driven by parental anxiety and with the potential to result in significant harm to the child. Paediatricians discussed the challenging nature of their role in managing MUS and FII, identifying issues including risk of over-investigation and iatrogenic harm, early identification of FII, the emotional impact of the work, gaps in training, and current barriers children and families face when accessing appropriate care.

Conclusions: Improved service provision and more training for paediatricians about these important topics is needed to ensure early identification of MUS and FII and reduce risk of harm.

Introduction

Medically unexplained symptoms (MUS) are defined as symptoms not clearly linked to diagnoses of organic pathology or disease (Henningsen, Zipfel & Herzog, 2007). Common MUS reported by children and adolescents include headaches, abdominal pain, fatigue and musculoskeletal pains (Schulte, Petermann, McNeil, Hawkins, Moore & Wiles, 2011). MUS occur frequently and are estimated to account for 15-50% of all cases seen by GPs in primary care (Haller, Cramer, Lauche & Dobos 2015), and around a third of children and adolescents seen as paediatric outpatients in the USA and Ireland report MUS associated with emotional and functional impairment (Andresen, Woolfolk, Allen, Fragoso, Youngerman, Patrick-Miller & Gara, 2011; Kelly, Molcho, Doyle & Gabhainn, 2010).

Fabricated or induced illness (FII) is less common and is defined by a carer, usually the mother, exaggerating, fabricating or deliberately inducing a child's symptoms. Presentations of FII range from the exaggeration and false reporting of symptoms (a presentation usually driven by parental anxiety and erroneous beliefs about the child's health), to the conscious and deliberate deception or induction of illness, usually with the purpose of fulfilling the carer's needs and personal gains (Davis, Murtagh & Glaser, 2019). The latter is seen more rarely and might involve interference with investigations or specimens, overmedication, suffocation, poisoning or starving. FII is viewed as a form of child maltreatment and can have a serious impact on a child's physical, educational, psychological and emotional wellbeing (Bass & Glaser, 2014; London Safeguarding Children Board, 2017; Royal College of Paediatrics & Child Health [RCPCH], 2009). There is also a significant mortality rate associated with FII, with a literature review reporting that 6% of severe cases of FII identified resulted in death (RCPCH, 2009; Sheridan, 2003).

Several studies have explored doctors' experiences of managing MUS in adult populations, and conclude that doctors often find MUS difficult and frustrating to manage (e.g. Salmon, Ring, Humphris, Davies & Dowrick, 2009; Stone, 2014). This is thought to be due to its complexity and the uncertainty associated with presentations where the diagnosis is unclear (Yon, Nettleton, Walters, Lamahewa & Buszewicz, 2015). In adult populations, secondary care referrals for MUS and over-investigation are common, which risks iatrogenic harm to patients (Konnopka, Schaefer & Heinrich, 2012; Nettleton, 2006).

On the other hand, very few studies have explored doctors' experiences of working with MUS in child and adolescent populations. A recent literature review identified four studies exploring healthcare professionals' (HCPs) experiences of managing MUS in children and young people (Hinton & Kirk, 2016). Three were surveys (Glazebrook, Furness, Tay, Abbas & Hollis, 2009; Konijnenberg, de Graeff-Meeder, van der Hoeven, Kimpen, Buitelaar & Uiterwaal, 2006; Richards & Smith, 1998), with one survey reporting that doctors and nurses find the work 'demanding' and would like further support from child and adolescent mental health services (CAMHS) (Glazebrook et al., 2009). The fourth study was conducted in the UK with various HCPs including paediatricians, nurses and healthcare assistants. Three participated in qualitative interviews and nine in focus groups (Furness, Glazebrook, Tay, Abbas & Slaveska-Hollis, 2009), although the paper does not state which professionals took part in the interviews. Study participants reported frustration and anxiety about working with MUS, and themes of powerlessness and uncertainty when managing situations with families. Nurses talked about the role of parents in reinforcing some of children's symptoms, and paediatricians in particular talked about a fear of missing organic disease.

The mentioned studies indicate that doctors and healthcare professionals find MUS challenging to manage; however, beyond this very little is currently known about paediatricians' views and experiences of managing MUS. Furthermore, no studies examining doctors' experiences of managing FII have been identified.

Paediatricians play a key role in the identification and management of MUS and FII in children and young people, and are responsible for all healthcare decisions in cases of FII (RCPCH, 2009). There is an overarching need to provide safe and effective care in cases of both MUS and FII, and prevent direct or iatrogenic harm to children. In particular, it is essential that cases of FII be identified early and managed appropriately, given the risk of developmental and functional impairment and even death (RCPCH, 2009). It therefore seems imperative to gain a deeper understanding of paediatricians' views and experiences of working with these populations.

This study aimed to go beyond previous research by exploring paediatricians' experiences of managing MUS and FII using in-depth qualitative interviews. A significantly larger sample than the three HCPs interviewed in the previously mentioned qualitative study by Furness et al. (2009) was recruited, and the focus was exclusively on the views of consultant and trainee paediatricians. Qualitative interviews provided an opportunity to gather rich and detailed information about paediatricians' unique experiences of managing MUS and FII. Much like in adult populations, the over-investigation of symptoms risks causing iatrogenic harm to the child, which could have significant implications for multiple areas of development (Eminson, 2007). Exploring paediatricians' views about investigations and the doctors' role in management helped to clarify how cases are currently approached, and shed light on paediatricians' views about existing and optimal methods of

management. The research also explored whether paediatricians had received any training about these topics, as it is known that training about MUS for doctors at undergraduate (Howman, Walters, Rosenthal, Ajjawi & Buszewicz, 2012) and postgraduate (Yon, Habermann, Rosenthal, Walters, Nettleton, Warner, Lamahewa & Buszewicz, 2017) level is very limited. The research findings should help to determine any gaps in knowledge and current training for paediatricians about these important topics, with the overall intention of improving wider clinical practice.

The study had the following aims:

- To develop a deeper understanding of paediatricians' experiences of managing cases of MUS and FII in children and families
- To gain insight into the ways such cases are conceptualised and approached in practice
- To identify any potential gaps in training and service provision in these areas

Methodology

Design

In-depth semi-structured interviews were conducted in order to gather rich, detailed information about paediatricians' unique experiences of working with medically unexplained symptoms (MUS) and fabricated or induced illness (FII) in children and families. Individual interviews were considered to be more suitable than focus groups in order to facilitate discussions about personal topics such as the emotional impact of the work. Qualitative interviews also allowed for the potential discovery of novel and unexpected information which might have been missed by pre-determined measures.

Ethics

Ethical approval for this study was granted by UCL Research Ethics Committee on 28.05.18 (Appendix A) and NHS Health Research Authority (HRA) on 30.05.18 (IRAS ID: 243324) (Appendix B).

Participants

Twenty paediatricians (ten consultants and ten trainees) were recruited from three hospitals and three community sites in the North Thames region of London. Participant demographics are shown in Table 1.

Sampling Method

Purposive sampling for level of experience (trainee or consultant) took place.

Table 1

Participant Demographics

Variable	n/20
Level	
Trainee	10
ST1-ST4	7
ST5-ST8	3
Consultant	10
<25 years*	5
>25 years*	5
Gender	
Female	15
Male	5
Ethnicity	
White	16
BME	4

Note. *years of experience in medicine

Theoretical Orientation

The research reported in this thesis took place in a medical setting, with paediatricians who are required to work with diagnostic labels and to use these to inform decisions about treatment plans and management approaches. For this reason, the current research is approached from the perspective of the medical model, such that it is in keeping with the experiences of participants. It was hoped that by joining them where they were at, participants could truly explore their experiences, as introducing a new model is likely to have been too far from their perceived experience of the “truth”. As such, from an epistemological perspective this research attempts to understand what is “true” for participants by conveying their perspectives throughout the report, in their own language. However, the research acknowledges the limitations of the medical model, namely that the medical model is a nosological approach

interested in assigning discrete categories to symptoms, and may not take into account the role of contextual factors.

Procedure

Recruitment. Participants were introduced to the study via one of two methods. The majority of participants received a recruitment email sent by a senior paediatric team member at their clinical site introducing them to the study and asking them to contact the main researcher for further information. Others were recruited via a quarterly educational seminar about perplexing presentations held for paediatric trainees and consultants, during which the main researcher (KY) delivered a presentation about the study. Email addresses of interested participants were collected, and the main researcher subsequently contacted them individually via email.

Interviews. Face-to-face interviews were conducted by the main researcher. Participants were sent information sheets in advance of the interview (Appendix C), and gave written consent (Appendix D) prior to taking part. Participants were given a £20 high street voucher to compensate for their time. The interviews lasted on average 47 minutes (ranging from 26 to 70 minutes) and a curious, non-judgemental approach was taken. Participants were informed that there were ‘no wrong answers’, and that the researcher was interested in exploring a range of views and experiences.

The design, structure and content of the topic guide was informed by that used in a previous study conducted by the main researcher (KY) and external supervisor, a GP and Reader in Primary Care (MB), examining junior doctors’ experiences of managing MUS (Yon et al., 2015). It was further developed in reference to the background literature and discussions with two external collaborators; an honorary consultant child and adolescent psychiatrist at Great Ormond Street Hospital (GOSH)

(DG), and a consultant paediatrician at University College London Hospitals (UCLH) (DH), both of whom have a special interest in MUS and FII. The topic guide was revisited throughout the interview process and adapted to newly emerging topics. Questions covered paediatricians' understanding and conceptualisation of the topics MUS and FII, approaches to identifying and managing MUS and FII in practice (including case examples), attitudes towards MUS and FII, the emotional impact of being involved in such cases, and any prior training on the topic (see final version in Appendix E).

Data Analysis

Interviews were audio recorded and transcribed verbatim. The main researcher transcribed eight interviews. The remaining twelve were transcribed by an external transcription agency with participants' consent. NVivo software was used to assign initial codes to the data set and generate categories, which were then organised into themes. Data were analysed using thematic analysis (Braun & Clarke, 2006). This bottom-up approach was chosen in order to capture the main themes and sub-themes emerging from the large data set. However, this approach takes a less detailed and more surface-level approach to analysis which differs from more in-depth analysis enabled by other methods such as interpretative phenomenological analysis (IPA). IPA was not felt to be appropriate for this research as it involves adding additional layers of interpretation which might move away from the perspective presented by the participant. Other top-down methods like framework analysis were not selected, because as this is an unexplored area it was seen as important to draw the themes from the dataset and leave room for unexpected topics to emerge.

To address issues of credibility, a process of analyst triangulation took place. The main researcher, the two research supervisors (MW & MB), and the two external collaborators (DG & DH), acted as independent reviewers in the systematic theme identification stage of analysis. The reviewers thus brought a multidisciplinary approach to the study, interpreting the data from the varying perspectives of medical practitioners and psychologists. Initially, a process of data immersion took place: the main researcher read all twenty transcripts, and ten of these transcripts were also read by at least one other reviewer. Reviewers independently generated codes and initial ideas for themes. These ideas were then brought to a group discussion where a conceptual framework was created, including a hierarchy of overarching themes and subthemes.

Preconceptions and ideas were challenged by other team members in order to encourage a reflective and thoughtful approach to data analysis, and to ensure that consideration was given to all themes. Furthermore, ‘member checking’ (e.g. Tobin & Begley, 2004) took place, whereby a draft of the results section was reviewed by two of the study participants. The participants did not suggest any changes to the draft.

Results

The findings have been reported in accordance with the five main domains: Topic Conceptualisation, Factors contributing to MUS and FII, Approaches to Management, Emotional Impact of the Work, and Services and Training (see Table 2 for a full list of themes). Themes and sub-themes have been identified within each of these domains. Themes endorsed by only consultants or trainees have been indicated. In light of guidance on the reporting of qualitative data (e.g. Ritchie, Lewis, McNaughton, Nicholls & Ormston, 2014), and due to variation in the topics discussed

in each interview, quantitative statements about the number of participants endorsing a theme have only been included for topics raised by one or two participants.

1.0 Topic Conceptualisation

1.1 Definitions of MUS and FII. All participants were familiar with the term medically unexplained symptoms (MUS), and all participants but one trainee had encountered the term fabricated or induced illness (FII). Common definitions of MUS included symptoms that do not fit into a recognised pattern or diagnostic framework, or symptoms without a ‘medical’, ‘pathological’ or ‘organic’ cause. MUS was described as multifactorial. Some conceptualised it within a biopsychosocial framework, and most participants emphasised the influence of psychosocial factors. Several participants said symptoms could be linked to an organic cause not yet identified, or emerge after or alongside an existing illness. Importantly, all participants heavily emphasised the reality of symptoms, and the need to show patients that they are believed. One consultant used an analogy to illustrate this:

“No amount of blood tests, scans, stethoscopes, or examinations will find out why I’ve got a headache. What I’m trying to say to people is that I wouldn’t want to be disbelieved if I had a headache or a migraine, so I’m not disbelieving you. ... Just because I haven’t found a cause, doesn’t mean it doesn’t exist.” (P19, Consultant)

Participants gave a variety of responses about the difference between MUS and FII, with some describing them as very different concepts, and others seeing them as being on a spectrum with some overlap.

“I suppose it’s thinking of it more as a Venn diagram, that there is probably a great deal of overlap because of the uncertainty, the process you go through to find the cause... and the fact that people find it difficult to deal with situations where they’re not able to easily give an answer or an explanation.” (P15, Trainee)

Table 2

List of Themes

Domain	Theme	Sub-theme	Detail
1.0 Topic Conceptualisation	1.1. Definitions of MUS and FII		Reality of symptoms Difference between MUS and FII Parent/ carer involvement in FII
	1.2 The 'grey area'		The 'anxious' parent Varied conceptualisations of the 'grey area' 'Inappropriate help-seeking behaviours' Negative impact on children
2.0 Factors Contributing to MUS and FII	2.1 The role of the parent		'Collusion' vs disbelieving Influence of parents Child's role
		2.1.1 Parents' response to doctors	
		2.1.2 Personality characteristics of parents	'Controlling' parents 'Anxious' parents 'Angry' parents
		2.1.3 Factors contributing to parents' behaviour	Psychosocial factors Separation difficulties
	2.2 The role of the doctor		Iatrogenic harm Over-investigation Power
		2.2.1 Factors contributing to doctors' behaviour	Fear of 'missing something' 'Easier' to 'go along' with requests Psychological and social factors in the child
3.0 Approaches to Management	2.3 Other contributing factors		
	3.1 Approaches to investigations		'Do baseline then stop' 'Safety-netting'
	3.2 Exploring psychosocial factors		'No one really gets into it' (trainees) Explore and make links (consultants) Focus on the medical Record keeping Teamwork
	3.3 Managing potential FII		Negative emotions 'Overwhelming' to manage 'Most challenging' cases
4.0 The Emotional Impact of the Work			
5.0 Services and Training	5.1 The role of psychology		CAMHS in high demand Barriers to accessing CAMHS Joint sessions with psychology
		5.1.1 Multi-agency working	Barriers to social care access Children 'falling through the net'
	5.2 Training		Lack of training received Request for more training

However, one of the consistent main differences noted across participants was that in FII, a parent or carer solely or partly contributes to the child's symptoms.

"I just want to be clear that I think about FII very differently to MUS – FII has a perpetrator. ... To me they're really two different populations, completely." (P19, Consultant)

Two trainees also included children fabricating or inducing their own illness without the involvement of another person in the definition of FII, which may reflect confusion with other similar terms e.g. factitious disorder imposed on self.

Most participants identified FII as the classic fabrication or induction of illness in a child by a parent, such as by poisoning with salt or falsely reporting serious symptoms, such as seizures. All consultants had encountered this form of FII in practice at least once. Most trainees had encountered it at some point in their career, although some of the encounters were once-removed and had been managed by other colleagues in the team.

1.2 The 'grey area'. Interestingly, when defining MUS and FII, many participants talked about presentations which were characterised by anxious parents holding erroneous health beliefs about their child and seeking unnecessary medical input, often resulting in negative consequences for the child such as over-investigation. One participant referred to it as the 'grey area'. According to the recent literature, parental behaviours such as these, which have a negative impact on the child, fall under the definition of FII (e.g. Davis et al., 2019). However, paediatricians in the present study conceptualised this in a variety of ways, with some referring to this presentation as a form of FII, some seeing it as different from FII and more in the category of MUS, and others seeing it as 'somewhere in the middle' or 'a bit of both'. Participants who described cases related to this concept (mainly consultants and more experienced

trainees) said this type of presentation is much more common in medical practice than ‘classic’ FII, and often driven by parental anxiety.

“I think true FII is pretty rare, the salt in the milk... I think there’s a much more complicated greyer area that we see hugely, which is an anxiety-induced framework around symptoms where it is hard for families to see symptoms for what they are and to respond in an appropriate manner. This ends up creating over-medicalisation around symptoms that then exacerbates them rather than moderates them, in a way that another parent who parented in a different manner may do. Which of course is almost certainly fuelled by the parent’s anxiety and parent’s ability to parent...”
(P02, Consultant)

When asked about how this presentation could be categorised, one trainee described parents’ behaviours as ‘inappropriate help seeking behaviours’, and highlighted the emergence of an unhealthy relationship between families and medical services.

“[They are] inappropriate help seeking behaviours. ... It’s very unusual to have a formalised diagnosis of fabricated or induced illness, it often gets raised as a potential concern long before that stage. People have been saying I’m concerned that they’re attending to A&E too often. Or I’m concerned that the parents’ dependence on medical services is very inappropriate.” (P06, Trainee)

All participants who discussed cases falling into this ‘grey area’ were concerned about the impact of this type of behaviour on children. They talked about the disruption of multiple A&E attendances, hospital admissions and medical procedures, and the distress associated with moving repeatedly between different health professionals and services. Many participants described cases of children whose symptoms progressively worsened over time, with negative impacts on functioning. Common examples included children attending A&E on several occasions over weeks or months, initially presenting with symptoms such as limb pain and paralysis with no

apparent organic cause. The negative consequences of this as reported by participants included loss of function in limbs, wheelchair use, assisted feeding, bathing and toileting, becoming bed-bound, poor school attendance and/or school removal.

“This is a kind of emotional abuse, because this poor child is growing up having to forever listen to her mother talking about how terribly ill she is and how there's clearly something wrong with her.” (P09, Consultant)

2.0 Factors Contributing to MUS and FII

2.1 The role of the parent. Participants described how in cases of MUS, parental actions could have a significant impact on the child. Parental approaches might vary from persistence in the search for an organic cause (seen more commonly), to disbelieving the child and dismissing their symptoms altogether.

“Sometimes the parents are their key collaborators ... and sometimes they are there disagreeing with their child in front of you, and both of those can be really harmful I think.” (P06, Trainee)

A frequent theme across the MUS and FII cases discussed was the role of parental anxiety and an inability to tolerate feelings of worry about the child's unexplained symptoms. Some participants alluded to a 'snowball' effect of anxiety, whereby the parent and child become interlocked in an unhelpful interaction, which in turn increases the distress associated with the symptoms.

“Her mother took all of her symptoms extremely seriously – she felt that they all needed investigations and was quite resistant to the idea that there might not be a medical cause. That in a way led to a cycle between her and her daughter of increased anxiety around these symptoms. And as the anxiety increases, the symptoms become more and more real.” (P07, Trainee)

Overall, a parent's response to a child's symptom was seen to influence both the child's own experience of the symptom, and the subsequent series of events. Many participants suggested that in general, different parenting styles are likely to lead to different outcomes for children.

"If you've got abdominal pain and your mother says 'oh well don't worry I'm sure it's fine, go to school', then off you go to school and you live with a little bit of pain. But if that same child's mother said 'oh gosh, my grandmother died of cancer, what if she's got cancer', and they start going to the doctor... and then they want the test to be done. And then by the time they get what they want, they might have seen three or four doctors, and by that time they've missed some school, and the young person's pain is worse because it's being concentrated on. You can get into a really dangerous spiral there." (P12, Consultant)

Participants also mentioned cases of MUS where the symptoms seemed to be driven more by the child, and the parents played less of a role.

"I had a child [with MUS] who dropped out of school. And the mum was pretty desperate to get him back to a normal life – the child definitely drove a lot of that resistance. In that situation the mum wasn't exaggerating things ... I always wondered if that child was being bullied and it just never really came out." (P13, Consultant)

Fewer of these cases were discussed, however, as most featured some degree of parental input, particularly in cases involving children of primary school age or younger.

2.1.1 Parents' response to doctors. In terms of their response to doctors, participants said in some cases parents were satisfied with the doctor's reassurances.

"I just spoke to Mum and reassured her. She was happy with that, because as long as she knew that nothing serious was wrong she was happy." (P14, Trainee)

In most other case examples discussed, however, participants reported that parents were often dissatisfied with responses from medical teams, and sought further opinions to try and shed light on the cause of their child's symptoms.

"They [the parents] kept on coming, kept on wanting answers. ... And they weren't happy [with doctors' reassurances]. So, the outcome in the end was a large argument, fortunately I was in A&E so I kind of passed them on and then paediatrics dealt with it." (P14, Trainee)

Participants expressed concern that this could lead the child to collect multiple diagnoses, which could perpetuate the view that symptoms reflect an underlying serious illness, and in many cases lead to significant negative consequences for the child's education, quality of life and general wellbeing.

2.1.2 Personality characteristics of parents. The characteristic of a 'controlling' parent was a common theme branching across MUS and FII, along with the suggestion that some children might feel 'overwhelmed' by their parents.

"Overlying it all she has a mother who is very controlling. ... My feeling is that a lot of the girl's symptoms are being played through her by her mother. The mother has a mental health issue herself, and this young woman is under her total control. She is clearly overseeing, and definitely manipulating, the situation." (P08, Consultant)

Some participants noted that a common theme observed with parents of some children presenting with MUS is their regimented approach to managing their child's 'busy' lifestyle, and implied that the child's symptoms might emerge as an effort to escape from the pressures of everyday life.

"You see the parents that want their kids to go to a million classes ... the very systematic controlled kind of family where, you know, Mondays they have this, Tuesdays they have this, Wednesdays they

have this. ... Those children then turn around and in their own way, don't want to go.” (P03, Trainee)

One consultant talked at length about the level of anxiety in the room when meeting families presenting with FII, and emphasised how ‘draining’ it can often feel for doctors to manage these types of cases.

“I’m strong enough to deal with these patients, and sometimes it just becomes overwhelming. ... If this woman makes me as a X year old, very experienced paediatrician, feel like that, can you imagine [what it must be like for the child] living with it 24/7?” (P05, Consultant)

In cases of FII, other common descriptions of parents included ‘angry’, ‘aggressive’, ‘overbearing’ and ‘demanding’, who could be ‘forceful’ in their requests for medical investigations. Some mentioned parents with a medical background, describing them as highly knowledgeable about their child’s ‘illness’ and directive when requesting the treatments they felt their child should receive.

2.1.3 Factors contributing to parents’ behaviour. Several possible reasons were put forward as to why parents might engage in the behaviours described above. Some participants suggested that parents might find it difficult to acknowledge the role of psychological factors in their child’s unexplained symptoms, fearing it could reflect negatively on their parenting. In cases where parental actions or behaviours were thought to contribute to the child’s symptoms, many participants gave seeking ‘attention’ as a potential driving factor, and suggested that being attended to by multiple health professionals could feel comforting or bring about a ‘buzz’ for some parents.

“[Some parents] enjoy the process and the structure in hospital investigations, and the attention and label that goes alongside having a significantly sick child.” (P06, Trainee)

A number of participants also mentioned mental health difficulties such as personality disorder or depression, together with social isolation, ‘strained’ social circumstances and a lack of supportive older family members such as grandparents as factors that might affect parental behaviour. Some spoke about a parent’s ‘search for purpose’, and the satisfaction that might be derived from caring for their child.

“I think it gave her an identity, actually, in a way that maybe she didn’t have ... she was very isolated and that this was a mechanism that she’d found to be engaged. So it gave her a role as carer.”
(P06, Trainee)

One trainee spoke about how the unmet needs of the parents might be met via the child, as for example being the subject of doctors’ interest might increase a parent’s sense of worthiness or value.

“[It’s an] unmet psychological need... a need to feel important or valued, or to be heard and understood.” (P15, Trainee)

Some consultants said that in cases where parents play a role in maintaining the child’s symptoms, there often appears to be an enmeshed relationship between child and parent. A few said they have witnessed unexplained symptoms develop in some parents themselves as well as in their children, such as at key transition points involving separation. Two consultants described how the child’s symptoms, or the parent’s emphasis on symptoms, could inadvertently function as a way to keep the parent and child together, and how this appears to be driven by parents’ underlying separation anxiety. One consultant described cases of children with symptoms like constipation that seemed to be in the context of feeling ‘stuck’ in their lives, and in particular, stuck in their relationships with their mother.

“I see it all the time, that parents come to a big time in the child’s life, and they just are unable to separate. ... It’s nearly always the

mothers who have the issues. These mothers finally let go, and the functional problems [in both parent and child] disappear.” (P05, Consultant)

Interestingly, participants focused more on cases involving mothers, and cases involving fathers or other carers were rarely discussed. Participants suggested that in most cases where ‘parents play a role’ the motivation is usually unconscious and that parents are not really aware of the reasons for their behaviour, although in some cases of FII, parents might have more awareness.

2.2. The role of the doctor. Not only did participants talk about the part parents can play in perpetuating children’s symptoms, they also emphasised the role of doctors and the possibility of iatrogenic harm. Participants explained that consultants usually lead decisions about the degree to which children should be investigated, with one consultant highlighting the potential negative impact of holding such power.

“The medical profession are guilty of playing a big part in it. Instead of reassuring, they’re buying into what they think the patient wants.” (P12, Consultant)

Many participants said they frequently witness over-investigation in multiple settings, and described how important it is not to be drawn into a ‘relentless search’ for a rare diagnosis. A few emphasised that psychosocial factors are far more likely to play a role in children’s unexplained symptoms than rare diseases, and expressed frustration about doctors becoming caught up in seeking the rare diseases.

“I’m trying to help my paediatric colleagues stop doing the test. It’s when you catch wind of the fact that, you know, the kid with abdominal pain and divorcing parents and falling out of school is onto their third biopsy. Like please, stop you know? Because my colleagues are completely awesome doctors. If there was anything wrong with my kid I’d want them to see them. They’re doing all of

that because they worry so much they're missing something. ... If you look at the statistical likelihood of them picking up some bizarre gut neuropathy, versus the statistical likelihood of this child having tummy ache because their parents are divorcing ... the chances of the bizarre neuropathy are so slim. But people still carry on chasing those things!" (P02, Consultant)

Another consultant explained how doctors' actions can fuel the belief that an organic cause is yet to be identified, which can be counterproductive in the long run by helping to maintain the cycle of help-seeking and over-investigation.

"By constantly referring them to other specialists and doing more and more tests, I think you're perpetuating in their mind that you think there's a medical diagnosis to be found here." (P19, Consultant)

Some also spoke about their own tendency to over-investigate, explaining their desire to satisfy parents and address any fears.

"I think it's very easy, because you want to be helpful, you want to try and address parents' concerns, and so you can land up going down a route of lots of investigations" (P04, Consultant)

Trainees expressed a range of views about the ways that cases are managed by senior colleagues, and said they try to learn from consultants who they feel manage cases well. A few, however, gave examples of when they disagreed with the management approach of a consultant, but felt powerless to influence the outcome.

"The final decision [about investigations] tends to come from our consultants who are the boss. ... If you've got that gut feeling that there isn't an organic cause, then it can be a little bit frustrating sometimes, as maybe they haven't seen the patient, so they haven't got a real feel for the case in the same way that you have. But it's hard to go against the word of your boss." (P07, Trainee)

Generally, most participants, particularly consultants, said that over time and with experience, they investigate less. A few talked about having a ‘gut feeling’ about whether symptoms require further investigation.

“I’m not a very knowledge-based doctor, I’m quite an intuitive doctor. So if there’s something that’s ringing alarm bells, or something that just doesn’t quite fit, those ones I’d be more inclined to investigate. ... Having worried about it a lot at the beginning thinking ‘am I just missing anything’, actually not very many patients come back, it’s pretty rare. I think how I’m working is fine, because actually most children do just get better.” (P13, Consultant)

Sadly, however, participants gave several examples of cases where children had undergone, or had come close to undergoing, unnecessary invasive procedures such as MRI scans, endoscopies or major surgery for unexplained symptoms. A few participants mentioned cases of children who had either had, or were due to have, percutaneous endoscopic gastrostomy (PEG) tubes¹ inserted into their stomachs, or total parenteral nutrition (TPN)² set up to aid with feeding, only to later discover that the children did not have organic gastric difficulties. These were subsequently identified as severe cases of FII characterised by abuse and neglect, sometimes with parental mental health difficulties intertwined with other family difficulties. Participants expressed significant concerns about the impact of such interventions on the child and the level of distress such procedures are likely to induce.

“The child very, very nearly had an operation to put a surgical feeding tube in place that they never needed. ...I felt relief that this really difficult cycle had been broken, alongside surprise and alarm that we hadn’t known sooner.” (P06, Trainee)

¹ A method of inserting food directly into the stomach via the abdominal wall.

² A method of feeding that bypasses the gastrointestinal tract, and usually involves the insertion of a catheter into a large central vein via the chest.

2.2.1 Factors contributing to doctors' behaviour. A fear of missing something serious was identified by many as a driving factor behind over-investigation. Some consultants said that previous experiences of missing organic disease has led them to be more cautious. In addition to this, paediatricians spoke about how the nature of medicine encourages doctors to seek answers and causes, meaning doctors are accustomed to searching for definitive diagnoses.

"It's quite difficult to take that step back, I think, particularly for the specialist teams who see organic pathology every day and are desperate to find that. It takes a different mindset I suppose, and a change of approach, to think maybe we should stop doing tests and maybe there's not a clever answer that I can cleverly discover."
(P06, Trainee)

Several paediatricians highlighted the discomfort associated with disagreeing with families or 'saying no' to their requests, with one participant saying that by not carrying out investigations, it might imply that families are not believed. A few said it can be easier to 'go along' with the wishes or demands of the family and colleagues rather than introducing an alternative perspective.

"I think it's like anything in life, I think people really avoid challenge. And so it's just so much easier to collude with parents, and collude with patients, and collude with other doctors, because if you stand up and say something it's akin to being a whistleblower, you're really exposing yourself." (P05, Consultant)

2.3 Other contributing factors.

"MUS very rarely happens to happy children and families." (P06, Trainee)

Suggested psychological and social factors occurring in the child which could contribute towards MUS included anxiety, depression, loneliness, stress and general unhappiness. Many participants mentioned the possibility of MUS resulting from

trauma or child abuse, in particular sexual abuse. Social difficulties in the family, parental ‘mental health problems’ or difficult family dynamics were also suggested by many participants as possible factors, as well as bullying, school avoidance, parental separation, bereavement and illness in the family.

“Could this be a manifestation of stress, could this be a manifestation of a mental illness, could this be a manifestation of something that’s going on at home...” (P20, Trainee)

Several participants suggested that an unstable or unhappy home environment might lead some children to seek comfort from caring professionals in alternative settings like hospitals, particularly if the care they receive from medical staff is at odds with their usual experiences of care.

“If you’re a child from a happy well family, your hospital appointment where someone’s quite nice to you is probably not that big a deal. But if you’re a child going through all this trauma and where there’s very little stability, sometimes it can become quite a fixation.” (P06, Trainee)

Others described the safety and structure provided by hospitals, particularly for children with a strained home environment.

“I think she felt safer being where she was, in that ward, than maybe when she was at home. ... I think she enjoyed being in that role.” (P16, Trainee)

From a psychological perspective, a few paediatricians described how the level of attention the child pays to a symptom can influence their experience of the symptom, and how this can be significantly influenced by parental responses. Several others said how difficult it can be for some children to express their emotions verbally, and how MUS could be a manifestation of emotional distress being expressed via the body. A few cases were described where children confided in the doctor about how

they felt unable to express their anxiety or sadness at home for fear of upsetting their parents. A few also mentioned cases where children showed a good level of insight into the cause of their symptoms, and voluntarily suggested that worries or stress could be behind their MUS.

“Another young person was quite worried about her exams. So, she thought that some of her symptoms, change in her appetite and some of her headaches, were probably part of that stress and anxiety.” (P15, Trainee)

3.0 Approaches to Management

3.1 Approaches to investigations. Most trainees said they usually conduct baseline investigations initially in order to rule out serious illness. These might include blood tests and imaging.

“Because it’s quite dangerous to see a child and say ... this is a physical manifestation of a psychological... You’d have to make sure it’s not appendicitis, or gastroenteritis. I would go from the more serious ones first. That’s how I, and a lot of my colleagues, work, we rule out the serious things first.” (P20, Trainee)

The reported level of investigations differed, with some consultants and trainees saying they only organise investigations if absolutely necessary because of the potential for associated distress.

“When you’re a small child everything is a big deal. I think sometimes people forget that even just doing the blood on a primary school age child is a really horrible thing for them to experience. They hate it and they talk about it for a long time afterwards.” (P13, Consultant)

A few trainees mentioned that if tests are ‘normal’, they tend to reassure the family and ‘safety-net’ by encouraging them to ‘keep an eye’ on symptoms and return if any serious ‘red flag’ symptoms emerge. They said some families are satisfied with

this response, whereas others push for further investigation. Common approaches reported by trainees included reassuring families that ‘everything is fine’ and ‘there is nothing wrong’.

“It’s like an everyday practice, they just come in with a complaint... um... and we just clear them. As in, we say for example, no more pain, bloods are fine, everything is fine.” (P18, Trainee)

3.2 Exploring psychosocial factors. The majority of trainees reported that they tend not to explore psychosocial aspects of a child’s life, mainly because they do not have the time. This was particularly the case in busy settings like A&E.

“There were some psychological components in the history. But from a medical point of view, no one really gets into it. We don’t properly investigate this part, to be honest. Well, I haven’t seen it being done, so I don’t know.” (P18, Trainee)

However, a couple of the more experienced trainees said they now feel more confident in asking about the context around a young person.

“My training in safeguarding [has given me] ... the confidence to ask parents to leave the room, to speak to young people on their own, and to explore other aspects of health and well-being, about education, employment, drugs, alcohol, all of those fun things.” (P15, Trainee)

Of the consultants who were asked this question, most said that they ask about psychosocial factors to some degree (although this varied), and some said they might also suggest possible links between psychosocial factors and symptoms. Some consultants explicitly said that they consider the exploration of psychosocial factors to be an important part of a paediatrician’s role.

“I think the body and the mind is a complete thing. ... When you are looking into MUS it’s very important to make sure that you have a good understanding of the whole environment for the child,

to know if there is anything happening that you need to be worried about.” (C01, Consultant)

Two trainees described cases of teenage children who had life-threatening illnesses accompanied by anxiety and unexplained physical symptoms. In both cases, a medical approach was taken to address their MUS, and any discussions about psychological factors ‘left to’ psychiatry or psychology.

“Eventually, we just stopped talking about it [the anxiety] to her and focused on the cancer side of things ... the psychiatry team would come in and try to focus more on that. We also don’t want to feed the issue, asking her all those things all the time.” (P01, Trainee)

In one such case, a trainee held back on sharing with a child the team’s hypothesis that anxiety might have been driving the child’s unexplained heart palpitations, and instead focused on monitoring the child’s physical sensations.

“I think it’s quite hard to tell a patient that they’re anxious. ... For example in this case, I said, you’re in hospital, we’re keeping a very close eye on your symptoms, and actually let us do the worrying about it. ... We’re here and we’re always watching, and if something happens we know what to do. ... Just that act of just putting my stethoscope on his chest helped him to feel reassured” (P07, Trainee)

Consultants generally appeared to be more confident than trainees when discussing possible psychological factors related to MUS. Some consultants gave examples of analogies they use to explain MUS to families, and one said they find it helpful to ‘empathise’ with families by using themselves as an example.

“A very easy example to use with families is: so when I’ve taken an exam, I might feel my heart beating, I might be aware of my palms being a bit clammy, I might get butterflies – these are all physical symptoms, from my stomach, from my hands, from my heart. But they’re not due to a disease, they’re due to my state of mind affecting my body.” (P19, Consultant)

Overall, participants described varied reactions from families in response to discussions about psychosocial factors. Many participants reported that families often react negatively to the suggestion that psychological factors might be contributing to their child's symptoms, with some suggesting that parents might see it as a criticism of their parenting.

“So as soon as you talk to these families about the stress and anxiety being linked they automatically go into denial mode that any form of stress can cause a problem. And quite often these kids are in fact children who don't display stress terribly much, because they're talking with their bodies. So when their families say to us 'oh they're never stressed', you're like no dead right, you never see them being stressed because their stress is coming out through their tummy ache! It's not rocket science. But it's quite hard for them to conceptualise that ... they leap to the idea that [you think] they've got a significant mental health problem.” (P02, Consultant)

3.3. Managing potential FII. Of the few participants who discussed their approach to managing cases which potentially involved fabricated or induced illness, keeping a detailed record of all investigations and test results was suggested, with one trainee suggesting that records be shared with parents to demonstrate the medical perspective. One consultant highlighted the importance of trying to de-escalate any anxiety rather than becoming caught up in the vicious cycle of investigation, and being aware of the tendency for families to 'split' hospitals and teams. Empathising with anxious parents and gently proposing a possible psychosocial reason for symptoms, such as separation difficulties or anxiety in the family, was suggested.

“I think it's acknowledging her anxiety that in a way doesn't make her feel blamed, which is just saying, 'it's is just really tough being a mum'. ... And to get her to acknowledge that yes, she is quite an anxious person.” (P11, Consultant)

All doctors who mentioned FII emphasised the importance of teamwork, and sharing information and ideas with colleagues, the wider multi-disciplinary team (MDT) and other services. The majority said they felt well supported by their team, and valued the ability to share any concerns or doubts with colleagues.

4.0 The Emotional Impact of the Work

When discussing these topics, a significant theme that emerged was the emotional impact of the work. The participants expressed a range of emotions associated with working with children affected by MUS and FII, including sadness, anxiety, stress, frustration, uncertainty, helplessness, vulnerability and exhaustion. Some spoke about feeling overwhelmed by such cases, and some of the consultants said they endeavour to see patients in pairs or enlist the support of other colleagues within the MDT to help manage some of the anxiety in the room.

“I think you can only do a certain number of these cases at a time, cos they’re very draining, very overwhelming.” (P05, Consultant)

“They all do [stick in my mind], because they’re so difficult to cope with. ... It’s really hard, and the only way to do it is to talk amongst colleagues... to talk. Share.” (P11, Consultant)

One trainee described the strong feelings projected by some patients, and the emotional impact on the doctor.

“You would reflect a lot of his emotions... you would come out and you would feel really depressed... You would feel really low after spending 15 minutes with him... you would feel awful...” (P16, Trainee)

Overall, participants described both MUS and FII as challenging presentations, with one experienced consultant describing these as the most challenging type of cases

they encounter, above and beyond other presentations like meningitis which have a clearer approach to management.

“I think it’s the FII cases that worry me more, and I think about them more.” (P17, Trainee)

Importantly, one consultant emphasised that when working with MUS, it is helpful to recognise and make peace with one’s own limitations as a doctor.

“I think one of the anxieties or challenges that we have as a doctor, is that maybe we... think you can be God – think you can do everything, diagnose everything, but you can’t. It’s trying to realise that we do have feet of clay. ... All we can do is the best of our abilities. ... I think we have to realise we can’t do everything, we can’t cure everything, we can’t make everything better.” (P08, Consultant)

5.0 Services and Training

5.1 The role of psychology. Several participants spoke about the potential role of psychology in helping children affected by MUS and FII, whether that be via local CAMHS or paediatric liaison teams situated within hospitals. Consultants and trainees further into training had the most experience of referring to or working with psychologists, whereas less experienced trainees said this is usually beyond their remit.

“I’m not really aware of what they’re doing when we get to the point that we have to involve the psychologist. It’s mostly a consultant-led decision to be honest. And when it happens we’re not actively involved, unless it’s like something very serious and it needs medications or something like that.” (P18, Trainee)

Some trainees expressed surprise at having realised how often CAMHS involvement might be indicated for MUS and FII presentations.

“You go into medicine, and you think it’s all going to be facts and figures really, but there’s a lot of grey areas which I personally am not that experienced with. And the number of times that we get

CAMHS involved, there's a lot more, in terms of percentage, than I thought." (P03, Trainee)

Many consultants who talked about the value of CAMHS or psychology input and the high demand for these services, as illustrated by one response to a question about whether any of their patients affected by MUS or FII might need psychology involvement.

"In these situations, pretty much they all need it." (P08, Consultant)

Some consultants also spoke about the advantages of meeting families together with a psychologist or mental health professional in the room, with one saying this could help paediatricians adopt a more psychologically-minded approach. However, many consultants also said it can be challenging for families to engage with the idea of psychological support, as often psychology input occurs in a different location or team, and also because of the perceived stigma associated with having a mental health difficulty and the fear that the paediatrician may no longer be closely monitoring physical health issues. One consultant described how paediatricians might be left managing tricky cases without the support of other health professionals.

"I think part of the real problem with MUS, and the thing that I find quite stressful, is that families are so unwilling to engage in CAMHS type work that you often end up being the only person as the medic seeing children." (P09, Consultant)

A trainee highlighted the importance of timing when introducing discussions about mental health or possible psychological factors.

"Sometimes over-investigating without bringing the psychology side in early, can sometimes make it difficult to break down some of those psychological barriers that might be feeding into the pain." (P20, Trainee)

Many also expressed frustration about the divide between mental and physical health services, with some not only highlighting families' resistance to integrating mental and physical health, but also the barriers inherent within the system.

"It can be immensely frustrating that we don't have better provision and diagnostic frameworks. I'm frustrated that we don't treat physical and mental health together, that there's still this annoying divide and people have such an allergy to recognising the mental health component for what it is, which is part of their body, you know it's part of their mind and how it works. We should call it brain health or something." (P02, Consultant)

5.1.1 Multi-agency working. As well as these barriers, participants also expressed frustration with accessing social care services, particularly because cuts to hospital social work provision and differing risk thresholds might prevent cases of FII from being picked up early enough, if at all. One consultant emphasised the need to be persistent with social care referrals.

"As I've become more senior, I'm much more forceful than I was before. You have to actually say to social services, you have to do this. When we finally got them onto the child protection register, the chair of the case conference said 'why haven't these children had a [child protection] plan before? I cannot believe this family has reached this point and they haven't had a plan'." (P11, Consultant)

Some paediatricians suggested involving psychologists earlier, and carrying out joint assessments or delivering physical health, mental health and social care 'under the same roof'.

"I wouldn't start from here. I'd organise a completely different system to look after these kids and be much better resourced and have much more time. ... For me, the key goes back to this multi-agency working that we're all in the same place at the same time so that we don't end up having to refer on and then waiting six months and then not hearing the fruits of that work and then things all falling through the net." (P02, Consultant)

Several participants noted how the current system involves long waiting times and results in many patients ‘falling through the net’.

“I do think that if we could do joint assessments ... I'm the bait to get people into the clinic, basically, as the doctor that's not going to miss anything that's medical. [The barriers are] time and money. I think that CAMHS is massively, massively, massively underfunded. ... And actually, I think there's not a reluctance from professionals to do it, I think as paediatricians we would love to have someone from CAMHS there. And I don't want to put words into their mouths, but I think they would really like it too.” (P09, Consultant)

5.2 Training. Most participants said they had received very little training about MUS and FII throughout their careers.

“I've never... had teaching. It's not really been discussed, like formally, in handovers or by our seniors. Whatever I've said [in this interview] is just from my own experience...” (P18, Trainee)

“I don't really feel that confident in speaking to patients about it because I've not had that much experience in it” (P01, Trainee)

The majority had received no training at all, whereas a few had encountered the topic of MUS at some point during medical or paediatric training, and FII within paediatric safeguarding training. A few trainees had discussed these topics at educational seminars run by consultant paediatricians, and several experienced paediatricians said they have delivered training about these topics, or that the topics might arise as part of training they deliver about other subjects.

Most trainees said they would like further training, as they felt under-confident when managing MUS or knowing what factors might indicate FII. Most consultants said they have become more confident with managing these presentations over time, although several said they feel generally under-confident due to the challenging nature

of the client group and unclear treatment pathways. Overall, participants said they would like to be better able to support children and families.

“It’s a very interesting area, because now I’m realising how many patients we’re discharging home and we’re not sure what is going on, and there might be something underlying, not medical. And we’re not really addressing these problems.” (P18, Trainee)

Discussion

This qualitative study draws attention to paediatricians’ views and experiences of managing medically unexplained symptoms (MUS) and fabricated or induced illness (FII) in children and families; in particular their conceptualisation of the topics, views about contributing factors, approaches to management and some of the associated challenges. Importantly, this research emphasises the central role held by paediatricians, and a clear need to increase awareness and improve training about MUS and FII in order to promote optimal care for children and young people.

Participants’ views that MUS encompass symptoms not clearly linked to organic pathology corresponds with commonly used definitions (e.g. Henningsen et al., 2007). Participants emphasised the need to acknowledge the reality of patients’ symptoms, an approach which is also described in the literature (Hubley, Uebelacker & Eaton, 2016). In accordance with definitions of FII provided by official guidance (RCPCH, 2009), participants stated that the contributory role of a parent or carer is a defining factor.

The main difference between participants’ conceptualisations and the definitions provided in the literature occurred in their categorisation of a common presentation characterised by parents’ anxiety and erroneous health beliefs about their child’s symptoms, together with persistent inappropriate help-seeking behaviours.

Interestingly, although within the literature this type of presentation is now seen as a form of FII due to the harmful impact on the child (Davis et al., 2019; RCPCH, 2009), a number of paediatricians did not categorise this presentation as FII, with some seeing it as MUS or falling into a ‘grey area’ between the two. This finding highlights the ambiguity inherent in the definitions of these terms and the ways in which they are interpreted by clinicians. It seems difficult to identify which ‘category’ presentations fall into, as the definitions of the categories are not so clear-cut. Some paediatricians’ unwillingness to categorise parents’ inappropriate help-seeking behaviours as ‘fabricated or induced illness’ could reflect discomfort in the use of the label, as this term (or ‘Munchausen Syndrome by Proxy’) could be seen as having connotations of causing deliberate harm to a child, and potentially serious consequences for parents and families including social care involvement and child protection proceedings. The understandable confusion over categorising FII raises the question of whether some of these cases of FII might be at risk of being overlooked or missed. If cases within this wider range of FII are being categorised by some doctors as MUS, it also provides support for the suggestion that FII is more prevalent than currently indicated.

In their case discussions, participants emphasised the role of the parent, and in particular, the role parental anxiety can play in maintaining a child’s symptoms. Some studies suggest that disproportionate parental concern about symptoms can contribute to MUS (Lackner, 2005), and that if this concern results in harm to the child, it becomes FII (RCPCH, 2009). Much like in the current study, nurses participating in the qualitative study by Furness et al. (2009) also emphasised their observations of parents reinforcing unexplained symptoms, and described the unhelpful impact of ‘unusual’ behaviours, such as insistence on the unnecessary use of a wheelchair.

Participants highlighted the risks of over-investigation, and other studies have also identified this form of iatrogenic harm as an issue pertinent to MUS (e.g. Konnopka, Schaefer & Heinrich, 2012) and FII (e.g. Bass & Glaser, 2014; Glaser & Davis, 2019). They described how doctors and other health professionals can unintentionally play a harmful role in the maintenance of symptoms by searching for an organic cause, a problem commonly highlighted within the literature about MUS (Ring, Dowrick, Humphris & Salmon, 2004; Salmon, Humphris, Ring, Davies & Dowrick, 2007) and FII (Davis, 2009; Watson, Eminson & Coupe, 2000). Although psychosocial factors were mentioned by many in their definition of MUS, several paediatricians talked about pursuing potential medical causes before considering the possible role of psychosocial factors, and most trainees said that exploring psychosocial factors is not within their remit. Some trainees spoke about actively avoiding discussions about psychological factors for fear of ‘feeding the issue’, whereas overall, the consultants seemed more confident in asking about psychosocial factors and suggesting possible links to symptoms. Guidance for doctors managing adults suggests that in cases where MUS seem a possibility, it can be helpful to introduce a range of possible explanations for symptoms as early as possible, and prepare patients for the possible outcome of a normal test result (Hatcher & Arroll, 2008). If results are normal, validating the reality of symptoms for the patient rather than implying that nothing is wrong is important (Chew-Graham, Heyland, Kingstone, Shepherd, Buszewicz, Burroughs & Lamahewa, 2017), and then discussing possible explanations for symptoms that make sense to the patient. These should acknowledge the contributions of any relevant physiological, psychological and social factors (Burton, Lucassen, Aamland & Olde Hartman, 2015).

Guidance states that where FII is a concern, early communication amongst teams and with other services reduces the risk of iatrogenic harm, and that MUS and FII should not be addressed as a ‘diagnosis of exclusion’ (Davis, 2009). In the present study, most paediatricians said they would feel able to discuss concerns within supportive teams, although some described cases where they felt FII had not been identified early enough. Participants said it could be difficult to escalate concerns to other services like social care due to differences in risk criteria, highlighting an important barrier within the system and another potential source of harm to the child.

Emotions described by paediatricians in this study such as frustration, anxiety and uncertainty are echoed in other studies examining doctors’ experiences of managing MUS in adults (Salmon, Peters & Stanley, 1999; Wileman, May & Chew-Graham, 2002; Yon et al., 2015). In the present study, participants acknowledged the ‘difficult’, ‘demanding’ and ‘challenging’ nature of the work, findings similar to the reported experiences of doctors and healthcare professionals managing MUS in both adult and child populations (Glazebrooke et al., 2009; Hartz, Noyes, Bentler, Damiano, Willard & Momany, 2000). The study by Furness et al. (2009) identified professionals’ feelings of powerlessness and frustration when working with children experiencing MUS and their families, which are again similar themes to those reported by the paediatricians in the current study. In addition, in the current study some participants described feelings of sadness about some patients, and one expressed ‘surprise and alarm’ that a case of FII had not been identified sooner. It is important to recognise that professionals themselves can experience emotional trauma when they realise that they (in all good faith) might have unintentionally contributed to the cycle of harm in cases of FII (Lazenbatt & Taylor, 2011). This can include feelings like guilt or anger, or in some cases distressing symptoms such as flashbacks (Horwath and Tidbury,

2009). It is therefore essential that appropriate support structures are put in place following incidents of FII in order to provide staff with the opportunity to process their emotions and any feelings of devastation, particularly in circumstances where children have died as a consequence of FII (Morrison, 2001).

Clinical and Educational Implications

This research has important clinical and educational implications for paediatricians working with children and young people affected by MUS and FII. Most participants reported having had little training in these areas, an issue acknowledged by other studies looking at the amount of teaching provided for doctors about MUS (Howman et al., 2012; Yon et al., 2017; Yon et al., 2015). This study highlights how paediatricians' conceptualisations of MUS and FII might impact upon their practice, and draws attention to the need for further training and clearer guidance about these topics for all paediatricians working with children to alert them to the defining features of MUS and FII. In light of the varying definitions of the topics given by participants, it could be helpful for future guidance to explicitly emphasise the harmful impact that cases of FII driven by parental anxiety and erroneous health beliefs can have on a child (Davis et al., 2019). Guidance could therefore indicate that when assessing for FII, paediatricians should focus on evaluating the impact of parental behaviours, and less so on the underlying motivation.

The participating paediatricians also highlighted the barriers to accessing psychological and social care support for young people affected by MUS and FII, identifying issues around stigma, referral pathways, waiting times and service provision. Consultants raised these issues more so than trainees, perhaps as it is usually their responsibility to manage ongoing cases and organise appropriate support.

Provision varies depending on location, with one study reporting that only a third of London hospitals had access to paediatric liaison services (Woodgate & Garralda, 2006). The CAMHS teams who provided these services reported that 78% of outpatients and 43% of inpatients required support with ‘somatoform disorders’, evidence which supports the views expressed in this study that a large number of children affected by MUS or FII could benefit from some form of psychological support. This needs to be made more available and accessible, ideally in a multi-agency format as suggested by participants.

Research Implications

Following on from this study, it would be helpful to further understand paediatricians’ and other health professionals’ conceptualisations of these topics, in particular their understanding of the ‘grey area’ characterised by anxious parents holding erroneous beliefs. Participants in this study spoke mainly about cases involving mothers, and less about fathers or other carers. It would be interesting to explore whether gender or being a parent influences how paediatricians conceptualise cases.

It is important to note that this current study provides a one-sided account of MUS and FII from the clinician’s perspective, so conducting qualitative interviews with the parents and children falling into this ‘grey area’ category could also shed light on families’ perspectives. Understanding more about the role of psychology and clinical psychologists’ views about the way these cases are managed would assist in formulating an overall picture of the best way of integrating the care provided by physical and mental health professionals involved in such cases.

In addition, research to improve the clinical and supervisory support provided for paediatricians managing MUS and FII is needed. For instance, it would be helpful to understand if adequate support is in place for professionals involved in cases of FII, as the work can have a devastating impact on all those involved (Horwath and Tidbury, 2009). Clearer information about the amount and type of training currently provided for paediatricians about MUS and FII would also enable targeted improvements to be made to teaching programmes.

Work is also needed to improve the therapeutic treatment interventions offered for children affected by MUS and FII. This would need to address the current barriers to accessing appropriate medical, psychological and social care.

Strengths and Limitations

This study summarises the views of twenty consultants and trainees in this first-known study of paediatricians' experiences of managing MUS and FII. The research gives a comprehensive overview of multiple factors relevant to patient management, including not only paediatricians' views about the subject area, but also their reported approaches to management and perceived barriers to providing appropriate healthcare to children and young people. The participants were forthcoming when discussing their views about these complex and difficult topics, and the challenges faced when managing cases in practice. As well as highlighting paediatricians' significant efforts to deliver optimal care to children and young people, the study shows the need to increase awareness and understanding about these important topics in order to ensure that cases are identified early, managed appropriately and potential iatrogenic harm prevented.

Because of the varying experiences and interests of participants as well as the complexity and scope of the topics, it was not possible to address all aspects of the topic guide in every interview. Qualitative research attends to the phenomenological experiences of individuals. Although it is hoped that this data is a representational generalisation (Ritchie et al., 2014) of the range of views held by paediatricians working with these patient groups, it is important to note that the views expressed in this research study may not represent the views of all other paediatricians within the UK or elsewhere.

Seventy-five percent of participants in this study were female. This is not representative of the gender of those specialising in paediatrics, as currently 53% of doctors registered with the General Medical Council (GMC) under the speciality group of paediatrics are female (GMC, 2019). Furthermore, 20% of participants in this study were from a black and minority-ethnic (BME) background, whereas data shows 36% of doctors registered under paediatrics are of a BME background and 9.5% of unknown ethnicity (GMC, 2019). The information provided about approaches to management was based on self-report and may not be representative of true clinical practice. As participants opted to take part in the study, it is possible that they had a deeper interest in MUS and FII and greater awareness of the topics discussed.

Due to the main researcher's previous experiences of working clinically (Stern, Yon & Kent, 2016) and conducting research (Yon, Habermann, Rosenthal, Walters, Nettleton, Warner, Lamahewa & Buszewicz, 2017; Yon, Nettleton, Walters, Lamahewa & Buszewicz, 2015) in these areas, and special interests in the topics of MUS and FII, it was important to engage in a process of ongoing reflection to consider the impact of these experiences on the current study (McLeod, 2011). This involved

the main researcher taking part in a ‘bracketing interview’ (described by Rolls & Relf, 2006) conducted by three peers training on the DClinPsy programme. This process of ‘bracketing’ helped bring to awareness any existing assumptions, expectations and biases, which intended to reduce the impact of these factors on data collection, interpretation and reporting (Fischer, 2009).

Conclusion

Paediatricians in this qualitative study reported the challenging nature of managing MUS and FII in practice, and identified a ‘grey’ area related to these topics, characterised by anxious parents holding erroneous beliefs about their child’s health and seeking inappropriate medical support. Interestingly, although these presentations fall under official definitions of FII, not all participants categorised them as such. This suggests that cases of FII resulting in potential harm to the child might be overlooked, and highlights the need for further training and clearer guidance about the definitions of MUS and FII and appropriate management techniques. Participants also identified issues including risk of over-investigation and iatrogenic harm, the emotional impact of the work and the barriers children and families currently face when accessing services. Improvements to service provision and more comprehensive training for all paediatricians about these important topics is needed in order to ensure early and accurate identification of MUS and FII, and reduce risk of harm.

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Part 3: Critical Appraisal

Introduction

This critical appraisal offers some reflections on the empirical paper presented in Part II. Reflecting on how one's own values, beliefs and experiences shape a research project, as well as the impact of the work on the researcher, are important elements of any qualitative research study (Berger, 2015; McLeod, 2011). As well as reflecting on the personal elements of the work, it is also important to consider the epistemological standpoint from which one approaches the data, and the ways in which the scientific assumptions made and the process of carrying out the research impact upon how the data is interpreted (Willig, 2013). Here, I will offer personal and epistemological reflections on the research, followed by a discussion of some of the methodological considerations that arose. The critical appraisal concludes with an extended discussion of the clinical, educational and research implications of the work.

Personal and Epistemological Reflections

I was drawn to this subject area because of a special interest in medically unexplained symptoms (MUS). This interest stemmed from working clinically with individuals experiencing MUS (Stern, Yon & Kent, 2016) and in a research context (Yon, Habermann, Rosenthal, Walters, Nettleton, Warner, Lamaheva & Buszewicz, 2017; Yon, Nettleton, Walters, Lamaheva & Buszewicz, 2015) prior to clinical psychology training. From an epistemological standpoint, it is understood that my previous experiences of researching the topic of junior doctors' views about MUS and their approaches to management would likely impact upon my expectations of this research project and the assumptions made about what might be found in the current study (Willig, 2013; Dowling, 2006). It was therefore seen as important to remain aware of the background research on MUS and fabricated or induced illness (FII), as

well as my own personal views on the subject, and consider how these factors might affect assumptions made about the data.

Existing literature suggests that in practice, it can be particularly challenging for paediatricians and other health professionals to manage MUS (Hinton & Kirk, 2016) and FII (Horwath & Tidbury, 2009; Lazenbatt & Taylor, 2011) in children and families. Furthermore, in the already mentioned previous study which I conducted together with my external supervisor and colleagues, junior doctors reported feelings of anxiety, frustration and uncertainty about managing MUS, and noted a significant gap in their training on this topic (Yon et al., 2015). These findings contributed to my own assumption that paediatricians in the current study would likely report finding MUS and FII difficult to work with in practice, and a hypothesis that knowledge or training in these subject areas might be limited.

Addressing biases and assumptions such as these took place in a number of ways throughout the interview process, centring around a process of reflection known as ‘bracketing’.

Bracketing. Bracketing refers to the process of suspending one’s own assumptions in order to reduce the extent to which they impact upon data collection and interpretation (Ahern, 1999; Fischer, 2009). Although complete objectivity is neither possible nor necessarily the objective, as the researcher’s beliefs can be used as a source of insight (Finlay, 2008), it is seen as important to acknowledge one’s own beliefs and remain aware of them throughout the research process (Tufford & Newman, 2012). In the present study, ‘bracketing’ was addressed in a number of ways at the points of data collection, analysis and interpretation. Firstly, when conducting the interviews, I remained mindful of the questions being asked, and in particular, the

prompts used. Care was taken to ask open rather than closed questions in order to avoid leading the participant towards particular conclusions.

Secondly, I engaged in a ‘bracketing interview’ (described by Rolls & Relf, 2006) conducted by three peers training on the DClinPsy programme. This involved a 15-minute interview during which I was questioned about my own views, assumptions and expectations regarding the research. The bracketing interview facilitated the process of reflection by helping to access other unconscious assumptions and values that might have been made. For instance, through this interview it was helpful to notice my own feelings of sadness and frustration about a case of fabricated and induced illness I had been clinically involved in during my child and adult mental health (CAMHS) placement whilst training, and the strong feelings of concern for the child that the situation evoked. By reflecting on this I was able to consciously separate my own views from those of the study participants, particularly when writing the section about the emotional impact of the work. This was important in order to ensure their views were accurately reflected and not influenced in some way by my own thoughts or experiences.

Thirdly, discussions that took place during data analysis meetings with my research supervisors (MB & MW) and the study collaborators (DG & DH) helped with the process of bracketing. This process of triangulation allowed us to challenge each other’s views and actively discuss as a research team the impact of our individual perspectives. In qualitative research it can be helpful to reflect on one’s position as an ‘insider’ or ‘outsider’. An insider relates in some ways to the participant group, whereas an outsider is usually more detached and can hold more of a curious position (Berger, 2015). For instance, some of the team (MB, DG & DH) were ‘insiders’ due

to the nature of their role as medical doctors with past or current experiences of being trainees or consultants in medicine, and also their experiences of teaching about the subjects of MUS and FII. I aligned myself with both the insider and outsider position; the insider position because of my experiences of carrying out research in these areas and being a trainee in an NHS environment, and the outsider position because of my differing professional discipline. As well as having the helpful perspectives of the ‘insiders’, it was also invaluable to have the unique contributions of my main research supervisor (MW), a clinical psychologist, who as an ‘outsider’ looked at the data with a fresh perspective, and was able to question any assumptions that might have been made. For instance, through this process of discussion it was noted that some assumptions were potentially being made about the ‘grey area’ theme noted in the results section, and the meaning of this for participants. The ‘grey area’ refers to cases where the parents were perceived to contribute in some way towards the emergence or maintenance of a child’s symptoms. Most participants mentioned such cases but defined them differently, as some considered them to be FII, MUS or ‘a bit of both’. One described these cases as falling into a ‘grey area’, hence the active decision to stay as close to the participants’ wording as possible by using this phrase in the write up, rather than making interpretations about whether the described cases should be categorised as MUS or FII in line with formal definitions.

Finally, ‘member-checking’ (e.g. Tobin & Begley, 2004) took place by sharing a draft of the results section with two of the study participants. Actively encouraging any comments or suggestions for change helped to ensure that participants’ views were accurately interpreted and represented in the write up.

Methodological Considerations

A target sample size of 20 participants was chosen to facilitate the process of meeting data saturation (Fusch & Ness, 2015). Although saturation of the main themes was met, as the interviews progressed it became clearer that the topic areas of MUS and FII were so broad, and the topic guide so extensive, that meeting saturation for all subthemes would not be possible. Due to time constraints and the variety of participant experiences, it was not possible to cover all of the questions within the topic guide in depth during every interview. This contributed towards the decision not to include quantitative information about the number of participants endorsing every theme, as numerical indicators might not accurately represent all participants' views about a theme.

Because of the large amount of data collected and the broad questions included in the topic guide, there was limited space within the results section to describe each theme in depth. On reflection, it could have been preferable to narrow down the topics covered in the interviews and limit discussions to the exploration of one or two areas of interest, such as views about topic conceptualisation, or views about service provision and the role of psychology in managing MUS and FII. This might have enabled participants' rich experiences to be more fully represented in the write up by reporting these themes in more depth. However, as highlighted by Braun and Clark (2013), the nature of thematic analysis requires the researcher to be decisive in their judgements about which information to include, as it is not possible to cover all findings in great depth. A decision therefore had to be made to report the key themes and subthemes in the empirical paper which were most pertinent to the aims and research questions, particularly as this is the first known study examining paediatricians' views on these topics in detail.

Terminology and Conceptualisation

An aspect of the research process which was particularly challenging related to presenting an accurate representation of participants' conceptualisations of MUS, FII, and in particular, the newly-identified 'grey area'. Participants discussed on average two to four clinical cases per interview, and often the cases discussed were not exclusive to either MUS or FII as defined by the participants or the literature. For example, on several occasions participants were asked for an example of a case of MUS, and when discussing the case would describe features of FII as defined by the literature, such as the parent disagreeing with doctors' conclusions and pressing for further invasive investigations. Furthermore, during their discussion of cases doctors often changed their views about whether the case should be categorised as MUS or FII, or described presentations which fell into the 'grey area' described above. As discussed in the empirical paper, this highlights that there is likely to be some ambiguity in the official definitions of MUS and FII and the ways in which they are interpreted by clinicians. Some paediatricians' unwillingness to categorise parents' inappropriate help-seeking behaviours as 'fabricated or induced illness' could reflect discomfort in the use of the label, as this term (or 'Munchausen Syndrome by Proxy') could be seen as having connotations of causing deliberate harm to a child, and potentially serious consequences for parents and families including social care involvement and child protection proceedings.

In order to address this ambiguity in the write-up, themes emerging from cases which were not explicitly linked to MUS or FII and instead appeared to fall into the 'grey area' have been reported as being associated with presentations where 'the parents were thought to play a role in maintaining the child's symptoms'. It is hoped that this phrase accurately captures the participants' intention to convey the

contributory role of the parents, without making an assumption about which ‘category’ these cases fell under.

Where Next: Future Directions

Clinical and educational implications. As outlined in the empirical paper, this study has multiple clinical and educational implications. The research sheds light on the ways in which paediatricians conceptualise MUS and FII, and how their views might impact upon their practice. For instance, the varied conceptualisations of presentations captured by the ‘grey area’ indicate that some cases which fall within the official definition of FII could be missed, and the harmful impact of a parent’s behaviour subsequently underestimated or overlooked. It is understood that many cases of FII can take a significant amount of time to be identified and addressed (RCPCH, 2009), so clearer guidance about how to interpret the definition and the parental behaviours which may contribute to the fabrication or induction of illness is needed. This could reduce delays in recognition, and minimise the potentially very serious consequences to children’s health and wellbeing, which can also be exacerbated by iatrogenic factors such as over-investigation and unnecessary invasive procedures.

Participants’ reports that the topics of MUS and FII were not frequently encountered in their undergraduate and postgraduate training is somewhat concerning, given the prevalence of MUS, the serious implications of FII and the complex nature of both presentations. In this study, some participants reported a lack of confidence in managing MUS and FII. Requests for further training indicate a need for improvements to be made to medical, foundation and postgraduate paediatric training,

and highlight a need for training programme directors to consider incorporating teaching about these important topics into the various core curricula.

The paediatricians interviewed discussed the significant barriers they often experienced regarding access to psychological and social care for children and young people affected by MUS and FII. Participants' ideas about introducing mental health support earlier in treatment and working in a multi-agency format represent goals for optimal clinical practice, and indicate a positive psychological shift towards viewing the mind and body as related rather than separated entities. In a current NHS climate of funding cuts and limited provision, findings such as these provide support for the need to channel funding into services which address children's medical, psychological and social care needs in an integrated and holistic fashion. Providing care in one location would allow for effective communication between professionals, and improve access to tailored treatment pathways set up to ensure children's needs are at the centre of all interventions.

Research implications. Further research looking at the 'grey area' described by participants and defined above is needed. It would be useful to examine in greater detail the reasons why some paediatricians do or do not class cases where parents are considered to contribute towards the child's symptoms as FII, and to explore which features of a presentation might prompt clinicians to make onward referrals to psychologists or social care teams. It is important to note that this current study provides a one-sided account of MUS and FII from the clinician's perspective, so conducting qualitative interviews with the parents of children falling into this 'grey area' category could also shed light on the parents' perspectives, and provide insight into the rationale and any underlying anxieties driving their behaviours. Interviewing

children about their current and/or earlier experiences of unexplained symptoms and any contributing factors could also improve understanding of the views of the child, as often the child's perspective can be overlooked when considering cases of MUS and, in particular, FII.

In future studies examining these topics, more could be asked about any follow-up support which may be offered to doctors who have been involved in cases of FII. At its extreme FII can be life-threatening, resulting in death for some children, which understandably can be challenging and traumatic for doctors and other health professionals involved (Horwath & Tidbury, 2009). Recently, there have been discussions in the media about the lack of opportunities for doctors to process any difficult feelings which might arise when working with challenging cases, and how they can often be expected to return to work very soon after experiencing the death of a patient (e.g. Qureshi, 2019). The impacts of working in medicine on doctors' own mental health and the increasing suicide rates amongst both doctors and nurses is also a current topic of discussion (Office for National Statistics, 2017; Wickware, 2018), and given how devastating cases of FII can be for all those involved, it seems imperative to investigate further the emotional impacts on doctors and other healthcare professionals.

Conclusion

This critical appraisal discusses the steps that were taken to improve methodological rigour when carrying out this research study, including the ongoing reflection on personal and epistemological factors which involved the process of 'bracketing'. Methodological considerations and limitations have been discussed, including the challenges involved in accurately representing participants' views and

the terminology used. Finally, the wider implications of the work and possible directions for future research highlight the need for continued research into these important and fascinating topics, with the overarching aim of continuing to improve healthcare for children, young people and families affected by MUS and FII.

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Appendices

Appendix A: Ethical Approval (UCL)

UCL RESEARCH ETHICS COMMITTEE
OFFICE FOR THE VICE PROVOST RESEARCH



28th May 2018

Dr Stephen Butler
Research Department of Clinical, Educational and Health Psychology
UCL

Dear Dr Butler

Notification of Ethics Approval with Provisos

Project ID/Title: 12877/001: Paediatric staff members' experiences of managing medically unexplained symptoms and fabricated or induced illness in children and families

I am pleased to confirm in my capacity as Joint Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the UCL REC until **1st October 2019**.

Ethical approval is subject to the following conditions:

Notification of Amendments to the Research

You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form'
<http://ethics.grad.ucl.ac.uk/responsibilities.php>

Adverse Event Reporting – Serious and Non-Serious

It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Final Report

At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

1

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research: <http://www.ucl.ac.uk/srs/governance-and-committees/resgov/code-of-conduct-research>
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely



Dr Lynn Ang
Joint Chair, UCL Research Ethics Committee

Cc: Katherine Yon & Dr Marta Buszewicz

Appendix B: Ethical Approval (HRA)



Dr Stephen Butler
UCL Research Department of Clinical, Educational and
Health Psychology
1-19 Torrington Place
London
WC1E 7HB

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

30 May 2018

Dear Dr Butler

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

Study title: Paediatric staff members' experiences of managing medically unexplained symptoms and fabricated or induced illness in children and families

IRAS project ID: 243324

Protocol number: 18/0039

Sponsor: University College London (UCL)

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales*, as well as any documentation that has been updated as a result of the assessment.

**In flight studies* which have already started an SSI (Site Specific Information) application for NHS organisations in Wales will continue to use this route. Until 10 June 2018, applications on either documentation will be accepted in Wales, but after this date all local information packs should be shared with NHS organisations in Wales using the Statement of Activities/Schedule of Events for non-commercial studies and template agreement/ Industry costing template for commercial studies.*

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the *"summary of assessment"* section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed [here](#).

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

What are my notification responsibilities during the study?

The attached document *"After HRA Approval – guidance for sponsors and investigators"* gives detailed guidance on reporting expectations for studies with HRA and HCRW Approval, including:

- Registration of Research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?

You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name: Ms Jessica Broni-Tabi

Tel: 0203 447 7430

Email: randd@uclh.nhs.uk

IRAS project ID	243324
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Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **243324**. Please quote this on all correspondence.

Yours sincerely

Kevin Ahmed
Assessor

Telephone: 0207 104 8171
Email: hra.approval@nhs.net

Copy to: *Ms Jessica Broni-Tabi, Sponsor Contact, University College London Hospitals*
Mr Joe Marley, R&D Contact, University College London Hospitals

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	Version	Date
Copies of advertisement materials for research participants [Recruitment Advert Paediatricians]	1.0	09 May 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UCL Insurance Certificate]	1.0	24 July 2017
HRA Schedule of Events	1.0	30 May 2018
HRA Statement of Activities	1.0	30 May 2018
Interview schedules or topic guides for participants [Topic Guide]	1.0	11 May 2018
IRAS Application Form [IRAS_Form_16052018]		16 May 2018
Other [Recruitment Advert Paediatric Staff]	1.0	09 May 2018
Other [UCL Insurance Letter]	1.0	14 May 2018
Participant consent form [Paediatric Staff]	2.0	24 May 2018
Participant consent form [Paediatricians]	2.0	24 May 2018
Participant information sheet (PIS) [Paediatric Staff]	2.0	24 May 2018
Participant information sheet (PIS) [Paediatricians]	2.0	24 May 2018
Referee's report or other scientific critique report [Peer Review]	1.0	11 October 2017
Research protocol or project proposal [Research Protocol]	1.0	10 May 2018
Summary CV for Chief Investigator (CI) [Summary CV for CI]		11 May 2018
Summary CV for student [Student CV]	1.0	22 February 2018
Summary CV for supervisor (student research) [Supervisor CV]		11 May 2018

Appendix C: Participant Information Sheet

UCL Research Department of Clinical, Educational & Health Psychology
1-19 Torrington Place
University College London
London
WC1E 7HB



Information Sheet (Version 4) 05.10.18

We are inviting you to take part in a research project. We want to find out about paediatricians' experiences of managing medically unexplained symptoms (MUS) and fabricated or induced illness (FI). This study is being carried out by a trainee clinical psychologist undertaking the Doctorate in Clinical Psychology (DClinPsy) at UCL. Before you decide whether to take part it is important that you understand why the research is being done and what this study will involve. Please take time to read the following information carefully and discuss it with relatives, friends, and colleagues if you wish. Ask us if anything is not clear or you would like more information.

Title of Project:	Paediatricians' experiences of managing medically unexplained symptoms (MUS) and fabricated or induced illness (FI) in children and families
Project ID No:	12877/001
Student Researcher:	Katherine Yon (Trainee Clinical Psychologist) UCL Clinical Psychology Doctoral Programme
Supervisors:	Dr Michelle Wilson (Clinical Psychologist and Clinical Tutor) UCL Research Department of Clinical, Educational & Health Psychology Dr Marta Buszewicz (Reader in Primary Care and GP in North London) UCL Research Department of Primary Care and Population Health

This study has been approved by the Clinical, Educational and Health Psychology Research Department's Ethics Chair.

What is the purpose of this study?

Perplexing presentations where the diagnosis is unclear are common in medical settings in both primary and secondary care. Medically unexplained symptoms (MUS) and fabricated and induced illness (FI, formerly known as Munchausen's by proxy) account for some of these presentations.

This study aims to examine paediatricians' experiences of managing MUS and FI in child and adolescent populations. We do not expect you to demonstrate any specialist understanding of these topics, or even necessarily to have encountered any patients with these presentations; rather we are interested in finding out what paediatricians at differ

levels of experience already know and any thoughts about what might be appropriate management strategies if you are presented with a patient with MUS or FII.

This study will help us understand what is already known by paediatricians, as well as inform advances in training in this area.

Why have I been invited?

Both qualified paediatricians as well as paediatricians in training have been invited to participate. This is to ensure that the information gathered represents a wide variety of perspectives.

Do I have to take part?

No. You are under no obligation to take part in this study. It will not affect your employment if you do not take part or later withdraw from the study.

What will I be asked to do?

Your participation will involve taking part in a one-to-one interview with the main researcher (Katherine Yon, trainee clinical psychologist currently undertaking the UCL Clinical Psychology Doctorate programme).

Interviews will last up to 60 minutes depending on your availability. You will be offered a £20 High Street voucher to compensate you for your time.

Participation in this study is voluntary and you will be asked to give your written consent. You will be given the opportunity to ask the investigator any questions you may have, before being asked to read and sign the consent form if you are willing to take part in the subsequent interview. If you decide to take part you are still free to withdraw at any time during the process and without giving a reason.

What are the benefits of participating in this study?

Participating in this study will give you the opportunity to discuss cases of MUS and FII and think about how you might manage these presentations in practice. The findings will also be used to inform future training in this area, and as part of the interview you will be asked about any recommendations for training.

What are the risks of participating in this study?

Sometimes cases of MUS or FII can be distressing. If you feel distressed as a result of discussing any cases, you will be advised to speak to your clinical supervisor and will also be offered the opportunity to talk about any concerns with a consultant paediatrician involved in the design of this research.

What if I no longer want to take part in this study?

If you no longer want to take part in this study, please let the researcher know. Any data collected will be removed from the study. You do not need to give a reason for withdrawing from the study.

Who will have access to my information and how will my information be kept confidential?

Interviews will be audio recorded using a Dictaphone. All data will be kept confidential. The main researcher or an external agency will transcribe the data, and any identifiable information (such as your name or location) will be edited out of the audio file before the file is sent to an external agency. However, if you prefer for your data not to be sent to an external agency, you can request for the main researcher to transcribe your data instead.

Anonymised data containing no identifiable information (e.g. name, email) will be analysed by the research team (main researcher, two supervisors and two consultant paediatricians involved in the design of this research).

Audio recordings will be transferred at the earliest opportunity to a password-protected laptop or UCL computer and then deleted from the Dictaphone. Data will be stored electronically on password protected computers. All data will be handled according to the Data Protection Act 1998 and will be kept confidential. Audio recordings will be destroyed following study completion, and any personal data will be destroyed 12 months after the study ends.

What if there is a problem?

If you have comments or complaints about your participation in this research study, please contact Katherine Yon. If you are not satisfied with the response, please contact the chief investigator (details below).

What will happen with the results of this study?

Once the study has been completed the results will be published in a report as part of a thesis project. The results will also be submitted to peer review journals and you will be asked at the end of the interview whether you would like to be informed about any such publications, or if you would like to be sent a copy of the final thesis report. Confidentiality and anonymity will be maintained, and it will not be possible to identify you from any publications.

Who is organising and funding the study?

The study is sponsored by UCL Research Department of Clinical, Educational and Health Psychology.

Who has reviewed the study?

The study has been peer-reviewed by senior research staff members within the Research Department of Clinical, Educational and Health Psychology.

You are encouraged to ask any questions about the study. Please let us know if anything is not clear or if you would like any further information.

Thank you for your interest in this project.

The Research Team

If you have any questions about this study please contact:

Katherine Yon

Student Researcher

UCL Research Department of
Clinical, Educational & Health Psychology
1-19 Torrington Place
University College London
London WC1E 7HB
Email: Katherine.yon.12@ucl.ac.uk
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Dr Michelle Wilson

Chief Investigator

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Dr Marta Buszewicz

Study Supervisor

UCL Research Department of Primary
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Royal Free Campus
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Appendix D: Participant Consent Form

UCL Research Department of Clinical,
Educational & Health Psychology
1-19 Torrington Place
University College London
London
WC1E 7HB



CONSENT FORM

Project Title: Paediatricians' experiences of managing medically unexplained symptoms and fabricated or induced illness in children and families

Please initial box

1. I confirm that I have read and understand the information sheet version 4, dated 05.10.18 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason
3. I understand that my participation will be audio recorded and I consent to the use of this material as part of the project.
4. I consent to my data being transcribed by an external agency
5. I consent to the use of anonymised quotes or information in any resulting reports or publications. I understand that confidentiality will be maintained and it will not be possible for others to identify me.
6. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

Appendix E: Topic Guide

Version 5.0

26.09.2017

Page 1 of 2

Topic Guide

Paediatricians' experiences of managing medically unexplained symptoms and fabricated or induced illness in children and families

Introductions

- Introduction to study
 - Aim is to gain understanding of different views – "no wrong answers"
 - Length of interview (40-60 minutes), audio recording, confidentiality, anonymization, access to tapes/transcripts
 - Sign consent form

Background

- Can you tell me a little about your career path so far?
- Can you describe your current post?

Conceptualisation of MUS and FII

- What is your understanding of the terms 'medically unexplained symptoms' and 'fabricated or induced illness'?
- Do you think there is a difference between MUS/FII?
 - If so, how would you explain this difference?
 - If not, why not?
- What do you think causes MUS and FII? Do you have any thoughts/theories about this?
- What do you think might be precipitating and/or perpetuating factors?
- Can you think of any common comorbidities you are aware of – either physical or psychological?

How MUS is approached in practice

- What factors might indicate MUS when you see a child?
- In your time as a paediatrician have you seen cases of MUS? What did they present with? (If participant cannot think of an example, will ask them to imagine a hypothetical case, rather than giving an example)
- What steps did (or would) you take when (or if) you suspected MUS?
 - How did you/would you gather information about the case?
 - Do you/would you ascertain the child's view? If so, how? If not, what barriers might prevent you from doing so?
- In the case(s) of MUS you've described, what did you think was the problem underlying their symptoms?
 - Did you have any thoughts about the reality of the symptoms?
- How were the symptoms managed?
 - Did you order any investigations or make a referral?
 - What factors did you consider when making this choice?
- How did you/would you explain MUS to the child/parents?
- What was the outcome?
- How do you think the parents experienced this? And the child?

How FII is approached in practice

- In your time as a paediatrician have you seen cases of FII? What did they present with?
- What alerting features might prompt you to consider FII?
- What steps did (or would) you take when (or if) you suspected FII?

MUS/FII Paediatricians Study

- How did you/would you gather information about the case?
 - Do you/would you ascertain the child's view? If so, how? If not, what barriers might prevent you from doing so?
- What do you think caused the symptoms?
 - Did you have any thoughts about the reality of the symptoms?
- How were the symptoms managed?
 - Did you order any investigations or make a referral?
 - What factors did you consider when making this choice?
- How do you think the parents experienced this? And the child?
- Did you involve other colleagues?
 - If so, whom?
 - What might lead you to involve colleagues? Or other services (e.g. social services/CAMHS)?
 - How did you/might you involve a parent in this decision?

Other services

- What is your experience of CAMHS or other psychology services?
 - How do families respond to any suggested referrals?
- Are there any barriers that might prevent you from discussing concerns with colleagues or making referrals to other services?
 - Is there anything you might like to be different about other services (e.g. CAMHS or psychology services)?
 - How might this look?

Attitudes towards MUS and FII and ideas about causation/potential comorbidities

- How did you feel about managing the MUS case? And FII case? Can you say a bit more? What do you think elicited these feelings?
 - Did the presentations lead to different or similar feelings?
 - (If struggling to identify emotions) Sometimes cases of MUS/FII can leave doctors experiencing a range of emotions. Can you say a bit more about how working with such cases has left you feeling?
- What do you think has influenced your views about MUS/FII?
 - Do you think the views of other colleagues or senior staff members have influenced your views?

Prior teaching/training about MUS

- Have you received any training about MUS or FII? If so, when and in what format?
- How prepared/confident to deal with patients with MUS/FII do you feel?
- What do you think might help you, or other doctors, to feel more prepared when managing such patients?

Any further comments?

Thank you very much for your participation