The experience of emotion in people with Fibromyalgia: A thematic analysis

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This is to certify that this research report is my own unaided work

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ABSTRACT

Emotion is widely recognised as one of the central factors which influence the experience and management of pain (International Association for the Study of Pain, 2020). There is a substantial research base on how emotion may exacerbate or ameliorate pain, with evidence that the impact of chronic pain can lead to an increased risk of attempted and completed suicide. Fibromyalgia Syndrome (FMS) is a chronic pain condition which affects more women than men, and includes a diverse and unpredictable constellation of symptoms. This study qualitatively explored the experience of emotion in ten women with a diagnosis of FMS, using semi-structured interviews within a critical realist framework. Reflexive thematic analysis of the data produced two overarching themes; 1) 'FMS as an adversary' which had four themes; 'The emotional impact of being at war'; 'FMS attacks my vulnerabilities'; 'Grieving the losses inflicted by FMS' and '"Just got to fight it, got to" - mitigating the damage' and 2) 'The shame of FMS' with two themes; 'Suffering is a secret' and 'Features of a shameful condition'.

Participants perceived their condition as an external attacker which placed them in a perpetual threat position. FMS exploited their vulnerabilities due to trauma and interacting difficulties with emotion, causing emotional distress and inflicting global feelings of shame and grief for some. The results indicate how the affective impact of FMS due to trauma, shame as a threat-based emotion, psychological distress including grief, and difficulties with emotion can all be connected. These conclusions indicate that the diagnostic process and psychological interventions for FMS may benefit from a trauma-informed approach and sensitivity to adverse affective experience. Suggestions for further research endeavours are made.

INTRODUCTION

Outline of thesis

The aim of this study was to capture rich data from people with a diagnosis of Fibromyalgia Syndrome (FMS), as they described their emotional experience of this challenging chronic pain condition. My research interest in FMS and emotion derived from two sources. Firstly, two of my friends were diagnosed with the condition as adults, within a few years of each other, and I witnessed the impact upon both their lives and our friendships. I have reflected upon how this may have influenced my perspective as a researcher into FMS throughout this research process, in the section on reflexivity below. Secondly, and inextricably linked to my friends' and my own experiences, my academic interest in the affective features of chronic pain developed whilst undertaking a Master's level course.

I had undertaken a quantitative research project for my Master's dissertation to explore affect and coping styles in FMS. Participants were recruited for the current research from the same network of support groups as the Master's and they were asked to complete self-report questionnaires. Whilst this was successful and informative research, when speaking with group members, it was notable that a great deal of rich data was not captured in this quantitative endeavour. I therefore returned to the topic when the opportunity arose during my doctoral training, to capture a qualitative perspective of the experience of emotion in FMS.

The emotional component of pain is well recognised as central to its experience and management (International Association for the Study of Pain (IASP), 2020). Utilising one to one, semi-structured interviews, the researcher explored participants' experiences and understandings of their emotional lives. Careful consideration was given to participants' wellbeing to reduce the possibility of fatigue during the interviews. The study was framed within a reflexive thematic analysis (reflexive TA) (Braun & Clarke, 2018; 2020) with the data coded and analysed to answer the following research questions:

Primary research question:

- *How do people with FMS experience emotion in relation to their condition?*

Secondary research questions:

- *What are the emotional experiences that people with FMS experience in relation to their condition?*
- *How do they understand their experience of emotion?*
- *How do they understand any difficulties they have with emotion?*

To orientate the reader, I will first offer a critical appraisal of the pain literature from a psychological perspective, including the transition from acute to chronic pain, the role of emotion in pain and an exploration of the concept of alexithymia. Following this, I will present a critical evaluation of the key issues reported in the literature on FMS.

Later chapters of the thesis will include a reflexive TA of interview data collected from women living with FMS, discussed in relation to the research questions. In the discussion chapter, I will offer both a theoretical and methodological critique as well as an exploration of future implications for women with FMS. Finally, in the concluding chapter, I will bring together this piece of work and summarise its key messages.

CRITICAL LITERATURE REVIEW

Key search terms and literature sources

The literature was searched via the Medline, PsycINFO, Cochrane databases and key websites (eg, IASP) to search for keywords in combinations. Keywords included: Fibromyalgia, Fibromyalgia Syndrome, medically unexplained symptoms, functional symptoms, aetiology, diagnosis, symptoms, emotion, affective, psychological distress, depression, anxiety, pain, psychology and alexithymia.

Additionally, Boolean operators (AND, OR, NOT) were used to include different terms cited in the literature for the same concept, and asterisks were also inserted before or after words which may be cited in papers with various prefixes and suffixes (for example, emotio* aimed to capture ‘emotion’, ‘emotional’ and ‘emotionally’ etc).

Further searches were made on the basis of findings from each search or data analysis. Papers were selected for closer reading from the title and scanning the abstract for relevance to the research aims.

No dates were excluded during the initial searches. Where searches returned large numbers of results, the date range was reduced to the preceding ten years and then the last five years (where necessary) to manage the amount of information. Database searches of the keywords were originally undertaken during the planning phase of the study and repeated in May 2018 and September 2019. A final search was undertaken in December 2020 to include papers from September 2019 to that date. All retrieved papers were peer-reviewed and published in English. References cited in papers of interest were also searched for other sources of information. Additionally, other papers and sources of peer-reviewed literature collated from a previous master’s level study on the perception and experience of pain were included.

The psychology of pain

FMS is a chronic pain condition affecting 3-6% of the world's population (WHO, 2008), with a higher prevalence in women (3.4% female vs 0.5% male; Kroenke et al., 2007). Sim and Madden (2008) found pain to be "the most frequently discussed symptom" of FMS (p. 57) in a meta-analysis of qualitative studies and concluded that further work was required to explore the subjective experience of this condition. This suggests that pain is highly pertinent to the experience of FMS and is, therefore, worthy of attention. Of particular note to psychologists is the role of psychological processes which can offer options for interventions aimed at the reduction or management of pain. A critique of the literature on psychological perspectives on pain is offered, followed by consideration of the role of emotion in the pain experience.

Pain is a universal experience. Vowles et al. (2014) reported that 70% of adults in eight European countries had a major episode of pain in the last month. The well-respected International Association for the Study of Pain (IASP, 2020) reviewed large scale studies and concluded that approximately 50% of people undergoing surgery or physical trauma suffer "severe to intolerable" acute pain (p. 1), with the incidence of chronic moderate to severe pain in adults in Europe, North America and Australasia being around one in five. Additionally, they estimated that one in ten adults are diagnosed with chronic pain every year (ISAP, 2020).

The IASP have offered the following widely accepted definition of pain (Morris, 2005): "an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage " (IASP, 2020). The IASP placed central importance on the emotional component of pain: "It is unquestionably a sensation in a part or parts of the body, but it is also always unpleasant and therefore also an emotional experience" (ISAP, 2020). The IASP emphasised the affective component of the pain experience, reinforcing the need to understand more fully how emotion influences this aversive experience.

It is important to outline the framework within which authors have conceptualised pain. Counselling psychologist McCaffery (1968) said, “Pain is whatever the experiencing person says it is, existing whenever the experiencing person says it does, existing wherever the experiencing person says it does”. In the following critique of the psychology of pain, I hold this in mind and focus on the literature around psychological and affective mechanisms involved in pain, with an emphasis on individual experience.

Pain is generally categorised along a temporal continuum as acute, intermittent or chronic. Authors of the latest International Classification of Diseases-11 report categorised pain for the first time, describing chronic pain as that which is present for three months or more (ICD-11, 2019). Several terms are used interchangeably in the literature in reference to each of these categories. Given the emphasis of this study and the frequency with which this phrase is used in the literature, the phrase ‘chronic pain’ has also been used in this thesis for clarity and consistency.

Nociception is “the neural process of encoding noxious stimuli” (IASP, 2020), in which painful stimuli impact the body and are detected by peripheral nociceptors located throughout the body. The peripheral nerve transports the signal through the spinal cord to enter the central nervous system, travelling through the ascending pathway to the brain, where the stimuli are detected and protective responses are generated (Lumley et al., 2011). However, the IASP make a distinction between nociception and pain, noting that they are “different phenomena” and that “pain cannot be inferred solely from activity in sensory neurons” (IASP, 2020). They recognise that “pain is always a personal experience that is influenced to varying degrees by biological, psychological, and social factors” (IASP, 2020). The experience of pain, therefore, is not simply a cause-and-effect relationship between aversive stimuli and the sensory detection of injury. In this thesis, I have focused on emotion, one of the psychological influences in this process.

There is no discrete or localised pain centre in the brain. Rather, several different structures are involved in the recognition of painful stimuli and the neural response to such triggers. These triggers may be physical or psychological stimuli, in which thoughts, places and so on activate warning signals (Bushnell et al., 2013). Pain acts as an indicator of possible tissue damage, with acute pain being a threat-based system - an adaptive alarm to attend to present and future threats, thereby protecting the organism in the long-term (Davey, 2016; Eccleston, 2018; Lumley et al., 2011).

The transition from the interpretation of acute aversive stimuli to chronic pain occurs as a result of neurobiological changes and learning. In FMS, it is thought that progressively fewer incoming signals are required to fire second and third-order neurons which cause increased central sensitisation (Bushnell et al., 2013). This develops into a chronic problem where the threat alert system, which was designed to work in the short-term, continues over time, thus creating the experience of chronic pain. In response to this, behaviours can change and become maladaptive, thus exacerbating the pain experience (Nesse & Ellsworth, 2009).

Feedback loops between pain, emotion and cognition occur. Pain can negatively impact emotion and cognition, and negative affect can increase the pain experience (Bushnell et al., 2013). Positive emotion can reduce pain, while cognitive processes can also affect pain both negatively and positively (Bushnell et al., 2013).

This interaction of the diverse areas of brain activity involved in detecting and responding to pain creates an active interpretation of stimuli, in which our expectations and the meanings we attribute to stimuli can impact how we perceive pain. This can be seen in the phenomenon of phantom limb pain, where between 50-80% of people who have had a limb amputated experience pain at the missing limb, reporting sensations of throbbing and stabbing as well as pins and needles (Richardson et al., 2006). This tends to occur in the first week following amputation and decreases in severity over time (Bosmans et al., 2010). The absence of the limb in which the pain is felt demonstrates that the experience of pain is not limited to a direct cause and effect relationship between physical aversive stimuli and the brain recognising this input. Rather, we engage in active psychological processing to experience pain. There are likely to be numerous systems involved in phantom limb pain. One of these appears to be a misinterpretation, as the brain engages in a complex interpretative process to recognise pain (Aternali & Katz, 2019).

Impact of chronic pain

The impact of chronic pain can be serious. Tang and Crane (2006) conducted a systematic review and found that the risk of death by suicide was doubled for people with chronic pain compared to those without. These findings were updated by Petrosky et al. in 2018, who recently conducted a meta-analysis of the National Violent Death Reporting System in America to explore the possible role of chronic pain in suicide. They found evidence of a chronic pain condition in 8.8% of people who had taken their own life between 2003-2014, rising to 10.2% in 2014. This underlines the importance of understanding chronic pain from as many perspectives as possible. In this thesis, I focus on the perspective of emotion in an attempt to contribute to the research base.

Role of emotion in pain

Scholars have offered substantial evidence to suggest that a deeper exploration of the emotional life of people with FMS would be advantageous. As discussed above, the importance of emotion in the experience of pain has been well established in the literature, and pain is often the most pertinent symptom in FMS. The role of emotion was explored by Wiech and Tracey (2009), who conducted a useful review of studies in which authors induced emotional states to record changes in pain, with the aim of recording the influence of negative emotions on the experience of pain. They concluded that in addition to chronic pain leading to low mood and emotions such as frustration, worry, anxiety and depression, negative emotion can lead to increased pain. Tang et al. (2008) also showed that experimentally-induced negative emotion increased self-reports and lowered tolerance of pain, while induced positive emotions had the reverse effect. Therefore, people with FMS may experience a worsening of their symptoms due to psychological distress.

The effect of negative affect on pain in FMS has been shown to exacerbate its symptoms (Montoro et al., 2016). Authors have also shown that low mood is associated with increased pain intensity, functional abilities, sleep, and fatigue, and could be detrimental to quality of life (Thieme et al., 2004). Glass (2009) also found that negative affect harmed aspects of cognitive performance including working, episodic and semantic memory.

In their review of papers on the links between emotional regulation and chronic pain, Koechlin et al. (2018) concluded that maladaptive regulation could be a risk factor involved in the development and maintenance of chronic pain, due to associations with both pain and emotional distress. Maladaptive regulation may also indicate valuable routes of intervention for pain management (Koechlin et al., 2018). Based on the process model of emotional regulation (Gross & Thompson, 2007), Koechlin and colleagues concluded that response-focused emotional regulation (such as holding back tears in public) had a stronger association with increased pain, pain-related disability and depressive symptoms than antecedent-focused styles (such as moving attention to pleasurable activity; Koechlin et al., 2018, p. 39).

There is evidence therefore that affect impacts the pain experience, as well as our responses to and management of these emotions can alleviate or exacerbate pain. Koechlin and colleagues (2018) noted that the literature on emotional regulation and its relationship with chronic pain is in its relative infancy, although other affective theoretical constructs have been debated for decades. This will be further discussed later in the chapter. Moving on to the specific chronic pain condition which this study focussed upon, Fibromyalgia Syndrome.

Fibromyalgia Syndrome (FMS)

FMS can be a highly distressing chronic pain condition (Dennis et al., 2013). Authors of several papers referred to in this study used the term 'chronic pain,' while others discussed 'persistent pain'. Therefore, both phrases were included in literature searches. Participants did not refer to their experience of ongoing pain with either of these terms, but 'chronic pain' has been adopted in this thesis for consistency, as it is used by the IASP as well as in international classifications of pain in the Diagnostic and Statistical Manual 5 (DSM-5; American Psychiatric Association, 2013) and the International Classification of Disease 11 (ICD-11, 2019), and is adopted widely in the literature.

FMS is the most common cause of musculoskeletal pain in women aged between 20 and 55 (Wolfe et al. 1990), with diverse individual differences in how the condition expresses itself. For many, FMS results in a considerable decline in quality of life (Harth, 2013), affecting levels of psychological distress (Fietta et al., 2006), relationships (Briones-Vozmediano et al., 2013; Wolfe et al., 2010) and the possibility of paid work (Kleinman, 2009).

Diagnosis and aetiology of FMS

All patients diagnosed with FMS must meet the criteria of the DSM-5 (American Psychiatric Association, 2013) or the World Health Organisation's ICD-11 (ICD-11, 2019). They must satisfy the DSM-5 Criterion A for somatic symptom disorder (that is, one or more somatic symptoms that are distressing or result in significant disruption to daily life) while most also satisfy Criterion B of excessive thoughts, feelings or behaviours related to the somatic symptoms or associated health concerns. Criterion C is that the "state of being symptomatic is persistent for typically more than six months" (Wolfe et al., 2014, p. 311). The main symptom is suggested to be "more commonly pain" (p. 311). Wolfe and colleagues (2014) effectively demonstrated that Criterion B requires subjective judgement and so is uncertain and controversial, potentially resulting in a diagnosis with low validity and reliability. The pejorative approach of the DSM-5 towards this group demonstrates the position of privilege from which a diagnosis is made.

The ICD-11 (2019) categorises FMS as chronic widespread pain and gives a diagnosis if at least four bodily regions are affected by pain associated with "significant emotional distress (anxiety, anger/frustration or depressed mood) or functional disability (p. 328)". This categorisation system includes bio-psycho-social contributions to the experience of pain. The wider view of causation noted in the ICD-11 should be welcomed, while the language used in the DSM-5 may be construed as invalidating for those seeking a diagnosis or wishing to learn more about the condition. The diagnosis of somatic symptom disorder was formerly hypochondriasis; thus, the negative connotations this word may evoke in those with knowledge of its history may be retained.

The DSM diagnostic criteria were amended again in 2016, placing more emphasis on fatigue and cognitive symptoms, and less on tender point identification (Wolfe et al., 2016). They outlined generalised pain criterion to avoid regional pain syndromes being captured by the criteria and aimed to offer FMS as a valid construct, sometimes in the presence of other diagnoses. Thus, the diagnostic criteria are now as follows:

(1) Generalized pain, defined as pain in at least four or five regions, is present.
(2) Symptoms have been present at a similar level for at least three months.
(3) Widespread pain index (WPI) ≥ 7 and symptom severity scale (SSS) score ≥ 5 OR WPI of 4–6 and SSS score ≥ 9.
(4) A diagnosis of FMS is valid irrespective of other diagnoses. A diagnosis of FMS does not exclude the presence of other clinically important illnesses.

The process of FMS diagnosis can be difficult for both patient and clinician due to the lack of an objective test, the requirement for subjective clinical judgement to diagnose, and the diverse range and unpredictability of symptoms. This can result in a diagnosis which is arrived at by the elimination of other pain conditions (Harth, 2013), in contrast to many other pain conditions with a medical explanation such as rheumatoid arthritis. This lack of clarity poses a fundamental problem for diagnosing clinicians, placing them in a position of defining an illness or disorder by the *absence* of experience rather than the *presence* of distressing problems (Voigt et al., 2010). Thus, there is a crucial nosological issue in the classification of FMS within a system in which clinicians usually categorise on the presence of symptoms (Voigt et al., 2010). Despite diagnostic criteria being published, doctors in primary care often misdiagnose FMS, with the chance of accurate recognition of symptoms depending upon the doctor's skill and/or beliefs about the condition (Wolfe & Hauser, 2011). These beliefs may be informed by the pejorative nature of the classification systems and the negative connotations they retain with the term hypochondriasis.

It is therefore perhaps not surprising that, following diagnosis, treatment is often difficult, with medics trying several treatments over time and often achieving only minimal success in the management of pain and other symptoms (Borsook & Becerra, 2006). The lack of clear symptomatology and treatment protocols often results in ad hoc treatment (Harth, 2013), while the current lack of an organic explanation and the inherent difficulties with diagnosis have resulted in FMS being seen as a controversial condition by some (Goldenberg, 1995).

In part, this controversy emanates from the current absence of agreement in terms of the aetiology of FMS (Abeles et al., 2007). That is, authors of clinical investigations and laboratory studies have failed to identify abnormalities in the peripheral sites where patients report pain (Rosendal et al., 2017), leading to symptoms being categorised as 'medically unexplained symptoms' (MUS). A collection of other conditions currently without a widely accepted clinical explanation are also categorised as medically unexplained, including myalgic encephalomyelitis (ME), chronic fatigue syndrome (CFS), conversion disorder, irritable bowel syndrome and functional neurological symptom disorder (ICD-11, 2016).

The IASP stated that "Many people report pain in the absence of tissue damage or any likely pathophysiological cause; usually this happens for psychological reasons" (ISAP, 1994). Thus, this eminent body failed to detail the precise mechanisms, hence asserting that the cause of pain with no identified medical cause lies within the individual. This may support the view that some pain conditions are psychosomatic, risking an invalidating approach to those who live with conditions such as FMS.

MUS have been defined as "persistent bodily complaints for which adequate examination does not reveal sufficiently explanatory structural or other specified pathology" (Henningsen et al., 2007). This term is widely used by health professionals within primary and secondary medical services (Nimnuan et al., 2001; van Ravenzwaaij et al., 2010). The label of MUS may appear to be a neutral description of experiences for which there is no current medical explanation. However, on closer inspection, the term can be laden with “strong dualistic connotations” in psychiatry (Marks & Hunter, 2010, p. 110), resulting in the position that MUS are “physical symptoms caused by psychological distress” (Department of Health England, 2011). People with FMS may find this invalidates the legitimacy of their symptoms, and that the aetiology fails to fit the requirements of a medical condition, placing it instead within their psychology, possibly suggesting that they are to blame for their own suffering.

Despite the exact physiological causes of FMS being medically unexplained, there have been considerable developments in our understanding of its aetiology. Authors recently investigating the causes of FMS suggest that there are alterations in the neuroendocrine and cytokine systems in the hypothalamic-pituitary (HPA) axis, which regulates central pain processing. This dysregulation is thought to heighten pain sensitivity (Geiss et al., 2012; Powell et al., 2013). There are, therefore, some indicators of the physiological processes underpinning the experience of pain from which people with FMS suffer.

The impact of chronic pain in FMS

The rate of death by suicide is higher in people living with FMS than the general population (Dreyer et al., 2010; Wolfe et al., 2011). These studies were further supported by Calandre et al. (2015), who found that 48% of their sample experienced suicidal ideation and 8.3% experienced active ideation, forming plans for how they may take their life. Interesting, Jimenez-Rodríguez et al. (2014) suggested that an additional dimension of FMS places those with the condition at greater risk of suicide than individuals with other chronic pain conditions. They compared people with FMS to groups with lower back pain and no pain. Suicidal ideation and risk of suicide were “low” in the back pain group and “almost absent” (p. 625) in participants with no pain. This suggests that people living with FMS face a higher risk of suicide due to chronic pain, identifying FMS as potentially different from other chronic pain experiences. These differences may be due to people with FMS being more likely to belong to high-risk categories for suicide - that is, suffering from sleep disturbance (Moldofsky, 2008) and experiencing depression and anxiety (Arnold et al., 2011).

Difficulties in gaining and maintaining employment can impact income, resulting in further emotional stressors for people with FMS. White et al. (1999) found that around 26% of those diagnosed with FMS in the US and Canada relied on disability payments. Additionally, Kleinman (2009) reported that this group lost more days from work due to sickness and had lower productivity than employees who did not have FMS. These factors can undoubtedly impact upon quality of life (Harth, 2013), and may be more serious for those with the association of chronic pain and suicidality that has been demonstrated in the literature.

Experience of symptoms and course of FMS

Just as the process of diagnosis can be distressing for people with FMS, as discussed above, the impact of symptoms can also lead to difficult emotional experiences. Individuals can experience this chronic pain condition as “unspeakable suffering” (Steinweg et al., 2011, p. 255), with symptoms including widespread pain, fatigue and non-refreshing sleep. Around 48% of people living with FMS also suffer from migraine and a cognitive impairment known as ‘fibro fog’ which affects concentration, perception and memory (Steinweg et al., 2011, p. 255). Associated conditions also include irritable bladder and vulvodynia, that is, persistent and unexplained pain in the skin surrounding the entrance to the vagina (Fitzcharles & Yunus, 2012). The spectrum and severity of symptoms are diverse, with symptoms varying between and within individuals over time (Fitzcharles & Yunus, 2012).

Dennis et al. (2013) aimed to explore how participants perceived their symptoms of FMS in an Interpretative Phenomenological Analysis (IPA) of email interviews. Interestingly, they found no "one overall symptom"; rather, participants described a "giant mess" (Dennis et al, 2013, p. 68) of unpleasant symptoms (Dennis et al., 2013, p. 1). This casts doubt on the main diagnostic criteria and demonstrates the value of qualitatively studying the unique individual experience of FMS. The criteria used to diagnose FMS may have little relevance to the individual experiences of those living with the condition. Therefore, even the new DSM-5 diagnostic criteria fail to accurately capture this experience.

A participant in Dennis and colleagues' study also reported that "knowing what was wrong made it easier to deal with, since I had a definite answer, however emotionally, it was a lot harder" (p. 772). This theme was not explored further, as the participant's emotional struggles remained unclear. Dennis et al. (2013) reported the effect of emotion alongside other issues in their IPA study, in which they were exploring the general experience of FMS. Therefore, emotion was not discussed in depth during the interviews nor the analysis. In the current study, I aimed to create an in-depth exploration of this facet of the FMS experience.

Participants in the Dennis et al. study also reported a "struggle to understand the course of their illness" (2013, p. 765), which the authors reasonably interpreted as a reflection of individual differences in the presentation of FMS and the unpredictability of symptoms. Participants vividly described FMS as a "complex and uncertain experience" (p. 763). The unpredictable nature of FMS can compound the suffering of those with the condition, leaving them in a persistent state of readiness for the next change in symptomatology, and so posing meaningful challenges to emotional wellbeing. The course of their condition therefore contributed to their suffering, thus demonstrating both the potential for emotional distress in FMS and the value of hearing accounts of suffering from individuals with the condition. Bennett et al. (2007) and Okifuji (2002) conducted thematic analyses of semi-structured interviews and found that people with FMS defined stress and emotional distress as factors which aggravated their symptoms, with pain being the most common symptom. Hall et al. (2014) also found that stress is associated with increased symptom severity in FMS. Therefore, a greater understanding of the sources of stress may indicate interventions which ameliorate the effect of stress and promote greater wellbeing and quality of life for people living with FMS.

Alongside the symptoms of FMS, sufferers may experience other layers of distress relating to the nature of their condition. These layers can also contribute to emotional difficulties and often pertain to the social aspects of the condition. This was documented by Russell et al. (2018), who used thematic content analysis to explore focus group participants' perceptions of exercise. They found an overarching theme of "a lack of understanding of the condition by others" (p. 507), which led to participants feeling loss and change in themselves as their FMS developed. A lack of empathy from those close to us and those we depend upon, including healthcare professionals, can be a meaningful source of stress.

These findings have been reflected in the experience of people with other chronic pain conditions. One extremely valuable qualitative study, co-written by Jonathan A Smith, who devised IPA (Smith & Osborn, 2007), includes an insight into the effects of chronic pain. These authors explored the psychological impact of benign chronic back pain, using IPA to analyse their semi-structured interviews. Their main findings were that firstly, participants experienced fundamental changes and challenges to their sense of identity as a result of their constant pain and that, secondly, "their most 'unpleasant' experiences were all inherently socially undesirable, which highlighted the socialness of their chronic pain" (Smith & Osborn, 2007, p. 528). The authors reported that participants were living "in disabling fear of being judged critically by others, abhorred or pitied" (p. 528). These findings support Dennis and colleagues' work, in that the experience of chronic pain does not reside uniquely within the individual. Rather, the social environment within which the person resides frames their pain experience. When this frame is negative (such as a lack of understanding), it can contribute to the severity of emotional distress (such as feelings of loss and changes to identity).

However, none of these authors (Dennis et al., 2013; Russell et al., 2018; Smith & Osborne, 2007) explored the emotional dimensions of participants' reports either directly or in detail. The aim of the current study is to contribute to this gap in the literature. However, the existing work provides interesting phenomenological analyses upon which to base the present study, because it highlights, firstly, some of the fundamental psychological factors involved in chronic pain and, secondly, the social aspects of ongoing pain experiences.

The social impact of FMS has been the focus of other studies which reinforce these findings. The invisibility of FMS symptoms can lead to some people living with the diagnosis feeling invalidated by family, friends and healthcare professionals. This can have adverse effects. Ghavidel-Parsa et al., for example, wrote that "active negative social responses and the source of invalidation are important in predicting symptom severity and quality of life in FMS" (2015, p. 482). Russell and colleagues demonstrated that, in addition to the presence of the pertinent features in FMS, the condition is further impacted by its status as "medically unexplained" (American Psychiatric Association, 2013) and, therefore, more likely to attract negative social responses. This can complicate an already distressing condition with further layers of difficulty that someone with FMS must negotiate and manage.

The negative experience of this distressing condition can, therefore, be exacerbated by the responses of significant others. People living with FMS often look well, bearing the symptoms of a medically unexplained condition which lacks legitimacy in Western cultures, where the medical model dominates explanations of illness or distress. If the medical model can offer no explanation, the legitimacy of the condition and by inference, the patient, is placed in doubt. Kool et al. described how “negative social responses (denying, lecturing, and overprotecting) as well as a lack of positive social responses (supporting and acknowledging) […] perpetuates a perception of invalidation” (2009, p. 1650). This invalidation separates FMS from other chronic pain conditions that have the legitimacy of a medical explanation, which can exacerbate the debilitating symptoms of FMS further (Paulson et al., 2002).

This sense of invalidation was found in a Spanish study (Briones-Vozmediano et al., 2013) about the relationships between FMS patients and their healthcare providers. The authors reported using discourse analysis to identify themes, but only gave a general account of their method of analysis. Nonetheless, one finding of relevance was that participants felt that their professional healthcare providers (including psychologists) communicated a lack of moral support. Indeed, in their IPA paper, Dennis et al. (2013) advised health professionals to consider issues of stigma and legitimacy for people with FMS, as a result of participants reporting these in relation to their symptoms. It would, therefore, seem essential that these aspects of the experiences of people with FMS be heard, to improve the relational aspect of diagnosis and treatment.

The contribution of these studies to the literature on FMS highlights pertinent aspects of FMS which can cause difficulty and emotional distress, in addition to its specific symptoms. A diagnosis of FMS, living with the condition and experiencing some of the consequences can be extremely challenging. These challenges are captured in the literature, although the emotional response to and impact of these salient features are less well defined. In the present study, I aim to build upon the findings of previous researchers and explore further the specific emotional perspective of these issues.

Psychological distress and FMS

McCracken and Thompson (2012) examined the effect of chronic pain on mood and anxiety, and found that those with chronic pain were two to three times more likely to suffer with depression or anxiety than people with no pain. If we apply this finding to people with FMS, along with the well-established unpleasantness of pain (IASP, 2020), we can see that these people must tolerate or manage other features of the condition which can impact their affective wellbeing. This suggests that an exploration of the emotional experience of people with FMS would be valuable for understanding how this may impact their meanings and experience.

Given the scope and extent of the difficulties of FMS, perhaps it is not surprising that greater levels of depression and anxiety in FMS are well documented, suggesting that individuals with FMS are at higher risk of suffering psychological distress than the general population (Evren et al., 2006; Fietta et al., 2007). Indeed, Hassett et al. (2000) found that 51-63% of people living with FMS had experienced anxiety, while 26-80% had been diagnosed with depression. This was supported by Van Houdenhove and Luyten (2008), who argued that affective factors (p. 471) play an important role in FMS and CFS. They suggested that emotion was a perpetuating factor within a bio-psycho-social account, as affective distress influences FMS and CFS by “reinforcing symptoms and increasing the risk of patients negatively spiralling into more severe functional limitations” (Van Houdenhove & Luyten, 2008, p. 473).

However, Van Houdenhove and Luyten’s (2008) willingness to combine the two conditions may be a little misguided. The commonalities between FMS and CFS rely solely upon the status of an absence of medical explanation. The assumption that this is sufficient for comparing aspects of the conditions, such as the influence of emotion, is unhelpful. Although the explanations offered by these authors is of less interest to the present study in terms of theory and process, their findings serve to underline the importance of emotion in conditions characterised as medically unexplained.

Many authors have focused on emotional difficulties which some people living with FMS may experience as well as the effects this may have on the experience of chronic pain conditions. One of these areas most represented in the literature is alexithymia, which has particular relevance to chronic pain in general and FMS in particular. Some authors have defined alexithymia as difficulty in emotional regulation (Di Tella & Castelli, 2016), although the characteristics contained within the concept lend themselves more to emotional processing than regulation (Bagby & Taylor, 1997). I will now move onto a discussion of this construct given its considerable presence in the literature.

Background to alexithymia

Counselling psychologists offer the opportunity to explore difficulties with emotion from the perspective of individual experience and consider other dynamics which may influence their ability to engage with their emotional lives (O'Brien et al, 2017). The current literature contains an abundance of papers which quantitatively explore difficulties with emotion in chronic pain populations including FMS, MUS conditions and other chronic pain presentations. These emotional difficulties are diverse in nature and have been helpfully described as two types: emotional states and emotional processes (Lumley, 2010). The former includes short and long-term emotion states such as anxiety and depression, whereas 'emotional processes, in contrast, refer to the mechanisms by which emotions are generated, experienced, and used, and include emotional awareness, labelling, expression, processing, and integration' (Lumley, 2010 p. 3).

Despite this valuable delineation of difficulties with emotion, the chronic pain literature tends to focus upon alexithymia, which is conceptualised as a deficit within the individual that affects their ability to engage with their experience of emotion. In this thesis, I have adopted a critical stance towards the theoretical construct of alexithymia to enable an open exploration of any difficulties with emotion that participants may experience. This aimed to acknowledge alexithymia as a theory of emotion in the literature but to retain the central position which placed individual experience at the centre of all aspects of the study and to hear participants' meanings and interpretations.

The word alexithymia means "no words for feelings" (Sifneos, 1973, p. 255) and was originally conceptualised as a multifaceted personality construct, in which the difficulty was placed on and within the individual, as a defective aspect of their personality. Individuals with alexithymia are postulated to have difficulty identifying feelings and the differences between feelings and the physical symptoms of emotional arousal, as well as difficulty in describing feelings to others, limited imaginal processes and an externally oriented thinking style (Taylor et al., 1997).

The literature reports that alexithymia, as measured by self-report questionnaires, is higher in those living with chronic pain. Papciak et al. (1986) found that 36% of outpatients presenting with pain as their primary symptom scored within the range for alexithymia, which is greater than in the general population (6-8%; Nemiah & Sifneos, 1970). This, suggests these researchers, could indicate that alexithymia is a risk factor for the development of chronic pain and may exacerbate the pain experience. An elevated rate of alexithymia has been found in people living with FMS. Steinweg et al. (2011) studied the prevalence of alexithymia in general medicine, rheumatoid arthritis and FMS patients. They found a significantly higher rate of alexithymia in FMS patients (44%) than in the other two groups (8% and 21% respectively). Therefore, FMS patients had a higher prevalence of alexithymia than those living with another chronic pain condition, suggesting to these authors that FMS differs in some respects to other pain presentations (Steinweg et al., 2011).

Several authors have identified these difficulties as contributing to suffering in chronic pain presentations (Aaron et al., 2019) and in FMS specifically (Tesio et al., 2019). It has been postulated that FMS symptoms are exacerbated by alexithymia due to an increase in negative affect, chronic sympathetic nervous system hyperarousal and impaired immunity (Huber et al., 2009; Lumley et al., 1996).

There are currently no satisfactory explanations for the higher prevalence of alexithymia in FMS (Huber, et al. 2009; Taylor, 2000). This may be due to the complexity or even the validity of the concept of alexithymia. Montoro et al. (2016) suggested that, in contrast to the view of alexithymia as a unitary construct, it may be state (stable personality construct) or trait (variable stress response) dependent. Hence, high scores on alexithymia measures could indicate either a stable personality trait or a transient state in response to illness-related distress, without the sensitivity to distinguish between the two. Lumley et al. (2007) also argued that both state and trait components were present, with the balance varying at different times. This debate underlines the complex and dissatisfactory nature of alexithymia as an explanatory framework for emotional difficulties.

Along with the theory that alexithymia may predispose individuals to chronic pain or exacerbate the pain experience, the importance of identifying and treating alexithymia was suggested by Lumley and colleagues (Lumley et al, 2011), who conducted a useful review of studies in the field. They concluded that “alexithymia is a negative prognostic indicator for many psychological treatments” (p. 237), negatively influencing treatment process and outcomes. However, this may be due to the interpersonal difficulties faced by people who score highly on alexithymia measures. Vanheule et al. (2007) compared alexithymia and interpersonal self-report measures in psychiatric patients and students, and found that higher alexithymia scores were significantly related to cold, distant and nonassertive social functioning. They suggested that psychotherapists should assist clients to identify arousal states, and to develop an explanation for them. This could be achieved by mirroring and discussing the therapeutic relationship regularly (Vanheule et al., 2007).

Fitzgerald and Bellgrove (2007) argued that features of alexithymia overlap considerably with Asperger's. They quote Taylor et al. (1997), who detailed the cognitive problems (externally orientated thinking style, difficulties in social relationships (leading to less well-developed support networks), and speech and language problems, as well as the non-verbal behaviours associated with alexithymia. However, Fitzgerald and Bellgrove (2007) may have over-emphasised the similarities between the conditions. Whilst there are overlaps in terms of limited imaginal processes and an externally oriented thinking style, the features of alexithymia are specific in their presentation and limited to the affective dimension, whereas the difficulties present in Asperger's are more global in their effects. Nonetheless, these similarities should be considered, as they serve to emphasise the complexity or even difficulty of alexithymia as a concept.

This section has explored the complex concept of alexithymia at length, due to its prevalence in the fibromyalgia literature, where it has been put forward as a potential causal or contributory factor. The next section will explore the syndrome of fibromyalgia in more detail.

Psychological distress and alexithymia in FMS

The relationship between psychological distress and alexithymia in FMS remains unclear. Steinweg et al. (2011) compared alexithymia and depression self-report scores in people being treated for FMS, general medicine and rheumatoid arthritis. They found higher rates of both alexithymia and depression in the FMS group, although when depression was controlled for, the difference in alexithymia disappeared. Steinweg and colleagues concluded that the presence of low mood mediated the relationship between alexithymia and FMS. The mechanism by which this may occur, however, has not been established, suggesting that exploration into the subjective experience of people with FMS may be illuminating.

Implications of alexithymia for people with FMS

Difficulties with emotion may impact the experience of FMS. DiTella and Castelli (2016) conducted a critical review of the evidence for the role of alexithymia in people with different chronic pain conditions between 2012 and 2015. They attributed difficulties in regulating and processing emotions in these conditions, including FMS, to increased pain intensity (Celikel & Saatcioglu, 2006; Cox et al., 1994). This indicates the need to identify whether these difficulties are present in people with chronic pain conditions, including FMS with a view to offering psychological interventions to alleviate the effect of any difficulties related to emotion upon the pain experience.

DiTella and Castelli (2016) also concluded that the misattribution of emotional arousal as signs of illness could exacerbate the symptoms of chronic pain and, consequently, FMS. Adopting this model suggests that the presence of difficulties with emotion may exacerbate the onset and development of pain symptoms. This misattribution of symptoms may lead to help-seeking or symptoms that have no medical explanation (Lumley et al., 1996), thus perpetuating the conflictual relationship with clinicians that some people with FMS report (Briones-Vozmediano et al., 2013). Similarly, the interpersonal difficulties which may result from any difficulties with emotion are likely to be related to difficulties identifying and describing feelings in oneself and others (DiTella et al., 2015). This may impact on the ability of people living with FMS to manage their self-care and illness presentation. They may be unable to verbalise their distress to others and less likely to reach out to others for help or comfort (Taylor et al., 1997), leading to the development of low mood (DiTella and Castelli, 2016).

DiTella and Castelli (2016) aimed to offer a ‘critical discussion of the recent studies investigating the presence of alexithymia’ (p. 40), though they retained the position that alexithymia exists as a construct. Although the studies included in their review reported difficulties with the regulation and processing of emotion in chronic pain populations, it may have been wise to extend their critical stance in their review to consider these as difficulties with emotion as discrete problems rather than, or in addition to, features of the controversial concept of alexithymia.

The literature on alexithymia and chronic pain has traditionally been dominated by the medical model, which privileges the voice of the ‘expert’. This conflicts with the counselling psychology ethos, where more value is placed upon individual accounts of experience. Some qualitative exploration of the FMS experience has been undertaken (e.g., Dennis et al., 2013), although most researchers have used quantitative approaches, aiming to test hypotheses to gain further understanding of the concept. In this study, I aimed to capture the participants’ perspective and so offer another research dimension. Consider that Lopez-Munoz and Perez-Fernandez (2020) discussed alexithymia as “a theoretical psychotherapeutic construct” (p. 1), emphasising the utility of identifying difficulties in people with FMS and more generally. This contrasts with much of the literature, in which the difficulty as a dimension of the individual is cited, rather than our attempts to formulate individual distress. Authenticity to the principles of counselling psychology is key in this study. Therefore, alexithymia was held lightly in mind in this project, as a construct which may or may not be relevant to the experiences of the participants under study.

Summary

Counselling psychologists are concerned with giving voice to service users and advocating for under-served groups, as part of their focus on social justice (Cutts, 2013). Since people living with FMS experience a lack of moral support from and feel de-legitimised by their health professionals, conducting sensitive qualitative research in this area clearly fits within the aims of counselling psychology.

The role of psychological factors in the pain experience has been evidenced in the literature, with affective processes being of central importance to the development and maintenance of pain. FMS is a medically unexplained chronic pain condition which has characteristics that distinguish the suffering of individuals from those with other pain conditions, including diverse and unpredictable symptoms, higher rates of psychological distress and suicide, and larger numbers of people scoring within the alexithymic range on self-report psychometrics. In this study, I will focus on the experience of emotion in women with a diagnosis of FMS, to contribute a qualitative perspective to the pain and emotion research literature.

METHODOLOGY

Design

The aim of this qualitative study was to explore how people with Fibromyalgia Syndrome (FMS) experience emotion in relation to their condition and how they understand any difficulties they may have. Semi-structured interviews were conducted with a purposive sample of people who had received a diagnosis of FMS and attended support groups across South Wales. Reflexive TA (Braun and Clarke, 2018; 2020) was utilised within a critical realist framework with data coded inductively (that is, coding is guided by the content of the data) as part of an iterative process. The interviews were transcribed by the researcher and then analysed using QSR NVivo software, which is a widely used application that facilitates electronic coding and data organisation, thus enhancing researcher-led analysis (Silver & Fielding, 2008). Manual coding was also undertaken during familiarisation with the data.

Rationale for qualitative approach

As stated above, the aim of this study was to explore how people with Fibromyalgia Syndrome (FMS) experience emotion in relation to their condition and how they understand any difficulties they may have. A contextualised understanding of a small sample was the central aim, as opposed to that of generalisable findings, more frequently seen in quantitative research. Willig (2012) writes, ‘qualitative research is about attempting to discover new aspects of a totality that never can be accessed directly or captured in its entirety’ (p. 19).

Counselling psychologists are concerned with giving voice to service users and advocating for under-served groups as part of their focus on social justice (Cutts, 2013). Since people living with

FMS experience a lack of moral support (Dickson, Knussen, & Flowers, 2007) and feel de-legitimised (Närvänen & Asbring, 2002) by health professionals, conducting sensitive qualitative research in this area clearly fits within the aims of counselling psychologists. Furthermore, it is anticipated that a rich understanding of the emotional experience of a small sample of people living with FMS may illuminate avenues to explore in psychotherapeutic practice – a central focus for counselling psychologists within the relational tradition. Willig (2012, p. 6) helpfully pointed out that the use of qualitative research 'tends to prioritize depth of understanding over breadth of coverage, and as such, the knowledge it generates tends to be localized and context specific'; therefore, the aim was to contribute to an understanding of emotion in FMS rather than to produce generalisable findings. In this sense, analysis of detailed qualitative data could inform future qualitative and quantitative researchers concerned with a deeper understanding of FMS and improved treatments or services as well as ensuring that the research remains close to the experience of people using services.

Rationale for reflexive thematic analysis

Careful consideration was given to the methodology and method of analysis given the aims and research questions. One of the principal aims of this thesis was to explore the experience of emotion, which may suggest the adoption of interpretative phenomenological analysis (IPA; Smith, 1996) as a form of analysis. The phenomenological basis of IPA is a commitment to 'how people make sense of their major life experiences' (Smith, Flowers, & Larkin, 2009, p. 1), with no prior hypotheses assumed. The second aim of this study was to explore how participants understood their emotional lives and any difficulties they may bring. Data analysis included a consideration of the literature surrounding difficulties with emotion therefore the philosophical underpinning of IPA was incompatible with the research aims as there were prior hypotheses; namely that some participants may have difficulties with emotion. IPA was therefore not appropriate for this work.

Braun and Clarke's (2018; 2020) version of reflexive TA was chosen as a method because its use allows the analysis of these research aims with the flexibility to allow the construction of an epistemological and ontological framework which satisfied the research questions. Further, the use of this approach 'emphasises the importance of the researcher's subjectivity as analytic r*esource,* and their reflexive engagement with theory, data and interpretation' (Braun and Clarke, 2020, p. 3). Reflexivity was utilised throughout the research process to incorporate my subjectivity as a valuable and inextricable part of each phase. This was embraced rather than viewed as a 'problem to be managed' (Braun and Clarke, 2018, p. 107), placing great value on the actively interpretative role of the researcher throughout the process. This is further discussed below in the section entitled 'Reflexivity and quality: Researcher as instrument'.

Reflexive TA incorporates the possibility to analyse both inductively (data-driven) and deductively (theory-driven) though the authors see this as more of a continuum than a dichotomous distinction. The use of an inductive analytic process was appropriate for this endeavour given that the analysis was grounded in the data whilst recognising that theoretical, epistemological and ontological assumptions '*inescapably* inform analysis' (Braun and Clarke, 2020, p. 4).

Other forms of thematic analysis (eg Boyatzis, 1998) involve coding triangulation and a focus on reliability, thus retaining positivist leanings, with less value placed upon the integrated role of the researcher.

Counselling psychologists are primarily concerned with subjectivity and artistry in research and practice (BPS, 2005). Therefore, Braun and Clarke's framework fitted this study due to its flexibility for incorporating differing research questions and its appropriate qualitative approach, which reflected the philosophical principles of counselling psychology.

Ontological and Epistemological Orientation

Braun and Clark (2013) emphasise the importance of having a strong understanding of the philosophical assumptions which underpin qualitative research. Consequently, the execution of the research should operate within the principles of the adopted philosophical framework (Braun & Clarke, 2013, p. 17). This demonstrates sound research practice and builds rigour when utilising any given qualitative method or methodology.

Reflexive TA is an approach to qualitative research in which a technique for qualitative data analysis with no *given* ontological (beliefs about the nature of reality) or epistemological (beliefs about the nature of knowledge) assumptions are outlined. In this sense, reflexive TA is a method rather than a methodology (Braun & Clarke, 2013), offering the researcher the opportunity to compile a bespoke methodology that is authentic to the aims of the work. Thematic analysis in this sense, has been described as similar to the process of selecting the items for a gift hamper (Braun, Clarke, & Rance, 2015) in terms of its philosophical underpinnings; the ontological and epistemological framework for the work is compiled by the researcher to reflect their belief structure and fit the project aims. This is in contrast to some methodologies, such as IPA (Smith, 1996), which have a pre-determined ontological and epistemological framework; the ‘hamper’ items have already been selected within the methodology.

The ontological positioning of this work draws from both the nature of the research questions and my beliefs about the world. A critical realist (Bhaskar, 1998; Willig, 2013) framework was adopted for the planning, execution, analysis and reporting of results for this thesis. Critical realists posit that although reality exists independently of the observer, our access to this reality is limited to the interpretations we make from the language and other sources of communication offered by participants. The ‘reality’ that we, as researchers, can access is necessarily a window into the participant's world, meaning we cannot claim to know their reality for certain. This position is embraced within Big Q research (Braun & Clarke, 2006), in that I explicitly acknowledge that the results of this thesis are subjective interpretations of participant narratives which are influenced by my skills, knowledge base and theoretical concerns. Data does not overtly contain the meanings, influences or driving forces behind the participants' reports; therefore, researchers must utilise their resources to provide an account. The resultant themes in this thesis are therefore intended to be the product of this ontological framework and to offer suggestions of possibilities rather than certainties (Frosh & Saville-Young, 2008).

The critical realist approach fits securely within the philosophical underpinnings of counselling psychology; the British Psychological Society (BPS) Professional Guidelines for Counselling Psychology state that counselling psychologists 'bring aspects of themselves to their work, derived from their training, wider knowledge, and lived experience' (BPS, 2019). It follows that the reflective practitioner model we practice in the clinical field translates to how we undertake research. Critical realism captures my belief that an 'authentic reality' exists (Braun & Clark, 2013, p. 27) and that the meanings people with FMS make of their experiences are socially influenced. Therefore, my subjective interpretation of their narrative during analysis can only partially access their experience.

In addition to the ontological framework, a researcher's epistemological assumptions must be explicit to ensure rigor and quality. These are the positions we take on how and what kind of knowledge we can ultimately know and how these affect data collection and analysis. It is therefore important to clarify the theoretical and philosophical underpinnings of this aim in terms of the knowledge that can be created through it. This work was conducted within an empirical epistemology (see Chalmers, 1999; Willig, 2008) to capture participants' experience of emotion. Empirical research holds that all our knowledge of the world is based on our perception of sensory experience, though this is an interpretative process. This acquisition of knowledge occurs as the result of experience with the acknowledgement that ‘sense perception does not provide direct and uncontaminated access to ‘the facts’’ (Willig, 2008). Therefore, an empirical epistemological approach emphasises the role of experience which is central to the research aims and it allies with critical realism in that it also posits that the nature of being can only be accessed only through our interpretations of reality.

Selection and recruitment

Purposeful sampling has been widely utilised in qualitative research to create samples which are rich in the phenomena of interest (Palinkas et al., 2015; Patton, 2002) and to move closer to the depth of that experience. It involves the selection of participants with specific consideration to their knowledge and/or experience of the topic of interest – in this case, a formal diagnosis of FMS and a willingness to discuss their emotional life.

Hence, a purposeful sampling strategy was appropriate for the aims of this study and was adopted to identify ‘information-rich’ cases (Patton, 2002, p. 273) for a focus on the experience of emotion in people with FMS. The use of thematic analysis enables a search for commonalities and differences in participants’ reported experience of emotion, meaning a homogeneous sample is desirable.

The limitations of this sampling strategy must also be considered. Bernard (2002) noted that purposeful sampling must be balanced with the limitations of participants’ availability and willingness to engage. The selection of participants depended upon their attendance at support groups and their willingness to discuss their experience of emotion, in addition to meeting all other inclusion criteria:

Inclusion criteria

- Adults aged over 18 years
- Diagnosis of FMS
- Willingness to complete demographics form
- Able to sit comfortably for a minimum of 30 minutes up to approximately 60 minutes
- English as a first language
- Able to provide informed consent

Elliot, Fischer and Rennie (1999) documented the importance of situating the sample to provide context and so recognise the limitations and generalisability of the results. Demographic data about age, gender, employment status, occupation, sexuality, ethnic background, spirituality, social class and disability was collected, as is consistent with qualitative enquiry and based on the example quoted by Braun and Clarke (2013). Information which specifically related to this population was also captured to explore participants' 'disability' status – that is, years since first symptoms and since diagnosis. The demographic profile of the sample is discussed in the section on participants below and the discussion section.

Braun and Clarke (2020) suggest that there is no ideal number of participants for a reflexive TA study and that the researcher would be wise to exercise discretion on how many people to interview, based on the richness of the interviews for answering the research questions. I continued to recruit until sufficient data were collected to address the research questions. Following this process, all those who expressed an interest in participating were interviewed which communicated validation and compassion (Närvänen & Asbring, 2002). Ten people were interviewed in total for this study.

Participants

The sample was reasonably homogeneous. All participants identified as white, heterosexual females, nine were not currently employed (one was employed on a part-time basis), eight were part of the Christian faith and two quoted ‘no religion’. Nine participants described themselves as ‘disabled’. Age ranged between 50 and 73 years (mean = 63), with five participants aged between 50 and 61 and five between 62 and 73 years of age, representing a spread of ages across the range. Full details of demographics can be found in Appendix 1. Pseudonyms are used to protect the anonymity of all participants. Table 1 below shows demographic information.

Table 1: Participant demographic information

Removed to protect participant confidentiality.

Development of the research instrument

A prepared interview guide (see Appendix 6) was used to enable participants to discuss their emotional experience of FMS as openly as possible. Semi-structured interviews were undertaken, and the discussion was *guided* rather than *dictated* by the schedule. Open questions were centred around the experience of having FMS and were informed by the research questions.

Procedure

I visited two support groups in South and South West Wales to introduce myself and the study aims to group members. These groups were coordinated by Fibromyalgia Action UK, the leading UK organisation for those diagnosed with the condition. I have worked previously with this organisation when undertaking my master's dissertation. All participants were recruited on the basis that they were willing to take part (Patton, 2002) and that they fulfilled the inclusion criteria.

The nature of the study and the reasons for the inclusion were explained openly and transparently both verbally through presentations to the support groups and in writing through information and consent sheets (see Appendices 4 and 5). The opportunity for individual conversations around this was offered throughout the presentations and before the interviews to ensure that participants were giving informed consent and to put them at ease before the interview.

All participants were given written information on the purpose of the study and informed of what their participation would involve, their right to withdraw at any time, confidentiality protocols, procedures for anonymising the data and where to seek support should they find the interview process distressing. They were then asked to indicate their willingness to participate by signing a consent form. Examples of these can be found in Appendices 4 and 5.

Interviews

The time and venue for interviews were organised at the participants' convenience in locations where they felt comfortable, as suggested by Braun and Clarke (2013). Four participants were interviewed at home, with the researcher following the safety protocol for lone working outlined in the ethics application. Six participants were interviewed in the location of the support group on days when the group didn't take place. These interviews were held during the day in a quiet room in a community centre, with several other people present in the building and undertaking community activities.

Interviews were recorded on two digital voice recorders to guard against equipment failure. All recordings were stored in line with the University of the West of England's policy on confidential data storage and were deleted from the equipment after transcription. After the interviews, participants were directed towards the sources of support quoted on the information sheet.

In line with the methodological guidance for TA, ten interviews were undertaken to facilitate cross-case analysis (Braun & Clarke, 20013). Participants' wellbeing was prioritised throughout the study. Prospective participants were asked if they could sit comfortably for at least 30 minutes before recruitment, to comply with the inclusion criteria. They were reassured at the beginning of the interview that breaks were welcome at any point, and that ending the interview at any time without the necessity of an explanation was also an option. If participants experienced fatigue during the interview, they were given the option to break or discontinue the interview. No participants took up this offer.

The issue of participant fatigue was considered, both in terms of caring for participants and to reinforce the legitimacy of their discomfort (Dennis et al., 2013). Scholars have shown that dissonance between the lack of visible signs of disease in FMS and the inability of those with the condition to undertake some social activities can cause problems in relationships (Hallberg & Carlsson, 1998; Henriksson, 1995a). The legitimacy of the disease and, consequently, the individual's integrity can be called into question where this dissonance is apparent (Barker, 2005). The researcher utilised counselling psychology training to communicate empathy and warmth and to communicate the researcher's perceived legitimacy of participant distress.

Transcription

The audio recordings were transcribed verbatim to produce an orthographic transcript. In the absence of definitive or prescriptive guidelines for transcribing verbal data for thematic analysis (Braun & Clarke, 2006), care was taken to note all spoken words as they were said with no amendments. Pauses and intonation that were judged to be meaningful were also recorded to facilitate analysis in greater depth. Punctuation marks such as commas and full stops were used as they would usually be in written language. It was overtly recognised that this process was necessarily interpretive and depended upon my subjective judgement in this context.

Ethical Considerations

All procedures were granted full approval by the University of the West of England's Ethics Committee before data collection and complied with the ethical criteria of the BPS' Code of Human Research Ethics (BPS, 2014).

Analysis of Data

The Braun and Clarke (2020) six-phase model of data analysis was adopted to search for themes and patterns of meaning within and across the dataset. These phases are outlined in the table below, taken from Braun and Clarke, 2020:

Table 2: Phases of analysis

Phase	***Description of the process***
1. Familiarising oneself with the data and writing initial familiarisation notes	Transcribing data, reading and re-reading the data, noting down initial codes
2. Systematic coding of data	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code
3. Generating initial themes from coded data	Collating codes into potential themes, gathering all data relevant to each potential theme
4. Developing and ongoing review of themes	Checking if themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis
5. Defining, refining and naming themes	Ongoing analysis to refine the specifics of each theme and the overall story the analysis tells, generating clear definitions and names for each theme
6. Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis

(Braun & Clarke, 2020, p. 3)

Audio recordings of all interviews were listened to and read through, and notes about early ideas for themes were made. The interviews were then imported into NVivo 12 for Mac software to enable coding and theme development. All data were retained on a password-protected laptop in accordance with ethics approval.

The main focus when coding in relation to the research questions was to interrogate the data to record and interpret the meanings that participants gave their experiences. Most codes were created on the latent level, that is, concepts and assumptions were interpreted from the data. Some codes remained at the semantic or more descriptive level, remaining close to the explicit content of the data to inform the development of themes. The overall emphasis, however, was on developing latent codes which were intended to capture a deeper analysis of the conceptual meanings within the data. To maximise data analysis, the supervisory team ensured that my coding was of sufficient depth and clarity throughout the process of analysis. This was continued during the phase of theme development, where my Director of Studies checked my development of meaningful patterns and candidate themes, moving through to the development of mature themes.

A recursive approach to the data was taken to ensure themes remained as close to the data as possible. Hence, the stages of analysis proposed by Braun and Clarke (2020) were adopted flexibly rather than as a restrictive linear process, as the authors advised.

Reflexivity and quality: Researcher as instrument

Braun and Clarke (2006) discussed the overtly subjective nature of qualitative research as a defining strength of pure qualitative enquiry (‘Big Q’ studies; p. 4), thus separating it from ‘small q’ (p. 4) studies which rely on positivist ontological assumptions. I have embraced the approach that my analysis was inherently a process of subjective interpretation intended to achieve depth and detail in the search for themes and that the findings were congruent with a qualitative epistemology. I aimed to achieve a deeper understanding of how a small number of people with FMS experience their emotional life.

An awareness of my position as the researcher within this study was critical (Finlay, 2002a; 2002b) for exploring how my subjective biases may have influenced the planning and execution of this study. Most importantly, being aware of how ‘beliefs, assumptions and experiences may shape (both limit and facilitate)’ my ‘reading of qualitative data’ given that ‘meaning is always given to data and never simply identified or discovered within it’ (Willig, 2012 p. 6). Working within a purely qualitative paradigm meant that I continuously monitored how my own experience of having two close friends diagnosed with FMS influenced each stage of the research process. Their experiences of FMS differed though both suffered greatly and they had to make adaptations to their lifestyles and relationships as a result of the condition.

I reflected at great length on my responses to their difficulties and the enforced changes to our friendships in a reflective diary which was used throughout the process of this thesis. Much of my response centred around the injustice of the stigma that people with FMS can experience due to a lack of knowledge or lack of empathy in others. This position had been one of the most powerful motivations to study FMS in both the Master’s and the current project. In order to produce research which acknowledged my subjective interpretation of the data whilst also ensuring that the outcomes were faithful to participants’ reports, a process of bracketing (Morrow, 2005) was adopted.

There were occasions during the interviews which triggered responses in myself that were linked to my own and my friends’ experiences of FMS. These were noticed and bracketed whilst interviewing the participants in order to remain focussed upon their perspective as far as possible. An entry in my reflective diary was made following the interview and these entries were considered alongside the coding and theme development to ensure that the data was present in the interviews to substantiate the analysis. The process of bracketing these experiences limited their influence on the interviews and data analysis and also allowed a deeper analysis which was grounded in the data. By noticing my own assumptions and moving back to data content, acknowledgement and acceptance of the inherent subjectivity of qualitative research could be achieved, whilst attempting to limit how far this influenced the analysis.

This awareness extended to my cultural background and beliefs and how I related to the participants. Reflecting on my position in relation to the participants in this study revealed ‘multiple insider and outsider positions’ (Braun & Clarke, 2013). Sharing characteristics with participants locates the researcher as an insider while differences locate them as an outsider. My insider position was characterised by being a white, heterosexual female, while my outsider position was characterised by a difference in age (to most participants), employment status, occupation, spirituality, disabilities and, most crucially, having no pain conditions. I was aware of my distinctive outsider position as an academic coming into the support groups for a short time with limited experience of pain and no experiential understanding of chronic pain.

During the execution of the thesis, I experienced a period of extreme acute pain from a localised injury which continued for several weeks. My mood dropped immediately, and I experienced fluctuating negative emotions – despair (that most things I tried to ease the pain failed), fear (of how much worse the pain could get, that the medication would not control the pain and there would be many weeks of pain to endure), loss of self (where had the woman who copes with anything gone?) and loss of time (to complete the thesis and spend with my family). The first few weeks after receiving the injury were an extreme challenge which saw me focus entirely on managing physical sensations, above everything else that was usually important to me. I defaulted to the medical model for a solution, disregarding knowledge of psychological pain management techniques I had learnt and previously had faith in during my many years of psychology training, instead seeking several changes to my prescribed medication to ease the pain. None of the medication was successful in eliminating the pain completely. Sometimes the pain levels were intolerable and I struggled to function cognitively and socially, isolating myself as a coping strategy to avoid any other demands on my overwhelmed resources. I have since reflected on the futility of someone asking me to attempt psychological pain management whilst adopting this position of being under threat, and this has increased my respect for people who suffer pain indefinitely.

Medics had advised me that the pain would begin to diminish after six weeks; therefore, I was aware that my pain experience was temporary. Despite this advice, I retreated into a defensive position in a desperate attempt to survive the threat of such intense pain. Heathcote and Eccleston (2017, p. 5) describe pain as a ‘salient cue of threat,’ which fits with my experience. Occasionally, my thoughts turned to the people I had interviewed and how their experience of pain had been similar. Following my recovery, I have reflected on the difference between my experience and theirs; people with a diagnosis of FMS often have no quantifiable recovery point in sight, as I did. My acute pain experience offered an insight into some of the issues participants discussed. By far the most impactful reflection has been that I had found the pain almost impossible to tolerate for a short period, even with an awareness that I would make a full recovery – and yet this was potentially a daily struggle for my participants for the rest of their lives. My respect for the women who participated in this study deepened following this experience.

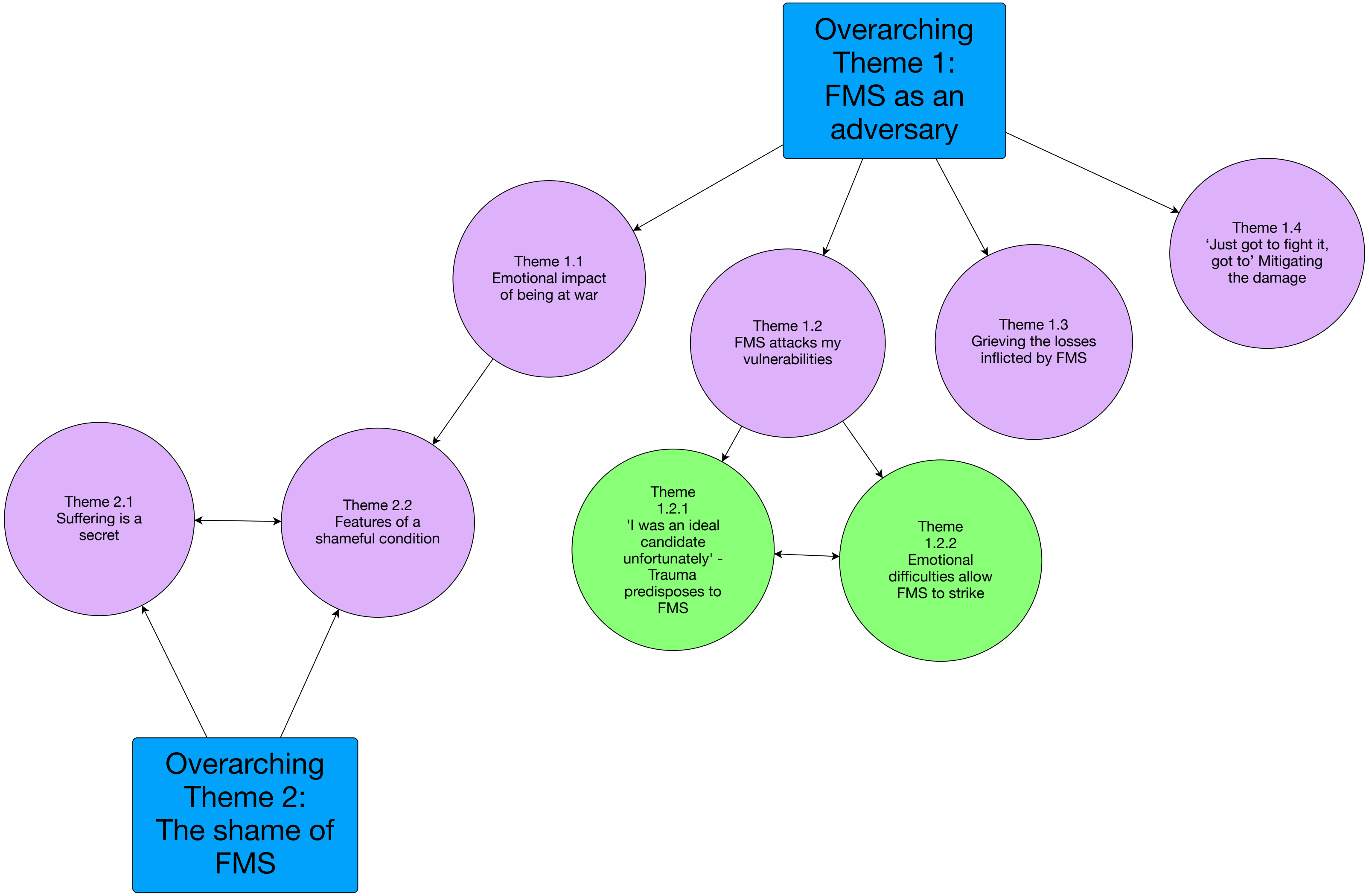
RESULTS

The themes generated from the thematic analysis of ten semi-structured interviews with people who had a formal diagnosis of FMS are outlined below. Participants' emotional experiences and understandings were explored. Analysis resulted in two overarching themes: 1) FMS as an adversary and 2) The shame of FMS. The themes and sub-themes are listed in Table 3 below followed by a thematic map.

Table 3: Overarching themes, themes and subthemes

Overarching theme 1: FMS as an adversary	
Theme	***Sub-theme***
1.1 Emotional impact of being at war	
1.2 FMS attacks my vulnerabilities	1.2.1 ‘I was an ideal candidate unfortunately’ – Trauma predisposes to FMS
	1.2.2 Emotional difficulties allow FMS to strike
1.3 Grieving the losses inflicted by FMS	
1.4 ‘Just got to fight it, got to’ Mitigating the damage	
Overarching theme 2: The shame of FMS	
Theme	***Sub-theme***
2.1 Suffering is a secret	
2.2 Features of a shameful condition	

Figure 1: Thematic map



Findings are presented for each of the key themes. When extracts from the data are given, the line number(s) from the data are quoted: for example (Line 1002-1005). ‘LJ’ denotes the researcher conducting the interviews. Explanatory comments are included in brackets in some extracts to aid the reader. Punctuation marks such as commas and full stops are used as they would usually be in written language. Underlined text shows emphasis upon words, (.) denotes a short pause, (…) indicates a pause of more than a few seconds and [---] marks where material has been omitted to aid the clarity of quotes.

Overarching theme 1: FMS as an adversary

Participants tended to refer to their condition as an external enemy, thus framing their emotional experience as a battle, where FMS is the aggressor. The themes represent the emotional impact this state of threat imposed upon them as they lived with the condition and suffered continuous attacks. The aggressor exploited participants’ vulnerabilities to get into their lives and, subsequently, caused distress. This distress was underpinned by grief, as numerous losses were experienced. The final theme illustrates how participants coped and fought to mitigate the damage.

Theme 1.1: Emotional impact of being at war

This theme represents how participants experienced emotion emanating from frequent FMS attacks. All the women spoke of their condition generating distress, which related to their global wellbeing in addition to certain specific emotions. Diane likened having FMS to ‘walking through treacle with a sack of potatoes on your back’ (Line 434-435), offering a vivid image which emphasised the difficulty of continuing with everyday life whilst carrying the heavy burden of this chronic pain condition.

Participants spoke of attacks on their global wellbeing. Diane described FMS as an overwhelming attacker that strikes at her core resilience. These attacks subjugated any natural abilities to manage emotional difficulties despite these strategies being sufficient in other areas of her life;

Diane: It's the Fibro. It's not your personality, it's not in your nature to, to be irritable or you know, I've always been happy, well I haven't that's a lie [laughs] umm I've always been resilient and that's one thing that throughout my entire life I've recognised my own resilience but Fibro isn't, is, it'll attack that, it'll attack everything you know
(Diane, Line 167-170)

Diane characterised the attacks in terms of the pain she experienced;

Diane: I think Fibro is a very painful condition so it's constantly living with pain from the time you wake up in the morning umm until you go to bed and then throughout the night there's always this battle. And that's how I feel emotionally like I'm in a battle with my body [laughs]
(Diane, Line 56-59)

The global effects of FMS on affect were supplemented by more specific emotional states, which were reported by most participants. These were anger, frustration, fear and anxiety, and depression.

Anger

Charlotte described her anger towards FMS as arising from the limitations it placed on her leisure activity. For example, she went roller skating despite knowing that she would be in severe pain afterwards in angry defiance of her condition.

Charlotte: But also it's the fact of why should I not be able to do anything I love any more, why should I not have to stop. No, I understand physically I can't be stupid, I wouldn't do it every week. Umm, and but yeah, pretty much. I do get really, really annoyed and really angry at the Fibro.
(Line 873-877)

The emotional impact of a lack of awareness of FMS in others is discussed in more detail in sub-theme 2.2.

Frustration

Physical changes prevented many of the women enjoying the activities they valued, which led to frustration.

Carol: I used to love walking, used to love gardening and that's only in the last 12 months that I haven't been able to do it and I think it's like a tension. Like a coiled spring of – I want to do it [---] but I physically can't do it.
(Line 457-462)

Carol’s metaphor of a coiled spring conveys her frustration that she is bursting to do something, and being held back by strong, external forces creating a strong tension.

Kate’s frustration was combined with sadness at being forced to give up a vocational career:

Kate: it does make me feel sad all the time. Because I’m missing out on things I’d love to go back to work with the children again, children but I know I can’t do it, I can’t bend, I can’t walk properly, I can’t lift, I get dizzy. All these things are frustrating and you know, they, they make you feel inadequate. And, and I don’t want to show people that I am inadequate.
(Line 272-276)

Being unable to undertake her job was internalised as her own inadequacy as opposed to the consequence of a chronic pain condition. Leaving her vocation was her way of protecting her reputation as a competent teacher and disguising her perceived emerging personal inadequacies

Fear and anxiety

Many participants reported fear and anxiety as emotional reactions to FMS. Abbie vocalised future-focussed fear relating to other health problems she had, anticipating her heightened sensitivity to pain as a result of FMS and its consequences in the future:

Abbie: I’m dreading surgery because I didn’t have Fibromyalgia as such when I had the surgery before, the pain was horrific but is it gonna be hundred times more horrific.
(Line 857-859)

Kate’s fear emerged from how uncertain the course of FMS might be:

Kate: you just wonder ‘how long will this go on, how long are you gonna cope with it?’
(Line 40-41)

Catryn experienced a more general feeling of anxiety:

Catryn: I feel jittery, really, really jittery. I’m looking it up, that’s another part of Fibromyalgia apparently that is a jitteriness due to nervousness or uncertainty
(Line 301 -302)

Depression

Depression featured in most participants’ experiences. It was viewed as an external force which waited in the wings for an opportunity to strike. Diane’s description of ‘that terrible [incomprehensible] depression that tries to sneak in when you’re umm, when you’re feeling so bad for yourself and so sorry for yourself’ (Line 408-410) characterises the reports of many participants. Rhian equated social withdrawal with self-pity:

LJ: what’s going on for you on the days when you just want to shut yourself away?
Rhian: ummm well, I suppose you could sort of feel sorry for yourself you know a bit.
(Line 599 -600)

The opportunity for low mood to develop occurred when participants acknowledged the emotional impact of their suffering (‘feel so bad for yourself’), causing a compromise of their defences. Feeling ‘sorry for yourself’ suggests that participants perceived themselves as self-pitying, *allowing* depression to attack, perhaps suggesting that they were in some way to blame.

Rhian supported the notion that depression was under her control and therefore partly her responsibility when she said ‘well, it does give you a low mood you know then isn’t it. But as you say then, another day, try and be a bit more positive. It comes and goes then, you know’ (Line 241-242).

Conversely, others felt that depression was an inevitable consequence of FMS. Charlotte said: ‘I think if you kind of load up the emotional responses to Fibro, umm depression is always a natural end result’ (Line 911-912).

Theme 1.2: FMS attacks my vulnerabilities

Participants tended to conceptualise that FMS exploited any vulnerabilities to inflict suffering. Two types of vulnerability were identified: 1) traumatic experiences either early in life or before the onset of symptoms and 2) where difficulties with emotion may be present. These factors may have left participants more vulnerable to the symptoms of FMS.

Theme 1.2.1: ‘I was an ideal candidate unfortunately’ - Trauma predisposes to FMS

A common theme in the women’s experiences was that serious and/or multiple trauma occurred before symptoms became apparent, leading them to believe that traumatic events which precipitated the onset of FMS were a key factor in the development of their condition. Kate reported that her rheumatologist linked her FMS to the death of her partner:

Kate: it was just one thing after another and the doctor kept telling me ‘oh, it’s just grief’ and then it was only four years ago that after all this, that the Fibromyalgia issue came up and they said ‘well, this is, this must be what you have’ [---] ummm, I did go to see um a rheumatologist

and it was confirmed. And, but I didn't know for all that time what it was but they said it was the, the grief that had brought it on, the shock of it.
(Line 208-214)

Kate's numerous symptoms were invalidated for some time by her GP as '*just*' grief. It was only when she saw a specialist that a FMS diagnosis was made. The rheumatologist validated her symptoms as an illness that had developed because of unbearable loss rather than as a grief reaction alone, identifying the relationship between traumatic experience and physical symptoms. Kate believed that the trauma she experienced following the death of her husband may have created a deep vulnerability to the development and severity of FMS.

Many participants experienced numerous traumatic events in the years before their diagnosis. Ruth described how she believed three difficult events led to her FMS; she was diagnosed with a heart condition and within a few months faced the death of her mother and loss of her job on the same day:

Ruth: I had the three in one there and I still swear that that's what's brought a lot of this on. [---] Well it's it's only that yeah, I think in the long run because I started to have these aches and pains which I was putting down to the heart.
(Line 623-627)

Catryn also spoke of numerous stressful events occurring just before her diagnosis including her husband being made redundant following a serious illness:

Catryn: I was trying to up his sort of self-esteem then because he'd been hit with such a massive blow on top of his illness and the money worries, they just kept on coming in all the time then [---] but there was another family issue as well around the same time. Was my mother with her Alzheimer's. She had lung cancer.

(Line 179-184)

Ruth's and Catryn's emotional load appeared to increase with the onset of additional stressors. A period of time when more than one distressing experience occurs appeared to increase participants' vulnerability to the development of FMS and exacerbate its symptoms. They felt that a cumulative effect had occurred; the combination of several challenging experiences overpowered their capacity for coping, leaving them susceptible to FMS.

In addition to the number of distressing events, childhood trauma also contributed to participants' increased vulnerability. Diane discussed how she believed the parental abuse she was subjected to inevitably triggered an inherited, stress-related condition in addition to the development of FMS:

Diane: I was kind of the punchbag but umm (.) so you know you can imagine then if you've got this condition that's going on in your family, you, it, needs triggers for it to show itself. Like the [pain condition shared with father] is triggered by stressful and emotional events and so is the Fibro and umm, I think I was an ideal candidate unfortunately.

(Line 185-189)

Adverse childhood experiences perpetrated by abusive parents or schoolteachers had long-term effects on their emotional resilience, leading to a greater susceptibility to stress-related conditions.

Some participants linked their FMS to the physical and emotional trauma of serious, invasive operations. Abbie linked physical shock to her FMS after researching the condition:

Abbie: I've read that it can come after a massive shock to the system like umm, obviously I had life-saving surgery and I nearly lost my life. [---] Five years ago [---] so I tied it in with, it's the aftermath of that.
(Line 402-407)

Finally, some participants described how FMS snuck into their lives when they were physically compromised due to fatigue:

Rhian: I think then, 'oh, did all this fatigue', do you know and then maybe the underactive thyroid because I was working and looking after my mother, that was lurking and I think 'have I overstressed my body?' [---] and as a result, this is my theory, the Fibro got in, you know.
(Line 287-290)

Rhian conceptualised FMS as an adversary waiting for an opportunity to strike. FMS 'got in' when her defences were low due to fatigue and physical health problems.

Theme 1.2.2: Emotional difficulties allow FMS to strike

The second potential source of vulnerability to FMS related to participants' reports of their emotional experience. Some participants reported having difficulty in describing how they were feeling which may suggest that they had difficulty in their relationship with emotion. It was perhaps notable that these participants had also reported psychologically and/or physically traumatic experiences either as children or as adults shortly before the onset of FMS. For these women, therefore it would seem that their level of vulnerability may have been increased by the potential impact of traumatic experiences and/or any difficulties in their relationship with their emotional lives.

Some participants reported how FMS had exacerbated an existing difficulty with emotion as they found it difficult to describe their emotions:

Betty: I can't describe how I feel though, I can't

(Line 317)

Betty: I've always felt the same I think [---] it's just I dunno if it's my brain not functioning right because you get the brain fog with the [auto immune condition] and the Fibromyalgia and I think 'am I having a double dose?' [laughs] [---] because I get so exhausted

(Lines 322-326)

For Betty, the impact of FMS on her ability to describe emotion was in the form of fibro fog and fatigue (in addition to a comorbid physical health condition), and therefore these FMS symptoms limited her descriptive abilities. However, Betty believed that she had this difficulty before the onset of either of her chronic physical conditions. Therefore, her difficulties may not have been caused by these; rather, they seem to have exacerbated an existing difficulty via fibro fog and fatigue.

Generally, participants discussed their relationship with their emotions in terms of their upbringing and the messages they received as young children. Carol, for example, grew up feeling that her family were consistently disappointed in her. The family culture of having a 'stiff upper lip' blocked dialogue and any possibility of disconfirming her assumptions:

Carol: (.) probably because we as a family was umm stiff upper lip. You didn't talk about [---] ummm anything to, (…) you kept it to yourself and umm (…)

LJ: and what's that like for you, are you like that nowadays? Do you keep a stiff upper lip nowadays?

Carol: Yeah, I try to, yes.

(Line 410-418)

As described by Carol, participants believed that because their parents were emotionally unavailable or abusive, they had matured into adults who habitually did not verbalise their emotional experience due to trauma or lack of role modelling and/or practice.

Theme 1.3: Grieving the losses inflicted by FMS

Participants discussed emotional and functional losses due to FMS. These included identity, familial role and activities of daily living. These losses were experienced as a process of FMS actively stealing roles and activities away, cheating participants out of what they would have been entitled to had they not developed the condition. This was verbalised by Betty, who said 'it's awful cruel' (Line 30). This loss was likened to grief by several women including Carol who spoke about having to depend on others:

Carol: [pause] it's [long pause] I suppose in a way it's almost like a bereavement umm.

(Line 335-338)

The impact of loss on identity was verbalised by Charlotte, who could not imagine how she would have been if, free from FMS, she was able to function fully. These losses resulted in meaningful reductions in her self-confidence, which she framed in terms of her emotions and personality:

Charlotte: so I don’t have a sense of umm myself any more as what I maybe have naturally been at the age of 50. It’s kinda taken stuff away. [---] Not just physically, not just lifestyle but like my confidence in, in umm (.) in the kind of assessment of myself then [---] emotionally [---] you know, and my personality.
(Line 425-433)

Equally, Catryn also described how being dependent on others had impacted her self-worth, which she found distressing:

Catryn: That, as I say I’m really, it’s upsetting. Really upsetting. I’m less able, I used to enjoy doing things which I can’t do now and that’s really sad. And I do, I just feel worthless, I feel useless having to rely on everybody all the time to help me when I can’t do things.
(Line 345-348)

Catryn went further than merely reporting that her self-worth has been impacted, she used the word ‘worthless’ thus saying that she was now completely without any worth at all as the result of FMS, reinforcing the devastating impact of this condition.

Catryn became distressed when asked how she felt about her condition:

Catryn: it’s stolen me, that illness has stolen me away… from the fact, that’s how I feel. It’s stolen me away from the family.
(Line 50-53)

She described how her core being had been stolen by an external force (‘that illness’), taking her out of her natural place in the family. FMS had taken on the characteristics of a criminal, a kind of kidnapper such was the strength of her characterisation of FMS.

Almost all participants spoke of the loss of physical abilities due to pain and fatigue, and the grief that this provoked. When asked what having FMS brought up for her emotionally, Diane described this eloquently:

Diane: [tuts] ummm well I feel very sad about having it you know, it’s almost a grief really.
(Line 38-41)
Diane: there’s this constant having to, to grieve for what you once could do and uhh, can no longer do.
(Line 41-50)

The impact of having important elements of themselves, their very being in some cases stolen by a cruel adversary was likened to the grief process by many participants. Having a similar emotional reaction to FMS as the loss of treasured parents highlighted the deep and powerful impact the condition had on them. This was reflected in the experience of many participants.

Charlotte described how she understood the process of loss, noticing as she thought it through during the interview that it was much like grief after a close loved one dies:

Charlotte: I feel like I’m lost and that maybe is where it links to the grief, that I’ve lost umm me (...) a bit like I lost, you know I’ve lost people to death I suppose.
(Line 790-792)

Charlotte continued this train of thought, linking her experience of loss due to FMS to her distress following her mother's death:

Charlotte: you know, I'd sit in the car when I was getting the kids from school coz I didn't want anybody to come up to me and [---] I didn't want, and I feel exactly the same. Exactly the same without having lost somebody. [---] And I didn't realise that until I said it to you either. I mean it's useful to make the comparison I suppose. For me it is anyway because I'd never actually realised I was doing it.
(Line 800-808)

This powerful insight in the moment shows Charlotte not only linking her current and previous experience, she appeared to realise that her behaviour patterns, feelings and motivations now, in light of her FMS, are the same as after her parents' death. A deeper analysis may conclude that she was speaking about how she was mourning her own death as a parallel experience. This sub-theme, together with the preceding two, represented how participants perceived FMS as a cruel attacker, exploiting their vulnerability and causing distress. The final sub-theme in this section details how participants found some strength to resist their adversary.

Theme 1.4: 'Just got to fight it, got to' - Mitigating the damage

Despite the impact of FMS potentially leading to physical, psychological and emotional pain, participants exercised self-help to cope with and reduce these difficulties, with examples ranging from seeking external support to psychological and behavioural strategies.
Several participants found their regional FMS group a valuable source of support, which both normalised their experience and validated their suffering due to contact with others who had

also received a formal diagnosis. Catryn found it helpful to relate to others' experiences, which provided evidence that her symptoms were real and that FMS existed in the outside world rather than just in her head.

Catryn: The support group is even better because we know we all have it because we've all had diagnoses of it. And we can, when I'm in the support group, it's just total relaxation. Cos I do, I sort of have a big sigh of relief because I know everybody in there has it. It might not be exactly the same but you can share your experiences and you know somebody else might have a similar experience to you, [---] that you can relate to and it just, you know it's not just imagining. It's there. It is a physical or a mental thing that you have and I think that's been the biggest help to me of all.
(Line 539-547)

Psychological strategies were common, with some participants using acceptance and gratitude as a way to reduce distress. Carol, for example, compared her condition to life-limiting illnesses:

Carol: ummm with Fibro, yes I've got it (.) umm, it took a long while to accept it but I feel I've accepted it. It's not going to kill me, it's not the dreaded C word, umm (.) I can accept the Fibro.
(Line 603-605)

However, whilst acceptance was valuable for some, others found that this was accompanied by a sense of defeat or regret that they were not more combative. Charlotte said:

Charlotte: So I'm very umm, I am accepting of it which makes me really sad because I think maybe I should be pushing the boundaries. (Line 397-398)

The physical metaphor used by Charlotte may have related to her physically active former self who was ‘really, really active … I’ve got that urge to go ‘yeah, come on let’s go and jump out of a plane’. She was sad that her condition forced her to accept a dramatically different way of responding.

Others resisted the power of FMS by denying its impact. Catryn was reluctant to use aids for daily living, supplied by an occupational therapist, perceiving this to be a sign of defeat or compliance:

(…) Catryn: I don’t, I try not to. I do not want to give in [---] because I associate them with somebody really disabled. I don’t, I don’t want to class myself as disabled as such (.). I’m not as able but I’m not, I don’t class myself as ‘totally disabled’ if you know what I mean.
(Line 332-338)

Catryn was expressing her power by resisting surrender to FMS, preventing the external cues that using aids can bring; being defeated by disability.

In summary, this overarching theme represented how the women in this study experienced FMS as a cruel adversary that resulted in intensely negative emotions. Its cruelty was characterised by FMS actively stealing their very selves and exploiting their vulnerabilities. The second overarching theme incorporates the global emotional impact of this adversary and how the women responded to this.

Overarching theme 2: The shame of FMS

This theme represents the data in which participants tended to internalise their coping strategies and the lack of support by the systems and society around them. This was represented as a negative reflection of themselves and their ability to cope with a chronic pain condition, driving them to hide their suffering from others. Their meanings and attributions were suggestive of shame as a global emotional response, evoked by FMS for many though not all participants. Additionally, participants spoke of the specific characteristics of FMS which influenced their affective response and this was suggestive of shame.

Ruth and Mary are under-represented in this theme as they did not speak of shame as part of their experience. For many other participants, FMS appeared to generate a global feeling of shame, leading them to hide their suffering. Charlotte eloquently expressed this as a loss of pride, the opposite of shame:

Charlotte: I've been proud. I remember it. I don't feel proud now (…) because and I don't think that a physical ailment should affect how you, sorry I'm gonna cry now (…). I don't think a physical ailment should make you feel less proud, I don't think it should umm affect how you're, you feel about yourself.
(Line 764-767)

She found it distressing that a physical illness could create detrimental changes to how she perceived herself and the unfairness that FMS could strip away her pride. An external force had affected her internal sensations and mental states which she found difficult to understand.

The first sub-theme contains an exploration of how participants appeared to experience shame as a consequence of FMS, creating a drive to hide their suffering from others. In the second sub-theme, the specific features of FMS that participants felt contributed to their negative experience of the illness are outlined.

Theme 2.1: Suffering is a secret

Many participants hid their symptoms to preserve their loved ones' perception of them as physically well, concealing the reality of their condition. Pretending that all was well for a short period allowed them to engage in family gatherings as if FMS was not part of their experience. Diane described how she managed any feelings of shame to protect her family from the 'imposition' of her illness on their time together despite it coming at a cost:

Diane: I'm putting on a brave face for the sake of my grandchildren and my family but when they go home, I'm exhausted for two, three days afterwards. So they don't see me, they only see me when I've got the brave face on, trying to you know, have a happy family day for everyone and not impose my illness on them for that (.) brief time.
(Line 230-233)

Despite the cost, Diane concealed her suffering for discrete periods by creating the illusion of health. Kate also noted that 'it is hard but it's (.) it's my way of sort of trying to get through it. If I can hide it to a certain extent' (Line 164-165).

Hiding the extent of their suffering from loved ones may have resulted in secondary shame, as participants felt they were being dishonest. Kate said:

Kate: all these things want, you just want to hide so you don’t go out. I wait in bed until my daughter’s gone to work so she can’t see. It makes me feel I’m living a lie really, I’m hiding all these things.
(Line 146-148)

Shame appeared to be the affective response for those who perceived that they were failing to cope with FMS. For some participants, this resulted in a drive to hide the pain:

Kate: I don’t want people to see that I can’t cope. I don’t want them to see me, that I’m constantly in pain and I don’t want to have to explain myself.
LJ: Do you mind me asking why it would be bad for other people to see that you’re in pain?
Kate: I’ve always been independent and I can’t cope with my pain. I don’t want others to really know how bad it is either.
(Line 83-88)

Participants tended to view effective coping as synonymous with independence, an attribute they valued. When chronic pain presented a challenge to their independence, they worried that others may notice their perceived inability to cope. They did not want others to see them ‘not coping’, so they tried to make themselves invisible.

Some participants described the motivation to hide FMS due to the reactions of others, particularly their care professionals. Charlotte explained how she was dissuaded from discussing her symptoms in GP consultations due to previous dismissive attitudes but then experienced a supportive doctor:

[---] Charlotte: well that was fantastic bec, and it’s almost as a little bit or sort of ummm I

didn't believe it was happening cos I've had more of the other side. I've had more of the more un [---] unwilling to sort of either recognise it as a condition or sort of poo-poohing it, ummm so then you start to not mention it and that.

(Line 84-90)

Charlotte's experience with most GPs led her to assume she would receive dismissive responses from others. She tended to be secretive about her FMS due to the shame it evoked:

Charlotte: [laughs] I just, you know I've just got used to doing it now. I've just (…) don't talk about it coz I feel stupid. I'll speak about those, people say 'how's your migraine?' 'fine'. Umm, same old you know, 'how's your back?' I say 'yeah, fine'. I don't tell people about the Fibro. Umm, because of the responses I've had from the medical professional I think because I'm thinking if I get those responses there, coz I've thought about this. Why is it the one thing I don't mention?

(Line 255-261)

Other consequences of keeping FMS hidden and internalising suffering included exacerbated symptoms of fatigue and social isolation. Kate experienced both of these:

Kate: I don't, I, I, don't go. It's, I feel I'm living two lives really. (.) And it's it's very wearing. You get tired with the Fibro, ever so tired. I think I get more tired trying to hide things.

(Line 282-284)

LJ: what words would you use to describe your emotional response to having Fibromyalgia?

Kate: (.) it's, it's the loneliness really because you have to hide it from everybody, you feel (...) you're an outcast basically.
(Line 340-342)

Kate spoke of the isolation inflicted by her response to FMS which she saw no alternative to. Hiding must be done despite the cost to herself and loss of any external validation for her suffering.

Theme 2.2: Features of a shameful condition

Participants discussed the features of FMS that they felt influenced their feelings about themselves and their condition. These themes combined to create a profile of FMS which could evoke shame, as many participants felt it did not fit the accepted profile of 'a proper condition' (Abbie, Line 323).

The responses of healthcare professionals and those close to participants were sources of emotional distress, coupled with these specific features of FMS, which informed the perception of FMS as a less legitimate illness than other chronic pain conditions. This resulted in a lack of awareness and empathy from others.

Abandoned by those we should rely on

Medics are typically present to care for those who are suffering from a chronic condition. Therefore, it is reasonable to expect to receive treatment and empathy if suffering from FMS. However, many women, including Abbie, said this source of support was absent: 'There's no treatment, there's no help' (Line 364).

The lack of definitive treatment pathways and the invalidating attitudes of medics left participants feeling abandoned and vulnerable:

Charlotte: I suppose part of the fear is that there was nowhere else to go. So if you don't get the response, or a helpful response from a GP, [---] ummm what do you do next?
(Line 142-145)

Some participants may have felt shame when their honesty was questioned by medics. This resulted in an exacerbation of distress, as they felt abandoned by those they should rely on. Charlotte felt her GP dismissed her suffering in several encounters, which she interpreted as being disbelieved:

Charlotte: What sort of response am I gonna get? Am I gonna get poo-poohed? Am I gonna get sent out feeling like I've been there for no reason? Am I gonna umm?'. The appointments were really difficult as well because I'd always go in on the back foot because I'd be thinking 'they're gonna judge, they're judging me on the fact I keep coming back.'
(Line 70-74)

Abbie had a similar experience with a gastroenterologist when she mentioned her FMS:

LJ: so how does it feel when he makes that face and says (…)?
Abbie: oh, his face yeah. He just doesn't believe, they don't believe it's some people don't believe it's an illness (.) or how <u>serious</u> it can be.
(Line 58-60)

Unpredictability

There was a lack of control over how and when FMS might strike, which was difficult for participants to tolerate. This mainly related to the unpredictability of FMS symptoms, which meant that the threat of pain and other diverse symptoms was ever-present, compounded by the uncertainty of where FMS might attack. This was eloquently described by Charlotte:

Charlotte: I think mainly for me it was the pain. And the not knowing what's coming next and not knowing when it's gonna get really, really bad again. So it's almost like when the pain stops, it should be a relief, you're always thinking about am I gonna start again, in two days or when the hell is it gonna start again? Your brain just can't handle it anymore, it just goes into sort of like, 'I can't carry on like this because I need some,' I've got an answer of what it is but there is no cure, it gets really, really, really bad.
(Line 926-931)

Mary explained how she was stuck in an ever-changing present and this unpredictability could make her condition seem unreliable to others or making it difficult for others to understand her suffering:

Mary: But it's very hard for somebody to see you one week and you've got the most dreadful pain in your shoulder and down one arm. And the next time you see them, you've got it in your other shoulder down the arm.
(Line 561-564)

Complexity of emotion

Diane colourfully described the complexity of her emotions relating to FMS.

(…) Diane: it's just umm, spaghetti. It's just like unravelling you know every day is a day when you think 'right, OK (.)' you open your eyes and you think 'actually yeah, I slept a bit yesterday but last night that feels better'… But umm, it's it's a crazy bag of stuff.
(Line 287-300)

She conceptualized how she made sense of her emotional life as a bagful of emotional experiences. Her rich language described an indiscernible collection of emotions that were tangled together in an uncontrolled and unpredictable cluster. The strands of spaghetti (her emotions) could unravel (become clearer and easier to cope with) as the grip of FMS relaxed (more sleep) thus allowing some relief (less craziness):

Carol reflected this experience, finding the interview illuminating as it helped her to reflect on her emotional life. She also colourfully described a complex and dynamic process of emotion in relation to FMS:

Carol: it's (.) probably in a way, [pause] umm focussed my own thinking on why I've had the whirlwind, not whirlwind but the jumble of emotions.
(Line 774-775)

Lack of awareness in others

Many participants described how the lack of awareness of FMS in others deprived them of the empathic support received by other chronic pain sufferers:

Abbie: if you say ‘I’ve got Fibromyalgia’, people just look at you blank. People off the street, you know if you say ‘I’ve got Fibromyalgia’ or like say it to the Council or, and you say you’ve got arthritis, ‘oh dear, dear, dear’.
LJ: So what do you think the difference is?
Abbie: Arthritis is a well-known, established disease or condition shall I say.
(Line 642-646)

The apparent lack of awareness others displayed resulted in many participants feeling they had to defend their suffering and explain themselves more than if they had other chronic pain conditions with greater awareness. Charlotte described how this injustice angered her:

Charlotte: I’m really annoyed at having to explain myself all the time. I’m really annoyed that I can’t just say ‘I’ve got Fibromyalgia’ and people don’t question.
(Line 509-511)

She went on to say:

(…) Charlotte: I don’t know whether it’s my ability to communicate (.) correctly or anger at the fact that I’ve got something that’s impossible to explain [laughs] to somebody unless they have Fibro. Umm, and but yeah, pretty much. I do get really, really annoyed and really angry at the Fibro. Why can’t I have something else [laughs] you know, why can’t I have something that has a self-explanatory sort of title [---] a broken leg is good, you know.

(Line 875-881)

This frustration was widely reported by participants and tended to reside in either the lack of knowledge others had of FMS as a condition or, more damaging views of the suffering in FMS as a psychological problem rather than a legitimate chronic pain condition. Charlotte appeared to internalise these difficulties as partly her fault that she was unable to communicate sufficiently whilst at the same time, acknowledging that much of the difficulty lay with features of the condition not fitting conventional medical models.

DISCUSSION

The critical literature review above highlighted the important role of emotion in the experience of pain, the transition to chronic pain, and the impact of psychological distress and any difficulties an individual may have with emotion upon FMS symptomatology. Despite the presence of a great deal of research activity into emotion and FMS in the literature, these studies have been limited in their coverage of this centrally important aspect of the condition. Currently, the lived experience and subjective meanings of emotion in FMS are not well represented in the literature. Most of the papers exploring emotion in FMS to date have utilized quantitative methodologies which, whilst highly valuable, gives a very limited perspective on emotion in this chronic condition. Whilst FMS has been well researched qualitatively, these studies do not explore the emotional experience of FMS directly. Instead, they tend to discuss emotion in FMS when this is noted in the process of data analysis rather than an interest in emotion as the explicit research aims.

The aim of this study was to offer a contribution to this gap in the literature by conducting a qualitative exploration into how a group of women with a diagnosis of FMS experience emotion in relation to their condition, how they understand their affective lives and any difficulties they may have with emotion. This was a qualitative study therefore participant numbers were limited. Whilst the findings are indicative and useful for future researchers and practitioners, it should be noted that there was no intention that firm conclusions on causal mechanisms for all women with FMS would be drawn from this study.

In this section, the findings will be discussed with reference to the research questions and the wider literature. A critique of the study will also be undertaken, and conclusions will be drawn.

Overview of key findings

The women in this study offered an insight into their emotional experience of FMS. They perceived the condition as an external adversary which could result in shame and grief. FMS seemed to be sensitive to vulnerabilities, striking those who had suffered physical and/or emotional trauma as well as those who experienced difficulties in their experience of emotion. Some women attempted to fight back, with limited results.

FMS could cause emotional responses including anger, frustration, fear, anxiety and low mood. Anger and frustration built up due to functional limitations, whereas the fear of uncertain painful attacks generated anxiety. Low mood was seen by many as inevitable, although some believed mood was controllable.

FMS appeared to reduce participants' resilience against distress due to the struggle to live whilst under continuous threat of attack. Many felt powerless in the face of attacks on their bodies, lives and emotional resilience. FMS also tended to reduce participants' previous affective support structures.

Trauma

This study offered a qualitative account of the experience of trauma in women with FMS which is currently lacking in the literature. Most participants spoke of serious and/or multiple traumatic events during their childhood, throughout their lives and/or prior to the onset of FMS symptoms. These were traumatic psychologically, physically or both. Many women believed that these events created a vulnerability which contributed to the development of their condition, and that the cumulative effect of traumatic experiences and the fatigue these invoked reduced resilience, thus offering FMS an opportunity to develop.

Many authors support the association of trauma and the development of FMS and CWP more generally (Buskila, 2009; Coppens et al., 2017) as well as several other rheumatologic conditions including RA, psoriatic arthritis and seronegative spondyloarthropathy (Brawer & Goel, 2016; Jun et al., 2000; Thorarensen et al., 2016), post-concussive syndrome and chronic regional pain syndrome (CRPS; Marinus et al., 2006; Wurtman et al., 2010). This association is therefore well established in the literature.

Several scholars have reported associations between emotional responses to psychological and physical trauma and the development of FMS (Buskila, 2009; Gardner, 2000). Yavne et al. (2018) conducted a systematic review of papers exploring psychological and physical trauma as precipitating events in the development of FMS and concluded that “the evidence for this association is extensive and generally considered to be adequate” (p. 129). They asserted, however, that the methodological robustness of these papers was low (Yavne et al., 2018), on the basis that several authors failed to select participants using the current diagnostic criteria. Yunus (2013), for example, considered that a diagnosis of FMS would be equally legitimate if five or six tender points out of 11 were present, despite the criteria of the time requiring all 11. The authors argued that given successive updates to diagnostic criteria, it would seem wise to rely upon the current diagnostic criteria to ensure valid comparison and methodological robustness. The use of discretion in selecting participants with FMS discredits many studies, they argue, due to inconsistent definitions of the condition.

This, of course, is a criticism if a quantitative approach is taken within the medical model. Counselling psychologists value first-person accounts, which go a long way to negate these difficulties. Participants' reports of traumatic experiences are centrally valuable within qualitative studies, whereas Yavne et al. (2018) considered this to be a weakness.

Notably, the difficulties in accurately identifying FMS when selecting research participants appear to be a parallel process with participants' experience of diagnosis as frustrating and complex. The issue is with the concept and process of diagnosis itself which underlines the importance of the current study.

Leading academics have expressed these frustrations (Wolfe et al., 2016), arguing that although the published criteria for diagnosis is clear, authors frequently failed to recruit according to those criteria. Equally, primary care physicians and consultant specialists have access to these criteria but FMS is still often misdiagnosed. The chance of accurate recognition of symptoms tends to depend upon the doctor's skill and/or beliefs about FMS (Wolfe & Hauser, 2011). This was how many of the participants in this study found the diagnostic process, that GPs could dismiss their suffering before and after diagnosis, leaving them feeling abandoned and suggesting either unawareness of the criteria or disinterest.

Additionally, the mechanism of the association between FMS and trauma remains unclear. Participants believed that their FMS developed following trauma either acutely or chronically. They believed that trauma reduced their emotional resilience, creating vulnerability to attacks. This belief is reflected in their perception of FMS as an adversary that was waiting for an opportunity to strike. This hypothesised process has support in the literature. Afari et al. (2014) conducted a meta-analysis and concluded that those exposed to trauma had a 2.5 fold chance of developing FMS. Further evidence can be found in fMRI neuroimaging studies, where an association between the regions of the brain involved with pain processing and those activated by trauma have been found (Geuze et al., 2007). Together with the research discussed above, this supports the participants' view of the opportune FMS attacks when they were emotionally vulnerable.

Traumatic experiences are more prevalent in people with FMS and other chronic pain conditions than in the general population. Disrupted cortisol patterns have been found in people with FMS who reported suffering abuse (Weissbecker et al., 2006; Yeung et al., 2016). Increased cortisol levels can result in greater inflammation (Wilkinson & Pickett, 2010), exacerbating pain, as discussed earlier. This suggests a chronic response to trauma which may mediate the effect of trauma on FMS symptomatology. However, researchers have suggested that the interpretation of these events has more influence on the onset and progression of FMS. The prevalence of PTSD in FMS populations is significantly higher than the general population (Arguelles et al., 2006; Häuser et al., 2013; Roy-Byrne et al., 2004), with increased severity in both FMS and PTSD when presented concurrently (Amita et al., 2006; Häuser et al., 2015). An individual's response to traumatic events which develops into PTSD for those with FMS may exacerbate their pain condition. Perhaps the presence of prior trauma is less of a predisposing factor for some people with FMS if PTSD did not develop.

Dell'Osso et al. (2011) offered further support for the association between FMS and the detrimental effect of PTSD symptoms in women. They used self-report questionnaires to measure health-related quality of life, trauma and loss and found that the impact of FMS on quality of life or symptom severity was related to the number of loss events, grief reactions, traumatic events, reaction to losses, re-experiencing and avoidance as well as numbing and arousal. The pain measure was related to all of these features except arousal. The greatest effect was found for traumatic events involving loss, which was evident in the present data in the accounts of participants including Diane and Charlotte. Dell'Osso and colleagues also highlighted that trauma can negatively impact the severity of FMS symptoms.

Authors have reported that participants experienced loss due to FMS. This can be a loss of function, relationships and pleasurable activity, as noted by Dell'Osso et al. (2011), who helpfully identified grief reactions as the result of trauma. They linked this grief process to the trauma of losing a loved one, thus indicating enduring and unresolved grief. In contrast, participants in the current study noted a similarity between their affective response to FMS and the loss of a close family member. The effect of FMS potentially compounded the trauma responses that were present for many participants which possibly increased their vulnerability to FMS and exacerbating symptoms.

A feature of PTSD as a clinical presentation is hypervigilance (DSM-5, 2013) or constant checking for potential threats. Although signs of trauma were not explored during the interviews, several participants reported anxiety as part of their experience of FMS, together with a fear of the next pain attack. This parallels the threat-based emotion of shame, as discussed above. Shame and PTSD are associated with increased psychological distress (Kotera et al, 2019) and this has been shown to exacerbate pain (Tang et al, 2008), therefore participants who were experiencing shame and features of PTSD potentially faced increased severity of symptoms. It may be that threat-based emotion was a driver of their pain experience, suggesting that for those who experienced difficulties with their emotional lives, the effect of traumatic events remains pertinent

The presence of psychological distress appears to be important in the association between FMS and trauma (Häuser et al., 2012; Häuser et al., 2013). The comorbidity of FMS, PTSD and depression is common, suggesting a link (Goldenberg, 2009; Raphael et al., 2004). This may indicate a mediating effect of psychological distress, or as Raphael and colleagues postulated, 'joint dependence on some fourth factor' (p. 34). They suggested that traumatic life events whilst necessary for PTSD may be risk factors for FMS and depression resulting in the three comorbidities being evidenced in research studies. As with the association between trauma and FMS, we currently do not understand the process, although it is clear that, for some people with FMS, psychological distress and PTSD can impact their symptomatology independently (Saariaho et al., 2011).

Moving onto the second source of vulnerability for the women in this study who experienced difficulties with their emotional lives, the effect of traumatic events remains pertinent.

Difficulties with the experience of emotion

The second source of vulnerability to FMS evident in the data was difficulties with the experience of emotion, or a difficult relationship with their emotions, that is, participants tended to describe their feeling states in general terms and report some difficulty in their relationship with their affective lives. If one followed the dominant academic literature, the features of the postulated concept of alexithymia are likely to be relied upon to understand this, particularly difficulty describing feelings. However, the data suggested other explanations for why the women in this study appeared to find it difficult to describe their affective states, indicating that it may be less helpful to consider these as belonging within the concept of alexithymia. It would appear that it may be valuable to consider wider possibilities when exploring why women with FMS may find it difficult to describe their affective states.

Much of the existing literature has explored difficulties with emotion quantitatively and within the theoretical context of alexithymia. Any difficulties that participants reported in the literature thus far tended to be analysed within this framework, with little consideration of other possible explanations. This study sought to offer a qualitative analysis of any difficulties participants experienced and their understanding of these difficulties in order to contribute to this debate.

Some of the women in this study understood their difficulties in terms of their upbringing, in that their parents were either abusive, or emotionally unavailable, or both. This meant that they matured into adults who tended not to verbalise emotional experiences due to trauma, a lack of practice, or a lack of role modelling. It would seem possible that adverse childhood experiences may interfere with their relationship with their experience of emotion. Indeed, it was perhaps notable that most of the women with emotional difficulties had experienced traumatic events, including adverse childhood experiences, which may indicate that their difficulties were associated with a trauma response. Many researchers have associated the difficulties of describing emotion and trauma. It has been argued that adverse childhood experiences may interfere with the development of emotional regulation abilities, leading to increased difficulties which have been conceptualised as alexithymia (Berenbaum, 1996; Taylor, 2018). Similarly, Aust et al. (2013) found a positive correlation between alexithymia scores and emotional neglect in the early years, which supports the data in the current study. It may be that quantitative studies into alexithymia may have been detecting a trauma response, rather than a separately differentiated psychological construct.

Other participants believed the symptoms of FMS contributed to these difficulties - in other words, that Fibro Fog and fatigue impaired their cognitive and affective abilities. The literature on Fibro Fog outlined the features as forgetfulness, being easily distracted, speech and language difficulties and disorganised thinking patterns (Williams et al., 2011), which affected 50% to 90% of people with FMS (Katz et al., 2004). These widely recognised symptoms of FMS could therefore have interfered with the ability of participants to describe their emotion states.

Teodoro et al. (2018) conducted a systematic review of cognitive difficulties in functional neurological disorders such as FMS and CFS. They commented that that the quality of the existing research in this area had shortcomings, and therefore more exploration would be required before clarity on cognitive difficulties in these conditions could be reached. They concluded that 'attentional dysfunction' (p. 1315) was the main difficulty, and that this was impacted by pain and fatigue in FMS. This interpretation supports the understanding of their difficulties given by participants in the current study.

It may be that participants in this study experienced difficulties in their ability to describe emotion as the result of traumatic experiences and/or the cognitive difficulties which FMS symptoms can create, rather than some personality deficit, as the concept of alexithymia may suggest. This brings into question the concept of alexithymia and suggests that the literature which explores alexithymia may be detecting difficulties with emotion derived from multiple influences, rather than a single conceptual construct.

The effectiveness of the concept of alexithymia to explain participants' difficulties also comes into question when one considers that the data analysis in this study did not result in themes related to difficulties in the full spectrum of postulated features of alexithymia, that is, difficulty identifying emotion, difficulty identifying the difference between bodily feelings and the physical symptoms of emotional arousal, and limited imaginal processes (Taylor et al., 1997). The present data suggests that the concept is flawed as an explanation for the difficulties in emotion seen in this study and perhaps more widely.

In recent years, the complexity of the concept of alexithymia has been illuminated (Aaron et al., 2019). Some authors have concluded that alexithymia is either 1) state-dependent, meaning it is only present when the person is, for example, stressed or 2) a permanent trait (Montoro et al., 2016). This model suggests flexibility in terms of when the difficulty is expressed but fails to account for presentations which only feature some of the characteristics of alexithymia.

Further, inconsistency in findings in the literature suggests that alexithymia does not work as a concept. Indeed, Aaron et al. (2019) conducted a meta-analysis of 14 papers exploring correlations between mood and the effect of alexithymia on pain and found that the latter was not significantly associated with either pain intensity or interference when mood was controlled for. The importance of psychological distress in the emotional experience of FMS once again becomes apparent when we explore alexithymia, as it was for traumatic experiences. This can have meaningful implications for psychological interventions for people with FMS, as discussed below.

One reason why the concept of alexithymia may not be helpful lies in the methods which have been used to analyse the area. Quantitative studies on alexithymia generally use self-report measures to detect its features and so categorise participants as ‘alexithymic’ or not, depending on psychometric cut-off scores (Evren et al., 2006). The use of self-report questionnaires may conceal important features of these apparent difficulties. Alexithymia measures converge with measures of low mood; perhaps because those suffering low mood are more likely to evaluate themselves negatively (Leising et al., 2009; Lumley, 2000). The standard measures used to measure alexithymia (such as the TAS-20) may, therefore, have lower validity than claimed. In this case, the method of inquiry may contribute to the confusion around alexithymia, supporting the use of qualitative methods for a more in-depth analysis of cognitive difficulties relating to emotion.

Alexithymia as a concept has been used to understand FMS and other conditions involving MUS in the past. Although its roots were in the psychodynamic tradition (Weiner, 1982), it would appear that this concept has become strongly aligned to the medical model and utilised to support approaches to understanding which situate distress within individual deficits. This is clearly in contrast to counselling psychology philosophy in general, and this dataset in particular.

The results of this study would suggest a different position to that of both the psychodynamic tradition and those who subscribe to the concept of alexithymia. It may be more appropriate for understanding emotional difficulties experienced by women with FMS to inhabit a position within a psychologically-informed understanding of such conditions that is formulation driven and acknowledges the frequency and nature of trauma, in all its forms, in individuals' histories; symptomatic features of FMS which may contribute to emotional difficulties; and the experience of psychological distress in general, including low mood.

Shame

Numerous studies have reported shame as an emotional response to FMS (Wuytack and Miller, 2011; Boyington et al., 2015; Gustafsson et al., 2004). This study therefore adds to this research base, offering the qualitative perspective of the women in this study.

Participants reported that they needed to conceal their FMS diagnosis and suffering due to the negative behaviours and attitudes of others which invalidated their experience and to maintain the perception of others that they were able to cope with the condition. Allowing the extent of their suffering to be visible may be interpreted by others as their failure to cope. This resulted in a drive to hide their symptoms and suggests they experienced feelings of shame related to their condition. Shame is an important, powerful and complex social emotion which orientates us in response to social cues such as those experienced by participants (Gilbert, 1998; Tracy &

Robins, 2007). Gilbert defined it as “a state of experiencing oneself as devalued, diminished and an object of derision in the mind of another or others, which when internalised, textures a sense of oneself” (2017, p. 211). Participants spoke of how others treated them with derision which had implications for their concept of self.

Some participants described a loss of pride, an emotion which could be considered the opposite of shame (Gilbert, 1998). Thus, their drive to hide their suffering seemed to result in feelings of shame.

Much of this shame was attributed to specific features of FMS, laying the foundation for a condition which was difficult to cope with emotionally. These features included a feeling of abandonment by health professionals and loved ones, condition unpredictability and symptom complexity. Additionally, emotional responses to and poor awareness of FMS left participants feeling that FMS was not a legitimate condition. Invalidating reactions from family, friends and health care professionals suggested that their suffering was not as legitimate as that caused by other, well-known conditions, contributing to a global sense of shame. Other authors have named shame as a part of the FMS experience (Åsbring & Närvänen, 2002; Boulton, 2019).

Participants therefore hid their emotions. Gonzalez, Baptista and Bianco (2015) found that women with FMS preferred to “keep feelings inside” (p. 534), although this was to avoid burdening others or being in denial of their emotion. The women in this study hid their feelings as a function of their experience of how others related to their condition and their desire to conceal the impact that FMS had on them, fearing negative evaluation by others.

The women in this study reported a loss of their prior identity which impacted their self-esteem. Shame appears to have been involved in participants’ reduced sense of themselves following

FMS. Indeed, Galvez-Sánchez et al. (2018) found more loss of self-esteem in people with FMS than in controls with no pain condition, supporting the previous findings of Michielsen et al. (2006) and Garaigordobil (2013). For the participants in this study, the loss of reliable support from health professionals and loved ones was important, leaving them feeling abandoned. This was exacerbated by a loss of pleasurable activity and familial roles, thus reinforcing negative affect.

Tracy et al. (2007) found that chronic shame can lead to social withdrawal and changes in attentional focus, which then became more sensitive to cues that reinforce our perception of others judging us. Social isolation was a common outcome of FMS for the participants in the current study. The opportunity for social interaction was limited by the fear of being shamed due to the extent of their perceived inability to cope, being disbelieved and the unpredictability of symptoms forcing them to cancel social engagements. Whilst it is possible that attentional shifts to cues which reinforce the negative evaluations of others may have occurred for these women, much of their experience of shame was based on direct experience of being disbelieved or dismissed by medics, family or friends and their fears of social evaluation.

Gilbert (1998, 2007) noted that shame is closely associated with other emotions, including anger, anxiety and disgust, and is focused upon creating favourable impressions of ourselves in the minds of others or avoiding the opposite. This assists our understanding of participants' reports in this study, since they reported anger and anxiety as specific emotions which could be said to reinforce their experience of shame with associated emotions.

Gilbert's (2007) multifaceted, tripartite explanatory framework illuminates this. He suggested three types of shame: external, internal and reflected. The participants appeared to experience all three:

1) *external shame* involves attending to others whom we perceive as looking down on us. Two of the greatest sources of participants' shame were having their suffering doubted by others and a lack of awareness about the condition. Participants reported interactions where disbelief was overtly verbalised or communicated non-verbally by family, friends and/or health care professionals. Therefore, a combination of actual or interpreted attacks on their integrity appear to be present which may have resulted in external shame.

2) *internal shame* occurs as a consequence of negative evaluations of the self. A negative evaluation of their ability to cope with FMS suggested participants were not as independent as they were pre-diagnosis. The threat to their self-image and the potential exposure of their reduced coping generated internal shame. Many women therefore hid their symptoms, perhaps increasing their internal shame as they felt they were being dishonest.

3) *reflected shame* is experienced when our associates bring shame to us, for example, if a partner goes to prison, or when we bring shame to others. The women often attempted to conceal their FMS from others to protect relationships, or to prevent FMS becoming the focus of social events, thus avoiding reflecting their shameful condition onto their loved ones. Participants appear to have spoken about all three types of shame, demonstrating the complex nature and powerful impact of this social-evaluative emotion for women with FMS.

Shame can influence physical health and, notably, the pain experience. It is correlated with heightened anxiety and a physiological stress response (Gilbert, 2000; Wilkinson & Pickett, 2010), in a similar mechanism to the fight or flight response (Dickerson et al., 2004). The stress response stimulates higher cortisol and pro-inflammatory cytokines (PICs) which, in an acute situation, would be adaptive in alerting to the presence of physical threat (Dickerson et al., 2004). However, when shame becomes a chronic experience, these physiological levels can remain elevated and detrimental to health (Wilkinson & Pickett, 2010). The chronic presence of cortisol and PICs can increase inflammation and has a role in pain, activating nociceptive sensory pathways and inflammation-induced central sensitization. Therefore, the physiological response to the emotion of shame may have exacerbated the pain experience for participants who experienced shame as a result of their condition.

Shame is an affective experience that has been reported extensively in the FMS literature as a response to the condition. Shame was associated with cognitive difficulties (Wuytack and Miller, 2011), particular bodily areas (Boyington et al., 2015), others perceiving them as lazy (Sabik, 2010), doubting that their pain was real or they were hypochondriacs (Gustafsson et al., 2004), not being believed by health professionals (Stone, 2014) and stigma (Åsbring and Närvänen, 2002). These sources of shame parallel the features of FMS which evoked shame for participants, feeling abandoned and a lack of awareness which reduced empathy from others.

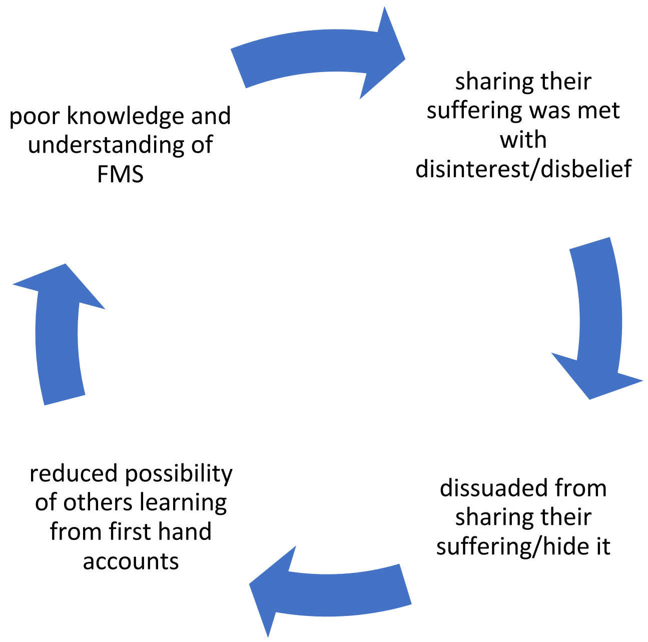
This is also reflected in other pain conditions. Snelgrove and Liossi (2013) conducted a meta-ethnographic review of qualitative studies on chronic low back pain and found that shame was related to the loss of social roles in participants' family and work lives, along with the perception of not being believed, which parallels themes in this study. Equally, Smith and Osborne (2007), the founding authors of IPA, used semi-structured interviews to explore chronic benign back pain which, in 85 per cent of cases, has no identifiable cause (Clabber Moffet et al., 1995). Smith and Osborne studied how the greatest impact of this pain condition was experienced in the social domain, expressed as shame which was, "at times, more uncomfortable and unbearable than their pain sensation or immobility" (p. 529). This shame was the result of self-criticism, embarrassment and fear of criticism and punishment, rather than features of the participants' condition. Similarly, participants in the current study experienced shame as a consequence of feeling abandoned by health professionals, the unpredictability of symptoms and a lack of awareness of the condition, supporting the work of Smith and Osborne.

Additional authors who have explored MUS conditions with similar results include Williams et al. (2019) for people with chronic fatigue syndrome, Wyatt et al. (2014) for non-epileptic seizures, and Inês et al. (2020) for inflammatory bowel disease. Whilst this further emphasises the importance of shame as an affective feature of MUS conditions, shame is also a feature for some people with organic conditions. Poh et al. (2015) reviewed studies on rheumatoid arthritis (RA) and found several records of shame as part of the RA experience (Ahlstrand et al., 2012; Feldthusen et al., 2013; Hewlett et al., 2005; Hughes et al. 2009). Shame is therefore not isolated to people with FMS, but seems to be a common response to chronic pain.

The diverse and unpredictable range of possible symptoms connected to FMS both within and between individuals makes it harder to share their experience in a culture which prizes the medical model of clear, recognisable symptoms leading to diagnosis by clinical methods, followed by a reliable treatment plan. Shame for these women, therefore, seemed to be in part associated with the perception of FMS as an illegitimate condition, a function of its MUS status (Åsbring and Närvänen, 2002). They experienced stigma towards their diagnosis because it did not match the accepted standard for a socially acceptable condition.

Participants' strategy for dealing with shame was to conceal symptom presence or severity, leading them to feel they were living a lie. For some, this resulted in a perception of themselves as dishonest which could be considered to be a secondary shame which reinforced the anxiety that a lack of awareness of FMS created. Hence, the women in this study were trapped in cyclical difficulty as shown in Figure 2:

Figure 2: Cycle of difficulty



Whilst the suggestion is not to place the responsibility for increasing knowledge or awareness of FMS with those with a diagnosis, this cycle highlights that hiding symptoms had the paradoxical effect of reinforcing the damaging perception that their suffering was less intense than it actually was. This is in line with the work of Rodham et al. (2010), who interviewed participants with FMS and their spouses for an IPA study. Participants reported trying to "be active anyway" despite their pain (p. 74), thus preserving identity. Therefore, the cyclical difficulty for the women in this study is reflected in the FMS population more widely.

From an evolutionary perspective, shame alerts us to threat, stimulates threat defences and closes down the frontal cortex to prioritise the effectiveness of these defences (Dickerson & Kemeny, 2004). As noted earlier, participants spoke of a continuous feeling of threat from FMS, so the presence of shame as a threat-based emotion may have contributed to their emotional load. Several participants feared these attacks. For some, the combination of fear and shame could have led to a heightened vulnerability and increased hypervigilance to the affective consequences of FMS. These experiences may have been compounded by the role of trauma in participants' chronic pain.

Specific emotional responses to FMS

The specific emotions reported by participants in this study are reflected in the wider FMS literature. Glass (2009) found that participants reported specific negative affect states including anger, sadness, fear and guilt. Anger has also been widely reported (Ricci et al., 2016; van Middendorp et al., 2008). Other scholars found higher reported stress levels (Kivimäkis et al., 2004; Van Houdenhove et al., 2005), anxiety (Fietta et al., 2007) and low mood (Uçar et al., 2015). The results of this study, therefore, mirror those found in other FMS work, reinforcing the experience of negative emotions in this chronic pain condition.

It has been shown that negative affect can exacerbate FMS symptoms (Montoro et al., 2016). It would appear that some participants in this study entered a cycle of negative affect as FMS developed, exacerbating their symptoms which led to further negative affect. Since emotion occupies a central role in the pain experience and the women in this study reported a complex picture of negative emotion, it may be that their negative emotional responses to FMS exacerbated their suffering.

These findings are not isolated in the FMS literature but are reflected in studies of people with other medically unexplained conditions. Williams et al. (2019) performed a thematic analysis of interviews with people suffering from CFS and myalgic encephalomyelitis (ME) and identified a theme of internalised anger attributed to the unpredictability of symptoms and interference in participants' lives, roles and goals. These findings are supported by Raymond and Brown (2000), who carried out an earlier study with the same populations.

Relevance of findings for therapeutic practice with people with FMS

The results of this study highlight the role of emotion in the experience of FMS for the women who participated. The data indicated the presence of emotional processes of trauma and emotional difficulty which may have increased vulnerability to FMS and which exacerbated pain and other symptoms. The underlying threat responses as the result of prior trauma and shame evoked by FMS, in addition to the complexity and individual emotional experience of FMS, indicates that a trauma-informed, formulation driven approach to psychotherapeutic intervention such as that espoused Van der Kolk (2015) and Johnstone et al. (2018) may be helpful for this client group. Collaborative therapy which is sensitive to the emotional component of the FMS experience would be more thorough and likely to produce a working formulation which indicated avenues of intervention.

Cohen (2017) argued strongly for FMS treatments to be framed within the biopsychosocial model. This is supported by the current data, given the association of cognitive, physiological and social aspects of shame, which may contribute to greater symptom severity (Adams and Turk, 2015). The Western medical model of first-line treatment for FMS consists of pharmaceutical options. This can artificially raise the expectation of complete pain control. However, authors of efficacy trials show that this is rarely the case, with an estimated 10-25% achieving clinically meaningful pain relief from medication (50% reduction in pain intensity; Fitzcharles et al., 2016). The medical model can discourage clients from exploring psychological approaches to alleviating symptoms and can undermine clients' openness to exploring the role of emotion in their suffering. The lack of effective pharmaceutical pain relief may reinforce feelings of abandonment by health professionals and the belief that because FMS was not as well known or treatable as other conditions, it was therefore not legitimate. If this belief system is in place for a client with FMS, this can suggest further areas for exploration in psychological treatments.

Shame and the physiology of the fight or flight response (Dolesal & Lyons, 2007; Turner-Cobb et al., 2015) demonstrate the value of treatment within the biopsychosocial approach. If a trauma-informed approach can alleviate these processes, the emotional component of suffering may be relieved. The participants experienced chronic shame, which was potentially detrimental to their social and physical health. Therefore, it would be valuable to consider this when designing pain management interventions (Gustafsson et al., 2004).

Williams et al. (2020) reviewed the effectiveness of psychological therapies for chronic pain, including FMS. They found that CBT had the largest evidence base, although the quality of the studies was low and, when compared with no treatment or other types of treatment, CBT resulted in “small or very small” levels of symptom reduction (p. 3). CBT can help to both increase functioning and manage pain (Williams et al., 2012). This suggests that CBT may be helpful for re-framing FMS from a threatening adversary to a more neutral presence, thus reducing the threat responses evident for some participants.

Based on the results of this study, it appears that cognitive behavioural approaches are likely to benefit from increased sensitivity to emotional factors such as shame, grief and difficulties in the affective experience for this population. Emotion is considered within the model though this study suggests that for some clients with FMS, a deeper understanding of this feature of the formulation may be beneficial. Interventions which target shame or that cultivate self-compassion have been postulated and this is supported by the present data (Gilbert et al, 2019).

Equally importantly, clients with FMS are likely to benefit from being screened for PTSD (Sommer et al., 2012), grief, low mood and/or difficulties with emotion before engaging in CBT or trauma work for pain management, thus increasing the potential effectiveness of psychological interventions.

Clients' sense-making around loss and its role in their FMS may be worthy of consideration. Utilising the dual process model (Stroebe & Shutt, 2010) for women experiencing grief may assist progress through therapy by matching the oscillation between loss-oriented and restoration-oriented presentations with appropriate interventions. A shared understanding of the client's difficulties using a psychological formulation (Johnstone and Dallos, 2014) could identify which emotional component was contributing to their suffering and identify associations between these to create a personalised understanding of their affective experience.

A creative approach may be effective in overcoming cognitive difficulties. Lumley et al. (2011) espoused emotional awareness and expression therapy to improve these difficulties, while Brown (2018) used creative ways to gather reports of embodied emotional experience to avoid participants' difficulties with verbalising their experience of emotion. An individual formulation could incorporate these for clients with difficulties.

Finally, future studies may be able to access people with more limitation on their activities as well as those who are in employment, and so unable to attend the groups, to further explore emotion for these groups of people.

Relevance for counselling psychology

FMS qualitative researchers have shed light on the value that counselling psychology philosophy and practice bring to psychological research and the development of interventions (Gonzalez et al, 2015; Furness et al, 2018). The literature is saturated with experimental studies which seek to develop models to explain and predict the aetiology, development and treatment of FMS, with limited success (Yavne et al., 2018). This research paradigm is less helpful clinically than a deep psychological understanding of the individual and their difficulties. Counselling psychologists emphasise the intersubjective experience, thus focusing upon working relationally.

As previously discussed, counselling psychologists value first-person accounts, without the requirement to categorise psychological distress within diagnoses (British Psychological Society, 2014). Based on this study, it is valuable to formulate an individual's distress utilising psychological knowledge and theory to understand the affective mechanisms which contribute to their FMS-related suffering.

We also work within a relational framework, where the relationship is utilised to maximise opportunities for recovery and growth in therapy. The client-psychologist relationship remains key to this type of intervention. Given that these can be fraught for those with FMS, it may be important to consider the difficulties expressed by the current participants.

Limitations and suggestions for further exploration

This study aimed to contribute to a gap in the literature by offering a qualitative analysis of emotion in women with FMS. Given that this was one of the first studies of its kind, the research aims were general in their scope and sought to explore participants' emotional experience as well as their understanding of this and any difficulties they may have with their affective experience. As with all qualitative enquiry, the findings are limited to the women who participated in the study with no anticipation of generalisability. It may be valuable, therefore, to firstly replicate this study with participants who have similar demographics to expand this novel area of research and also with samples who have different characteristics. This would offer an exploration of emotion in FMS amongst more diverse groups.

Other researchers have studied aspects of FMS in wider contexts including Moore Schaefer (2005), who interviewed African American women, and Cooper and Gilbert (2016), who explored the experience of a FMS diagnosis for people in South Africa. Exploring emotion in other groups of people with FMS would therefore be highly valuable to add to this research base.

This study offered an overview of the emotional experience of people with FMS. Future projects may offer a more specific exploration of the emotional issues raised. For example, Donezal and Lyons (2017) strongly suggest exploring the role of shame in health-related outcomes. For some participants in this study, shame was a consequence of FMS which may have exacerbated their symptoms. Shame is reported by FMS, MUS and chronic pain patients (Gilbert, 2017), meaning further investigation would be highly valuable. Identification of the process by which shame may affect pain conditions may lead to interventions which alleviate symptoms.

The appropriate research methodology for this study was thematic analysis. The use of other approaches may offer further perspectives on this topic and allow, for example a phenomenological enquiry into the lived experience of emotion in FMS, perhaps utilising an Interpretative Phenomenological Analysis (IPA) approach.

The sample in this study was limited to people attending a support group therefore it was only possible to interview women who were higher functioning, with manageable symptoms, and so able to attend such groups. The adoption of more creative methods of participant recruitment and data collection may be necessary to access those with less mobility or those facing other barriers to participation. These methods could incorporate interviews conducted via online video, social media, telephone or email to enable the inclusion of more people with FMS in research.

One may ask why most people affected by FMS are women in later middle-age and older with lower socio-economic status. Further analysis or work with a feminist or a social-constructionist lens may illuminate facets of this condition which this work did not aim to capture. Werner et al. (2004) used a feminist lens and found that women with chronic pain gave a narrative about themselves which fit with “normative and biomedical expectations” (p. 1035), that if they spoke of their suffering too much, they risked their complaints being interpreted as having no foundation, rather it was the result of their maladaptive relationship with their health. Telling positive stories of their strength was seen as an acceptable of way of communicating their suffering in an “acceptable and (gendered) moral manner” (p. 1041), suggesting that this lens is extremely valuable for obtaining perspectives of chronic pain conditions. Additionally, Briones-Vozmediano (2017) suggested looking at this “invisible women’s disease” (p. 1).

In summary, this study suggests several avenues which further research may take. The data contributes a valuable qualitative lens to the area and given that it has been shown that the mainstream intervention is CBT, it would seem likely that a more robust approach to evaluation of this intervention would be informative. Williams et al (2020) concluded that the quality of CBT was low and produced small gains in the control of pain symptoms, it would seem likely that a more robust approach to evaluation of this intervention would be informative. Future studies may adopt a mixed-methods methodology in which participant interviews, broadly based on this study, are analysed thematically and CBT interventions are formulated with particular emphasis upon the individual experience of emotion. This may include additional therapeutic interventions on shame or self-compassion, or adopting more creative ways to overcome any barriers to verbalising the affective experience as Brown (2018) suggested.

CONCLUSIONS

The aim of this qualitative study was to contribute to the limited research on emotion in FMS. Emotion has a central role in the pain experience, influencing and mediating the strength and duration of pain, indicating that an in-depth exploration of this feature is essential. Affect in ten women was explored and avenues of interest were generated for future research endeavours. The data confirmed prior FMS and chronic pain research on the affective impact of FMS and illustrated how a focus on the affective processes experienced by participants could lead to more trauma-informed, formulation-driven care.

The identified themes offered a narrative of the women suffering the symptoms of FMS with a perceived increase in the chance of FMS striking if they had vulnerabilities. These included physical and emotional trauma and difficulties in their relationship with their affective lives which could result in negative emotional experiences and global feelings of shame and grief. An interconnectedness of the affective impact of FMS due to trauma, shame as a threat-based emotion, psychological distress including grief and difficulties with emotion was suggested.

The data cast doubt upon the concept of alexithymia as a collection of specific features of personality. Participants' accounts of their relationship with emotion suggested that this concept may be more usefully considered to be based in a trauma response or the result of Fibro Fog or fatigue.

Participants believed that traumatic experiences influenced the development of their condition, with a large body of research supporting this association. In addition to prior trauma, chronic feelings of shame evoked by FMS placed participants in a threat position, compounding the long-term effects of trauma. This negative affect reduced their psychological wellbeing and is likely to have exacerbated their symptoms, including pain severity, as supported by the literature.

These findings support previous work which indicated that emotion has a role in the pain experience and FMS as a condition. Whilst the impact of low mood and anxiety-related distress has been identified as important in the association of FMS with trauma, it is currently unclear how the mechanism of psychological distress may impact FMS. However, it remains likely that the alleviation of some emotional influences on the pain experience may have a beneficial effect on the constellation of FMS symptoms and is worthy of further research. Equally, threat-based emotions like shame may play a key role. Screening people with FMS for PTSD, shame and low mood could inform their care and psychological intervention.

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SUMMARY OF THE RESEARCH

The experience of emotion in people with Fibromyalgia: A thematic analysis

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Abstract

Emotion plays a fundamental role in the experience of both acute and chronic pain therefore a deep exploration of this experience in people living with chronic pain would offer a valuable contribution to the research base. Fibromyalgia Syndrome (FMS) a chronic pain condition which is the leading cause of musculoskeletal pain in women. This paper presents part of a study which aimed to capture rich data on how people with FMS experience emotion, and how they understand any difficulties they may have. A critical realist framework was adopted, and semi-structured interviews were undertaken with ten women who had a diagnosis of FMS. The data were analysed using reflexive thematic analysis (Braun and Clarke, 2020), producing one overarching theme entitled 'FMS as an adversary'. These themes offered a narrative of the women being attacked by an external adversary which exploited vulnerabilities created by trauma and interacting difficulties with cognitions.

These findings support previous work that trauma and emotional difficulties can adversely affect the symptoms of FMS yet challenge the theoretical construct of alexithymia which may more usefully be considered to be the result of trauma, negative affect, Fibro Fog or fatigue. Screening people with FMS for PTSD and difficulties with emotion could inform both their care and psychological interventions to alleviate the suffering of people with FMS.

Introduction

The psychology of pain

One in ten adults are diagnosed with chronic pain (present for three months or more) every year (The International Association for the Study of Pain, IASP, 2020). An emphasis upon the affective component of the pain experience is widely accepted in the IASP definition of pain, which is "an unpleasant sensory and *emotional* experience associated with, or resembling that associated with, actual or potential tissue damage " (IASP, 2020, emphasis added). This reinforces the need to understand more fully how emotion interacts with and influences this aversive experience.

Feedback loops occur between pain, emotion and cognition. Pain can negatively impact emotion and cognition, negative affect can increase the pain experience, and positive emotion can reduce pain, while cognitive processes can also affect pain both negatively and positively (Bushnell et al., 2013). Petrosky et al. (2018) demonstrated that this can have profound effects when they found evidence of a chronic pain condition in 8.8% of people who had taken their own life between 2003-2014, rising to 10.2% in 2014. This underlines the importance of understanding chronic pain from as many perspectives as possible.

Role of emotion in pain

The role of emotion was explored in a review by Wiech and Tracey (2009), who concluded that in addition to chronic pain leading to low mood and emotions such as frustration, worry, anxiety and depression, negative emotion can also lead to increased pain. Koechlin and colleagues (2018) noted that the literature on difficulties with emotion states and emotion processes (Lumley et al. 2010) and their relationship with chronic pain informed this association. One of these areas is alexithymia, which has relevance to chronic pain in general and Fibromyalgia Syndrome (FMS) in particular. In this summary, I have adopted a critical stance towards the theoretical construct of alexithymia to enable an open exploration of any difficulties with emotion that participants may experience. This aimed to acknowledge alexithymia as a theory of emotion in the literature but to retain the central position which placed individual experience at the centre of all aspects of the study and to hear participants' meanings and interpretations.

Background to alexithymia

Counselling psychologists offer the opportunity to explore difficulties with emotion from the perspective of individual experience and consider other dynamics which may influence their ability to engage with their emotional lives (O'Brien et al, 2017). The chronic pain literature tends to focus upon alexithymia, which is conceptualised as a deficit within the individual that affects their ability to engage with their experience of emotion.

The word alexithymia means "no words for feelings" (Sifneos, 1973, p. 255) and was originally conceptualised as a multifaceted personality construct, in which the difficulty was placed on and within the individual, as a defective aspect of their personality. Individuals with alexithymia are postulated to have difficulty identifying feelings and the differences between feelings and the physical symptoms of emotional arousal, as well as difficulty in describing feelings to others, limited imaginal processes and an externally oriented thinking style (Taylor et al., 1997).

An elevated rate of alexithymia has been found in people living with FMS. Steinweg et al. (2011) studied the prevalence of alexithymia in general medicine, rheumatoid arthritis and FMS patients and found a significantly higher rate of alexithymia in FMS patients (44%) than in the other two groups (8% and 21% respectively). Therefore, FMS patients had a higher prevalence of alexithymia than those living with another chronic pain condition, suggesting that FMS differs in some respects to other pain presentations (Steinweg et al., 2011).

Fibromyalgia Syndrome (FMS)

FMS is a chronic pain condition affecting 3-6% of the world's population (WHO, 2008), with a higher prevalence in women (3.4% F vs 0.5% M; Kroenke et al., 2007). It is the most common cause of musculoskeletal pain in women aged between 20 and 55 (Wolfe et al. 1990). There is currently no identified organic explanation for FMS, categorising it as a 'medically unexplained symptom' (MUS) alongside myalgic encephalomyelitis (ME), chronic fatigue syndrome (CFS), conversion disorder, irritable bowel syndrome and functional neurological symptom disorder (ICD-11, 2016).

The term MUS can be laden with "strong dualistic connotations" in psychiatry (Marks & Hunter, 2010, p. 110). People living with FMS may find this invalidates the legitimacy of their symptoms. The aetiology fails to fit the requirements of a medical condition, placing it instead within their psychology, possibly suggesting that they are somehow to blame for their suffering.

Individuals can experience this chronic pain condition as "unspeakable suffering" (Steinweg et al., 2011, p. 255), with symptoms including widespread pain, fatigue and non-refreshing sleep. Around 48% of people living with FMS also suffer from migraines and a cognitive impairment known as ‘fibro fog’ (Steinweg et al., 2011, p. 255). The spectrum and severity of symptoms are diverse, with symptoms varying between and within individuals over time (Fitzcharles & Yunus, 2012).

The unpredictable nature of FMS can compound the suffering of those with the condition, leaving them in a persistent state of threat, waiting for the next change in symptomatology and posing meaningful challenges to emotional wellbeing. Bennett et al. (2007) and Okifuji (2002) conducted thematic analyses of semi-structured interviews and found that people with FMS reported stress and emotional distress as factors which aggravated their symptoms, with pain being the most common symptom. Living with FMS can be extremely challenging, and although these challenges are captured in the literature, the emotional response to and impact of these salient features are less well defined.

Psychological distress and FMS

McCracken and Thompson (2012) examined the effect of chronic pain on mood and anxiety and found that those with chronic pain were two to three times more likely to suffer with depression or anxiety than people with no pain. This suggests that an exploration of the emotional experience of people with FMS would be valuable for understanding how this may impact their meanings and experience.

Higher levels of depression and anxiety in FMS than the general population are well documented (Evren et al., 2006; Fietta et al., 2007). Indeed, Hassett et al. (2000) found that 51-63% of people living with FMS had experienced anxiety, while 26-80% had been diagnosed with depression. This was supported by Van Houdenhove and Luyten (2008), who argued that affective factors (p. 471) play an important role in FMS and CFS. They suggested that emotion was a perpetuating factor within a bio-psycho-social account, as affective distress influences FMS and CFS by "reinforcing symptoms and increasing the risk of patients negatively spiralling into more severe functional limitations" (Van Houdenhove & Luyten, 2008, p. 473).

The effect of negative affect on pain in FMS has been shown to exacerbate its symptoms (Montoro et al., 2016). Authors have also shown that low mood is associated with increased pain intensity, decreased functional abilities, poor sleep and fatigue, and could be detrimental to quality of life (Thieme et al., 2004).

Psychological distress and alexithymia in FMS

The relationship between psychological distress and alexithymia in FMS remains unclear. Steinweg et al. (2011) compared alexithymia and depression self-report scores in people being treated for FMS, general medicine and rheumatoid arthritis. They found higher rates of both alexithymia and depression in the FMS group, although when depression was controlled for, the difference in alexithymia disappeared. Steinweg and colleagues concluded that the presence of low mood mediated the relationship between alexithymia and FMS. The mechanism by which this may occur, however, has not been established, suggesting that exploration into the subjective experience of people with FMS may be illuminating.

Implications of alexithymia for people with FMS

DiTella and Castelli (2016) conducted a critical review of the evidence for the role of alexithymia in people with different chronic pain conditions between 2012 and 2015. They attributed difficulties in regulating and processing emotions in these conditions, including FMS, to increased pain intensity (Celikel & Saatcioglu, 2006; Cox et al., 1994). This indicates the need to identify whether these difficulties are present in people with chronic pain conditions, including FMS with a view to offering psychological interventions to alleviate the effect of any difficulties related to emotion upon the pain experience.

DiTella and Castelli (2016) also concluded that the misattribution of emotional arousal as signs of illness could exacerbate the symptoms of chronic pain and, consequently, FMS. Adopting this model suggests that the presence of difficulties with emotion may exacerbate the onset and development of pain symptoms. People with FMS may be unable to verbalise their distress, making them less likely to reach out to others for help or comfort (Taylor et al., 1997), potentially leading to the development of low mood (DiTella & Castelli, 2016).

The literature on alexithymia has traditionally been dominated by the medical model, which privileges the voice of the 'expert'. This study aimed to capture participants' perspectives, to offer an additional and valuable research dimension.

Method

Selection and recruitment

A purposeful sample (Palinkas et al., 2015; Patton, 2002) of people with a medical diagnosis of FMS was compiled from FMS support groups across South Wales. Selection was therefore dependent upon attendance at the group (explored in the discussion) and meeting the inclusion criteria:

Inclusion criteria:

- Adults aged over 18 years
- Diagnosis of FMS
- Willingness to complete demographics form
- Able to sit comfortably for a minimum of 30 minutes up to approximately 60 minutes
- English as a first language
- Able to provide informed consent

Braun and Clarke (2020) suggest that there is no ideal number of participants for a reflexive TA study and that the researcher would be wise to exercise discretion on how many people to interview, based on the richness of the interviews for answering the research questions. With this in mind, ten women were interviewed.

Participants

All participants identified as white, heterosexual females. Nine were not currently employed, eight were part of the Christian faith and two quoted ‘no religion’. Nine participants described themselves as ‘disabled’. Age ranged between 50 and 73 years (mean = 63). The mean for years since first symptoms was 10.6 years and ranged from 4-20+ years with an average of 5.85 years since diagnosis (range 6 months – 18 years).

Procedure

Members of two support groups in South and South West Wales, coordinated by Fibromyalgia Action UK were invited to participate.

A presentation on the nature of the study was given to the groups and the opportunity for individual conversations around this was offered. All participants were given written information about the study and informed of what their participation would involve, their right to withdraw at any time, confidentiality protocols, procedures for anonymising the data and where to seek support should they find the interview distressing. They were then asked to indicate their willingness to participate by signing a consent form.

Interviews

The time and venue for interviews were organised at the participants' convenience in locations where they felt comfortable, as suggested by Braun and Clarke (2020). Interviews were recorded on two digital voice recorders to guard against equipment failure. All recordings were stored in line with the University of the West of England's policy on confidential data storage and were deleted from the equipment after transcription.

The issue of participant fatigue was considered, both in terms of caring for participants and to reinforce the legitimacy of their discomfort (Dennis et al., 2013). If participants experienced fatigue during the interview, they were given the option to break or discontinue the interview. No participants took up this offer. All interviews were transcribed by the researcher, noting all spoken utterances with pauses and intonation to facilitate depth of analysis.

Ethical considerations

All procedures were granted full approval by the University of the West of England's Ethics Committee before data collection and complied with the ethical criteria of the British Psychological Society's Code of Human Research Ethics (BPS, 2014).

Analysis of data

The Braun and Clarke (2020) six-phase model of data analysis was adopted to search for themes and patterns of meaning within and across the dataset:

1. Familiarising oneself with the data
2. Generating initial codes
3. Searching for themes
4. Reviewing themes
5. Defining and naming themes
6. Producing the report

Audio recordings of all interviews were listened to and read through, and notes about early ideas for themes were made. The stages of analysis proposed by Braun and Clarke (2020) were adopted flexibly rather than as a linear process, utilising the phases as the authors advised. Most codes were created on the latent level; that is, concepts and assumptions were interpreted from the data. Some codes remained at the semantic or more descriptive level, remaining close to the explicit content of the data to inform the development of themes. The overall emphasis, however, was on developing latent codes which were intended to capture a deeper analysis of the conceptual meanings within the data.

Reflexivity and quality: Researcher as instrument

Braun and Clarke (2018; 2020) discuss the overtly subjective nature of qualitative research as a defining strength of pure qualitative enquiry (‘Big Q’ studies; p. 4), thus separating it from ‘small q’ (p. 4) studies which rely on positivist ontological assumptions. An awareness of my position as the researcher within this study was critical (Finlay, 2002a; 2002b) for exploring how my subjective biases may have influenced the planning and execution of this study. When these assumptions were noticed, a process of bracketing (Morrow, 2005) was adopted to limit their influence and to allow a deeper analysis which was grounded in the data.

During the execution of the thesis, I experienced a period of extreme acute pain from a localised injury which continued for several weeks. I defaulted to the medical model for a solution, disregarding knowledge of psychological pain management techniques I had learnt and previously had faith in during my many years of psychology training, instead seeking several changes to my prescribed medication to ease the pain. I reflected on the difference between my experience and that of my participants; that my pain experience was temporary whereas people with a diagnosis of FMS often have no quantifiable recovery point in sight. This experience increased my understanding of the condition and my respect for those who suffer with FMS.

Results

The themes presented in this paper formed part of a larger study which explored the experience of emotion generated from the thematic analysis of ten semi-structured interviews with people who had a formal diagnosis of FMS. Participants described how FMS was experienced as an external aggressor, which took advantage of their vulnerabilities to inflict suffering. The overarching theme of ‘FMS as an adversary’ contained the theme; ‘FMS attacks my vulnerabilities’. Two types of vulnerability were identified, creating two sub-themes and these will be explored here; ‘‘I was an ideal candidate unfortunately’ – Trauma predisposes to FMS’ and ‘Emotional difficulties allow FMS to strike’.

‘I was an ideal candidate unfortunately’ - Trauma predisposes to FMS

A common theme in the women’s experiences was that serious and/or multiple trauma occurred before symptoms became apparent, leading them to believe that traumatic events which precipitated the onset of FMS were a key factor in the development of their condition. Kate reported that her rheumatologist linked her FMS to the death of her partner:

Kate: it was just one thing after another and the doctor kept telling me ‘oh, it’s just grief’ and then it was only four years ago that after all this, that the Fibromyalgia issue came up and they said ‘well, this is, this must be what you have’ [---] ummm, I did go to see um a rheumatologist and it was confirmed. And, but I didn’t know for all that time what it was but they said it was the, the grief that had brought it on, the shock of it.
(Line 208-214)

Kate’s numerous symptoms were invalidated for some time by her GP as ‘*just*’ grief. It was only when she saw a specialist that a FMS diagnosis was made. The rheumatologist validated her symptoms as an illness that had developed because of unbearable loss rather than as a grief reaction alone, identifying the relationship between traumatic experience and physical symptoms. Kate believed that the trauma she experienced following the death of her husband may have created a deep vulnerability to the development and severity of FMS.

Many participants experienced numerous traumatic events in the years before their diagnosis. Ruth described how she believed three difficult events led to her FMS; she was diagnosed with a heart condition and within a few months faced the death of her mother and loss of her job on the same day:

Ruth: I had the three in one there and I still swear that that's what's brought a lot of this on. [---] Well it's it's only that yeah, I think in the long run because I started to have these aches and pains which I was putting down to the heart.

(Line 623-627)

Catryn also spoke of numerous stressful events occurring just before her diagnosis including her husband being made redundant following a serious illness:

Catryn: I was trying to up his sort of self-esteem then because he'd been hit with such a massive blow on top of his illness and the money worries, they just kept on coming in all the time then [---] but there was another family issue as well around the same time. Was my mother with her Alzheimer's. She had lung cancer.

(Line 179-184)

Ruth's and Catryn's emotional load appeared to increase with the onset of additional stressors. A period of time when more than one distressing experience occurs appeared to increase participants' vulnerability to the development of FMS and exacerbate its symptoms. They felt that a cumulative effect had occurred; the combination of several challenging experiences overpowered their capacity for coping, leaving them susceptible to FMS.

In addition to the number of distressing events, childhood trauma also contributed to participants' increased vulnerability. Diane discussed how she believed the parental abuse she was subjected to inevitably triggered an inherited, stress-related condition in addition to the development of FMS:

Diane: I was kind of the punchbag but umm (.) so you know you can imagine then if you've got this condition that's going on in your family, you, it, needs triggers for it to show itself. Like the [pain condition shared with father] is triggered by stressful and emotional events and so is the Fibro and umm, I think I was an ideal candidate unfortunately.
(Line 185-189)

Adverse childhood experiences perpetrated by abusive parents or schoolteachers had long-term effects on their emotional resilience, leading to a greater susceptibility to stress-related conditions.

Some participants linked their FMS to the physical and emotional trauma of serious, invasive operations. Abbie linked physical shock to her FMS after researching the condition:

Abbie: I've read that it can come after a massive shock to the system like umm, obviously I had life-saving surgery and I nearly lost my life. [---] Five years ago [---] so I tied it in with, it's the aftermath of that.
(Line 402-407)

Finally, some participants described how FMS snuck into their lives when they were physically compromised due to fatigue:

Rhian: I think then, 'oh, did all this fatigue', do you know and then maybe the underactive thyroid because I was working and looking after my mother, that was lurking and I think 'have I overstressed my body?' [---] and as a result, this is my theory, the Fibro got in, you know.
(Line 287-290)

Rhian conceptualised FMS as an adversary waiting for an opportunity to strike. FMS ‘got in’ when her defences were low due to fatigue and physical health problems.

Emotional difficulties allow FMS to strike

The second potential source of vulnerability to FMS related to participants’ reports of their emotional experience. Some participants reported having difficulty in describing how they were feeling which may suggest that they had difficulty in their relationship with emotion. It was perhaps notable that these participants had also reported psychologically and/or physically traumatic experiences either as children or as adults shortly before the onset of FMS. For these women, therefore it would seem that their level of vulnerability may have been increased by the potential impact of traumatic experiences and/or any difficulties in their relationship with their emotional lives.

Some participants reported how FMS had exacerbated an existing difficulty with emotion as they found it difficult to describe their emotions:

Betty: I can’t describe how I feel though, I can’t
(Line 317)
Betty: I’ve always felt the same I think [---] it’s just I dunno if it’s my brain not functioning right because you get the brain fog with the [auto immune condition] and the Fibromyalgia and I think ‘am I having a double dose?’ [laughs] [---] because I get so exhausted
(Lines 322-326)

For Betty, the impact of FMS on her ability to describe emotion was in the form of fibro fog and fatigue (in addition to a comorbid physical health condition), and therefore these FMS symptoms limited her descriptive abilities. However, Betty believed that she had this difficulty before the onset of either of her chronic physical conditions. Therefore, her difficulties may not have been caused by these; rather, they seem to have exacerbated an existing difficulty via fibro fog and fatigue.

Generally, participants discussed their relationship with their emotions in terms of their upbringing and the messages they received as young children. Carol, for example, grew up feeling that her family were consistently disappointed in her. The family culture of having a 'stiff upper lip' blocked dialogue and any possibility of disconfirming her assumptions:

Carol: (.) probably because we as a family was umm stiff upper lip. You didn't talk about [---] ummm anything to, (…) you kept it to yourself and umm (…)
LJ: and what's that like for you, are you like that nowadays? Do you keep a stiff upper lip nowadays?
Carol: Yeah, I try to, yes.
(Line 410-418)

As described by Carol, participants believed that because their parents were emotionally unavailable or abusive, they had matured into adults who habitually did not verbalise their emotional experience due to trauma or lack of role modelling and/or practice.

Discussion

Participants spoke of the threat of the onset of FMS symptoms, with several participants fearing its attacks. This led to a heightened vulnerability and increased hypervigilance to the affective consequences of FMS. These experiences may have been compounded by the role of trauma in participants' chronic pain.

Trauma

This study offered a qualitative account of the experience of trauma in women with FMS which is currently lacking in the literature. Most participants spoke of serious and/or multiple traumatic events during their childhood, throughout their lives and/or prior to the onset of FMS symptoms. These were traumatic psychologically, physically or both. Many women believed that these events created a vulnerability which contributed to the development of their condition, and that the cumulative effect of traumatic experiences and the fatigue these invoked reduced resilience, thus offering FMS an opportunity to develop.

Many authors support the association of trauma and the development of FMS and CWP more generally (Buskila, 2009; Coppens et al., 2017) as well as several other rheumatologic conditions including RA, psoriatic arthritis and seronegative spondyloarthropathy (Brawer & Goel, 2016; Jun et al., 2000; Thorarensen et al., 2016), post-concussive syndrome and chronic regional pain syndrome (CRPS; Marinus et al., 2006; Wurtman et al., 2010). This association is therefore well established in the literature.

Several scholars have reported associations between emotional responses to psychological and physical trauma and the development of FMS (Buskila, 2009; Gardner, 2000). Yavne et al. (2018) conducted a systematic review of papers exploring psychological and physical trauma as precipitating events in the development of FMS and concluded that “the evidence for this association is extensive and generally considered to be adequate” (p. 129). They asserted, however, that the methodological robustness of these papers was low (Yavne et al., 2018), on the basis that several authors failed to select participants using the current diagnostic criteria. Yunus (2013), for example, considered that a diagnosis of FMS would be equally legitimate if five or six tender points out of 11 were present, despite the criteria of the time requiring all 11. The authors argued that given successive updates to diagnostic criteria, it would seem wise to rely upon the current diagnostic criteria to ensure valid comparison and methodological robustness. The use of discretion in selecting participants with FMS discredits many studies, they argue, due to inconsistent definitions of the condition.

This, of course, is a criticism if a quantitative approach is taken within the medical model. Counselling psychologists value first-person accounts, which go a long way to negate these difficulties. Participants’ reports of traumatic experiences are centrally valuable within qualitative studies, whereas Yavne et al. (2018) considered this to be a weakness.

Notably, the difficulties in accurately identifying FMS when selecting research participants appear to be a parallel process with participants’ experience of diagnosis as frustrating and complex. The issue is with the concept and process of diagnosis itself which underlines the importance of the current study.

Leading academics have expressed these frustrations (Wolfe et al., 2016), arguing that although the published criteria for diagnosis is clear, authors frequently failed to recruit according to those criteria. Equally, primary care physicians and consultant specialists have access to these criteria but FMS is still often misdiagnosed. The chance of accurate recognition of symptoms tends to depend upon the doctor's skill and/or beliefs about FMS (Wolfe & Hauser, 2011). This was how many of the participants in this study found the diagnostic process, that GPs could dismiss their suffering before and after diagnosis, leaving them feeling abandoned and suggesting either unawareness of the criteria or disinterest.

Additionally, the mechanism of the association between FMS and trauma remains unclear. Participants believed that their FMS developed following trauma either acutely or chronically. They believed that trauma reduced their emotional resilience, creating vulnerability to attacks. This belief is reflected in their perception of FMS as an adversary that was waiting for an opportunity to strike. This hypothesised process has support in the literature. Afari et al. (2014) conducted a meta-analysis and concluded that those exposed to trauma had a 2.5 fold chance of developing FMS. Further evidence can be found in fMRI neuroimaging studies, where an association between the regions of the brain involved with pain processing and those activated by trauma have been found (Geuze et al., 2007). Together with the research discussed above, this supports the participants' view of the opportune FMS attacks when they were emotionally vulnerable.

Traumatic experiences are more prevalent in people with FMS and other chronic pain conditions than in the general population. Disrupted cortisol patterns have been found in people with FMS who reported suffering abuse (Weissbecker et al., 2006; Yeung et al., 2016). Increased cortisol levels can result in greater inflammation (Wilkinson & Pickett, 2010), exacerbating pain, as discussed earlier. This suggests a chronic response to trauma which may mediate the effect of trauma on FMS symptomatology. However, researchers have suggested that the interpretation of these events has more influence on the onset and progression of FMS. The prevalence of PTSD in FMS populations is significantly higher than the general population (Arguelles et al., 2006; Häuser et al., 2013; Roy-Byrne et al., 2004), with increased severity in both FMS and PTSD when presented concurrently (Amita et al., 2006; Häuser et al., 2015). An individual’s response to traumatic events which develops into PTSD for those with FMS may exacerbate their pain condition. Perhaps the presence of prior trauma is less of a predisposing factor for some people with FMS if PTSD did not develop.

Dell’Osso et al. (2011) offered further support for the association between FMS and the detrimental effect of PTSD symptoms in women. They used self-report questionnaires to measure health-related quality of life, trauma and loss and found that the impact of FMS on quality of life or symptom severity was related to the number of loss events, grief reactions, traumatic events, reaction to losses, re-experiencing and avoidance as well as numbing and arousal. The pain measure was related to all of these features except arousal. The greatest effect was found for traumatic events involving loss, which was evident in the present data in

the accounts of participants including Diane and Charlotte. Dell'Osso and colleagues also highlighted that trauma can negatively impact the severity of FMS symptoms.
Authors have reported that participants experienced loss due to FMS. This can be a loss of function, relationships and pleasurable activity, as noted by Dell'Osso et al. (2011), who helpfully identified grief reactions as the result of trauma. They linked this grief process to the trauma of losing a loved one, thus indicating enduring and unresolved grief. In contrast, participants in the current study noted a similarity between their affective response to FMS and the loss of a close family member. The effect of FMS potentially compounded the trauma responses that were present for many participants which possibly increased their vulnerability to FMS and exacerbating symptoms.

A feature of PTSD as a clinical presentation is hypervigilance (DSM-5, 2013) or constant checking for potential threats. Although signs of trauma were not explored during the interviews, several participants reported anxiety as part of their experience of FMS, together with a fear of the next pain attack. This parallels the threat-based emotion of shame, as discussed above. Shame and PTSD are associated with increased psychological distress (Kotera et al, 2019) and this has been shown to exacerbate pain (Tang et al, 2008), therefore participants who were experiencing shame and features of PTSD potentially faced increased severity of symptoms. It may be that threat-based emotion was a driver of their pain experience, suggesting that for those who experienced difficulties with their emotional lives, the effect of traumatic events remains pertinent

The presence of psychological distress appears to be important in the association between FMS and trauma (Häuser et al., 2012; Häuser et al., 2013). The comorbidity of FMS, PTSD and depression is common, suggesting a link (Goldenberg, 2009; Raphael et al., 2004). This may indicate a mediating effect of psychological distress, or as Raphael and colleagues postulated, 'joint dependence on some fourth factor' (p. 34). They suggested that traumatic life events whilst necessary for PTSD may be risk factors for FMS and depression resulting in the three comorbidities being evidenced in research studies. As with the association between trauma and FMS, we currently do not understand the process, although it is clear that, for some people with FMS, psychological distress and PTSD can impact their symptomatology independently (Saariaho et al., 2011).

Moving onto the second source of vulnerability for the women in this study who experienced difficulties with their emotional lives, the effect of traumatic events remains pertinent.

Difficulties with the experience of emotion

The second source of vulnerability to FMS evident in the data was difficulties with the experience of emotion, or a difficult relationship with their emotions, that is, participants tended to describe their feeling states in general terms and report some difficulty in their relationship with their affective lives. If one followed the dominant academic literature, the features of the postulated concept of alexithymia are likely to be relied upon to understand this, particularly difficulty describing feelings. However, the data suggested other explanations for why the women in this study appeared to find it difficult to describe their affective states, indicating that it may be less helpful to consider these as belonging within the concept of alexithymia. It would appear that it may be valuable to consider wider possibilities when exploring why women with FMS may find it difficult to describe their affective states.

Much of the existing literature has explored difficulties with emotion quantitatively and within the theoretical context of alexithymia. Any difficulties that participants reported in the literature thus far tended to be analysed within this framework, with little consideration of other possible explanations. This study sought to offer a qualitative analysis of any difficulties participants experienced and their understanding of these difficulties in order to contribute to this debate.

Some of the women in this study understood their difficulties in terms of their upbringing, in that their parents were either abusive, or emotionally unavailable, or both. This meant that they matured into adults who tended not to verbalise emotional experiences due to trauma, a lack of practice, or a lack of role modelling. It would seem possible that adverse childhood experiences may interfere with their relationship with their experience of emotion. Indeed, it was perhaps notable that most of the women with emotional difficulties had experienced traumatic events, including adverse childhood experiences, which may indicate that their difficulties were associated with a trauma response. Many researchers have associated the difficulties of describing emotion and trauma. It has been argued that adverse childhood experiences may interfere with the development of emotional regulation abilities, leading to increased difficulties which have been conceptualised as alexithymia (Berenbaum, 1996; Taylor, 2018). Similarly, Aust et al. (2013) found a positive correlation between alexithymia scores and emotional neglect in the early years, which supports the data in the current study. It may be that quantitative studies into alexithymia may have been detecting a trauma response, rather than a separately differentiated psychological construct.

Other participants believed the symptoms of FMS contributed to these difficulties - in other words, that Fibro Fog and fatigue impaired their cognitive and affective abilities. The literature on Fibro Fog outlined the features as forgetfulness, being easily distracted, speech and language difficulties and disorganised thinking patterns (Williams et al., 2011), which affected 50% to 90% of people with FMS (Katz et al., 2004). These widely recognised symptoms of FMS could therefore have interfered with the ability of participants to describe their emotion states.

Teodoro et al. (2018) conducted a systematic review of cognitive difficulties in functional neurological disorders such as FMS and CFS. They commented that that the quality of the existing research in this area had shortcomings, and therefore more exploration would be required before clarity on cognitive difficulties in these conditions could be reached. They concluded that ‘attentional dysfunction’ (p. 1315) was the main difficulty, and that this was impacted by pain and fatigue in FMS. This interpretation supports the understanding of their difficulties given by participants in the current study.

It may be that participants in this study experienced difficulties in their ability to describe emotion as the result of traumatic experiences and/or the cognitive difficulties which FMS symptoms can create, rather than some personality deficit, as the concept of alexithymia may suggest. This brings into question the concept of alexithymia and suggests that the literature which explores alexithymia may be detecting difficulties with emotion derived from multiple influences, rather than a single conceptual construct.

The effectiveness of the concept of alexithymia to explain participants' difficulties also comes into question when one considers that the data analysis in this study did not result in themes related to difficulties in the full spectrum of postulated features of alexithymia, that is, difficulty identifying emotion, difficulty identifying the difference between bodily feelings and the physical symptoms of emotional arousal, and limited imaginal processes (Taylor et al., 1997). The present data suggests that the concept is flawed as an explanation for the difficulties in emotion seen in this study and perhaps more widely.

In recent years, the complexity of the concept of alexithymia has been illuminated (Aaron et al., 2019). Some authors have concluded that alexithymia is either 1) state-dependent, meaning it is only present when the person is, for example, stressed or 2) a permanent trait (Montoro et al., 2016). This model suggests flexibility in terms of when the difficulty is expressed but fails to account for presentations which only feature some of the characteristics of alexithymia.

Further, inconsistency in findings in the literature suggests that alexithymia does not work as a concept. Indeed, Aaron et al. (2019) conducted a meta-analysis of 14 papers exploring correlations between mood and the effect of alexithymia on pain and found that the latter was not significantly associated with either pain intensity or interference when mood was controlled for. The importance of psychological distress in the emotional experience of FMS once again becomes apparent when we explore alexithymia, as it was for traumatic experiences. This can have meaningful implications for psychological interventions for people with FMS, as discussed below.

One reason why the concept of alexithymia may not be helpful lies in the methods which have been used to analyse the area. Quantitative studies on alexithymia generally use self-report measures to detect its features and so categorise participants as ‘alexithymic’ or not, depending on psychometric cut-off scores (Evren et al., 2006). The use of self-report questionnaires may conceal important features of these apparent difficulties. Alexithymia measures converge with measures of low mood; perhaps because those suffering low mood are more likely to evaluate themselves negatively (Leising et al., 2009; Lumley, 2000). The standard measures used to measure alexithymia (such as the TAS-20) may, therefore, have lower validity than claimed. In this case, the method of inquiry may contribute to the confusion around alexithymia, supporting the use of qualitative methods for a more in-depth analysis of cognitive difficulties relating to emotion.

Alexithymia as a concept has been used to understand FMS and other conditions involving MUS in the past. Although its roots were in the psychodynamic tradition (Weiner, 1982), it would appear that this concept has become strongly aligned to the medical model and utilised to support approaches to understanding which situate distress within individual deficits. This is clearly in contrast to counselling psychology philosophy in general, and this dataset in particular.

The results of this study would suggest a different position to that of both the psychodynamic tradition and those who subscribe to the concept of alexithymia. It may be more appropriate for understanding emotional difficulties experienced by women with FMS to inhabit a position within a psychologically-informed understanding of such conditions that is formulation driven and acknowledges the frequency and nature of trauma, in all its forms, in individuals' histories; symptomatic features of FMS which may contribute to emotional difficulties; and the experience of psychological distress in general, including low mood.

Relevance of findings and limitations

The data indicated that trauma responses, including difficulties with emotion, may have increased vulnerability to FMS and could have exacerbated pain and other symptoms. This indicates that a trauma-informed, formulation driven approach to psychotherapeutic intervention such as that espoused Van der Kolk (2015) and Johnstone et al. (BPS, 2018) may be particularly beneficial for people living with FMS.

CBT has the strongest evidence base for treating FMS (Williams et al., 2020), assisting with both increased functioning and pain management (Williams et al., 2012). This suggests that CBT may be helpful for re-framing FMS from a threatening adversary to a more neutral presence, thus reducing the threat responses evident for some participants. Equally importantly, clients with FMS are likely to benefit from being screened for PTSD (Sommer et al., 2012) to increase the potential for effective intervention.

Additionally, a creative approach may be effective in overcoming difficulties with emotion. Lumley et al. (2011) espoused emotional awareness and expression therapy to improve cognitive difficulties conceptualised as alexithymia.

This study is limited, in that only women who were higher functioning, had manageable symptoms, and were able to attend support groups were available for selection. Notwithstanding such limitations, one may ask why most people affected by FMS are women in later middle-age and older with lower socio-economic status. Further analysis or work from a feminist or a social-constructionist lens may illuminate facets of this condition which this work did not aim to capture, such as the work by Werner et al. (2004) in CWP. Briones-Vozmediano (2017) also suggested looking at this “invisible women’s disease” (p. 1) from a feminist perspective.

This study offered an overview of the emotional experience of people with FMS. Future projects may offer a more specific exploration of the emotional issues raised.

Conclusions

The aim of this qualitative study was to contribute to the limited research on emotion in FMS, despite its central role in the pain experience. The identified themes offered a narrative of the women who participated suffering the symptoms of a difficult chronic pain condition which they believed exploited their vulnerabilities due to trauma and interacting difficulties with emotion. Participants believed that traumatic experiences influenced the development of their condition, with a large body of research supporting this association.

The data confirmed prior FMS and chronic pain research and illustrated how a focus on the affective processes experienced by participants could lead to more effective care using trauma-informed, formulation-driven approaches.

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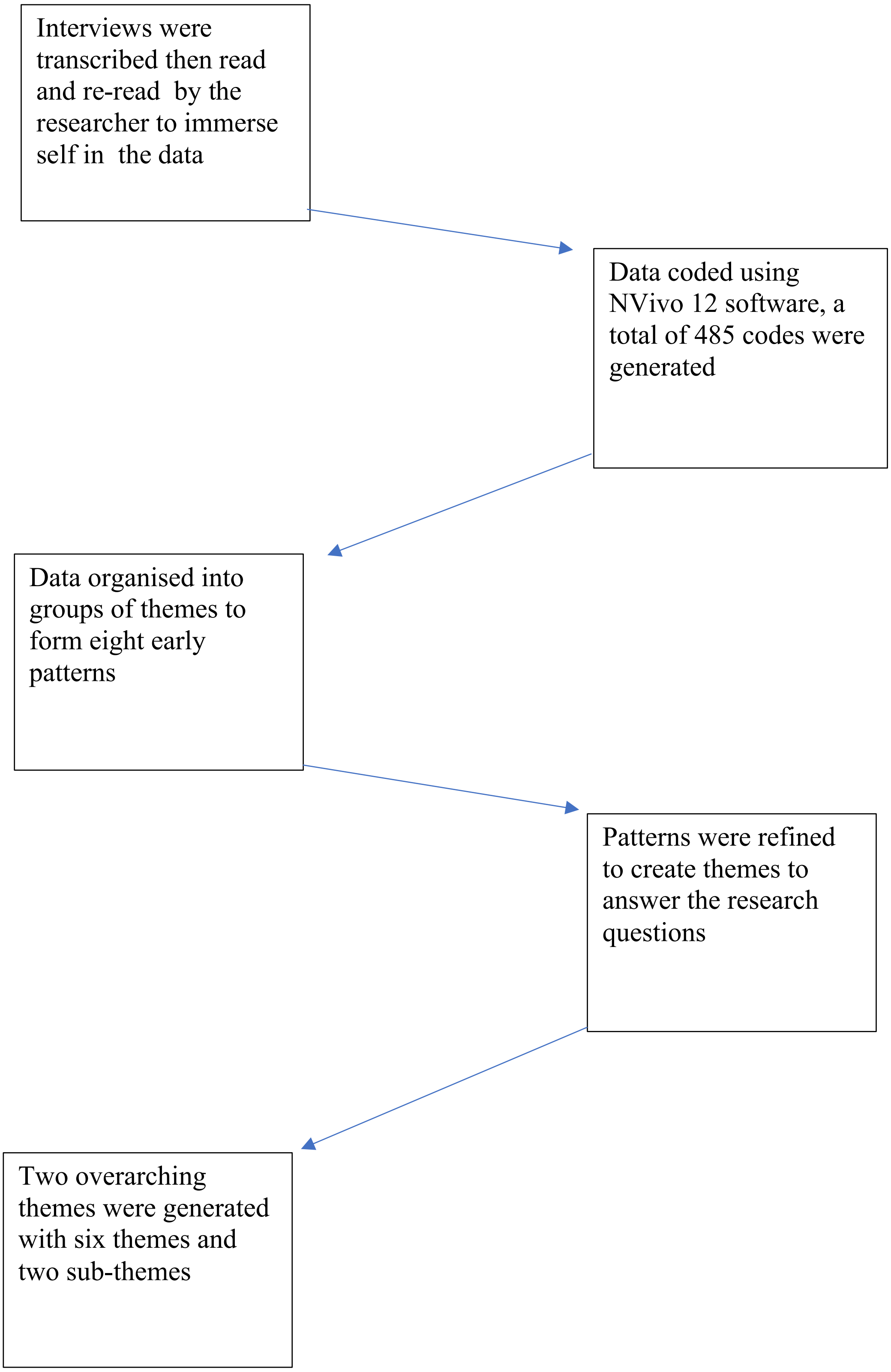
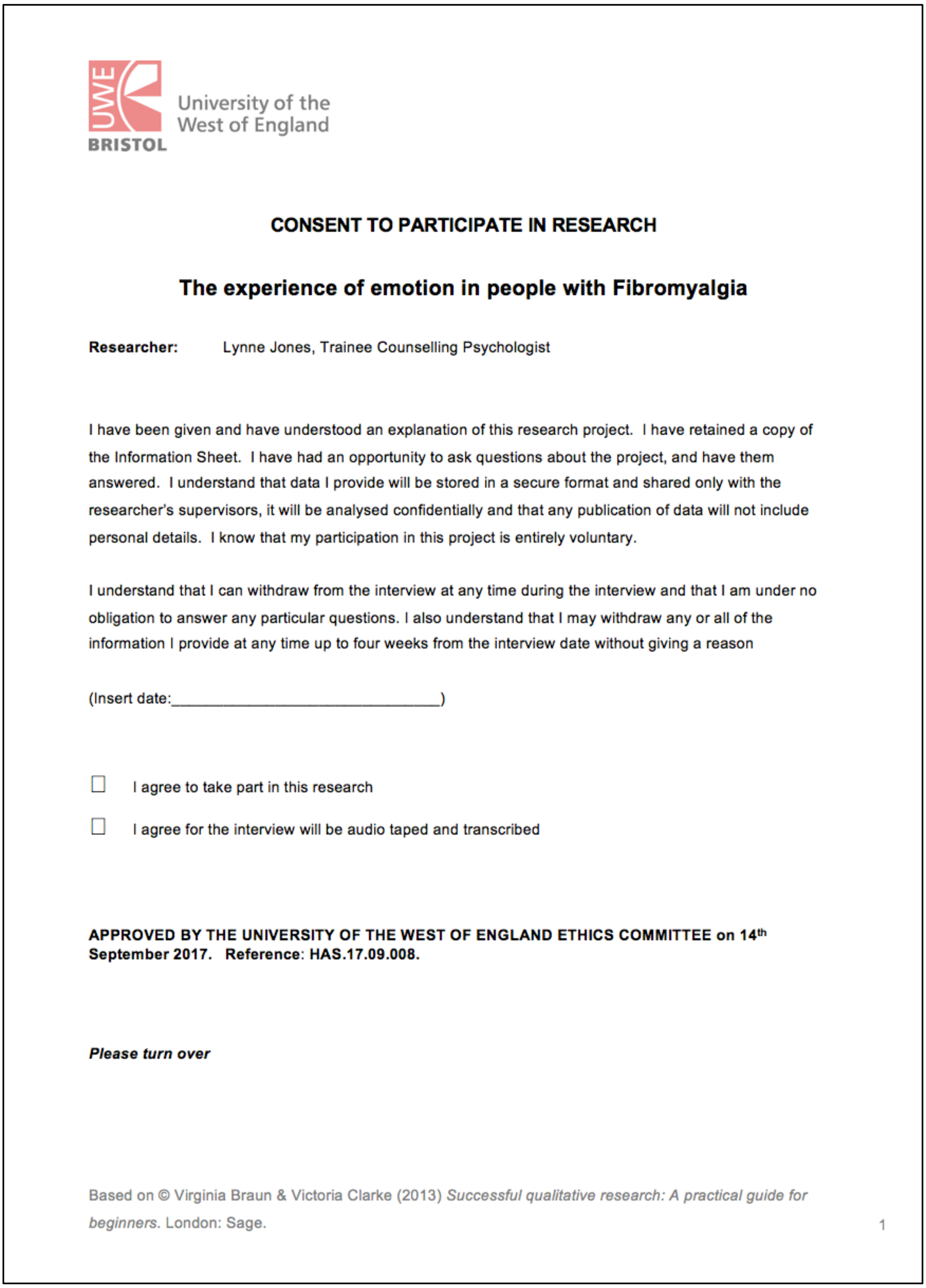
APPENDICES

APPENDIX	
1	Participant demographics and interview length
2	Process of thematic analysis
3	Extracts from coded interview
4	Participant information sheet
5	Participant consent form
6	Interview guide
7	Letter granting ethical approval

APPENDIX 2 Process of thematic analysis



APPENDIX 5 Participant consent form



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CONSENT TO PARTICIPATE IN RESEARCH

The experience of emotion in people with Fibromyalgia

Researcher: Lynne Jones, Trainee Counselling Psychologist

I have been given and have understood an explanation of this research project. I have retained a copy of the Information Sheet. I have had an opportunity to ask questions about the project, and have them answered. I understand that data I provide will be stored in a secure format and shared only with the researcher's supervisors, it will be analysed confidentially and that any publication of data will not include personal details. I know that my participation in this project is entirely voluntary.

I understand that I can withdraw from the interview at any time during the interview and that I am under no obligation to answer any particular questions. I also understand that I may withdraw any or all of the information I provide at any time up to four weeks from the interview date without giving a reason

(Insert date:_______________________________)

☐ I agree to take part in this research

☐ I agree for the interview will be audio taped and transcribed

APPROVED BY THE UNIVERSITY OF THE WEST OF ENGLAND ETHICS COMMITTEE on 14th September 2017. Reference: HAS.17.09.008.

Please turn over

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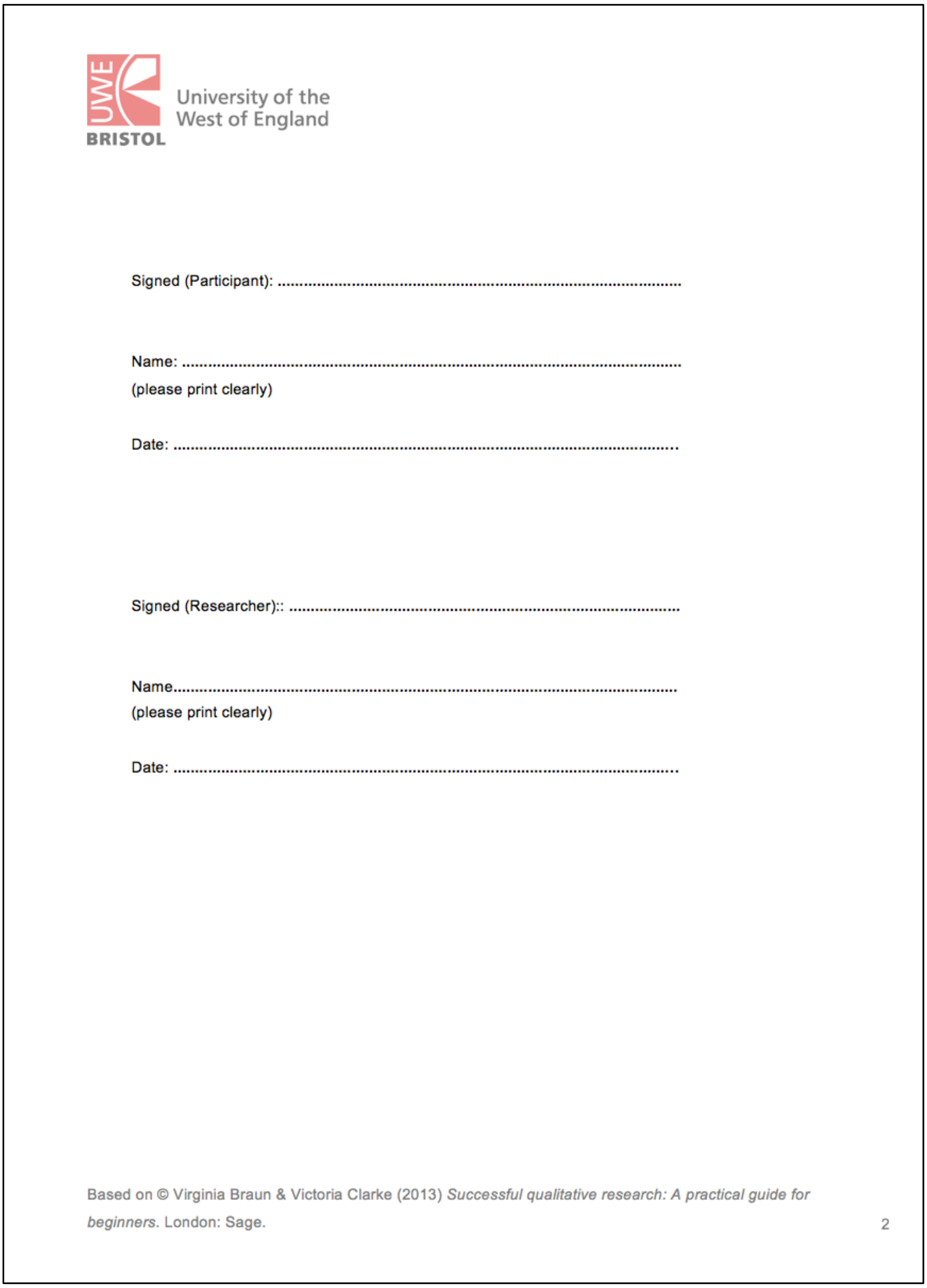

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Signed (Participant): ....

Name: ....
(please print clearly)

Date: ....

Signed (Researcher):: ....

Name..
(please print clearly)

Date: ....

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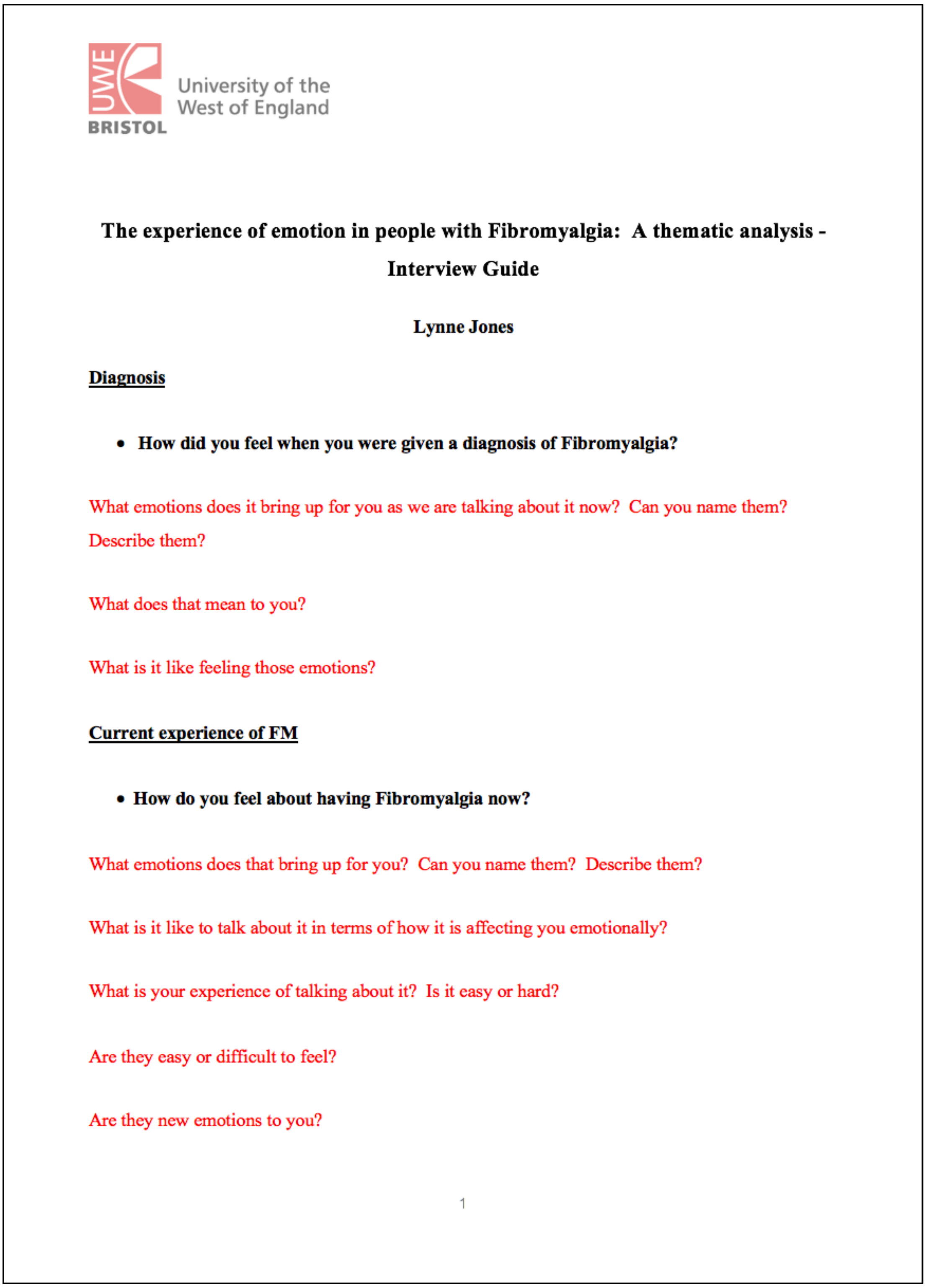
APPENDIX 6 Interview guide



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The experience of emotion in people with Fibromyalgia: A thematic analysis - Interview Guide

Lynne Jones

Diagnosis

- **How did you feel when you were given a diagnosis of Fibromyalgia?**

What emotions does it bring up for you as we are talking about it now? Can you name them? Describe them?

What does that mean to you?

What is it like feeling those emotions?

Current experience of FM

- **How do you feel about having Fibromyalgia now?**

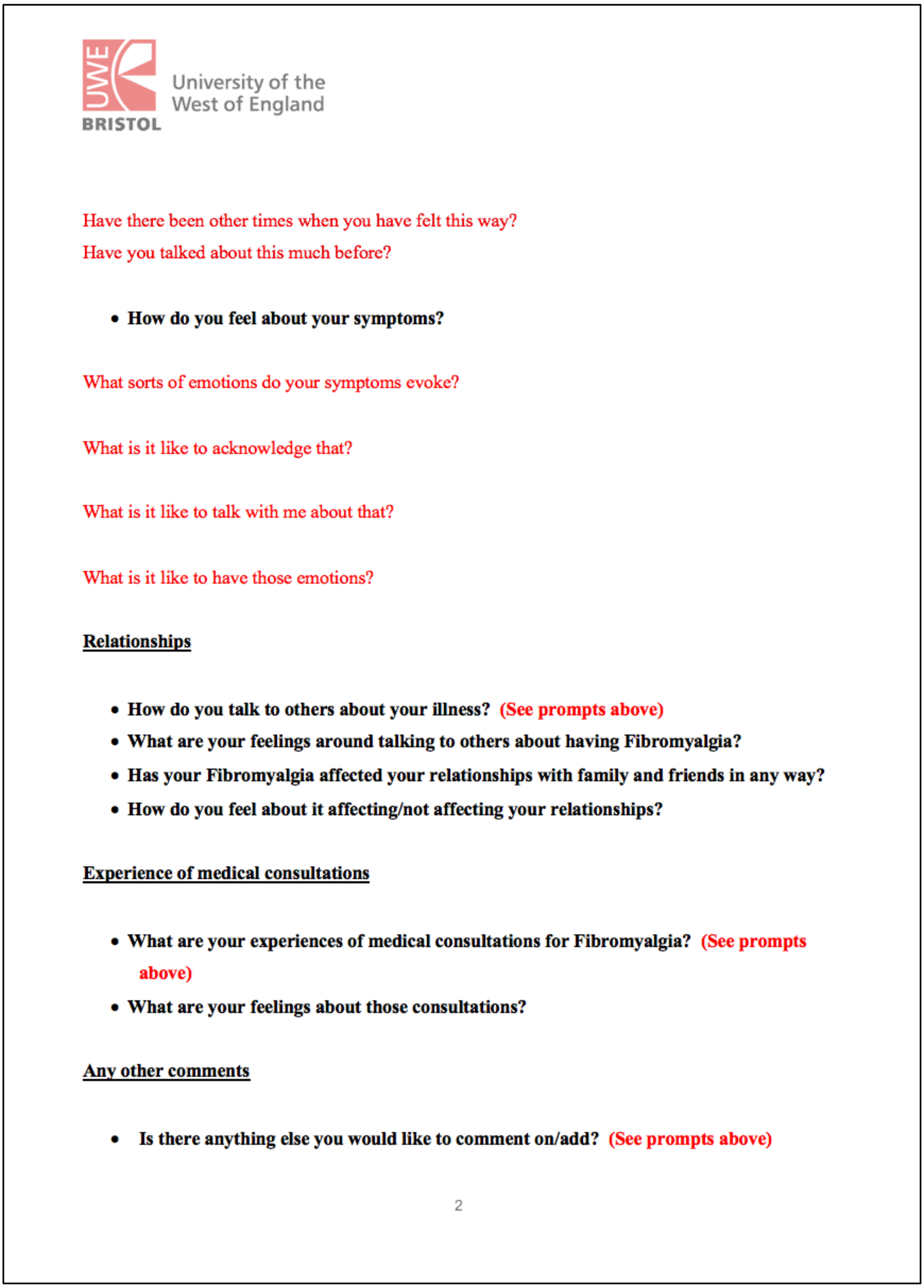
What emotions does that bring up for you? Can you name them? Describe them?

What is it like to talk about it in terms of how it is affecting you emotionally?

What is your experience of talking about it? Is it easy or hard?

Are they easy or difficult to feel?

Are they new emotions to you?



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Have there been other times when you have felt this way?

Have you talked about this much before?

- **How do you feel about your symptoms?**

What sorts of emotions do your symptoms evoke?

What is it like to acknowledge that?

What is it like to talk with me about that?

What is it like to have those emotions?

Relationships

- **How do you talk to others about your illness? (See prompts above)**
- **What are your feelings around talking to others about having Fibromyalgia?**
- **Has your Fibromyalgia affected your relationships with family and friends in any way?**
- **How do you feel about it affecting/not affecting your relationships?**

Experience of medical consultations

- **What are your experiences of medical consultations for Fibromyalgia? (See prompts above)**
- **What are your feelings about those consultations?**

Any other comments

- **Is there anything else you would like to comment on/add? (See prompts above)**