



Living, Coping, and Restructuring with Fibromyalgia: A Narrative Analysis

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ABSTRACT

Fibromyalgia is a functional somatic syndrome that is characterised by widespread pain and sensitivity throughout various sites on the body (Fayaz et al., 2016). The aim of the present study was to explore how individuals with Fibromyalgia integrate the illness into their personal biographies, develop coping strategies, and restructure their biographies. A narrative analysis was conducted on data collected from semi-structured interviews, with four key themes emerging from the data: 1) Confusion and attempts to defy pain 2) Biographical disruption in the search for a diagnosis 3) Diagnosis leads to becoming an ‘illness expert’ 4) Accepting the illness does not mean giving in. The narrative explores how the biographical disruption caused by Fibromyalgia forces six female Fibromyalgia patients to reconsider their identity in light of new limitations, adapt, and develop new areas of the self. Participants who were able to successfully adapt were able to discover life enrichment despite the presence of Fibromyalgia. Acceptance, illness understanding, and identity reconstruction were key factors in enabling participants to cope with Fibromyalgia. Thus, this study expands current knowledge on how patients with Fibromyalgia reconstruct their biographies.

KEY WORDS:	FIBROMYALGIA	NARRATIVE ANALYSIS	BIOGRAPHICAL DISRUPTION	IDENTITY RECONSTRUCTI ON	COPING
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Introduction

Fibromyalgia is a debilitating, chronic syndrome that is believed to affect 5.4% of the population in the UK, and over 200 million people worldwide, with prevalence among women 5-9 times higher than that of men (Fayaz et al., 2016). Fibromyalgia is characterised by widespread pain, and heightened sensitivity throughout the body, with the origin of these symptoms still unknown. Fibromyalgia also presents further symptoms, such as chronic fatigue, sleep disturbance, irritable bowel syndrome, and memory lapses (Walker, 2016). The elusive aetiology of Fibromyalgia presents difficulties for clinicians aiming to effectively diagnose and develop treatment strategies for patients (Jay & Barkin, 2015). Whereas some symptoms such as 'Fibrofog'; a term used by individuals when describing memory lapses and a loss of mental clarity, implies a neurological basis for the condition, the pain and tenderness experienced by individuals implies a biological aetiology, making effective treatment difficult (Johnson & Sheth, 2016). Inevitably, researchers and clinician's inability to identify the origin of these symptoms leads to psychological challenges for patients, as the legitimacy of the illness continues to be debated (Asbring & Narvanen, 2002).

Although the literature surrounding the subject continues to grow, there remains a lack of research exploring the subjective experiences of individuals with Fibromyalgia, the psychological challenges faced, and the mounting impact of the illness over time (McMahon et al., 2012). Due to the lack of knowledge regarding the illness, frustration and a feeling of helplessness appear to be common issues for individuals with Fibromyalgia (Cedraschi et al., 2015). In a recent study conducted by Ferrari (2012), 67.3% of Fibromyalgia patients stated that they understood very little about the about the cause of their pain. Consequently, the fact that Fibromyalgia is associated with a higher level of perceived injustice, anxiety and depression when compared to other chronic illnesses, such as rheumatoid arthritis may come as no surprise (Ferrari & Russell, 2014).

This failure to adequately inform individuals of their condition leads to further issues that can make effective treatment even more challenging. Research conducted by Russek et al., (2015) discovered that Kinesiophobia (fear of movement) was prevalent in 72.9% of respondents. Issues such as this have led to psychological interventions such as Cognitive Behavioural Therapy (CBT) being included in treatment programmes more regularly, as the psychological challenges of living with chronic illness are becoming increasingly acknowledged (Jancin, 2010). CBT aims to draw attention to unhelpful thought processes and assist individuals to modify their psychological beliefs surrounding the subject, increasing perceived control (Giles, 2014). However, psychological interventions such as this have proved effective in increasing quality of life for some, but ineffective for others (Bernardy et al., 2010).

A reason for the limited impact of interventions such as CBT is that Fibromyalgia does not present in the same way for every individual, meaning it is often necessary to combine a number of different interventions that aim to address a range of patient goals simultaneously (Rooks, 2007). Whilst this may contribute to some form of improved life satisfaction for patients, this form of treatment can fail to identify active components for change, and can neglect the patient specific characteristics that would make treatment

more person centred and therefore, more effective (Marcus et al., 2014). This suggests that clinicians and patients must work together to develop person centred management, through the trial and error of different strategies before the most effective combination of interventions is discovered (Rossey et al., 1999). Despite this, patient-clinician relationships have had a negative impact on individuals in many cases according to Patel et al., (2016), with many patients feeling overlooked, as some clinicians admit to feeling as though they are being manipulated by patients who exaggerate symptoms and waste resources (Annemans et al., 2008).

Therefore, an understanding of the concerns of those with Fibromyalgia must be developed before effective treatment strategies can be constructed (Wick, 2011). Research should aim to elicit rich accounts of the impact that living with Fibromyalgia has on patients' lives, before these accounts are then used to inform clinicians of the severity and life changing consequences of living with the condition (Sarzi-Puttini et al., 2008). An improved understanding can be used to develop person-centred interventions which have each individual's specific needs and goals in mind, consequently enhancing treatment and management of Fibromyalgia (Wick, 2011). Grape et al., (2017) argues that to successfully gather such information, qualitative research must be the method of choice for exploring the lived experiences of Fibromyalgia patients. Qualitative research understands that each case of Fibromyalgia is unique to the individual, allowing us to better understand personal contexts of health, disease and illness (Grape et al., 2015).

A meta-synthesis of existing qualitative studies was conducted by Sim & Madden, (2008) exploring subjective illness experiences of Fibromyalgia patients across 23 separate studies. Sim and Madden's study highlighted that individuals with Fibromyalgia were keen to frame their experiences of symptoms within the biomedical model, in which Fibromyalgia is viewed as an organic entity that can be explained and identified through biomedical tests. However, medicines inability to successfully identify an aetiology for Fibromyalgia re-emphasises that Fibromyalgia remains an ambiguous and invisible illness for many clinicians, resulting in questions over its legitimacy and credibility (Sabik, 2010). Sim and Maddens findings suggested that the continued dispute over the legitimacy of patients' illness leads to a picture that appears bleak for Fibromyalgia sufferers. Ongoing pain, frustration when searching for a definitive diagnosis, and belief that lifestyle restrictions are necessary before their illness is legitimised by others, were all key themes uncovered from the data. These issues appeared to present challenges to individuals' identity, as well having a damaging impact on their relationships. Furthermore, individuals commonly expressed their frustration when aiming to communicate their symptoms to health-care professionals due to clinician's lack of understanding of their condition, instead citing peer support as a key coping mechanism.

More recent literature exploring Fibromyalgia has attempted to build upon the meta-synthesis conducted by Sim and Madden by utilising a narrative approach. A narrative perspective offers a unique account of patients' experiences of living with Fibromyalgia, as it ensures the preservation of the context and temporal dimension of lived experience (Sallinen et al., 2012). Consequently, this makes it a suitable and valuable method of exploring this unpredictable illness, which leads to constant self-questioning regarding how and why they became ill, the limitations of their 'new' body, and their ever-changing

biographies (Homma et al., 2016). Furthermore, by considering illness narratives of those with Fibromyalgia, it is possible to understand life changes whilst living with Fibromyalgia, and articulate this information in a way that can be shared (Gonzalez et al., 2015). A study conducted by Undeland & Malterud, (2007) used this method to build upon common findings in qualitative literature, which suggest that receiving a definitive diagnosis of Fibromyalgia represents a significant step towards the coping process.

However, Undeland & Malterud, discovered that whilst receiving a diagnosis of Fibromyalgia represents a step towards legitimising their illness and feeling accepted by others, this feeling descended back into frustration as others failed to understand the severity of the illness due to patients perceived 'healthy look'. Undeland & Malterud concluded that receiving a diagnosis was 'hardly helpful' for patients, who reported feeling lonely and helpless as they aimed to process a life with Fibromyalgia. The apparent disregard of the severity of Fibromyalgia from outsiders appears to lead to increased importance of peer support in the recovery process. Participants in a study conducted by Sallinen et al., (2011) highlighted the importance of being able to discuss issues with fellow Fibromyalgia sufferers who understood, accepted, and supported them through their illness journey. Sallinen discovered that peer support acted as an impetus to an ongoing process of reconstruction of identity, accepting their illness, consequently allowing them to cope.

While many narrative studies such as Sallinen et al., and Undeland & Malterud, have explored a single aspect of living with Fibromyalgia, only one previous study (McMahon et al., 2012) has utilised a narrative approach to explore how individuals' experiences of Fibromyalgia evolve over time. McMahon et al., consider patients' experiences prior to diagnosis, through to their present situation, providing a deep understanding of how individuals place their experiences into their personal biographies, and how this shapes their identity. The themes highlighted in McMahon et al., (2012) study illuminate the lack of movement, understanding and resolution of Fibromyalgia patients, suggesting that living with Fibromyalgia represents an ongoing struggle due to the debilitating effects of the illness, and current lack of successful intervention methods. Individuals frequently referred to times of better health, whilst stating that they felt as though they were perceived to be constantly complaining due to frequent visits to their GP before a diagnosis was reached. Following their diagnosis, a feeling of frustration arises, as they must now learn to 'listen to their body' and accept the limitations of this new 'painful body', suggesting that individuals must become 'illness experts' in order to cope. Consequently, participants highlighted the biographical disruption upon being diagnosed with Fibromyalgia, with participants stating that they thought of themselves as 'active and self-sufficient' prior to diagnosis, but now felt like 'old women', believing that they have now lost their independence.

This theme of biographical disruption is common among chronic illness literature, and although commonly identified in narratives of Fibromyalgia, research surrounding Fibromyalgia has not adequately explored the consequences of the illness on individual's identity (Homma et al., 2015). Biographical disruption is common in many chronic illnesses (Zinn, 2005). Individuals must re-consider their identity as activities which were once simple, now become more difficult, or in some cases impossible (Wilson, 2007).

This leads to the structures in daily life becoming disjointed, resulting in disruption between the individual's past, present and anticipated future (Townsend et al., 2006). According to Madden & Sim, (2016), the importance of biographical disruption in chronic illness cannot be overlooked. This disruption requires individuals to discover which aspects of their identity have been lost, which aspects remain, and if there are any new aspects that have been added. Consequently, this results in an identity that has been redefined, leading to the creation of a partially new identity that the individual must take forward into the next stages of their personal biographies (Asbring, 2001).

In many cases, this disruption of one's identity is viewed as a traumatic event in which the individual's life is thrown into turmoil, closely followed by a feeling of helplessness (Bury, 1982). However, research into Fibromyalgia has suggested that re-evaluating one's identity, accepting the limitations of the 'new' painful body, and 'listening' to this new 'painful' body can be key contributors in enabling individuals to begin to cope with the illness and move forward (McMahon et al., 2012). Literature surrounding chronic illness has explored the concept of biographical repair, in which the disruptive event of becoming chronically ill has led to identity restructuring, new meaning in life and the restoration of normality in the lives of individuals (Locock et al., 2009). However, a thorough literature search has highlighted a lack of studies exploring how Fibromyalgia sufferers develop coping strategies over time, and use this knowledge to reconstruct their biographies, thus suggesting a gap in the literature.

Therefore, the current research project aims to explore how biographical disruption following a diagnosis of Fibromyalgia can encourage the development of coping strategies following the acceptance of limitations and the construction of a 'new' identity. A narrative analysis will be conducted to explore patients' experiences of living with Fibromyalgia, how they integrate the illness into their biographies, and how patients with Fibromyalgia reconstruct their identities over time.

Research Questions

- 1) How do people with Fibromyalgia learn to cope with their condition?
- 2) How do Fibromyalgia patients re-construct their biographies following the biographical disruption caused by Fibromyalgia?

Methodology

Design

The present study utilised a qualitative design, based upon semi-structured interviews, which were analysed using narrative analysis. A qualitative methodology was selected as it aims to understand individuals' behaviours, beliefs and interactions by eliciting a rich account of their experiences (Sim & Madden, 2008). Qualitative research possesses the ability to add a new dimension to studies of chronic illness, which cannot be obtained through the measurement of variables alone (Duggleby et al., 2012), thus making it a

suitable methodology for the present study. The use of qualitative methods provided the opportunity to collect narrative accounts, using semi-structured interviews that were designed to encourage participants to discuss their personal life stories, exploring when and how Fibromyalgia had entered their lives (Frost, 2009).

The narratives collected from the interview process were analysed in a way that was sensitive to the narratives, aiming to discover more about how individuals with the condition have learnt to negotiate the fluctuating symptoms of Fibromyalgia and integrate these experiences into an ongoing story of their lives.

Participants

A purposive sample of six women was collected. All participants were recruited via Fibromyalgia discussion forums within the UK. Although males were not purposely excluded, given the high prevalence of Fibromyalgia in females when compared to males, it is unsurprising that an all-female sample was obtained. As the researcher was a third year psychology student at Manchester Metropolitan University with a limited number of hours to complete the study, the scope of the project was limited to a smaller sample size. Despite these restrictions, this sample size affords the opportunity to explore each person as a whole, allowing for an in-depth analysis of each illness story, considering the unique challenges faced by each individual (Crossley, 2000). The participants included in the study were:

Abigail (Appendix 1) - 21-year-old female, who was diagnosed with Fibromyalgia in 2016. She works part time and is currently living with her parents.

Shirley (Appendix 2) - 52 year old female, retired due to her condition. Shirley has 2 children and lives with her husband. She was diagnosed with Fibromyalgia in 2016.

Janice (Appendix 3) - 52-year-old female, who is currently co-habiting with her partner. She now works on a voluntary basis within the NHS. Janice was diagnosed with Fibromyalgia 9 years ago.

Valerie (Appendix 4) - 39-year-old female, who was diagnosed with Fibromyalgia in 2014. She currently lives with her partner, and is in part time employment.

Mandy (Appendix 5) - 49-year-old married female, who is currently unemployed due to her condition. Mandy was diagnosed with Fibromyalgia 5 years ago, and lives with her husband.

Ellie (Appendix 6) - 21-year-old female, who was diagnosed with the illness in 2015. She works part time and lives with her parents.

Data Collection

Before the process of data collection could begin, suitable participants were sent an invitation letter by email (Appendix 7). If the selected individual declared an interest in participating, an information sheet (Appendix 8) was provided, outlining the aims of the study, why they have been approached, and participant requirements. Following this,

individuals who stated their interest in participating were given a consent form (Appendix 9) to confirm whether they understood the aim of the project and their role within the project. If participants provided their consent for data collection to proceed, the interview process began. Upon completion, participants were given a debrief sheet (Appendix 10). This explained that any information they provided would be kept anonymous, whilst also providing information if they wished to seek support following participation, or withdraw.

To collect appropriate data, semi-structured interviews were conducted using a recording device to store this information. Semi-structured interviews allow for an element of structure to the interview schedule, ensuring that the research question is answered, whilst also providing the opportunity for serendipity to arise within the data (Larun, & Malterud, 2007). The semi-structured interviews were constructed in a way that was suitable for encouraging the narratives of participants, by exploring individual's past and present experiences of Fibromyalgia, but also their imagined future. According to Frost et al., (2011) encouraging individuals to discuss narratives can empower them and enable them to reconstruct the past and infer new meaning to their experiences.

Crossley, (2007) states that it is key to ensure that the focus of the interview remains on eliciting narratives, whilst also providing the participant with enough time to make their own connections, imposing order that makes sense for them. The present research collected data with the current principles in mind, using an interview schedule (Appendix 11) which was informed by themes uncovered in previous literature surrounding experiences of Fibromyalgia, whilst considering methods of narrative interviewing proposed by Atkinson (1998) which focus on eliciting significant stories in participants' personal biographies. This method of narrative enquiry provides the opportunity to explore the current research questions as comprehensively as possible.

Data Analysis

Upon completion of the interview process, all information gathered was analysed using narrative analysis. Narrative analysis recognises that individuals use stories as a way of understanding their lives, but also as a way of presenting themselves and their experiences to others (Frost, 2009). Therefore, by listening to the way people narrate their experiences of Fibromyalgia, it allows us to learn the processes involved in the individual reconstructing meaning and re-orientating themselves following their diagnosis and subsequent experiences (Frost et al., 2011). Consequently, this makes it an ideal method of analysis for the present study. There are no fixed guidelines on how to conduct a narrative analysis. While many approaches have been utilised in previous research, the present study adopts a pluralistic approach to exploring narratives as outlined by Murray (2000), in which the researcher will be open to various perspectives, with the aim of gaining the deepest understanding possible of the accounts provided. Murray proposes epistemological pluralism as a way developing an interpretation of narratives that is not possible using a single model alone.

The present study used the principles outlined by Murray, connecting different levels of narrative analysis, considering the personal, interpersonal, positional, and ideological levels, thus providing a unique understanding of the narratives articulated by participants. According to Murray (2000), narrative analysis at the personal level considers participants

process of understanding their 'new' body, and reorganising their identity through their experiences. Considering the interpersonal level of narrative is important, as previous research (Soderberg et al., 2002; Cunningham & Jillings, 2006) has highlighted individuals' awareness of the image they portray to others, as challenges to the legitimacy of the illness are faced regularly. Therefore, the researcher acknowledged the importance of the interview context in shaping the illness narratives portrayed by participants, understanding that the story told by participants is jointly constructed by interviewer and interviewee (Frost, 2009). The positional level considers the way in which differences in social position between researcher and participant can influence the way in which the participant conveys their life story (Arduser, 2014), whereas the ideological level of analysis explores the broader socio-cultural assumptions that may shape the participant's thoughts of themselves (McMahon et al., 2012).

To complete the narrative analysis, interview transcripts were read over to develop a familiarity and understanding of the content, before the subsequent identification of key themes. Following this, the information gathered was developed into a coherent story of participants' lived experiences of the illness, whilst considering the different levels of narrative analysis discussed previously. Subsequent re-examination of the transcripts aimed to highlight narrative elements such as metaphors, imagery, and narrative tone. Furthermore, in line with qualitative quality criteria as outlined by Yardley, (2000) the current study is mindful of possible researcher subjective biases, which may have impacted on both the interview process and data analysis. These considerations have been articulated transparently in the reflexivity section of this article. Additionally, the researcher has acknowledged the personal meaning of the accounts articulated by the six female participants by sensitively selecting key themes from the data and illustrating these themes with extensive extracts from the interviews, a key aspect of quality qualitative research according to Meyrick, (2006).

Ethical Considerations (Appendix 12)

All participants involved in this study were over the age of 18, reducing participant vulnerability and risk of emotional distress. Participants were briefed regarding the aims of the research with an invitation letter and subsequent participant information sheet before they decided to provide their informed consent. No deception took place in this study, and all information provided by participants remained anonymous, as they were given a pseudonym within the journal report. To reduce the risk of potential harm for both researcher and participant, all interviews were conducted in a public place, providing security for both parties. Because participants were diagnosed with Fibromyalgia and present symptoms such as chronic pain and fatigue, participants were informed that they could take breaks at any stage during interviewing. All information collected was stored on a recording device, which was accessible to only the researcher. Upon completion of the study, all information was deleted, and will not be used for any purpose other than the present study.

Analysis and Discussion

Results from the narratives are displayed in the form of a meta-narrative, which integrates data from all six-interview transcripts. Rich excerpts are used to highlight key themes that emerged from the accounts elicited by participants involved in the present study. These themes will be used to illustrate how the participant's stories of living with Fibromyalgia unfolded, and how they incorporate the illness into their personal biographies over time.

Confusion and Attempts to Defy the Unexplained Pain

The narrative begins with participants displaying their confusion as Fibromyalgia begins to 'take over' their body. Participants regularly revisited their lives prior to becoming ill, explaining this process by comparing their formerly 'healthy' body with their developing 'painful' body.

Abigail (Lines 4-8): "Before I started getting symptoms I was very active... I played football at weekends and during the week as well as dance as a younger child. There wasn't much time I wasn't out and about and was very healthy... then all of a sudden it all changed... I didn't know what was happening to me".

The theme of initial shock is common among narrative literature exploring chronic illness (McMahon et al., 2012). This initial shock is unsurprising as literature such as that conducted by Ferrari (2012) suggests that the majority of Fibromyalgia sufferers are unable explain what has caused the sudden onset of pain and fatigue.

Despite the debilitating onset of Fibromyalgia symptoms, the participants described how they attempted to defy the condition by continuing to work or study until they became too physically or mentally fatigued to continue their daily roles in work, or in education. Participants attempted to explain their symptoms as 'minor' or 'nothing to be concerned about' before eventually succumbing to the illness. Fibromyalgia had 'taken over their bodies' and forced them to seek an explanation for their symptoms.

Shirley (Lines 21-25): "...Through this period I was always very fatigued to the point where I felt like I could go to sleep standing... I became very breathless and found myself constantly profoundly sweating. Erm...I brushed this aside thinking these were menopausal symptoms, until July 2015 when I was no longer fit for work and went off sick".

This seeming disregard for Fibromyalgia symptoms was similarly observed in a study conducted by Sallinen et al., (2010), who discovered that individuals with Fibromyalgia regularly continued despite their symptoms until they 'fell over the edge of exhaustion'. This desire to remain 'strong and silent' and work to maintain continuity in their lives by making efforts to portray a picture of the self as healthy, could be explained by dominant cultural expectations in which the ability to cope with a hectic lifestyle is viewed as a valuable attribute in Western culture (Williams, 2000). The apparent dissatisfaction with

stopping to acknowledge their symptoms suggests that they view this as weakness, and unacceptable at this stage of their biography.

Biographical Disruption in the Search for a Diagnosis

Whilst the narrative began with participants highlighting the strength they displayed prior to their diagnosis of Fibromyalgia, the tone of the narrative quickly switches to one of vulnerability, and a questioning of their morality takes its place. The process of searching for a diagnosis appeared to have a damaging impact on the participants' self-esteem, and sense of self. This is clearly displayed by Janice, as she highlights how her positive outlook on life was challenged by constant stigmatising, and questioning by clinicians.

Janice (Lines 83-86): "Absolutely... I was lost, alone and felt that I was worthless. I had always, been such a positive individual, a person who always looked on the bright side of life. Blimey Aaron... I felt like no one cared. I hated myself for not getting well. The more I asked the more I got no answers or conflicting answers".

Difficulties between Fibromyalgia patients and clinicians appear to be common among the literature, with Patel et al., (2016) finding similar frustrations in Fibromyalgia patients. Furthermore, the impact that stigmatising, and clinicians doubting the legitimacy of symptoms can have on Fibromyalgia sufferers is highlighted by Asbring & Narvanen, (2002). Asbring & Narvaven, concluded that questioning from clinicians and accusations of lying can have a greater impact on individuals than the illness itself. This research appears to be supported by the participants in the present study. Questions over the legitimacy of their illness led to participants even questioning their sanity.

Valerie (Lines 93-96): "I was also relieved that I finally knew what was wrong with me and that it had a name because I felt I was going mad... I really wasn't sure if I had just lost the plot and that I was making it all up".

Sim and Madden (2008) findings, that suggested Fibromyalgia sufferers are keen to frame their experiences within a biomedical model are supported by the narrative accounts within the present study. Participants highlighted their anguish as they explored their experiences of aiming to receive a diagnosis. Participants begin to question their identity during this period, as they reveal inner turmoil at being unable to add legitimacy to their 'invisible symptoms'. Research conducted by Fonseca et al., (2016) states that individuals with higher levels of illness uncertainty have more difficulty coping with their condition. The uncertainty surrounding the changes to participants' bodies clearly prevents them from being able to immerse their illness into their personal biographies.

Participants are in a process of defending their identity during this stage, aiming to find a diagnostic label to add legitimacy to their new 'slowed down' lifestyle, which they believe is unacceptable due to cultural and societal beliefs. The apparent distress evident in this section of the narrative could be explained by considering the findings from Sim & Madden (2008) article, in which Fibromyalgia patients highlighted a need to restrict their lifestyle

before they were listened to and believed by clinicians and society. However, due to cultural expectations, restricting their lifestyle presented a number of challenges to the participants, which could explain why they would rather gain legitimacy through receiving a diagnosis, rather than succumbing to their illness, restricting lifestyle, and being portrayed as 'weak'. An identity crisis is being portrayed by the participants, as they battle between the desire for acceptance from others, and maintaining their identity and sense of self. Biographical disruption, as outlined by Bury (1982), in which the onset of chronic illness is seen as a disruptive event in the biographies of chronic illness patients, is evident in the participants as they look to understand and find meaning in their evolving situation.

Diagnosis Leads to Becoming an 'Illness Expert'

Interestingly, the next theme represented a shift in narrative tone, as the tone of vulnerability and confusion was briefly replaced by relief, as participants discussed the period where they received a diagnosis. However, in line with a study conducted by Undeland & Malterud, (2007), simply having a name for the symptoms was not enough to provide a socially acceptable explanation. Participants were left feeling that their experiences of Fibromyalgia were being trivialised. Interestingly, in the present study participants used the frustration caused by this to conduct their own research, and become 'illness experts' on their condition. The process of becoming an illness expert was highlighted in McMahon et al., (2012) study, and was identified to be a key factor in enabling patients to develop coping strategies.

Mandy (Lines 149-153): "I found that I needed to help myself, because there was no one out there that could help me, or understand me the way I wanted to be helped and understood. By the 3rd year of my illness I had realised that I had to have an inquiring mind, so that I could get answers to the many hundreds of questions I had".

Whilst the limited understanding provided by clinicians even after diagnosis was a setback for participants, this only appeared to motivate them to take charge of their illness and learn more about the changes they were experiencing. Taking charge of their illness appeared to build strength in participants, allowing them to understand and accept the limitations of their bodies. Furthermore, participants' newfound strength was only supported when their inquisitiveness about the illness led them to find support groups in which they could discuss their issues with other Fibromyalgia sufferers.

Ellie (Lines 109-113): "So what I find helpful about that is there's people on these forums that have had the condition for ages... they totally understand what I'm saying and it's just good to be able to speak to people who actually believe what you're saying, because they've felt it too... you know?...It made me feel sane again."

This supports the work of Sallinen et al., (2011) who concluded that peer support was a key coping mechanism for individuals with Fibromyalgia. The support and understanding provided by discussing issues with peers proved key in enabling participants to accept

their illness and to integrate the illness into their lives. The development of coping strategies appears to begin once participants can accept their illness, and receive support regarding the legitimacy of the symptoms. The tone of the narrative begins to shift from pessimism to growing strength and defiance, as participants now had support in place that could enable them to 'fight' the illness with the support of their Fibromyalgia 'community'.

Accepting the Illness Does Not Mean Giving in

Interestingly, whilst accepting the illness enabled participants to cope, some of the participants highlighted that they were able to surpass this, and were keen to voice how they were now thriving despite Fibromyalgia. The participants who were able to 'embrace the biographical disruption', and use the disruption of chronic illness to re-evaluate their identity appeared to be coping better with the illness. Mandy and Janice, accepted that their illness now meant that they were unable to complete tasks that were once simple, but used this as an incentive to develop other areas of interest, or to develop areas of themselves that were neglected before the onset of their illness. The excerpts from Janice and Mandy display a clear move towards positivity, and a desire to inspire others with their condition.

Mandy (Lines 164-166): "We survive and stay strong and positive. I look at things so differently and certainly don't worry about things... not worth it".

Janice (Lines 229-234): "Adapt yourself, grow in new areas of mind, education and care about people... find people who care enough to listen and understand your strengths and educate them on what you are able to do in your daily life. Don't be pushed around by anyone or anything... Illness brings out new areas of interest that you did not even believe possible".

It must be noted, that Janice and Mandy were the most experienced Fibromyalgia sufferers, having been diagnosed 5 years, and 9 years ago respectively. Clearly, having more time to process their illness and reconstruct their identities was a key factor in enabling them to cope with their new lives following the illness. Studies of chronic illness have suggested that biographical continuity can be a successful way of coping with certain illnesses, by simply integrating the illness into their existing biography, and not allowing the illness to change their chosen lifestyle (Simpson et al., 2015). However, Fibromyalgia appears to desire an acceptance of the disruption the illness will bring before effective coping strategies can be developed. This is apparent in less experienced Fibromyalgia patients such as Ellie, who appeared to be still in the phase of reconstructing her identity following their diagnosis, thus having more difficulty in moving forward since their diagnosis.

Ellie (Lines 123-127): "My plans have changed dramatically.... I can no longer join the RAF and achieve my dream of helping injured soldiers... I was

forced to give up the physical activities in my life such as keep fit classes. I can also only choose jobs which I feel able to do which in some cases has mean missing out on opportunities and promotions”.

Whilst Ellie has accepted her illness and incorporated the illness into her life, unlike Mandy and Janice, she has not yet completed the process of identity reconstruction. Ellie has reached a point where she can cope with the illness, but has not yet uncovered new areas of interest following the illness, suggesting that Fibromyalgia patients simply need time, space and support in order to enable them to reconstruct their identities, uncover new areas of interest and move forward with their lives. Interestingly, long-term sufferers such as Janice were keen to stress that they are eager to use their experiences to help others who have been diagnosed with the illness.

Janice (Lines 478-482): “But I am there for others who need help. That's what is now important to me now. I remember what it was like, being left in the cold by so many professional people, who I thought would save me. It is true Aaron that "You don't get it, until you get it”.

The vital impact that hearing Fibromyalgia stories from peers can have on newly was highlighted in recent research conducted by Homma et al., (2016). Homma et al., found that hearing stories from peers can repair patients disrupted biographies. Consequently, this suggests that experienced Fibromyalgia sufferers such as Janice can prove vital in inspiring, supporting, and motivating newly diagnosed individuals to understand that accepting the condition does not mean you are giving in, but enabling yourself to move forward in life, by accepting limitations, and discovering new areas that fit the reconstructed self. Moreover, it seems that they are more than willing to help if given the opportunity.

To conclude, the present research has highlighted that new areas of interest can be uncovered if participants are successfully able to negotiate a period of biographical disruption and reconstruct their identities. Furthermore, the participants who were able to do this most successfully were also the most experienced Fibromyalgia sufferers. Research conducted by (Sallinen et al., 2011; Homma et al., 2016) displaying the importance of peer support in coping with the illness, illuminate the role that these ‘illness experts’ could have in supporting and navigating newly diagnosed Fibromyalgia patients along their illness journey. Moreover, it seemed that experienced Fibromyalgia patients were keen to use their experiences to help others.

Interestingly, the present research again highlighted the turbulent relationship between Fibromyalgia patients and clinicians, thus suggesting that experienced Fibromyalgia patients could prove vital in bridging the gap. Clinical settings could attempt to utilise the subjective knowledge and understanding developed by ‘illness experts’, to not only develop their own understanding of the illness, but to make the process of diagnosis and ongoing disruption following diagnosis a less daunting experience. Moreover, further research should be developed which highlights the progression that can be made despite Fibromyalgia. Participants in the present study display the possibility of overcoming

adversity and using these experiences in order to develop and create a stronger version of themselves. Studies such as this can be used to inspire newly diagnosed Fibromyalgia patients to believe that despite the seemingly negative circumstances, positives can emerge in their ever-changing biographies.

Limitations of the Study and Areas for Future Research

Despite this, limitations of the previous study must be considered. All of the participants in the study were females, suggesting that dominant discourses surrounding gender which have been shown to influence participants' stories in studies of chronic illness were neglected. Research surrounding males and chronic illness suggests that males have difficulty reorienting themselves and reconstructing their identities, as they fail to fulfil 'masculine' roles they were once capable of (Gibbs, 2005). Consequently, this is an area that may have impacted on the present results. Future research should consider this aspect Fibromyalgia studies, to explore whether males and females experience the illness differently, and whether dominant discourses surrounding gender can impact upon the way individuals integrate Fibromyalgia into their lives.

Reflexive Analysis

I am a 23 year old male undergraduate currently studying Psychology at Manchester Metropolitan University. I am completing this project as part of my dissertation project. My interest in studying how people live with Fibromyalgia has stemmed from a family member being diagnosed with the illness. This has encouraged me to learn more about the illness, and add new insight into the illness.

The present study used semi-structured interviews to collect data, and this method of data collection may have impacted upon the results displayed in the project. Some participants appeared to view me as someone who could make a difference to the way in which Fibromyalgia is viewed, due to my role as 'researcher'. This appeared to aid in the development of rapport, and may have influenced the accounts that the participants gave. As I had prior knowledge of Fibromyalgia, I expected participants to discuss the difficulties they had faced and portray how their lives had declined following the onset of the illness. However, whilst this was apparent in some stages of the interview, participants also highlighted how the illness had allowed them to identify new areas of interest and in some cases, how they had grown as a person. As I have been involved closely with the illness, this may have impacted upon the way in which I have understood and analysed participants' accounts.

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