

## **What causes Fibromyalgia? An online survey of patient perspectives.**

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# What causes fibromyalgia? An online survey of patient perspectives

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## Abstract

Fibromyalgia is a severe chronic pain condition that affects every aspect of life. Causes of the condition remain unclear, and quantitative research cannot account for patients' personal illness narratives and perceptions. This online survey gathered qualitative accounts of the perceived causes of their condition from 596 people with fibromyalgia, which were analyzed thematically. Themes were “Bodily assault, ill-health, and change”; “Emotional trauma and distress”; “Stress and vulnerability”; and “Explaining and authenticating fibromyalgia.” Discussion focuses on the complexity of causation, the importance of understanding and having symptoms validated, and the potential for benefiting from patient expertise in building better practitioner–client relationships.

## Keywords

chronic pain, etiology, fibromyalgia, rehabilitation, stress, survey, trauma

## Background

Fibromyalgia is a severe chronic pain condition with a global mean prevalence of 2.7 percent (Queiroz, 2013). It negatively impacts psychological well-being, sleep, social relationships, physical health, and work life (Andrade et al., 2018; Chinn et al., 2016; Wuytack and Miller, 2011). Uncertainty surrounds the validation and etiology of fibromyalgia (Dow et al., 2012), and this lack of understanding complicates its diagnosis and treatment (Wolfe et al., 2010).

The majority of etiology research is quantitative, focusing on genetic, environmental, and personality contributors, with relatively small samples. Only a few larger-scale surveys of fibromyalgia patients have considered etiology (Bennett et al., 2007; Nakamura et al., 2014). Qualitative research provides narratives of living with fibromyalgia (McMahon et al., 2012), but references to causality are limited. Recent cross-cultural studies (e.g. Häuser et al., 2015; Jiao et al., 2015), however, suggest that people perceive fibromyalgia as a coherent development from definable life events. The study of chronic illness narratives has focused on patients' ability to express suffering (Hyden, 1997), create meaning (Riessman, 2001), and reconstruct a sense of order in lives and identities disrupted by illness (Williams, 1984). Illness narratives may include personal explanations

of illness causality and effect (Bury, 2001); they may also extend beyond the individual to create a collective story which improves understanding of the condition (Hyden, 1997).

In the context of ongoing uncertainty and debate regarding the validity, cause, and treatment for fibromyalgia, the patient–doctor relationship can be problematic and cause frustration (Bartlett and Coulson, 2011). When patients doubt the expertise of their care professionals, they may instead seek help from other patients in online information-sharing (Ziebland and Wyke, 2012). Online networks offer a source of legitimacy and support for fibromyalgia patients (van Uden-Kraan et al., 2008) and may help patients develop narratives about their condition.

This study aimed to investigate in detail this highly significant aspect of the illness narrative of people with

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fibromyalgia. It is, to the authors' knowledge, the first qualitative study to do this with a large sample.

## Methods

### Design

A mixed-methods UK-based online survey was used to gather data from a large sample about their experiences of fibromyalgia and associated treatments. The survey was approved by the University Research Ethics Committee and applied the British Psychological Society's guidance for research with human participants. Survey questions were informed by a prior in-depth interview study with 16 participants (Ashe et al., 2017) and existing literature.

Online fibromyalgia networks advertised the survey to members. Full information was provided on the front page and survey completion was taken as consent. Participants were able to skip questions, partially complete, and return later to the survey. They could also withdraw consent by discontinuing and not saving the survey. Anonymity was assured. Data were collected between November 2015 and March 2016.

This article reports findings relating to respondents' perception of causal factors responsible for their condition. They were asked, "Do you believe a certain event (injury, illness, experience, etc.) was linked to the start of your fibromyalgia symptoms?" and "If you answered yes to the previous question, would you describe this event to us?"

### Participants

Survey completers numbered 941, ranging in age from 18 to 87 (mean, 47.1) years. The vast majority were female (94.8%) and identified as White British (95.9%). Participants were asked to confirm that they had received an official diagnosis of fibromyalgia.

A total of 606 (64.3%) responded positively to the first question, of whom 586 went on to answer to the second question. Ten who ticked "no" nonetheless responded to the second question describing causal factors, generating 596 responses for analysis. Responses ranged from a few words to detailed accounts up to 750 words in length.

### Analysis

Responses were analyzed inductively for themes, using Braun and Clarke's (2006) approach of immersion in data through reading, followed by data coding and categorization based on comparative analysis, and creation of themes. Two analysts worked to develop categories and themes, which were discussed and agreed within the team. Themes reflected participant stories and the individual and collective interpretations of the researchers, whose backgrounds include Health and Social Psychology and Biomedical Science.

## Results

Four themes were generated: (1) Bodily assault, ill-health, and change; (2) Emotional trauma and distress; (3) Stress and vulnerability; and (4) Explaining and authenticating fibromyalgia. In the following account, data extracts are contextualized with a pseudonym, and the age and gender of respondent, plus the dates of their symptom onset and diagnosis. For example, F, 40, S98, D04 refers to a female respondent aged 40 whose symptoms started in 1998 and who received a diagnosis of fibromyalgia in 2004.

### *Bodily assault, ill-health, and change*

This theme comprises explanations citing physical causes for fibromyalgia, including bodily assaults, physical ailments, ill-health, and body changes.

Bodily assaults included accidents, third person attacks, surgery, infections, poisons, and allergens. Commonly cited were car accidents, skeletal injuries, and nerve problems, with many participants highlighting the importance of damage to the cervical spine. Isolated incidents were described, but accounts more often suggested cumulative physical events:

I have had multiple bodily ailments—Bus crash, back injury in a fall, heavy lifting during employment, physical assault—which I feel led to my issues. (Anne, F, 55, S07, D08)

Responses highlighted both the shock of the incidents and the experience of acute pain over several weeks, often while waiting for appropriate medical interventions, which compounded the impact of the original injury:

I believe it started after a fall I had, breaking an ankle. The fracture was not diagnosed until three weeks after the fall and I had been in agony during that time. (Joan, F, 80, S00, D03)

Industrial accident. Took 12 months for MRI and a further 6 months for surgery. (Cathy, F, 40, S97, D00)

Surgery was also an explanation for fibromyalgia onset. Some participants reported a series of operations: "three lots of surgery in four years" (Dawn, 65, S03, D05). Others described traumatic surgical interventions with post-operative complications which had left them "very ill and have been suffering the consequences of this surgery ever since" (Emily, F, 48, S07, D12), and "an extremely stressful period with a nasty, not properly managed recovery ... Body in shock and never got over it really" (Gill, F, 37, S99, D14).

Other assaults on the body included poisoning (e.g. from industrial chemicals, chemotherapy, medications, food), allergens, vaccinations, infections, and viruses. As above, these were often viewed as cumulative events in the onset of fibromyalgia:

I had very severe chicken pox. I already had musculoskeletal and neuropathic pain from skiing, work and car accidents, but the pain was localised. The general chronic pain and fatigue did not go away after I'd started recovering from the chicken pox infection. (Hannah, F, 52, S06, D07)

Participants identified a range of viral and bacterial infections, illnesses, and inflammatory responses as possibly implicated in their fibromyalgia. Some participants believed that their physical well-being had been undermined by long illnesses or symptoms which were not properly recognized and treated:

I have PCOS and pernicious anaemia from being a teenager that was not diagnosed until I was in my mid-forties. I think that both health problems undermined my health and that fibromyalgia has developed because of the strain trying to live a normal life has had upon my body. (Jane, F, 54, S75, D14)

Finally, some of the perceived causes were linked to physical events which represented significant changes in the body and life stage. In this predominantly female sample, "pregnancy," "childbirth," "hysterectomy," or "menopause" were frequently identified as onset events:

The extreme tiredness, brain fog and pain started after a planned C-section. (Kaye, F, 32, S01, D15)

Adjectives such as "difficult" (pregnancy, birth) and "traumatic" (labor) were used to reflect the psychological and physical impact of these events. In addition, there are broader impacts on a woman's role and identity. Pregnancy and birth represent transition to a new life stage and the onset of demands of motherhood. Menopause and hysterectomy represent the loss of reproductive capabilities, changes in hormonal function and their impact on health, alongside challenges to sexual identity, femininity, and youthful identity. These aspects will be discussed below.

### *Emotional trauma and distress*

This theme is composed of experiences, which had a primarily emotional or psychological impact. It includes accounts of mental ill-health, loss and bereavement, shock and trauma, abuse, and bullying. It also incorporates the psychological impact of trying to live an outwardly normal life under abnormally difficult psychological and emotional conditions.

A number of participants wrote about mental illness, such as depression, as a primary cause of their fibromyalgia:

I suffered from an episode of major depression in 2008. I had my first episode in 2005, but had managed to recover in the meantime. However in 2009 when the depressive symptoms started to lift, my body remained in the same state and then

fibromyalgia symptoms took hold. I believe that my system was overwhelmed by what had happened and unable to recover properly. (Laura, F, 27, S09, D09)

This notion of comorbidity is supported by other participant accounts, in which emotionally traumatic events, such as physical and sexual assaults, were described as leading to distress, mental ill-health, and fibromyalgia. Participants also described bereavements and how the loss of a loved one—parents, partners, or children—acted to bring on their fibromyalgia symptoms:

I lost my dad and mum within a year of each other. I used to look after them both and when they died, this is when all my pain and stiffness started. (Lisa, F, 50, S10, D13)

The previous pattern was repeated here, whereby most participants reported repeated or complex losses with profound impacts. Our findings indicated that not all traumatic losses were bereavement-related; some losses were implied in events such as menopause and hysterectomy or through family changes. For example, one participant described her daughter moving out under complicated circumstances, which caused distress and anxiety as well as "the onset of acute pain" (Maureen, F, 47, S14, D15).

Other accounts referred to shocking, often violent, events, experienced directly or witnessed against strangers, friends, and loved ones, which had deeply traumatizing effects, often with long-term effects on well-being:

I was involved in an incident at work where a colleague was seriously assaulted by a patient. I have never seen violence like that before and since then I have felt very anxious when I think about what happened. I could no longer work in that environment and asked to be moved to a less dangerous area. (Melanie, F, 44, S11, D11)

I have bi-polar disorder too. I believe both conditions were triggered by my experiencing the Birmingham Pub Bombings in 1974 ... at 17 years old. (Naira, F, 58, S90, D00)

I found out that my (then) husband had sexually abused my daughter; I had to leave my home; I was stalked by him after leaving; he held me at knifepoint twice, before being sent to prison. (Pamela, F, 58, S06, D07)

These extracts illustrate the variety and severity of experiences in participant narratives, which included violence and abuse in childhood and adulthood:

I was sexually abused as a child, my dad and husband were both alcoholic and violent, so many years of stress, pain, anger, resentment, fear, I think, have contributed to fibromyalgia. (Peggy, F, 46, S94, D06)

Many years ago I was sexually abused, then I was gang-raped. Had a horrible divorce. My ex took all my children away from

me. He took my home and my friends and left me homeless. I suffer with personality disorder because of my traumas. But it also caused my fibromyalgia [and] migraine. (Rachel, F, 51, S04, D09)

Although brief, these accounts clearly communicate the horror and impact of the experiences. Participants described a range of effects on their well-being, such as anger, fear, anxiety, resentment, homelessness, personality disorder, and bipolar disorder. They also clearly implicated these events in their fibromyalgia onset.

The impact of suffering intense or lasting traumatic experiences was exacerbated when participants felt unable to disclose or discuss them. One wrote simply “rape and the trauma of hiding it” (Rebecca, F, 35, S96, D00); another described a complex situation where they internalized distress to protect others:

I lived in a very volatile situation for many years. My partner of 20 years was an alcoholic although he didn't physically abuse me there was much mental manipulation and abuse. I pretty much brought my two boys up on my own. It was difficult trying to hide everything from them and bring them up to be good, polite, responsible people. I had symptoms of aches and pains in my arms and legs and believed it was the inner kept-in stress trying to release itself and would gradually dissipate as it worked its way through my body. However it gradually became worse when I finally managed to get rid of him ... I strongly believe that I wouldn't have Fibromyalgia if I hadn't have had that kept-in inner stress and worry. (Sally, F, 48, S09, D14)

Participant data led to the creation of the two discrete themes above, relating to either physical or emotional trauma; indeed related literature also tends to be divided along similar lines. Our impression, however, was that many traumas were both physical and emotional. For example, being attacked, raped, and abused represented both physical and psychological trauma, and the emotional loss of bereavement could be accompanied by the physical effects of associated phenomena such as insomnia. The experience of injury and pain challenged resources on both an emotional and physical level. Consideration of our dataset and the literature related to it indicated that two key moderating factors between traumas, both physical and emotional, and the development of fibromyalgia, were the experience of stress and individual sensitivity. These aspects are reflected in the following theme, Stress and vulnerability.

### *Stress and vulnerability*

The third theme developed from references to burdens participants faced in their everyday life, such as care responsibilities, loved ones' ill-health, work or financial concerns, moving house and relationship troubles. The terms “stress”

and “strain” were often used to describe their impact. In some cases, the “ordinariness” of these experiences was distinct from the extraordinary and traumatic life events described above. In addition, the theme reflected accounts suggesting vulnerability to developing fibromyalgia under stressful conditions based on individual responses or patterns of disease within families.

Stresses associated with caring were commonly mentioned:

My husband had a stroke abroad while on holiday with our three children, aged 6, 7 and 10. My husband was 30 years old. He has been disabled since then. In 2004 and 2008 my parents died. Both illnesses and deaths were equally harrowing. I was the main carer. (Sharon, F, 52, S96, D13)

Caring here involved multiple care-taking responsibilities. Use of the term “harrowing” illustrates the emotional impact of the changes on this participant, in which the burden of care was exacerbated by loss and grief.

Work life also featured strongly in participants' responses, in particular the challenges of high demands and expectations:

The more I achieved, the more they wanted. (Tanya, F, 50, S07, D15)

I was often left running a project on my own without another staff member and so overworking to the point of exhaustion as I was doing the work of 2 people. (Trish, F, 55, S09, D11)

Work stress was not always the result of external demands: our participants acknowledged putting pressure on themselves, admitted “over-working,” or being “very stubborn and [carrying] on through relapses when I maybe should have rested” (Theresa, F, 63, S70, D93). Accounts explaining how self-imposed pressures had contributed to onset and deterioration in fibromyalgia may reflect perfectionist tendencies, discussed below.

Another individual factor reflected in the data was family heritability. Family histories of fibromyalgia or related conditions and symptoms were recurrent:

[Following hysterectomy] I seemed to get worse after medication such as antibiotics. I now have high sensitivity to medication and often get very bad side effects. My daughter has also been diagnosed with the condition after the same operation ion as I had and her sensitivity to medication has become very severe. My aunt has also been diagnosed with condition. People in my family have a history of spondylitis of the spine, brother is the nearest one. My other brother also has rheumatism in [his] joints. (Violet, F, 71, S84, D90)

The idea that fibromyalgia or related symptoms can occur across generations in families is supported in existing literature, as discussed below. However, family history

aside, our data suggested that additional external negative events were important perceived triggers for fibromyalgia. These events seemed to make the person vulnerable—physically, emotionally, or both—to fibromyalgia, often through a stress response.

### *Explaining and authenticating fibromyalgia*

The majority of our sample offered clear explanations for the onset (and often the deterioration) of their condition, despite living in an environment in which the etiology, validation, and even the existence of fibromyalgia is still debated. This final interpretive theme arose from the prevalence, clarity, and detail within these explanatory accounts. Fibromyalgia had become a legitimate and logical part of these participants' stories, despite denial, dismissal, and controversy about the condition from their families, medical professionals, and wider community.

A number of participants did not offer an explanation, which cannot be reliably interpreted as inability to identify a cause. The negative responses to question 1 were easier to interpret, although a few of these offered tentative links between events and fibromyalgia: "There have been many traumatic events in my life but none that I can directly link to the start of my symptoms" (Vicky, F, 32, S12, D15). Two-thirds (around 63%) of participants had clear ideas about the causality of their symptoms. Some participants had taken many years to make sense of their symptoms, perhaps because of the dismissal—sometimes from an early age—of their experiences:

Do not remember not being in pain, told they were "growing pains" and I was "too young to be sick" and/or "attention-seeking." (Vinnie, gender fluid, 27, S89, D15)

These individuals came to realize only later in life that the validity and significance of these experiences. The causal explanations provided here had gained clarity and resonance over the years of experience and reflection, perhaps aided by sympathetic practitioners and a supportive online community:

My symptoms would seem to go back to this time [being widowed] but only recently have all the dots been joined together. (Violet, F, 48, S99, D15)

Participants were apparently making sense of events and changes using acquired knowledge and understanding to reinterpret previously apparently unconnected events. Our retrospective design means we could not capture change and development in the meaning of fibromyalgia, its symptoms, and surrounding life events; however, when these participants completed the survey—at different stages in their trajectories—most pinpointed distinct events that were responsible and wrote clear chronological accounts.

Fibromyalgia had become an integral part of their life histories and identities, albeit not one they embraced:

Up to falling ill (with glandular fever, followed by gall bladder removal 2 years later) I'd been "very sporty" and played or practiced various sports 6 days a week. After my operation I tried to go back to my sports but could not perform to anywhere near that previous standard. From then on I found that every time I was ill I became "less able" to carry out sport and exercise ... It took decades for me to get to the state I'm in now. (Wanda, F, 55, S82, D15)

Considering *how* these participants told their stories, some aspects seemed significant. The participant-inserted quotation marks seemed to reflect aspects of their identity in the "before-and-after" story of their fibromyalgia. In their causal accounts, many used the phrase "I believe," reflecting a sense that others' perspectives (including those of professionals) could differ; however, it might also demonstrate the personal significance of described events in their fibromyalgia story, and the importance that others accept them. It may also be a demonstration of the strength and legitimacy of their explanations in the context of dismissive or delegitimizing medical opinion and social responses. Another legitimizing device in responses was aligning one's view with and drawing support from established academic medical opinion:

Vaccination. I have since learned that a Canadian, whose daughter has Fibro/chronic fatigue successfully researched and concluded that the vaccine I had causes Fibro/chronic fatigue. In addition, my MD in Las Vegas, NV, a world specialist in Fibro/chronic fatigue said that the majority of her patients had that vaccine who had chronic fatigue. (Yvonne, F, 41, S93, D01)

In the context of dismissal and disbelief from others, being able to make a clear statement of causality may be a way of reasserting the validity of personal experience.

## **Discussion**

The findings from this study argue for the complexity of fibromyalgia etiology. Fibromyalgia may arise through the experience of one or many physical and/or emotional traumatic events, which create stress and distress for individuals. People may vary in their susceptibility to stress and, therefore, to fibromyalgia. Many of these participant attributions for fibromyalgia onset have support in the literature; and, as reflected in both, causality emerges as complex and heterogeneous.

The perception of many of our participants that physical injuries, ill-health, infection, and surgery were key triggers for fibromyalgia onset is in keeping with surveys in the United States and Japan (Bennett et al., 2007; Nakamura et al., 2014), showing that similar physical causal

explanations exist across cohorts from different cultural and healthcare settings.

Spinal injuries featured strongly in our data. Busilka et al. (1997) reported a 20 percent prevalence of fibromyalgia diagnosis among neck-damaged patients. A significantly lower figure was reported elsewhere (Ferrari, 2015; Tishler et al., 2006), with fibromyalgia prevalence rates at 1 year only 1 percent among whiplash patients. However, all Tishler et al.'s participants were male and 1 percent prevalence actually (and implausibly) suggests a protective effect of whiplash in fibromyalgia, given it fell below the general population prevalence of the condition (Mader et al., 2015). Ferrari (2015) reported that 48 participants were still reporting pain at 1 year, and 2 newly met fibromyalgia criteria at this point, thus fibromyalgia may take longer than 1 year to develop. Mader et al. (2015) concluded that more research is required. Indeed, reviewing objective evidence for a link between physical trauma and fibromyalgia, Wolfe et al. (2014) argued that most research demonstrating a link lacks quality while research of higher quality reports modest or inconclusive associations.

This study was novel in implicating life change events, such as pregnancy, childbirth, and menopause, in fibromyalgia onset. Ostensen et al. (1997) found deterioration in pre-existing fibromyalgia symptoms during pregnancy; however, there is little scientific evidence for a role in fibromyalgia onset. Nonetheless, previous quantitative surveys made similar findings: 9.5 percent and 3 percent of Japanese fibromyalgia participants, respectively, identified "menopause" and "childbirth" as triggers (Nakamura et al., 2014) with 10 percent and 8 percent, respectively, identifying these causes in a US sample (Bennett et al., 2007). Haagen et al. (2015) described childbirth as potentially traumatic through a complex interplay of situational, interpersonal, and intrapersonal factors, with Grekin and O'Hara (2014) reporting post-traumatic stress disorder (PTSD) in 3 percent of new mothers. More work is merited to explore the link between these key life events and fibromyalgia, given their perceived implications in fibromyalgia onset in this and other self-report studies.

Our data clearly suggested mental ill-health as a precipitating factor in fibromyalgia. Anxiety and depressive symptoms are relatively high among fibromyalgia patients (Hadlandsmyth et al., 2017; Malt et al., 2002; Okifuji et al., 2000); however, the direction of any causal relationship is unclear (Adams and Turk, 2015). Hadlandsmyth et al. (2017) found a significant association between poor sleep and depression in fibromyalgia. Indeed, sleep quality has been shown as negatively associated with number of fibromyalgia symptoms, and evidence suggests causality may be bidirectional (Andrade et al., 2018; Choy, 2015).

Bereavement, childhood abuse, and adversity were commonly reported in our sample, in keeping with previous findings. In Anderberg et al. (2000), 40 percent reported bereavement as a precipitating factor and 48 percent of

fibromyalgia patients (compared with 24 percent of matched healthy controls) reported at least one negative event in childhood or adolescence. Waller et al. (2015) found evidence for unresolved attachment in half of their sample of 34 women with fibromyalgia, based on either loss or abuse in childhood. Comparable findings are described in the literature, in both clinical and community samples (e.g. Bennett et al., 2007; Häuser et al., 2015; Nakamura et al., 2014; Olivieri et al., 2012). While authors were typically unable to make direct causal inferences, these experiences may well contribute to a complex etiology.

PTSD prevalence among people with fibromyalgia has been estimated as 15–56 percent (Fietta et al., 2007). PTSD has been described as the mediator between a traumatic event and fibromyalgia development (Ciccone et al., 2005). Events linked to PTSD and fibromyalgia onset have included sexual and physical abuse (Häuser et al., 2011), sudden unexpected death of a loved one, or diagnosis of terminal illness (e.g. Cohen et al., 2002). However, it is not clear whether PTSD is a risk factor for fibromyalgia, or fibromyalgia increases the risk of PTSD. Trauma could cause both, or there may be a different causative factor for both, such as depression. Häuser et al. (2013) found that fibromyalgia symptoms occurred subsequent to the traumatic event and the development of PTSD in their sample. They argued that "PTSD can be viewed as a marker of stress vulnerability in which persons susceptible to stress are more likely to develop health problems including fibromyalgia when a potential traumatic event occurs." "Stress" has featured strongly in previous surveys of fibromyalgia patients in other countries (Bennett et al., 2007; Nakamura et al., 2014), and many participants in our UK-based survey also cited stress in the onset of their symptoms. Adams and Turk (2015) characterize fibromyalgia as one of the groups of "central sensitivity syndromes" in which biological, psychological, and social influences interact to sensitize the individual and create ill-health and symptoms, a perspective which has clear resonance with our findings.

Existing models of stress may be relevant. Based on an apparent clustering of certain life-changing events prior to the onset of various illnesses, Rahe and colleagues developed (Holmes and Rahe, 1967) and later revised (Miller and Rahe, 1997) a scale to measure and quantify the impact of life events and the likelihood of consequent ill-health. Based on their responses, participants in our study would score very highly on this scale. The transactional model, in contrast, characterizes the stress response as a function of both life events *and* individual responses to those events (Lazarus and Folkman, 1984). This model assumes that similar stressors can have different meanings and arouse different responses, based on individual differences (Lazarus, 2006). Given participant perceptions relating to individual vulnerability, this model also offers some theoretical support for our findings, with stress as the link

between event and fibromyalgia. As discussed below, individual vulnerability may be linked to genetic, personality, physiological factors, and gender.

One individual difference variable relevant to fibromyalgia is gender. Indeed 95 percent of respondents were women. Perhaps not surprisingly, no participant identified their gender as implicated in fibromyalgia; nonetheless fibromyalgia has a much higher prevalence in women (Crofford, 2007). A stress-gender link has been reported elsewhere (Becker et al., 2010), and Miller and Rahe (1997) found that women both assessed and reacted to life events at higher stress levels than men.

In contrast, some have argued that the prevalence of fibromyalgia in women is partly due to a greater tendency to ascribe symptoms to—and therefore diagnose—fibromyalgia in women. Haviland et al. (2010) explored links between gender and fibromyalgia diagnosis in a US sample of over 10,000 people, within which 4.8 percent of women and 1.3 percent of men were diagnosed. The nature of precipitating life stressors differed yet, despite similar symptoms, women were significantly more likely to be diagnosed. Interestingly, recent qualitative work with professionals also suggested some reluctance to diagnose men (Briones-Vozmediano et al., 2017). Nakamura et al. (2014) noted that the proportion of women reporting symptoms reaching diagnostic criteria had fallen between 2003 and 2014 (82.7%–60.5%), suggesting a shift in this apparent gender bias.

A personality trait, which seemed to be tentatively indicated in our data, was perfectionism, especially as expressed within the work environment. Perfectionism includes high self-expectations, concern to achieve those standards and self-criticism, and acts as a vulnerability factor for stress in “socio-evaluative contexts” such as the workplace (Zureck et al., 2014). Kivimäki et al. (2004) observed a link between work stress and fibromyalgia, and there have been suggestions that fibromyalgia patients may tend toward perfectionism and unrealistic expectations of themselves (Malin and Littlejohn, 2012). Some have suggested this tendency may be especially true for women (Ayats et al., 2006). Our work did not gather personality trait information, so it is not clear whether participants describing having pushed themselves reflected perfectionism or simply work pressures. However, a recent study by Grisart et al. (2018) found a positive link between self-oriented perfectionism and hyperactivity, mediated by neglect of bodily needs, in their sample of 45 women with fibromyalgia. Thus, fibromyalgia may be precipitated in vulnerable individuals by heavy demands, high self-imposed expectations, and self-neglect in meeting those demands and expectations. This interesting finding and interpretation lends support to various aspects of our findings, including individual trait differences and vulnerability to stress. Our understanding of these precipitating factors, their complex interrelationships, and links to fibromyalgia would benefit from further research.

Our participants described family patterns of fibromyalgia and similar conditions. The notion of fibromyalgia and similar conditions as genetic and heritable has been studied at length, including in twin studies (Markkula et al., 2009). Ablin et al. (2006) note that family patterns in fibromyalgia are well established and argue for both environmental and genetic bases for this association. The idea that some individuals may be particularly vulnerable to fibromyalgia has some support. According to a “trait” view of fibromyalgia (Katz et al., 2006), a diagnosis of fibromyalgia is permanent, but a person can experience differing degrees of fibromyalgia, depending on their circumstances.

This perspective has resonance with some participant accounts of increasing and decreasing symptoms, with life events playing a key role in determining this. Usui et al. (2013) measured the stress response in 80 female fibromyalgia patients to a devastating natural disaster in Japan in 2011. Compared with other groups, they found extremely high stress scores in the fibromyalgia group 1 month after the disaster, equivalent to the scores which would be expected in PTSD patients, although scores returned to baseline by 7 months, in keeping with other groups. Results suggested fibromyalgia patients were highly sensitive and responsive to negative events and also supported a close link with PTSD (Häuser et al., 2013). Similarly, Toussaint et al. (2015) found that the arousal symptoms of PTSD were particularly severe in people with fibromyalgia compared to healthy controls, suggesting that this represented “cognitive-emotional sensitization,” an excessive vigilance toward and attention to symptoms. Usui et al. (2013) noted that depression-related symptoms increased for more than 1 year post-disaster in fibromyalgia patients, despite excluding major depression at baseline which, authors contended, were suggestive of vulnerability to chronic stress in this group.

The role of individual differences and vulnerability to stress are relatively novel ideas in the literature. According to a recent detailed review, there is substantial heterogeneity in patients who fulfill the American College of Rheumatology (ACR) 1990 diagnostic criteria for fibromyalgia: patients vary in symptoms, biomedical markers, and response to different therapies (Borchers and Gershwin, 2015). Authors concluded that individual and environmental vulnerability influenced the development and form of the condition and argued for further investigation into subgroups of fibromyalgia, based on both biomedical and psychological bases.

The apparent evidence, from this study and others, for a role in fibromyalgia of physical and psychological trauma, and the impact of individual vulnerabilities, suggests that fibromyalgia rehabilitation could highlight stress management strategies, especially for potentially vulnerable clients. Interventions might include counseling about avoidance of stress-inducing environments and activities, training in relaxation techniques, work toward acceptance



coping and the development of resilience, and building helpful support networks. Rasmussen et al. (2017) demonstrate positive impacts on perceived acceptance coping and self-efficacy following a group-based multidisciplinary rehabilitation program, although participants wanted a longer program and more individual attention from the psychologist.

Our participants engaged with online support. Sharing online can have positive impacts on people's knowledge, choices, understanding, social support, and service access (Ziebland and Wyke, 2012), and support groups also offer the opportunity to help others, with powerful effects on quality of life, confidence, self-esteem, and depression (Schwartz and Sendor, 1999). Internet and multimedia interventions may be particularly helpful for people with limited ability to access face-to-face support and care. A recent trial of a therapeutic mobile Smartphone app for young people with fibromyalgia reported that trial users valued its simplicity and accessibility. Popular features were the app's support for relaxation and users' sense of autonomy in monitoring their own progress (de la Vega et al., 2016).

The final theme was based on the apparently important place within our participants' life stories of the onset and experience of fibromyalgia. Two-thirds of our participants could identify a clear cause. Adamson (1997) notes that diagnosis begins a gradual process of discovery about the condition and what it means for the individual. Meaning-making is an important part of a positive coping process (Park, 2013). People are driven to make sense of their lives, often through creating narratives of life events (Baumeister and Newman, 1994). This may involve drawing on a range of resources, including personal experience, medical advice, Internet research, and information from other people with the condition or support groups (Madden and Sim, 2006).

Creating narratives of their condition has been shown to be beneficial among chronic illness patients (Candib, 2004). Madden and Sim (2006) argue that explaining symptoms allows an individual with fibromyalgia "to impose order upon and regain control." Similarly, Cipolletta et al. (2013) found that ill-health could represent an opportunity to change, find new possibilities, roles, and meanings. The journey from "then" to "now" is an important part of the adjustment and rehabilitation process, through which patients could be supported in understanding the validity of their experiences, managing and accepting changes, and reorganizing their life around fibromyalgia.

The accounts in this study demonstrate participants' perception that understanding their own fibromyalgia is important, with many narratives showing both self-belief and, unfortunately, an awareness of others' skepticism. Given the individual variability within the current dataset, and the lack of clear research evidence for any one type of life event in fibromyalgia onset, it may be tempting to dismiss

these participants' accounts of causality as anecdotal, unreliable, and unscientific. According to a number of studies (e.g. Ashe et al., 2017; Dow et al., 2012; Kool et al., 2009), the experience of people with fibromyalgia symptoms in their encounters with the medical community is, indeed, one of invalidation and frustration. This is mirrored by the experience of professionals, who often feel anxious or frustrated by fibromyalgia encounters and perceive that their professionalism and explanations are being undermined (Werner and Malterud, 2005).

Given that fibromyalgia is poorly understood, patients' experiences and causal attributions could be a useful tool in helping to develop a clearer picture of and effectively intervene in this complex condition. Werner and Malterud (2005) suggest that medical professionals should resist dismissing individual explanations as invalid and, instead, admit the shortcomings of current medical knowledge. The notion of the "expert patient" relating to chronic illness highlights patients' expertise in managing and coping with their condition, educating and supporting others, and improving services; indeed patients often know more about their condition than medical staff (Donaldson, 2009; Greenhalgh, 2009).

Patients' perspectives offer personal expertise in fibromyalgia that the professions involved in their diagnosis, treatment and rehabilitation might profit from, were they to also treat their narratives as "expert" accounts. Cipolletta et al. (2013) note the importance to illness adjustment of the collaborative healthcare relationship, within which the patient takes an active role. Validating patient narratives and accounts could also reduce frustration and improve the doctor-patient relationship (Ashe et al., 2017), enhancing doctors' ability to support patients, and build self-efficacy, empowerment, and positive identity (Donaldson, 2009; Kool et al., 2009).

Patient beliefs about their condition, including its cause, are considered important determinants of their coping strategies, emotional responses, and the recovery process (Leventhal et al., 2008). Cipolletta et al. (2013) discuss the importance of overcoming the mind-body separation associated with a biomedical approach, and how people's needs extend beyond medical and surgical interventions. Lawson (2008) notes that the management of fibromyalgia has moved from a traditional biomedical model to a rehabilitation approach, which focuses on health and quality of life, and in which interventions are tailored to individual needs. Mannerkorpi (2005) argues for a care and rehabilitation plan based on a sound knowledge of the biopsychosocial aspects involved the development of fibromyalgia, which is individualized, based on the person's concerns and values, and focuses on enhancing health, function, and confidence.

These approaches involve talking with patients about their experiences, perceptions, and concerns in order to build trust and confidence and develop a shared plan for

functioning and living well with the condition. Evidence has shown that the better the relationship between practitioners and patients, the greater the adherence to treatment plans, both pharmacological and non-pharmacological (e.g. walking) rehabilitation (Dobkin et al., 2006; Sanz-Baños et al., 2017; Sewitch et al., 2004). Sallinen and Mengshoel (2017) note that expectations upon the practitioner to focus on the individual and explore the meanings they attribute to fibromyalgia, its cause and consequences, may be difficult to meet, if time or skills are insufficient. However, building these skills—or ensuring they are addressed in training—can facilitate the development of a shared understanding with a client, goals that are realistic and relevant to them, to which they are more likely to commit.

Limitations of the study include our inability to validate participants' self-reported fibromyalgia diagnoses, thus it cannot be guaranteed that all would meet medical diagnostic criteria. The study was advertised via UK-based fibromyalgia support networks; however as a web-based survey, which collected no “nationality” data, it is possible that participants outside the United Kingdom accessed the survey or were referred by others. All of the current participants were online support group members. Encounters with peers have most likely offered support and validation of participant fibromyalgia stories (Van Uden-Kraan et al., 2008) and assisted in the development of narratives which afford fibromyalgia a logical place in personal life stories.

The cohort was overwhelmingly White and female and results from a more varied sample may have differed (e.g. our few male participants identified primarily physical—rather than psychosocial—events as causative). Qualitative data were collected from a large sample; however, the survey responses were based on a single question, varied considerably in length, and were not equivalent to in-depth interview data. There were no opportunities to ask for additional detail or clarification. Richer, thicker data might have been obtained via interviews, but this would have severely limited sample size.

To the authors' knowledge, this was the first large-scale UK-based survey of people with fibromyalgia to collect detailed qualitative data about their perceptions of etiology and onset. The findings highlight the complexity of fibromyalgia causality, adding detail and depth to existing knowledge, and support varied explanations evident in the literature, especially the notions of stress and vulnerability. The findings argue for the importance of a coherent narrative among fibromyalgia patients in understanding their condition and its precedents. As such, they have relevance for the field of etiology research, and for all practitioners involved in their care, in considering how best to legitimize, support, treat, rehabilitate, and learn from their patients, in a context within which our understanding of fibromyalgia remains under-developed. Practice implications include the importance of acknowledging, validating, and valuing patient understandings of their own symptoms,

and supporting positive, holistic approaches to living with fibromyalgia. This may involve focused education during professional training or development programs for qualified practitioners. Future directions for research could include investigation of the role in fibromyalgia development of personality traits such as perfectionism. Other issues worthy of further exploration are the impact of different forms of physical and emotional trauma, the role of individual stress vulnerability, as well as possible links between the disease and complications during pregnancy and childbirth. The perspectives of men and Black and minority ethnic populations with fibromyalgia should be actively sought and represented. In addition, small-scale qualitative studies and case studies could be employed to explore individual experiences and narratives in greater detail and depth.

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