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To cite this article: Nicole Brown [www.nicole-brown.co.uk](http://www.nicole-brown.co.uk) | (2018) Exploring the lived experience of fibromyalgia using creative data collection methods, Cogent Social Sciences, 4:1, 1447759, DOI: [10.1080/23311886.2018.1447759](https://doi.org/10.1080/23311886.2018.1447759)

To link to this article: <https://doi.org/10.1080/23311886.2018.1447759>



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Published online: 14 Mar 2018.



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Received: 13 November 2017  
Accepted: 28 February 2018  
First Published: 06 March 2018

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Reviewing editor:  
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## SOCIOLOGY | RESEARCH ARTICLE

# Exploring the lived experience of fibromyalgia using creative data collection methods

Nicole Brown<sup>1\*§</sup>

**Abstract:** This paper reports the findings of a qualitative study into the lived experience of fibromyalgia. Fibromyalgia is a complex condition that is characterised by variability of symptoms and severity. Instead of applying a purely narrative interview approach, this research used a creative and expressive means drawing on interpretative phenomenological analysis (IPA) to make sense of the data, whilst applying an attitude of openness and responsiveness. In line with IPA, the findings reported here refer to a homogenous group of 5 participants drawn from a larger pool of participants. Participants were asked to create an identity box. They were required to respond to questions using physical and metaphorical representations and objects. The analysis and discussion highlight the link between existing theoretical conceptualisations of illness experiences and the participants' fibromyalgia experience. The women talk about losses and gains in relation to fibromyalgia, but their overall sentiment is one of acceptance of the illness whilst continuing to fight the symptoms and trying to mitigate their impact. While liminality, biographical disruption, identity continuity and new normalcy are experienced and while elements of restitution, quest and chaos narratives can be identified, the fibromyalgia experience is more complex. It is argued that the chosen methodology through the identity boxes and the metaphorical representation allowed for this more holistic view of the fibromyalgia experience.

**Subjects:** The Body; Disability Studies - Sociology; The Body & Identity; Disability; Health & Illness; Medicine - Sociology; Research Methods - Soc. Policy; Qualitative Methods; Communication Research Methods; Research methods

**keywords:** fibromyalgia; restitution; chaos and quest; identity box; representations; metaphors; combative acceptance; biographical disruption; liminality; identity



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### ABOUT THE AUTHOR

Nicole Brown is a Lecturer in Education at UCL Institute of Education, and a doctoral researcher at the University of Kent. She holds the Magistra Philosophiae, Master of Teaching, Diploma in Translation and is a Senior Fellow of the Higher Education Academy. Nicole's research interests relate to identity and body work, physical and material representations and metaphors, the generation of knowledge, and advancing learning and teaching within higher education. Her current research "The construction of academic identity under the influence of fibromyalgia" uses the identity box projects presented here to explore academics' experiences of fibromyalgia.

### PUBLIC INTEREST STATEMENT

Fibromyalgia is a complex condition that is often contested even within the medical profession, although the condition is experienced as debilitating amongst those diagnosed with it. This article explores how five women with fibromyalgia experience life with the condition and how they make sense of the chronic illness in relation to their social networks. The analysis shows that the women accept their illness to an extent, but at the same time continue to find ways to improve their symptoms and the impact the condition has. This article helps understand how those diagnosed with fibromyalgia feel in relation to who they are.

## 1. Introduction

Fibromyalgia is a chronic condition of unknown aetiology that is characterised by persistent, widespread pain, fatigue, cognitive dysfunctions, sleep disturbances and psychological disorders (White & Harth, 2001). There is currently no definitive test for fibromyalgia and diagnosis is based on the patient's medical history, the exclusion of other diseases and the determination of tender points and further related conditions such as chronic fatigue, irritable bowel syndrome, headaches, muscle weakness and sun sensitivity (McCain, 1996; Wolfe et al., 2010). This lack of definitive diagnosis makes fibromyalgia a contested illness (Ehrlich, 2003; Wolfe, 2009). Most recently, the cause for fibromyalgia has been linked to a central sensitisation issues and deficiencies relating to pain processing (Bennett, 2004; Yunus, 2008, 2009). The prevalence of fibromyalgia is described as ranging between 0.66 and 10.5% (Assumpção et al., 2009) among the general public with a male to female ratio of 1:9 (Grodman et al., 2011). Due to the fact that fibromyalgia is a changeable condition, is as of yet of unknown cause and presents itself differently in sufferers, treatment includes pharmaceutical and psychological approaches, pain management education and moderate physical exercise (FitzGibbons, 2007). Research into fibromyalgia considers treatment options (Giacomelli et al., 2013), experiences of treatments (Ashe, Furness, Taylor, Haywood-Small, & Lawson, 2017) the applicability of specific medication (Cording, Moore, Derry, & Wiffen, 2015), the influence of diet (Rossi et al., 2015), exercise programmes (Jones et al., 2012) but also psychological treatments (Lami, Martínez, & Sánchez, 2013) or psychological factors (Thieme, Turk, Gracely, Maixner, & Flor, 2015) in relation to fibromyalgia. Research has also started considering the felt impact of the illness in relation to quality of life (Arnold et al., 2008; Fletcher, Booth, & Ryan, 2015; Pagano, Matsutani, Ferreira, Marques, & Pereira, 2004; Wuytack & Miller, 2011), status of health, employment and disability (Henriksson & Liedberg, 2000; Henriksson, Liedberg, & Gerdle, 2005; Verbunt, Pernot, & Smeets, 2008), emotional experiences of sufferers (Cunningham & Jillings, 2006; Kashikar-Zuck, Vaught, Goldschneider, Graham, & Miller, 2002) and experiences of relationships (Armentor, 2017; Arnold et al., 2008; Wuytack & Miller, 2011). Further qualitative studies relate to the experience of exercise and (Russell et al., 2018; Sanz-Baños et al., 2016) or focussed on pain symptoms of fibromyalgia (Vincent, Whipple, & Rhudy, 2016).

While qualitative research has therefore provided insights into the lived experience of fibromyalgia, McMahon, Murray, and Simpson (2012) and Sallinen, Kukkurainen, and Peltokallio (2011) have called for the adoption of narrative approaches in order to explore the lived experience of fibromyalgia and to gain a more holistic understanding of the condition.

Narrative approaches are commonly considered as advantageous as narratives provide an insight into the participants' emotions and feelings, but also give voice to the unheard groups (Atkinson, 1997). However, narratives are not unproblematic in that the stories told by participants are told for specific reasons, in specific contexts (Jordens, Little, Paul, & Sayers, 2001) and under specific circumstances—the research (Atkinson, 1997; Bury, 2001). The challenge for the researcher therefore is to make sense of narratives and embed them in the wider socio-cultural context of the researched. It is this granular analysis (Atkinson, 2017) that enables the holistic exploration of experiences as part of the social fabric in which they are felt. Frank's (2013) narratives have been used to explore illness experience as for example those of people diagnosed with cancer (Jordens et al., 2001; Thomas-MacLean, 2004), dementia (Phinney, 2002), chronic headache (Lonardi, 2007), chronic fatigue syndrome (Whitehead, 2006), and stroke (France, Hunt, Dow, & Wyke, 2013). These and other narrative explorations (Bally et al., 2014; Carless & Douglas, 2008, 2013; Ezzy, 2000; Garrett, 2001; Prussing, Sobo, Walker, & Kurtin, 2005; Smith & Sparkes, 2005, 2008) evidence the wide applicability of narrative approaches.

And yet, further theoretical conceptualisations of health and illness are required to explore, describe and ultimately better understand illness experiences, as illness and more specific chronic illness can have a profound impact for individuals. Bury (1982) describes illness as a “biographical disruption”. Individuals have certain expectations in and of their lives, but with the experience of illness this pre-conceived life trajectory undergoes change, becomes disrupted. While Bury based the biographical disruption on the experience of rheumatoid arthritis patients,<sup>1</sup> the concept of disruption has since been explored in the context of cancer (Navon & Morag, 2004; Trusson, Pilnick, & Roy, 2016), chronic pain (Richardson, Ong, & Sim, 2006), multiple sclerosis (Green, Todd, & Pevalin, 2007), spinal cord injuries (Dickson, Allan, & O’carroll, 2008), Parkinson’s disease (Gisquet, 2008) and stroke (Wolfenden & Grace, 2012). However, as Williams (1984) study shows illness experience is more complex as disruptive life events may trigger illness rather than the illness disrupting life, initially. Also, changed patterns of social life and more flexible employment statuses, personal circumstances and periods of adjustment mean that illness may no longer be experienced as significantly disruptive (Williams, 2000). While Williams (2000) acknowledges the contribution of the concept of biographical disruption to understanding illness, he suggests that it should not be applied uncritically. Consequently, concepts of identity continuity, normalisation and liminality have been used to complement biographical disruption.

Identity continuity (Llewellyn et al., 2014; Wolfenden & Grace, 2012) and normalisation (Sanderson, Calnan, & Kumar, 2015; Sanderson, Calnan, Morris, Richards, & Hewlett, 2011) both refer to a chronically ill individual’s attempt to incorporate the illness experience within an adapted lifeworld. While the onset or exacerbation of illness may well be experienced as a disruption, individuals seek to attribute meaning to their lives and so learn to adjust to this new illness situation. Ultimately, therefore, the onset of an illness may well disrupt the planned and expected lifeworld of the ill person, but chronic illness does not lead to continued and continual biographical disruption. Instead, after a period of adjustment, the chronically ill reconstruct their identity and develop a new concept of normality, a new, revised or adjusted biography. This new normalcy then allows for continuity in patients’ lives. Due to recurrence or increased severity of their illness this new biography may again become disrupted, so that this cycle of redefinition and reconstruction of identity starts anew. In an attempt to describe patients living between health and illness, experiencing phases of remission Turner’s (1969) concept of liminality is often applied. In their study relating to prostate cancer and hormonal therapy Navon and Morag (2004) report how men entered this in-between space as their experiences do not fit typical, socially recognised categories of being well or ill. The consequences and side-effects of hormonal treatment lead to patients questioning their sexuality and masculinity, thus considering themselves as “not healthy” and “not well”. On the other hand, the men are no longer considered as cancer patients and “ill”. Breast cancer patients in Trusson et al.’s (2016) study describe their experience of remission phases in similar terms, in that they are cancer-free at certain stages, but may encounter a recurrence at different points in time. It is this particular stage of adjustment, being ill and yet well that Frank (2013) describes when he talks about the “remission society” (p. 9).

These conceptualisations of illness experiences are not necessarily clearly identified or linear in their occurrence, can overlap and intertwine. Within the context of fibromyalgia research tends to focus on specific elements of experiences or symptoms of the condition, rather than taking a more holistic approach to exploring the lived experience. This paper aims to provide the missing link and reports on a study exploring the lived experience of those diagnosed with fibromyalgia through creative methods.

## 2. Method and methodology

### 2.1. Research approach

Due to the variability in range and severity of fibromyalgia symptoms the experiences of fibromyalgia in all their facets are difficult to capture, as language and words often elude those trying to describe their emotions and feelings (Eccleston, 2016; Scarry, 1985; Sontag, 2003). Interviews, although helpful in the meaning-making process, are not necessarily the best possible tool for expressing the embodied experiences. Therefore, additional and alternative means were used to explore this relationship between perception, experience and language. The starting point for the methods used in this study were therefore metaphors. Human understanding is embodied (Finlay, 2015) and human communication reflects this embodied understanding through the common application of metaphors in everyday life, which may or not be a conscious choice on the part of the speaker (Lakoff & Johnson, 2003). If communication is so strongly linked to embodiment, and words themselves fail to describe experiences, it is therefore necessary to seek out a research approach that will allow for embodied data collection.

For the researcher employing metaphors as a data collection involves the danger of potential misrepresentation and incorrect analysis. Within commonly applicable contexts there are metaphors that take on generally valid interpretations, but within the context of individual experiences, such interpretations could differ between the speaker's intentionality and the listener's understanding. Therefore, the analytical framework applied to this study was interpretative phenomenological analysis (IPA) (Smith, Flowers, & Larkin, 2009). The overall theoretical framework for the research is phenomenological and hermeneutic in tradition. At the core of IPA lies the understanding that data analysis is a meaning-making process between researchers and participants. IPA is described as "double hermeneutics" in that researchers are making sense of the participants making sense of their experiences (Smith et al., 2009, p. 35). Research participants therefore take an active role within the analytical process and support the researcher in identifying key themes and concerns. Applying IPA allows for a participatory approach to meaning-making, but at the same time demands specific considerations in relation to the research process itself. For example, in order to enable the detailed, collaborative, meaning-making analysis the researcher is asked to focus on a small group of participants who form an as homogeneous group of participants as possible. The following section will detail the sample used for this study.

### 2.2. Participants

The study presented in this paper is taken from a larger research in relation to the illness experience of those with fibromyalgia and the impact of fibromyalgia on identity. For the full research 40 participants were recruited. The study works with 38 female and 2 male participants, which generally reflects the typically higher number of females diagnosed with fibromyalgia. In order to be able to identify common themes regarding the lived experiences with fibromyalgia and in line with IPA the data used for this paper was reduced to a homogenous group of participants chosen from the larger pool of participants. All participants were coded for general attributes, such as age, ethnicity, the time lived with the diagnosis, the way diagnosis was received and perceived levels of activity. Through a process of elimination, the homogenous group reported on in this paper consisted of 5 participants. They were all white females, aged between 24 and 65, they all had been formally diagnosed with fibromyalgia by doctors and they all had lived with this formal diagnosis for a minimum of 3 years. All women considered themselves as active, although only 1 of them was in employed work. The women no longer in work were unable to work due to their health issues and 2 women emphasised that they depended on financial support through the benefits system. All names used in the following are pseudonyms.

### **2.3. Procedures**

After obtaining University ethics approval, participants were recruited from fibromyalgia support groups in the UK and online, and through calls for participants via conference participations, direct mailing and via social media. The research aims, purpose and processes, as well as benefits and challenges of participation were explained verbally and in writing through information leaflets. Participants were given time to reflect on their potential participation and were only involved in the data generation process, once the signed consent form had been received.

### **2.4. Identity boxes**

In practice, the theoretical framework of metaphorical communication and embodied understanding that goes beyond language and words was translated into “identity boxes” (Brown, 2017). The concept for identity boxes is modelled on memory boxes used to support memory retrieval in dementia patients (Hagens, Beaman, & Bouchard, 2003; Nolan, Mathews, & Harrison, 2001) and in work with terminal cancer patients, who create such boxes to help them and their families come to terms with end of life experiences (Macmillan, 2014). The identity box is also a collection of items, but rather than trigger memories, the items represent physical answers to specific questions. The identity boxes were created over several weeks, during which participants were sent five questions, one question at a time. The questions were: “Who are you?”, “What affects you?”, “How do others see you?”, “What role does fibromyalgia play?” and “What is life with fibromyalgia like?”. For each question participants had as much time as they needed to be able to find the appropriate object or objects representing their response. Once the question was answered, participants were asked to take photographs of the objects and their box. These photographs were then emailed together with a brief explanation of what the objects were and what they represented. This first stage of the research took place between September 2016 and March 2017. Depending on the participants’ personal circumstances and how long participants took for each task, the projects took between 5 and 15 weeks. The data generated at this stage were the photos of the identity boxes in their evolving states and the brief email messages explaining the photos.

### **2.5. Interviews**

After the completion of the fifth task, the individual photos, email messages and photos of the identity box in its entirety were compiled to prepare for an interview. In line with the hermeneutic, phenomenological approach of IPA (Smith et al., 2009), the interviews were aimed at getting as close as possible to the individuals’ experiences, and to enable the participants to make sense of their own identity boxes. This was achieved by embracing Brinkmann and Kvale’s (2015) concept of interviews as interactions between the researcher and the participant. Although an interview schedule for a semi-structured interview was prepared, the interview schedules were very much individualised based on the participant’s own input through the photographs and emails. The interviews themselves were conversational and loosely followed the interview schedule, but allowed for deviations. By maintaining openness to the conversation and following the lead of the participants, it was possible to hone in on what was important for the individuals without tainting these relevant essences through the researcher’s preconceptions and views.

### **2.6. Data**

Overall, the data took one form of three: pictorial submissions through photos, the accompanying email explaining the photos and the interview following the identity box project. As the identity box project was the same for all participants, the following graph is supplied to identify the materials submitted:



	Who are you?	What affects you?	How do others see you?	What role does fibromyalgia play?	What is life with fibromyalgia like?
Dawn	Pony tail, Hessian libra wall hanging, needle and thread in red	Photo of twin sister and brother, two letters, cardboard cut outs, medication, jigsaw piece	Nail, light bulb, diary/calendar	Swimming goggles and timetable, country club membership card, apple, a torn piece of orange paper	Sent an email letter explaining thoughts
Charlene	Smiley face, turtle, angel, diamond	My children	Rock, also sent an email letter explaining thoughts	Sent an email letter explaining thoughts	Sent an email letter explaining thoughts
Charlotte	Marriage certificate, one gardening glove, broken cooking measure	Photo of husband, thermometer, figurine representing friends, cookery book	Snowman figurine, cookery book, paintbrush, needle and thread	Broken watch, a broken piece of tree, a bent nail, an empty, hollow toilet paper roll	A series of photos created specifically for this project to depict “shattered”, “frustration” and “empty”
Lindsay	A paint brush, spool of thread, bottle of glue, photo card of family journal, also sent an email letter explaining thoughts	Book of prayers and beads, book, music box, flower, adrenal insufficiency magnet and hydrocortisone	Doll with the face drawn upon it	Native Texan sticker, calendar, mobile phone, mobile phone clock, volunteer ID badge, playing cards, book, soft fabric in green and blue, box of decaffeinated green tea, also sent an email letter explaining thoughts	Sent an email letter explaining thoughts
Sue	A plain box, a candle, a glittery heel, passport	Sunglasses, makeup, condom, staff badge	Pen, pawn, safety pins, box of hayfever medication	A mindmap explaining thoughts	A pillow on top of the box

### 3. Reflexivity and positionality

The following section will detail some key concerns about researcher positionality and reflexivity in relation to the research reported here. In order to provide detailed and rigorous discussion this section will—untraditionally for research reports—use the first person writing.

The original call for participation in this research was made within the forums of face-to-face and online support groups. Therefore, participants were fully aware of my own status of a person with a fibromyalgia diagnosis. Within the early stages of the study participants commented on my “knowing” the experiences and explained what a difference that experience made to how they were usually received within their immediate and wider social structures, but more importantly by health professionals.

Initially, this insider position was problematic for me on two levels. Firstly, although I believe in getting as close as possible to the research experience (Brown, *in press*). I did not want the research to be tainted by my personal experiences. This was actively counteracted through the methodological approach of posing questions to be answered through objects. At this stage, I did not ask any questions nor did I try to clarify or probe deeper. When I had seen the final identity box, I analysed the data and developed the interview schedule coming out from that data. This was to ensure that in line with hermeneutic research traditions participants could make sense of their own boxes, thus their experiences (Smith et al., 2009). During the interviews, the participants engaged me in conversations, where I did allow myself to respond using my own experiences (Finlay, 2002; Holloway & Biley, 2011).

Secondly, I was concerned that participants would perhaps be over-sharing and too revealing in their interactions with me. This ethical issue was addressed by reconfirming consent with the participants at the end of the identity box project and at the end of the interview. This was particularly important as all interviews apart from one were conducted as skype interviews and therefore in participants' homes. In some interviews participants used their laptops to give me a tour around their homes and show me their favourite spaces in the house, their beds and desks, or they introduced me to family members. The ethical concerns relating to video-conferencing interviews are reported elsewhere (Brown, 2018), but suffice it to say that my role as researcher and peer demand special considerations.

The framework I used to avoid tainting data and thus to ensure rigour and validity was based on two cornerstones of phenomenological life-world research: "openness" (Dahlberg, Dahlberg, & Nyström, 2011) and "responsiveness" (Todres, 2007). As a researcher I am not a clean slate, on the contrary, I have preconceptions and assumptions, which I bring into the research field. I could identify these ideas and then try to exclude them from my knowledge throughout the entire research process. But in reality, this would merely be self-deception, as the knowledge is still very much there, even if I pretend it is not. This is where an attitude of openness (Dahlberg et al., 2011) can help. Instead of trying to exclude pre-existing knowledge, we acknowledge its existence and simultaneously adopting a consciously open stance towards the phenomenon under study. As a peer researcher, I was therefore able to apply my understanding of fibromyalgia, but at the same time I actively looked for the lived experiences of my participants. To further this openness, I also applied a stance of responsiveness. The premise for a responsive approach to research is that human understanding is embodied and that bodily sensations cannot truly be separated from language (Todres, 2007). This means that as humans we automatically and subconsciously interpret what we hear or receive. For example, we interpret tones of voices, intonation and tonal ranges as specific emotional experiences. As a researcher, I cannot completely exclude these interpretations. However, through applying responsiveness, I can mitigate the effects of such unwanted interpretations. Being responsive is to be reflexively aware of my body and my bodily reactions to my participants' responses, and to use these as a tool for the meaning-making process. I did not necessarily feel the same sensations as my participants, but through consciously engaging my body, I was able to follow and make sense of my participants' lifeworlds.

#### 4. Analysis

The analytical approach in this study drew heavily on IPA (Smith et al., 2009), which seeks to get as close as possible to the participants' experiences. However, data was not limited to textual forms of emails and interview transcriptions, but also entailed visual forms as photographs of the identity boxes. This required the incorporation of analytical elements from visual methodologies and approaches (Prosser, 1998; Rose, 2016). Therefore, the analytical process was an iterative spiral, where the researcher gradually delved more deeply into the participants' experiences. As the data in this study came in textual and visual forms, the data analysis process was adjusted to account for their individual relevance and their simultaneous interconnectedness (Rose, 2016). Additionally, data was accumulated over several weeks. Therefore, textual and visual data were initially considered in isolation where initial descriptive, organisational and linguistic observations (Smith et al., 2009) were recorded. Subsequently, the emails were connected with the photographs and this first noting was repeated. This process was repeated for each stage of the creative process before the identity box was considered in its entirety. The same process was applied for all participants as they worked through the process of creating their identity boxes. The interviews were then scheduled in order to probe deeper and to explore some of the created meanings in greater detail. In the conversations with the participants the researcher was able to verify and validate relevant elements of the lived experiences. The interview transcripts were subsequently also analysed using the IPA framework of noting linguistic, descriptive and conceptual elements (Smith et al., 2009). On the basis of the interview transcripts, emails and photographs common themes were clustered, organised and reviewed.



## 5. Results

The analysis of the identity boxes with the related emails and the interviews revealed several common themes in relation to factors influencing the construction of identity under the influence of fibromyalgia, the relevance of support networks, the connections between the experiences of fibromyalgia and work/life balance. The following section will be focussing on losses and gains due to fibromyalgia and the battle with fibromyalgia.

### 5.1. Losses

The onset of illness often coincides with the experience of loss and not being able to do or have what was once planned. All participants covered the experience of loss in the interviews, email communications and the identity box, although the women did not always refer directly to the feeling of loss. In response to “What role does fibromyalgia play?” Lindsay added a volunteer identification badge and a deck of cards to her box. Both items represent activities that she is no longer able to pursue in her life:

Volunteer ID badge for local hospital—I have had to resign as a volunteer from several organizations. Not enough energy. Not knowing if it will be a good day or not. Which days would be good—no one knows. No more volunteering.

Playing cards—I used to play cards every Monday. Now that is not always possible. I miss my card playing friends. We hope to get together soon. (Lindsay, email)

In a similar vein Dawn also recalls activities and relationships that she has lost due to her life with fibromyalgia:

For over 20yrs I used to socialise with my partner at our local Country Club, but now I use my Chemist Rewards card more than my Country Club Card (photo B). I can't work anymore & so I receive the Disability Pension. There's a card for that too, the blue one in photo B. (Dawn, email)

While Dawn appears to demonstrate hints of sarcastic humour in her communication, Lindsay is very factual, curt and abrupt in her email. The conversation with her demonstrated that Lindsay felt disappointment, sadness and frustration, but that she did not allow herself to indulge in or be overcome by this feeling of loss:

I have tried to removed stress from my life and accept the cards that have been dealt. As long as I stay proactive and not give in to any of my medical issues, life is good. Self-pity is not in my box of choices. Life is too precious to waste it. If I need prescription medication to help me through the day, so be it. If I need a nap, so be it. If I need a hug, I ask for it. If I need a friend's ear, I ask for it. (Lindsay, interview)

Charlotte expressed her experience of loss more openly and directly. She used a broken watch and a broken twig to represent the role of fibromyalgia in her life. The brokenness in itself was a powerful statement, but this was reinforced in two items. Charlotte already alluded to the theme of being broken in response to the first question “who are you?” where she says “I am also a bit old, a bit used and a bit broken” (Charlotte, email). But the depth of her brokenness and therefore the loss she was experiencing became fully evident in her description of the watch and the twig:

I have a broken watch, which depicts the time that has been stolen from me; the inability to move forward in my life. I have a broken piece of tree that represents my family which shows some parts have been broken and some have actually been severed because of my pain medication. (Charlotte, email)

In the conversation with her, Charlotte's experience of loss became more nuanced. Talking about no longer being able to practise her chosen profession as a paramedic, to play her 12-stringed guitar or

to make her own artisan breads, she no longer appears to be a broken person, much rather a person who mourns the pre-fibromyalgia self:

it's sadness because I can no longer do these things. And I'd love to be able to do them again. I guess it's more of a melancholy feeling, kind of like "I miss it". (Charlotte, interview)

However, when probed about the broken and severed ties with her family, she spoke of resignation. In order to help her manage her fibromyalgia symptoms Charlotte had been prescribed marijuana, which some family members did not agree with. In Charlotte's view, she was only taking medication to help her cope, whilst some family members "have gone so far as to try and stage an intervention". In this context, she clearly did speak of loss, but not her own, more that of her family's:

they have chosen to distance themselves from us and that is their loss. I cannot chase a relationship that isn't meant to be. (Charlotte, interview)

Sue, the youngest and the only participant in employed work, voiced her experience with fibromyalgia more strongly:

To me fibro robbed me of my dreams. I wanted to be a criminal psychologist but I struggled do [sic; so] bad at uni I couldn't carry on with it. My partner left me because he couldn't handle how little I did. Friends have left me because I don't go out much anymore. I see it [fibromyalgia] in a bad way, but when I have control of it it's not that bad, it's just difficult to stay in control and hard to get back once I've lost it. Both my pain and my tiredness has [sic] an impact on me. It stops me being who I want to be. (Sue, email)

All women described the profound impact of fibromyalgia on their lives and their bigger and smaller losses, which lead to feelings ranging from resignation or melancholy to sadness and disappointment. Simultaneously, however, the women talked about focussing on the positives in their lives.

## 5.2. Gains

Three women highlighted their attempt to focus on a silver lining of the fibromyalgia cloud. Sue's description of fibromyalgia being both "gift and curse" (Sue, mindmap) was most poignant and encapsulated her largely, ambivalent feelings towards the illness. Dawn, Sue and Lindsay all tried to emphasise how having fibromyalgia had changed their views of the world and therefore had had positive effects on who they were and who they had become:

Fibromyalgia is so complex it leads to a complex lifestyle that is always about learning new ways to deal with it every day. (Dawn, email)

or:

Sometimes life throw[s] you a curve ball, turn it into an opportunity. (Lindsay, email)

and:

gives me empathy and jealousy; appreciate my family more; loving means more as I don't have energy to spare on others; makes me grateful [sic] for what I have; puts life in perspective. (Sue, mindmap)

In the interviews, these three women expand on their concept of gains, which were not related to material gains. In fact, the gains were not expressed in tangible terms at all. The women explored how they had developed and grown as persons, how they had become more empathetic, compassionate, tolerant and patient. These were all qualities that they themselves were hoping for in others, but often did not encounter, and therefore through their experience with fibromyalgia they "understand other people's struggles" (Sue, email).

What becomes obvious in the conversations with all women is that optimism and positivity in relation to fibromyalgia as a gain did not come about naturally or easily, but represented an active choice and consistent commitment:

I am continuously working at being happy. I consciously choose happiness every day to avoid the depression that the constant pain Fibro brings. I have to fight to maintain my happiness which is tiring. (Charlotte, interview)

This may be also why their participation in the fibromyalgia research was described as a most tangible gain from fibromyalgia. Whilst the women dealt with the losses due to their health condition, they were still actively trying to find meaning in having fibromyalgia, giving back and being useful rather than becoming a burden. They interpreted their participation in this research as one such opportunity:

I feel proud that I am helping you out. I feel proud that you're not just talking to random people with fibro and whatever else the people say they've got when they talk to you because you're doing something with it. I feel like I'm fighting. I feel like I am potentially going to help make someone's life better. (Sue, interview)

When talking about their lived experiences of fibromyalgia, the participants regularly swayed between melancholy and optimism. However, across the identity boxes, the objects, the emails and interviews, the women tended to display a certain fighting spirit, which will be discussed in Section 6.

### **5.3. The battle with fibromyalgia**

Through the narrower analysis of the women's speeches and choices of words, it became apparent that the battle with fibromyalgia was an important theme for the women. Charlene, for example, explained how her children inspired her. Charlene's four children all have long-term medical conditions; her 26-year-old son was diagnosed with Duchenne Muscular Dystrophy. This means that her other three children have to help, because Charlene herself is unable to do so:

[he] was supposed to die at around 14 to 18 but is still fighting so they all are my inspiration for my fight with everything I have. (Charlene, email)

As with Charlene, Lindsay and Dawn, too, referred to the concept of fighting, although their tone was slightly mellower:

I have never considered being in combat mode regarding fibromyalgia. People who say they are happy and fighting probably have a wonderful support system. Again, probably. Personal attitude is the key factor. You can be happy and fighting and not have support. It all depends on mental health. Fighting day in and day out can become tiring and depressing whether you have support or not. (Lindsay, interview)

and:

Living with Fibromyalgia has become the primary concern in my daily life & most likely for the rest of it. Every day I strive to improve my health (...) I also have such severe fatigue it just hits me suddenly and overwhelmingly. This is dangerous if I am driving so I can't plan to drive if I am going through a "flare". I have learnt to rest up & don't over exert myself if I must drive the next day. In fact this has become the "golden rule" with fibro, pacing yourself. (Dawn, email)

Dawn's, Lindsay's and Charlene's fight was not so much one of open battle against the illness; it was more a struggle to keep active, to maintain a certain lifestyle and to continue living life as fully as possible. By contrast, the explanations of Sue and Charlotte was by far more explicit:

I have a nail. This represents the iron will that I have to fight this disease as hard as I can. It also represents the fact that I have to do it pretty much alone, as I am the only person that can fix me. But as strong as I am, I am bending. The last thing I have is a toilet paper roll. This represents how empty, hollow and lonely this fight leaves me feeling most of the time. (Charlotte, email)

For Sue, the fight with fibromyalgia worked on several levels. There was the topic of battling the illness, working against pain and tiredness, but there was also a narrative of fighting within society, fighting to remain in employment and fighting the health system.

I am always fighting pain. Some people think I am faking it. I fight to stay awake. I fight to stay true to myself. I fought the NHS for 6 years for a diagnosis. (Sue, mindmap)

Lindsay's reflections about the support system appears particularly relevant in that Charlotte, Sue and Charlene all talk about how fighting on their own but being inspired by their loved ones made the difference to how they encountered fibromyalgia. In all my conversations, it was the one with Charlotte that was most impactful:

Fibromyalgia is my enemy. Fibromyalgia is going to be defeated. I will win this war. I will eradicate fibromyalgia from my body. And when I do, I will tell the world how to do it. But fibromyalgia is going to be the loser and I will be the victor. (Charlotte, interview)

The data from the participants' identity boxes, their emails and the interviews show that the experience of and with fibromyalgia is multilayered and therefore very complex. The following section provides a more holistic discussion regarding the experiences described.

## 6. Discussion

Despite striving for homogeneity within the participants, through the variables of gender, ethnicity, onset and form of diagnosis of fibromyalgia, generalised conclusions cannot be drawn. This is due to additional factors such as individual family situations and relationships, financial circumstances, support networks within the medical profession and health care systems. As a matter of fact, by drawing on IPA the research approach was geared towards exploring individual experiences without aiming for generalisations. Instead, some common experiences are described and it is identified how these can be framed within wider sociological concepts. This is to deepen the understanding of and gain an insight into the holistic experience with fibromyalgia.

### 6.1. Biographical disruption, normalcy and liminality

Despite not specifically being asked about losses in relation to fibromyalgia, all participants reflected on the element of loss due to their health status. Whilst losses are expressed as resignation, melancholy or disappointment, it is evident that all women feel that their life has changed due to fibromyalgia, which hints at Bury's (1982) concept of biographical disruption. The women's planned life has taken an unexpected turn and so they are grieving for their previous identity and reflecting on the trajectory that could have been but is not. This is expressed most strongly in Sue's own words "to me fibro robbed me of my dreams" (Sue, email). However, the women's stories also convey that the disruption is definitely not permanent. They seek to find a purpose in their lives and to find a new stability. Through the employment of coping mechanisms, such as pacing or adjusting their lifestyles, the women work at remaining active members of their social circles. Biographical disruption (Bury, 1982) does not allow for a debate around that. On the other hand, however, the women do not explicitly talk of a new identity, a reconstructed or reformed identity. The normalcy or normalisation processes Sanderson et al. (2011) observe in rheumatoid arthritis patients cannot be identified here. Women clearly hold on to who they were before the onset of fibromyalgia:

Mentally, I am still the same. Physically, not so much. (Lindsay, email)

One of the reasons for this difference between the fibromyalgia and rheumatoid arthritis patients may be due to the nature of the illnesses. Drawing on a number of studies in relation to biographical disruption Williams (2000) highlights how the patients' age and illness are interrelated to the usually expected trajectory and consequently colour the experience of biographical disruption. Whilst middle-aged and elderly people accept pain as part of the usual life trajectory at their specific stages, being diagnosed with rheumatoid arthritis in childhood or young adulthood is felt as more disruptive (Williams, 2000). In the case of fibromyalgia, the illness does not follow a specific path; in fact, the very characteristic of fibromyalgia is its variability from one day to the next, or even from one hour to the next (Wolfe & Walitt, 2013). Therefore, it may be more difficult for individuals to adjust to life with fibromyalgia and to reframe their identity in the way that rheumatoid arthritis patients do. Lindsay's description of "[n]ot knowing if it will be a good day or not" (Lindsay, email) encapsulates this variability. In a way she demonstrates that fibromyalgia must be equated with liminality, living between good days and bad. Sue also expresses liminality, when she explains that it is important to stay in control and then life with fibromyalgia is "not that bad" (Sue, email). However, it appears that these women's experience of liminality is not as final and pronounced as that of prostate cancer patients in Navon and Morag's (2004) work. The prostate cancer patients felt that they were categorised in this space in-between health and illness or normality and deviance, whereas women here talk about good and bad days. This suggests that the overall conceptualisation of life is one of illness, within which there are days where the illness is at bay, yet still felt.

### **6.2. Narrative plots: Restitution, chaos, quest**

Despite the experiences of losses, the women in this study hold on to their selves, their roles and responsibilities within their immediate social environment and look to find new purposes. Narrative plots of restitution, chaos and quest (Frank, 2013) seem to lend themselves to being applied in order to understand these women's experiences. The most favoured plot amongst illness narratives within the Westernised world is restitution, in which the ill explore their experiences as a journey from health to illness and back towards a restoration of health. At the other end of the spectrum is chaos, a narrative that depicts destitution, loss of hope, a sense of giving up and giving in to the illness experience, with no expectation that life can become better again. The quest, by contrast, illustrates how patients ascribe meanings to their illness experiences by finding a positive effect and outcome, for example through becoming advocates or activists (Frank, 2013). What is problematic with the application of these narratives in the context of fibromyalgia (Diver, Avis, & Gupta, 2013) is that the plots are not applied to the holistic experience of fibromyalgia but to individual stages of the illness. Restitution, for example, is described at onset or during diagnosis, when patients are starting to understand the meaning of the label fibromyalgia.

In this study the women talk about wanting to get better and working at maintaining relationships. The resignation and melancholy expressed by Charlotte, Sue and Dawn sits alongside hope, levelled optimism and pragmatism regarding dealing with fibromyalgia. Charlotte, Sue and Charlene, in particular, mention their pharmacological approaches towards managing fibromyalgia. But it is that: management rather than cure, remission or restoration of health. This demonstrates that the importance of the research approach. Exploring a snapshot experience of particular stages in lives may have demonstrated chaos for Charlotte, for example, whose family relationships broke down due to her marijuana treatment. Yet, when fibromyalgia is considered holistically, beyond the experiences of pain at particular stages, the women are able to identify purposes and gains in their lives. Frank (2013) emphasises that narratives are considered as fluid, in flux and not as stable units, which hints at the framework attempting to provide an analytical basis for exploring snapshots of experiences. Viewed through the holistic lens, however, the fibromyalgia narratives uncovered in this study do not fall into these three categories. All women in this study accept their condition to a certain extent, but their narrative is not truly one of a quest, nor is it chaos and restitution. The plot is one that is in an in-between space between all three narratives. And interestingly, it is littered with a more aggressive tone and displays combative attitude.

The language used throughout the communications was one of “struggling”, “fighting”, “battling” and “being at war” with “the enemy”, where the only “victor” will not be fibromyalgia. This could be interpreted as the women in this study favouring a restitution narrative. After all, they talk about fighting fibromyalgia and winning the war against fibromyalgia. In that sense, there is an element of the women seeking restitution. However, the conversations and objects show that this restitution element in their narrative is only called upon within the context of relationships. Where the women are able to consider their stories in isolation from social networks, the narrative is one of acceptance. The women accept that their lives have changed under the influence of fibromyalgia and they come to terms with a new form of normality. While the women admit the transformative element in fibromyalgia, their attitude towards this new normality does not reflect the quest narrative. Their new normality is tinged with feelings of sadness, loss, grief and resignation into acceptance. In the context of their lives as lived within their social networks of family and friends the women seem to feel as if they must seek to improve their health and fight fibromyalgia in order to fit in with the social norms. The fight with fibromyalgia is not equally entrenched in all women. Indeed, Lindsay’s narrative seems to be one of passive resistance or a form of civil disobedience to remain with the war and fight analogy. However, all of the women in this study navigate their narratives between resistance, fight on the one hand and acceptance on the other hand. This combative acceptance is consistent with McMahon, Murray, Sanderson, and Daiches’s (2012) data. In their analysis, McMahon, Murray, Sanderson et al. (2012) also highlight the links and discrepancies between Frank’s (2013) suggested plots and the fibromyalgia narratives they uncovered. They also describe the role of relationships within the narratives of those diagnosed with fibromyalgia. Yet, the authors fail to explore the connection between acceptance and battle. From this study and the data presented in McMahon, Murray, Sanderson et al. (2012) it is evident that the women try to reconcile their individual, personal transformative experiences of fibromyalgia with the pressures exerted on them consciously and unconsciously by friends and family, and by society. To truly understand the lived experience of and with fibromyalgia therefore means to understand this resistance and fighting spirit coupled with partial acceptance and levelled positivity. This is best exemplified when considering whose battle cries are the loudest. Sue is the youngest of the women and the only one still in employment. It would be therefore quite natural to assume that her experience of fibromyalgia would be felt as most disruptive (Williams, 2000), and consequently that she would be trying to fight fibromyalgia hardest. However, the strongest war speech is Charlotte’s, who is 62 years of age, a former paramedic and who when asked directly expresses her overriding emotion in relation to fibromyalgia as balanced happiness and content. And yet, she is still actively fighting for a life without fibromyalgia, and it was her war speech that was most powerful regarding its use of war vocabulary. She embodies this fused stage of this combative acceptance strongest.

## 7. Concluding thoughts

The analysis of the data clearly highlights the complexity of the lived experience with and of fibromyalgia. The research aimed at providing a holistic lens through which fibromyalgia can be viewed, in order to actively step away from fibromyalgia as a pain syndrome and instead consider it in all its facets, with all its symptoms, its variability in symptoms and severity. Through the reflective exploration with objects, the women were asked to think deeply about their emotions, reduce those to an essence and reinterpret that by expressing it in objects. What happened in the course of the identity boxes project and the subsequent meaning-making processes was that participants reduced their personal experiences to an essence to then find a representation in the form of a metaphor. Subsequently, the women explained and interpreted the meaning of their chosen metaphors, thereby elaborating on the true essences of their experiences. This interpretative work provided an insight into the women’s deepest emotions in a way that interviews on their own would not have allowed for, as this approach requires deep reflections and represents a holistic view of experiences. The reduction of a phenomenon and the subsequent elaboration on that reduction (Finlay, 2008) are only possible if participants look at the entirety of their experiences and then reflect on their essences.

Through this holistic approach to fibromyalgia research, it has emerged that the concepts and frameworks commonly used to describe illness experiences are not fully applicable. The



fibromyalgia narratives uncovered in this study do not fall into the three categories of restitution, quest or chaos. All stages are evident as the women identify losses and gains, for example. But overall, the plot is one that is in an in-between space between all three narratives. The narratives clearly must be seen as fluid, in flux and not as stable units (Frank, 2013). It appears that women live through biographical disruption, experience liminality, attempt to reframe their selves and develop new normalcy. With the holistic lens applied, however, it is not possible to generalise the fibromyalgia illness experience using these existing frameworks. They are useful as tools to provide context and shape for explorations, in particular for the researcher to begin to understand which questions need to be asked. Overall, though, illness experiences are more complex than to be able to fit them within neat categories.

The key to understanding fibromyalgia may lie in the consideration of the character traits of the typical fibromyalgia patient, if he/she exists in that way. So far, little work has been done in this regard. Van Houdenhove, Neerinckx, Onghena, Lysens, and Vertommen's (2001) study reports that those diagnosed with fibromyalgia are more likely to be overactive or "action prone"; and Molnar, Flett, Sadava, and Colautti (2012) emphasise that high levels of self-oriented or socially prescribed perfectionism lead to lower health functioning. It may well be action-proneness and perfectionism that lead the women in this study to take the role of combative acceptance. Through battling with fibromyalgia and fighting for maintaining their existing selves, the women prove that they are assuming Parsons' (1991) sick role with all its roles and responsibilities. This includes seeking out competent health care, but more importantly, the active contribution towards getting better. On the other hand, perfectionism may result in the women to take on the kind of sick role they feel is expected of them. Within the current discourse of ableism and embracing differences, but also from their experiences with having lost friends and meaningful relationships, they feel that they need to find a way to arrange themselves with fibromyalgia and accept the illness. The perfect woman would not be one that succumbs to and withdraws into a chaos narrative, although they may do so temporarily during particularly difficult phases. More work around character traits and identity amongst those with fibromyalgia will be needed in order to be able to frame experiences more clearly and meaningfully.

#### Funding

The author received no direct funding for this research.

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#### Citation information

Cite this article as: Exploring the lived experience of fibromyalgia using creative data collection methods, Nicole Brown, *Cogent Social Sciences* (2018), 4: 1447759.

#### Note

1. The use of the term "patients" in this article is not to suggest that those diagnosed with specific conditions are passive or have no agency. This is merely a term to identify those diagnosed with a condition.

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